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"Impact of Parent-Caring on Women"

by

Patricia G. Archbold

DISSERTATION

Submitted in partial satisfaction of the requirements for the degree of

DOCTOR OF NURSING SCIENCE

in the

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## Abstract

This exploratory study of the impact of parent-caring on the lives of 30 Caucasian women is based on data from: 1) intensive interview, 2) participant observation, and 3) the OARS Multidimensional Functional Assessment.

Analysis of the qualitative data identified two caregiving modalities: 1) care provision in which the caregiver identifies those services the parent requires and provides them herself, and 2) care management in which the caregiver identifies those services the parent requires and manages their provision by others. The social and behavioral precedents of the decision to provide care to a parent include: 1) the caregiver's lower socio-economic background, shared housing with the parent prior to parental illness, and previous satisfying experience in a caregiving role, and 2) the parent's slow, progressive illness onset. Social and behavioral precedents of the decision to manage parent-caring include: 1) the caregiver's higher socio-economic background, and 2) the parent's rapid illness onset with sudden loss of major functional abilities.

Caregiving to a chronically ill elderly parent is usually a progressive, all-consuming activity which cannot be incorporated into a woman's life without significant disruption. Once the decision to provide or manage care is made, the caregiver must

develop strategies for dealing with the problems of the parent, herself, and her family. Provider strategies for handling the parent's problems can be placed in three categories--those which: 1) directly assist the parent with his/her activities of daily living, 2) manipulate the environment to decrease the problems encountered by the parent in activities of daily living, and 3) modify the parent's behavior. Manager strategies include: 1) obtaining and retaining the services of others to assist the parent with activities of daily living, 2) providing psychological and social support directly, 3) major environmental manipulation, and 4) parent education to facilitate independent performance of tasks.

The strategy used by providers to cope with their own problems related to parent-caring is ventilation to others. Managers also use ventilation to friends, family, and professionals. In addition, managers use self-help groups, the restructuring of their time to meet their own needs, and finding meaning in the experience of parent-caring, to help with their own reactions to caregiving. Finally, the providers attempted to "protect" their spouse and family from the impact of parent-caring; the managers manipulate their schedules to spend time with their families and parent separately, and engage in marital counseling to cope with their family's problems with caregiving.

Parent-caring has different consequences depending on the caregiving style employed. Few providers see any benefits to parent-caring. Managers identified a sense of satisfaction, increased knowledge about themselves and aging, improvement in the parent-child relationship, and a sense of meaning in the caregiving as benefits of parent-caring.

Both providers and managers experience difficulties in their marital and sibling relationships secondary to caregiving. Other "costs" to caregivers relate to the care modality they use. Providers report their main problems as decreased freedom, a lack of privacy, constant daily irritation, and guilt. Managers report that time restrictions, career interruption, financial problems, and guilt are the major costs of parent-caring.

Shifts in caregiving modalities occur with time, increasing functional limitations of parent or caregiver, changes in family dynamics, etc. The periods before and during the shifts are often times of crisis for the individual and family. At these points, expression of the complex intrapsychic and interpersonal correlates of caregiving is less inhibited.

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# Chapter I

## Introduction

This study examines the impact of parent-caring on women. Parent-caring, or the provision of needed services to functionally impaired elderly parents, is increasing in this society as the actual number and the relative percentage of frail elderly in the total population increase. Caregiving to a chronically ill elderly person is usually a progressive, all-consuming activity which cannot be incorporated into a woman's life without significant impact on her sense of self, time, freedom, career, and relationships with others. In general, the role of caregiver is assumed without an understanding of the consequences. As one particularly effective caregiver said when asked what advice she would give to a person considering assuming caregiving activities: "I'd tell them it gets rougher as you go on, and not to start unless you mean to continue and know the reality." Surprisingly little research exists to assist the woman to know the reality. This study takes a phenomenological approach in analyzing: 1) the conditions influencing decisions about caregiving, 2) the strategies used by caregivers, and 3) the consequences of caregiving.

Relatively little demographic data about caregiving are available. We do know that the number of deaths from acute ill-

ness in the aged population has significantly decreased with improved medical technology. Chronic illnesses, requiring varying degrees of long term technical and non-technical assistance are evolving as a serious problem among the aged and their families in the United States. At present 11% of the population in the United States is 65 years of age or older. Conservative projections suggest that the elderly population will reach 11.8% by the end of the century (Rice, 1978). Closer inspection of the population trends shows that a significant increase has already occurred in the percent of those persons over 85 years of age (Treas, 1977). This "old-old" group is particularly vulnerable to the problems of ill health and dependency associated with old age. The prevalence of dependency is 25% among persons 85 years of age and older, as compared with 2% among those persons under 85 (Akhtar, Broe, Crombie, McLean, Andrews, & Caird, 1973). Household surveys indicate that 12-14% of the population 65 years of age and older living at home can be left unattended for only short periods of time (Anderson, 1976). In general, the responsibility falls to the spouse where one exists, or to the daughter or daughter-in-law of the ill parent to provide the care and support services necessary for him/her to remain at home (Adams, 1970; Brody, 1974; Treas, 1977).

Findings of studies from England indicate that families provide care for their ill elderly members, often at extreme

expense and hardship to the family unit (Isaacs, 1972; Sainsbury & Grad, 1970; Sanford, 1975; Sheldon, 1948). Recent unpublished reports from England identify severe social and economic penalties paid by women caregivers (National Council for the Single Woman and Her Dependents, 1978b).

Despite this data, recent federal, state, and local policies suggest the government's stand is toward families providing all the home services required by their elderly members. Less than one percent of the budgets of Medicare and Medicaid are spent on home health services. Few community options exist for the home care of ill elderly. Women assuming parent-caring responsibilities do so with little social or economic support. In a recent report to the President, the Task Panels on Aging and Women recognize the need for community services for the aged to relieve strain on families, as well as to serve the aged him/herself (President's Commission on Mental Health, 1978).

Parent-caring to severely impaired older parents begins when the caregiver is in middle age, or early old age. Like childrearing, meeting the dependency needs of a parent is extremely demanding physically and psychologically. Unlike childrearing, in which the child's physical and emotional dependence gradually diminishes, parent-caring involves the caregiver in meeting the sustained or increasing physical and emotional dependency needs of the older person. Parent-caring

places great demands on the increasingly limited energy of the caregiver.

Purpose

The purpose of this study is to:

1) identify those factors which influence decisions about parent-caring.
2) analyze caregiving behavior.
3) describe the strategies used by caregivers to manage:
   a. the ill parent's problems
   b. their own problems in caregiving
   c. family problems associated with caregiving.
4) analyze the consequences of caregiving.

Significance

The potential significance of this study arises from 1) the population projections for the aged described earlier, 2) national policies which encourage or force families to provide care for ill elderly members, 3) the changing roles of women in the society, and 4) the lack of knowledge base in nursing and other health disciplines regarding the problems unique to middle-aged caregivers.

As a consequence of the projected increase in the aged population over the next several decades, more families will be confronted with the dilemma of caring for their elderly members. Little research has been done to identify: 1) those premorbid

factors which enhance or deter a family's ability to cope with illness in its elderly members, 2) the successful strategies employed by caregivers, or 3) the consequences (costs and benefits) of parent-caring.

## Chapter II

## Review of the Literature

The scope of the problem under study requires an understanding of the literature from the social, psychological and medical sciences related to: 1) the relationship between adult children and their parents, 2) caregiving to ill, elderly parents, 3) the impact of caregiving, and 4) women as caregivers. Additionally, parent caring is such an important issue in the society that it is highly visible in the lay literature. The final section analyzes the "public" view of parent caring.

### Scientific Literature

#### Relationship between Adult Children and Parents

A review of the literature focused on kinship in the United States,* reveals empirical data do not support the Parsonian view of the "isolated nuclear family." The following statement by Sussman (1965) summarizes the kinship studies of Blenkner (1965), Greenfield (1961), Litman (1971), Rosenmayer (1968), Shanas (1962, 1969, 1973, 1979a, 1979b), Shanas and Streib (1965), and Smith (1965):

> There exists in modern, urban, industrialized societies, an extended kinship family system, highly

---

* The interested reader is referred to two excellent review articles on family structure: Adams (1970) and Troll (1971).

> integrated within a network of social relationships and mutual assistance that operates along bilateral kinship lines and vertically over several generations. (p. 62)

The research on which this summary was based, however, does not assess the strain on family relations caused by increased dependency in old age. Most of the data were collected from families of the "young-old." The increasing number of "old-old" necessitates a rethinking of the kinship issue. Even Sussman (1976) in his more recent work suggests the need for economic incentives to mobilize kin networks in providing care for the infirmed elderly.

Variables influencing kin relations. Although social class and ethnicity influence extended family networks, ethnicity as a variable will be omitted here because the study sample is relatively homogenous. Many investigators note a stronger kinship orientation in working class as compared to middle-class families (Adams, 1971; Bott, 1957; Johnson, 1978; Komorovsky, 1962). However, Troll (1971) points out that the difference lies mainly in the visiting patterns which do not control for the increased mobility of the middle class.

Living arrangements influence kin relations and patterns of support (Shanas, 1969). Living arrangements are the key variable governing community or institutional placement of the elderly

(Brody, 1978). Donahue (1969) reports that three out of ten older people in the United States live in households with their children. Rosenmayer (1968) points out that half of the children in shared households in Austria are unmarried. Surveys conducted in a number of countries indicate that the sharing of households is acceptable only in cases where circumstances necessitate it (Germany: Baumert, 1962; Austria: Rosenmayer, 1968; United States, Britain, and Denmark: Shanas, 1969). However, Shanas (1969), in her cross national study, found that one third to one half of the old persons living separately from their children had at least one child living within ten minutes distance from their home. In Brody's (1974) sample, one quarter of the old people live in households with an adult child, 8% in three generational households, and 5% live with a very old parent.

Several factors foster shared living arrangements. One is economic; for example, grandparents may function as babysitters so that both parents can work or attend school. In some cases, the lower cost of a single dwelling is an incentive. Old people from white collar backgrounds are more likely than those from the working class to live apart from their children (Shanas, 1969).

Sex and marital status influence the decision to share households. Most of the older parents living with children are widowed women (Donahue, 1969). This is statistically expected. However, information on the percent of all elderly females as

compared with the percent of all elderly males sharing dwellings with children is not available. Other reasons for joint households are poor health, frailty and loneliness (Cavan, 1959). Beresford (1969) identifies a trend to share dwellings with relatives when activities or mobility are significantly decreased by a chronic illness. In a recent study of three-generational households in the United States, Neuman (1976) identifies the benefits of a shared residence: affection, enjoyment, contribution to task such as housework, and relief from worry that the older person is being cared for properly.

Kin relations: instrumental. A persistent focus of the intergenerational literature is on monetary exchange between generations (Black & Bengston, 1973; Sussman, 1976; Sussman, Cates, & Smith, 1970). However, this focus inadequately explains the complex intrapsychic, interpersonal, and social dynamics of intergenerational relations complicated by illness or functional loss in older family members.

Shanas (1973) reports that children constitute the primary social support for their elderly relatives. Although two-thirds of the elderly live alone or with a spouse, four-fifths of the elderly in this sample saw a child in the week prior to the interview.

Adams (1968) classifies "contact types" between generations of a family: 1) ceremonial (visits on holidays, birthdays, family

reunions, etc.), 2) home activities (card playing, picnics or meals, conversational visits), 3) social activities requiring the participants to leave their homes, 4) help from the parent to the child, and 5) help from the child to the parent. He also notes the interplay of three important middle class values in the relations of young middle-class adults to their parent(s): 1) the striving for individual success and independence, 2) the transactional nature of social relations, and 3) "filial piety" or the feeling of obligatory concern for one's parents. Unfortunately, the literature lacks contrasting data for upper and lower class families.

Shanas's (1969) classification of aid patterns is more specific than Adams's. She includes: 1) help from the old to the young (gifts to grandchildren, household objects, clothing, food, assistance in home repairs, mending, sewing, yardwork and housework) and 2) help from the young to the old (economic support, personal care, transportation, outings, holidays, cash, food, housekeeping and nursing). Sussman (1976) suggests that a new role for children of elderly parents is to act as a means of re-entry to the health and social systems, and a buffer against the pressures of bureaucracy.

In conclusion, Shanas and Streib (1965) and Townsend (1957, 1965) report that in general older people prefer to maintain independence as long as possible. However, when they can no

longer manage, they expect their children to assume the responsibility for their welfare.

Kin relations: qualitative. Little is known about the qualitative aspects of the parent-child relationship in later life. Clark and Anderson (1967) conclude that a good parent-child relationship depends on the good graces, autonomy and independence of the parent. Johnson and Bursk (1977) explore the affective quality of the parent-child relationship, and the social, psychological and environmental variables which influence it. Their findings indicate that both health and a positive attitude toward aging relate significantly to a positive parent-child relationship.

In summary, research of social scientists notes the existence of an extended family kinship structure among American families. Kinship relations are influenced by social class, ethnicity, and shared housing. The limited research on intergenerational support within kin networks suggests that children provide the primary instrumental support for aged parents. The qualitative aspects of intergenerational relations are essentially unexplored to date.

## Caregiving to Ill Elderly Parents

Accurate descriptive data on the extent of parent caring in the population does not exist. Both Shanas (1969) and Sussman (1965) found that old persons in distress turn to their children for help. Eighty percent of caregiving activities, both medically

related (injections, bandaging, etc.) and personal care (bathing, dressing, feeding, etc.), is provided by families (United States Public Health Service, 1972).

Few studies address the relationship between illness in an older family member and family structure. Although Sussman (1965) observes that the response to illness within generationally linked kin networks remains largely unstudied, he hypothesizes that illness in an older member of the structure would result in instantaneous response from well members, with the children of the ill member responding most vigorously.

On the other hand, Parsons and Fox (1952) suggest that the affective balance of the American family is so delicate that the imposition of a chronic illness could serve to throw it significantly out of kilter. Litman's (1971) exploratory study directed at health attitudes, values, and practices of 210 three generational families appears to support, at least in part, the Parson and Fox position. Half of the families studied indicate they would experience difficulties in caring for a sick family member for a prolonged period of time. Over half of those interviewed indicated a willingness to give up all responsibility for the care of the ill individual to the hospital, believing that convalescence would be better provided at home. However, nearly a third of the families indicated they would be unable to care for a sick person under any circumstances. Finally, while most (75%) of

the younger generation endorsed the notion that an ill family member has the right to expect care from his family, their grandparents voiced less certainty of this.

Treas (1977) identifies new demographic constraints on families in caring for older members. Increased geographic mobility, smaller family size, fewer children, fewer unmarried children, increased participation of women in the work force, and the increased numbers of "old-old" combine and form barriers to family caregiving for older members.

Impact of Caregiving

Variables influencing the impact of caregiving. Variation in the amount of family involvement in caregiving depends on economic resources, competing demands on the caregiver, the type of family structure and household, the amount and duration of physical or functional dependency of the older person (Isaacs, 1972; Sanford, 1975). Shelton's (1948) classic study of caregiving and its impact on families in Wolverhampton, England, assessed the medical and social problems of 477 randomly selected older persons living in their homes. A major finding showed that relatives caring for the elderly in their homes often suffer immense strain because of caregiving activities. Isaacs (1971) found that two-thirds of 280 patients admitted to a geriatric unit were admitted because they failed to receive basic care at home. Neglect by relatives did not constitute a major cause for admission. Hospitalization

usually occurred because of a lack of relatives in the area or because the relatives suffered undue strain on their own health, economic or occupational demands, or the presence of dependent children. In a survey of 612 people referred to a department of geriatric medicine, Isaacs (1972) found that many old persons and their caregivers live under extremely difficult physical and social conditions with great dignity and resilience.

Twelve percent of the admissions to another British geriatric unit resulted from a relative's or family's inability to cope with caregiving activities (Sanford, 1975). Interviews with fifty caregivers in the sample identified problems which could have been alleviated. Problems were categorized as: 1) dependent's behavior, 2) caregiver's own limitations related to the dependent, and 3) environmental and social conditions. Most of the caregivers (92%) identified the problem which needed to be alleviated to restore a tolerable situation for home care. Sleep disturbances and fecal incontinence were common and poorly tolerated problems.

Calkins (1972), using a grounded theory approach assessing the impact of caregiving on families, observed and interviewed medical professionals and 20 working and middle class families with a dying or recently dead family member regarding the burden of custodial care on the families. She found that conditions under which relatives assume care are: close kinship ties and

proximity of residence. The duration of care was determined by the supply of relatives and the patient's awareness of the situation. Re-evaluation of the "burden continuation" occurred with physical deterioration. Calkins found that the obligation to care for the relatives was unquestioned in these families; not to do so would be morally wrong. A superhuman effort was made to keep the person in the home. Neuman (1976) points out that the job of caregiving to ill parents can require the time investment of a full time position. Eggert, Granger, Morris, and Pendleton (1977) suggest that family supports erode over time with competing demands placed on the caregiver.

Mental deterioration and problematic behavior present the most difficult problems for families providing care for elder members (Isaacs, 1971, 1972; Kane & Kane, 1976; Robinson & Thurnher, 1976). In comparing the effectiveness of community versus institutional care for the elderly, Sainsbury and Grad (1976) report that of the families caring for psychiatrically disturbed elderly in the community, 40% consider the burden severe. Over half of the caregivers ascribe their symptoms of emotional disturbance to worry about the patient, and over a third ascribed neurotic behaivor and symptoms (insomnia, headache, depression) to the worry about the elderly person. Behaviors of the older person which the families considered worrisome include: accidental harm to self and others, strange ideas, restlessness,

and perversity. Hirschfeld (1978) reports that a family's ability to continue provision of care to persons with senile brain disease depends not on the functional capacity of the impaired person or the caregiver, but on the tension (number and kind of highly valued unmet needs) resulting from the disease and caregiving situation.

Psychological impact. A small but growing body of literature, primarily psychiatric in perspective, examines the specific effects of caregiving on caregivers. Blenkner (1965) uses the term "filial crisis" to describe the period when 40-50 year old individuals realize they can no longer look to their parents for support in times of trouble, but may themselves need to provide support for failing parents. This "role reversal" is accelerated by illness in the parent, and is often very traumatic for both the parent and child.

Berezin (1970) uses the term "partial grief" for the caregiver's reaction to loss (physical and mental) in the elderly person. The reaction to loss depends on the existance and degree of ambivalence, fixations, regressive movements and the level of libidinal organization. Without intervention, partial grief reaction in family members makes extended caregiving impossible.

Cath (1972) uses a psychoanalytic perspective to analyze the pathos undergone by families in deciding to give care and/or institutionalize a parent. He describes the "something has to be

done" stage during which: 1) the "least favored" child may assume caregiving activities with the unconscious desire for reward or devotion because of the deep-rooted need to establish the once desired special relationship with the parent, or 2) the most favored child now feels guilty for having been favored and seeks to make up. In deciding to bring the parent into a three generational home, Cath suggests that the child caregiver becomes caught between the demands of children, spouse, and increasing obligation to the parent. Old rivalries and jealousies among siblings may be activated at this time. In some families, members act out of grief and defend against rage by withdrawal of affect, and prematurely ending communication, leaving basic issues unresolved.

Physical and psychological impact of caregiving. Danis (1978) interviewed the primary caregiving relative of elderly patients about to be discharged from a hospital or extended care facility. The subjects were re-interviewed two months later. The results indicate that the caregivers--at least at the beginning of their elderly relative's convalescent period--fared physically and emotionally as well or better than the population at large. The report did not include information on the amount and kind of caregiving required, the premorbid relations between the caregiver and recipient, or the caregiver's lifestyle.

In summary, we know that children provide care to elderly parents, often at great expense to themselves. The parental problems causing crisis in caregiving systems and institutionalization (e.g., sleep disturbances and fecal incontinence) are ones amenable to treatment and control with adequate home supports and professional intervention. The most disturbing parental symptom is mental deterioration. The psychological impact of parent-caring to the caregiver is significant. Often families must confront filial crisis and grief reactions with no support.

Information about how caregivers provide for ill parents is missing. Research is needed on the qualitative aspects of the caregiving process, the relationships between and among interactants, and those factors which facilitate or form barriers to caregiving.

Women as Caregivers

Although women usually provide care to the elderly in this society (Adams, 1970; Brody, 1974; Neuman, 1976; Shanas, 1962; Stehaurer, 1968; Sussman, 1965), relatively little research has been undertaken about women caregivers. Basic information about the numbers of women involved in parent-caring and their characteristics is missing. Blenkner (1965) found that parents needing assistance prefer the middle-aged daughter as caregiver. Sussman (1965) reports that married daughters have closer ties to

their parents than sons, and are the ones to help in time of crisis. Adams (1970) suggests "assymetry" of family relations as an explanation of women's involvement in kin activities such as caregiving. He relates the assymetry to: 1) the matrilineal emphasis in intergenerational relations in our society, 2) the mother-daughter bond, 3) the close relationship of the daughter to both parents, and 4) the role of women in kinship.

Related literature from the disciplines of adult development and women's studies has proven useful. Even under optimum conditions, the losses and changes in mid-life can stress women and cause depression (Bart, 1971; Matthews, 1979). Lowenthal, Thurnher, and Chiriboga (1975) in their study of life transitions, found that middle-aged women are the most distressed group. Changes in one's parents (e.g., physical illness or functional loss) serve as stimulants for individual change. They remind one of one's own vulnerability and mortality.

Social supports serve as a buffer against stress (Caplan, 1974). Brown, Bhrolchaim, and Harris (1975) found that a confidant was the most valuable asset for women under stress. Parental caregiving is known to isolate single women (National Council for the Single Woman and Her Dependents, 1978). Danis (1979) found that while 95% of married women interviewed in the GAO Survey indicated that they have a confidant, only 11% named their husband as the confidant. Consequently, it is logical to

assume that caregiving activities may isolate both married and single women from sources of social support.

Spouse caregivers receive more attention in the literature than offspring caregivers. Klein, Dean, and Bogdonoff (1967) and Lopata (1978) identify strains on spouses incurred when caring for an ill person. Fengler and Goodrich (1979) found that low morale scores of wives caring for disabled husbands were predictive of the need for support if institutionalization were to be avoided. Problems encountered by the wives included: isolation, loneliness, economic hardship, and role overload.

The National Council for Single Women and Their Dependents in England provides the only data directly related to the impact of parent-caring on women. The National Council (1976, 1978, 1979a, 1979b) reports on a survey and case studies of its membership. It found that daughters undertake the responsibility of caring for parents from a deep-seated bond of affection, filial obligation, or because there is no alternative. The "carer" is often the only or youngest daughter. When she assumes the role of carer she forgoes career, marriage, and outside activities. Eventually, an intense interdependence develops: the parent becomes more reliant on the daughter, the daughter commits herself more to meeting the needs of the parent. With increasing parental frailty and dependence, what started out as a part-time undertaking becomes a 24 hour a day occupation. Problems confronting single women

caregivers include: low income, loss of personal time, loneliness, no relief from responsibilities, and physical and emotional strain. Many of the caregivers were depressed.

In summary, although women are the major providers of care to ill relatives, we know relatively little about this group. There is sociological and psychological speculation about the reason women provide care. We do know that caregiving creates social isolation, loneliness, and hardship, and that caregiving has a negative impact on a woman's career and economic potential.

## Lay Literature on Parent Caring

The phenomenon of parent caring is such an important issue in the society that it is highly visible in the lay literature. News accounts, novels, and short stories depict and analyze parent caring situations. Anecdotal accounts of parent caring influence the public's view, often over-riding the influence of the limited scientific knowledge in the area. In this section, the author analyzes the "public" image of parent caring in news accounts and literature.

### News Accounts

Newspaper, television, and periodical accounts of parent-caring fall into three general categories: 1) those which focus on the parent, 2) those which focus on the caregiver, and 3) those which focus on the phenomena of caregiving for the family and social system.

Focus on the parent. Newspaper, television, and periodical accounts in the first category are sympathetic to the vulnerable elderly and either ignore or are unsympathetic to the caregiver. They report incidences ranging from benign neglect to physical abuse of parents by their children. On Mother's Day, for example, a San Francisco news team interviewed an elderly woman in her single hotel room residence. The interview focused on her loneliness, isolation, and poverty. It inferred her daughter's irresponsibility for lack of support and contact with the mother. The reporter made no attempt to interview the daughter, or to analyze what are probably complex historical and current interpersonal factors leading to the situation. Headlines like "Parent Abuse--A New Plague, Too Many Elderly People Are Forced to Confront a Violent Enemy--Their Own Children" (Parade, January 27, 1980) create an emotional response in the reader. Articles typically contain brief accounts of frightening incidences of abuse or neglect. "In Chicago, a 19 year old woman confessed to torturing her 81 year old father and chaining him to a toilet for seven days. She also hit him with a hammer when he was asleep."

Focus on the caregiver. The second type of article is equally moving and equally narrow in focus. It treats with sympathy the long-suffering caregiver without assessing the parent's position. "At 61, Tina, a talkative woman with short-cropped dark hair, would like to start taking it easy. Instead,

she is keeping busy seeing her 83 year old father through occasional fits of loneliness and depression when, in her words, he 'smears the guilt like peanut butter.'" (Bergen Record, February 1980). The most widely read account of this nature is "Old Folks at Home" which appeared in Newsweek (Sloan, 1979). Sloan describes his own experience caring for his mother.

> "I have been through it. I have friends who are going through it. Caring, concerned sons and daughters who try, God know they try, but the harder they try, the harder it gets. Their elderly parents who should know better carp and criticize and complain. Instead of compromising they constantly test their children, forever setting up new challenges for them to meet, assuming the one-sided game can go on forever." (p. 14)

Focus on the phenomenon. The weakness of accounts which view parent-caring from the perspective of the parent or caregiver is that they focus on the intrapsychic and interpersonal problems of caregiving from the perspective of one or the other of the interactants. In doing so, they attribute (de facto) blame for problems to the family. The third category of article avoids this pitfall. Articles in the third category analyze the phenomenon of caregiving from the perspective of the parent, the caregiver and the social system. This is a more balanced and constructive

approach to the problem area. "The Hidden Problem: How Middle Income Families Deal with the Need for Long Term Custodial Care" (San Francisco Examiner, March 11, 1977) is an excellent depiction of the ill person and his family as victims not only of illness, but also of an unresponsive social system.

> "At the present moment there is no adequate long term custodial care in San Francisco. Most family doctors possess little information on the resources available or the legal problems involved. Family lawyers often are not familiar with the delicate points of such matters as conservatorships. Social workers, knowing there are no answers, may sound heartless . . . . 'Society is not ready for people with problems like yours.'" (p. 19)

An article from an East Coast paper identifies the toll on families due to the lack of social support.

> "The best of parent-child relationships can deteriorate as the burden of caring persists. Yet there are virtually no social systems for the caretakers, no useful roles for those who require care so that they will continue to feel like persons." (Parade, January 27, 1980, p. 16)

News accounts view parent-caring from three perspectives: that of the parent, that of the caregiver, and a mixed perspective

including the parent, caregiver, and social system. The last perspective, although not common, is particularly useful, in that it allows for an understanding of the social constraints which exist for families engaged in caregiving.

Literature

Fiction is an effective medium for presenting the intrapsychic and interpersonal intricacies of parent-caring: the motivations, societal expectations, impact on the caregiver, and impact on the parent. This section reviews a few of the modern novels and short stories dealing with parent-caring.

Motivations for caregiving are complex. Like many of the caregivers interviewed in this study, Isabel, the primary character in Final Payments (Gordon, 1978), never questioned her engagement in the role of caregiver to her father. "And we were connected by flesh, so if anyone should minister to the decay of my father's it should be me." The daughter who cares for her increasingly demented mother in The Summer of the Great-Grandmother (L'Engle, 1974) describes her motivations, " . . . my belief that we are supposed to share all life with each other, dying and decay as well as feasting and fun . . . ." Both the unquestioning sense of filial obligation and the attribution of meaning to the caregiving experience are common motivations among subjects in the study reported here.

Societal expectations are external variables which affect caregiving. The expectations of society for caregiving as portrayed in the literature are ambiguous. On the one hand, children are indicted for abandoning parents. On the other hand, caregivers are criticized for becoming "too" involved, "he had three more strokes between his first stroke and the day of his death. Can you guess how many times in those eleven years people suggested that I get someone to help, that I get on with my life?" (Gordon, 1978). The ambiguity of societal expectations in the literature reflects the social reality of conflicting expectations of caregivers.

The psychological impact of parent-caring on women is subtle and multi-dimensional. The impact of caregiving on Isabel's daily life, for example, is typical of that described by many of the interviewees in the study reported here.

> In the afternoons he would try to read or sleep, and I would go to the store and try to clean the house. But it always seemed impossible. Life had accumulated around me in the house before I was old enough to fight it; life had grown into the walls so that I began to confuse it with the dust that was everywhere and the magazines that collected that my father did not want thrown away, and the old letters and the grime that I could never get out of the furniture. (Gordon, 1978, p. 4)

Many of the subjects interviewed express the despair and sense of overwhelming invasion of their life described in this passage.

Another consequence of parent-caring is the rekindling of early, unresolved issues in the parent-child relationship. Clara, the oldest child in Tell Me a Riddle (Olsen, 1956), stands at the bed of her dying mother thinking, "Pay me back, Mother, pay me back for all you took from me. Those others you crowded into your heart. The hands I needed to be for you, the heaviness, the responsibility" (p. 116).

The confrontation with her own aging and death is particularly difficult for caregivers.

> If, at night in my bed, it suddenly came upon me that he could go on like this for twenty more years (his heart is strong, the doctors said), and if it came to me that I too was dying, and if in the bathtub I looked at my breasts and my thighs and saw the first signs of aging, and if I realized that for days I would go on not knowing what day it was, having no reason to know, and if I smelt his sick breath and wished for him only to be dead--still, I knew this was mine. (Gordon, 1978, p. 5)

> Now I cry because I want my mother to die.
>
> And I cry out of fear for myself. Will I ever be like that, a travesty of a person? It was the last thing she would have wanted . . . . (L'Engle, 1974, p. 44)

The quotes reflect each character's recognition of her own mortality, and the personal fear of aging and dependence. This is a universal theme in the interviews.

## Summary

A broad spectrum of research and clinical reports related to parent-caring are reviewed: 1) intergenerational family relationships (factors influencing relationships, types of relations and support), 2) caregiving to ill parents, 3) the impact of caregiving, and 4) women as caregivers. There are significant gaps in our knowledge base. Most of the studies in the area use a descriptive survey design. Consequently, the breadth of information available about the phenomenon is greater than the depth of knowledge. The lay literature, for the most part, focuses on emotional anecdotal accounts, demonstrating the "human" side of parent caring without regard to the "normative" experience. What is needed is some middle ground approach. For this reason, a phenomenological approach is used in this study in an attempt to "fill in the gap" in the literature--exploring the phenomenon of parent caring by women in depth by assessing the qualitative aspects of parent-child relationships in the face of increasing dependency in old age.

# Chapter III

# Methodology

## Sample

Thirty caucasian women caring for a chronically ill parent(s) or parent-in-law, and the ill parent participated in the study. The subjects met the following sample criteria:

1) Both the parent and the caregiver live in the urban, western study area.

2) The caregiver lives within thirty minutes of the parent, or in a shared household.

3) The ill parent has a chronic illness which limits his/her functional capacity so that he/she requires assistance in activities of daily living, and/or physical care.

4) Both the caregiver and parent give written permission for the interviews and observations.

## Sample Selection

The investigator identified and contacted agencies which serve the identified population, and which provide services to families from varied socio-economic backgrounds. Agencies delivering home nursing services, day care, homemaker, and general support services provided subjects for the study. In addition, five subjects volunteered for interview after learning of the study through a note in a university newsletter or discussion with friends.

Two caregivers declined participation in the study. Both were highly stressed; both had been referred through the home health agency. They felt that the interview would cause more stress for them because of the time involved and the topics discussed. In general, the aged subjects and caregivers obtained through the home health agency were the most frail, and had the least social and economic supports. The investigator assumes that the refusal of these families biased the sample group toward the healthier, better functioning elderly.

Procedure for Obtaining the Sample

The Committee for Human Research (or equivalent) of participating agencies and the University of California at San Francisco approved the project. After this, the following procedure was followed: 1) the investigator met with her contact person in each of the agencies and explained the study in detail, specifying the sample criteria, 2) the contact person or his/her designate, reviewed the client records to identify potential subjects, 3) a staff member from the agency contacted the potential subject, briefly explained the study, and ascertained the family's willingness to be contacted directly by the researcher, 4) if the family agreed, the investigator explained the study to them in more detail during a home visit and obtained written permission from them to particpate as subjects in the project.

Sample Description

The sample includes 30 caucasian women caregivers and their 31 ill parents or parents-in-law. Most (93.4%) of the women are daughters caring for parents; 6.6% are daughters-in-law caring for parents-in-law. One daughter cares for both her mother and father. The mean age of the caregivers is 53.9 years (range: 30-71); the mean age of the parents is 81.9 years (range: 59-102). All of the caregivers are women; 83.3% of the parents are women and 16.7% are men.

The marital status of the caregivers is: single = 30%, married = 40%, widowed = 13.3%, and divorced = 16.7%. The marital status of the parents is: married = 19.4%, widowed = 71.0%, and divorced = 16.7%. The mean yearly income of the caregivers is just under $10,000 (range: 4,800 - 32,000), and of the parents it is just under $5,000. Approximately half (54.7%) of the parents share a household with the caregiver; 45.2% of the parents live alone.

Instruments

Three types of data were collected: a focused interview, the OARS Multidimensional Functional Assessment, and participant observation.

Focused or Intensive Interview

(See Appendix II, page _____ for the interview guide.)

The investigator analyzed the phenomenon of parent-caring theoretically and clinically. She used the analysis to develop a

guide for a focused or in-depth interview (Lofland, 1971; Merton, Fiske, & Kendall, 1956). The interview obtains data from the caregiver related to: 1) the types of caregiving activities she performs, 2) the meaning of caregiving to her, 3) changes in her life resulting from caregiving (activities, income, relationships, habits), 4) supports in caregiving, and 5) decision making about caregiving. The interview guide was pretested with ten caregivers in 1978 and appropriate modifications were made (Archbold, 1980a).

OARS Multidimensional Functional Assessment Questionnaire (OMFAQ)

The OARS questionnaire (Pfeiffer, 1975, 1976; Laurie, 1977) measures the subject's functional level at the time of administration in each of the following areas: social resources, economic resources, mental health, physical health, and activities of daily living. A description of the individual sections and the cumulative scoring follows.

Social resources. Questions in this section assess the subject's social interactions in relation to their extent, quality, and availability. Specific assessment of marital status, living arrangements, the presence of a confidant and the availability of help in time of illness is included.

Economic resources. Items in this section assess the employment status, income and home ownership of the subject in addition to the subject's subjective evaluation of his/her financial status.

Mental health. Questions in this section assess several factors: intellectual functioning (orientation, recent and long term memory, and calculation), psychiatric symptomatology and the subject's subjective assessment of his/her mental health.

Physical health. Items in this section assess the number of physician visits, disability days and days spent in a hospital or nursing home, prescription and nonprescription drugs taken, and the presence of illness.

Activities of daily living. Items assess the individual's 1) capacity for living independently (e.g., use telephone, use public transportation, shop, prepare meals, do housework, take medications, and handle money), and 2) capacity to care for bodily functions.

Cumulative scoring. Data from each of the sections can be summarized in a single summary rating using the guidelines which accompany the instrument. The ratings are assigned a numerical value: 1 = outstanding functioning, 2 = good functioning, 3 = mild impairment, 4 = moderate impairment, 5 = severe impairment, and 6 = complete impairment. Summary ratings are made for each of the sections. The scores from the individual sections are added to form the "cumulative impairment score" (CIS). In general, CIS scores below 10 indicate excellent overall functioning, and CIS scores of 18 or more indicate that significant impairment exists in several areas.

The OARS provides a standardized means of collecting and recording comprehensive descriptive data. Additionally, specific items stimulate discussion of the subject's daily life which adds richness to the qualitative data. The reliability and validity of the instrument are satisfactory. The main limitation of the instrument is its length: it requires approximately one hour for administration and is boring for intact subjects and too long for the attention span and tolerance of intellectually impaired subjects.

### Participant Observation

The investigator used participant observation through out the data collection process. She observed: 1) the physical environment of the homes, 2) the functional status of the parent and caregiver, and 3) the verbal and nonverbal interactions between and among family members.

## Data Collection

Data were collected between October 1979 and March 1980. The process of data collection and the conditions under which it occurred are described below.

### Process

The data collection began with the focused interview with the caregiver. This section of the interview is less structured than the OARS, and allowed the subject to become comfortable with the investigator. Responses were recorded in writing during the

interview. The length of the focused interview depended on the caregiver's responses. The time ranged from one to four hours in one to three interview sessions.

The investigator administered the OARS to the caregiver in a separate interview session. Finally, the investigator administered the OARS to the parent in a one hour session. The caregiver served as informant for those parents with intellectual limitations.

Conditions

The interviews were conducted in the subject's home. The investigator requested that privacy be ensured in the selection of setting within the home. This was not always possible because of space limitations. In two cases the parent was present or nearby during the interview with the caregiver. In a third case, the spouse of the caregiver was present during the focused interview. Both situations inhibited the caregiver's response.

Three of the caregivers requested that the interviews be conducted in the investigator's office. They indicated that they would feel more free to respond openly outside the caregiving environment. Although this decreased the time for participant observation, the investigator decided that caregiver openness in response warranted this change in procedure.

Procedural Problems

Two procedural problems occurred during the data gathering process. The first related to the nature of the consent form. The study clearly focuses on the caregiver, and the consent form reflects this focus. It is the investigator's impression that some of the parents (particularly those with a difficult relationship with the caregiver) viewed the investigator as an ally of the caregiver after reading the consent form. This limited the quality of the parents' responses.

The second problem related to the investigator's dual identity as a researcher and clinician. In her clinical judgment, some of the caregivers benefited from the discussion of their situation. For them, the length of the interview was extended. For other caregivers, the interview was stressful because it necessitated articulating painful content. This raised the visibility of the difficulties the caregiver experienced in the caregiving situation. The investigator offered referral information about services available to caregivers when they requested it, or when she felt it was indicated.

## Data Analysis

Three types of data were collected from subjects: 1) unstructured interview data, 2) observations of their social setting and behavior, and 3) structured interview data. The data analysis involved several steps.

1) Qualitative analysis (Glaser, 1978; Glaser & Strauss, 1967) of the unstructured interview data and the observations began during the data collection phase. This process identified: a) two main categories of caregiving behavior (provision and management), and b) a process of caregiving.

2) All data were separated into two categories: provider data and manager data.

3) Qualitative analysis of the provider and manager data permitted identification of differences and similarities between the groups in the process of caregiving: a) variables influencing the choice of caregiving modality, b) strategies developed and implemented to handle caregiving-related problems, and 3) the consequences of caregiving activities.

4) Quantitative data (from the OARS) were correlated with caregiving styles to identify areas of similarities and differences in social resources, economic resources, mental health, physical health and activities of daily living between the two groups. The chi-square statistic was used to analyze the differences between the groups.

Chapter IV

Findings and Analysis

Qualitative analysis of the data identified 1) caregiving modalities and 2) a process of caregiving. Unlike most of the previous work in the area, which focuses on the psychological and emotional aspects of caregiving, this study examines the social and behavioral precedents and consequences of parent-caring.

## I. Modalities

Analysis of the interview and observational data identified two caregiving modalities: care provision and care management. The care-provider identifies those services the parent requires and performs them herself. The care manager identifies the needed services and manages their provision by others.

Another method of caregiving is theoretically possible: complete transference of care to another caregiving agent. Individuals selecting this option were ruled out of the study by the sample criteria. Transference could be done to an institution, such as a nursing home, or to a community agent. The institutionalization of a parent has received considerable attention in the literature (Brody, 1977; Krauss, 1976a, 1976b; Smith & Bengston, 1979). Transference to a community agent is not an available option in the study area, or in the country at the present time. The role had been enacted by visiting nurses prior

to the increased costs of care and implementation of the current insurance policies.

In summary, there are three options for parent-caring open to women: 1) care-provision, 2) care-management, and 3) care-transfer. This study focuses on two of the caregiving modalities: care provision and care management.

## II. Process

The process of parent-caring is discussed in terms of its structural components: 1) factors influencing the initial decisions about caregiving, 2) the decision to provide or manage care, 3) the characteristics of providers and managers, 4) the strategies used by caregivers, 5) the consequences of caregiving, and 6) modifications of caregiving decisions.

The organizational structure suggests that caregiving is a static phenomenon. In reality, this is not the case. Caregivers continually re-evaluate the costs and benefits of caregiving. The concluding section analyzes the major shifts in caregiving strategies made by subjects in relation to the caregiver's retrospective assessment of the cost/benefit ratio.

## III. Factors Influencing the Initial Decisions about Caregiving

This section addresses those variables which influence the caregiver's decision to provide or manage the care of her parent. The variables are categorized into caregiver characteristics and

parent characteristics. Caregiver characteristics found to influence the initial decision about caregiving include: 1) socio-economic status, 2) housing, and 3) previous experience with caregiving. Parent characteristics which influence the initial caregiving decisions include: 1) the degree of parental functional limitation and 2) the type of illness onset.

## Caregiver Characteristics

### Socio-Economic Status

The care-managers are from a higher socio-economic background than the providers. Socio-economic status, as indicated by income, education, and occupation, is important in the decision to provide or manage care. Holding constant the availability of community resources, income is the primary determinant of whether and how many services can be purchased. In general, a caregiver with a higher income has more options and flexibility in obtaining services to meet her parent's needs than a caregiver with a low income. The average yearly income of the managers ($15,000-19,999) is higher than that of the providers ($7,000-9,999). The average income of providers is significantly more impaired than those of the managers.

Table 1
Distribution of Caregivers' Scores
on the OMFAQ Economic Rating Scale

| Economic Resources Rating | Providers # | Providers % | Managers # | Managers % | Total # | Total % |
|---|---|---|---|---|---|---|
| Excellent | 1 | 6.7 | 5 | 33.3 | 6 | 20.0 |
| Satisfactory | 7 | 46.7 | 9 | 60.0 | 16 | 53.3 |
| Mildly Impaired | 5 | 33.3 | 1 | 6.7 | 6 | 20.0 |
| Moderately Impaired | 1 | 6.7 | 0 | 0.0 | 1 | 3.3 |
| Severely Impaired | 1 | 6.7 | 0 | 0.0 | 1 | 3.3 |

Chi Square test: p = not significant

The economic rating scale takes into account equity in a home; many of the providers own a home, but have a very limited income. Their scores on the economic resources rating scale are disproportionately elevated because of the unusually high property values in the study area.

The educational level of the managers in the sample is higher than that of the providers. Qualitative analysis of the unstructured data suggests that the problem solving required for care management is quite different from that required by care provision (see Section V for a discussion of the strategies used by both groups). It is likely that the differences in problem solving and strategy development relate: 1) to the increased flexibility provided by the managers' income and 2) the higher educational level of the managers.

Table 2
Caregivers' Educational Level

| Education | Providers | | Managers | | Total | |
|---|---|---|---|---|---|---|
| | # | % | # | % | # | % |
| 5-8 grade | 1 | 6.7 | 2 | 13.3 | 3 | 10.0 |
| High school (incomplete) | 3 | 20.0 | 0 | 0.0 | 3 | 10.0 |
| High school | 6 | 40.00 | 2 | 13.3 | 8 | 26.7 |
| 1-3 years college | 2 | 13.3 | 2 | 13.3 | 4 | 13.3 |
| College graduate | 1 | 6.7 | 3 | 20.0 | 4 | 13.3 |
| Post college | 2 | 13.3 | 6 | 40.0 | 8 | 26.7 |

Chi Square: p = not significant

Occupation is determined in part by educational level. In this sample, a majority of the managers (66.7%) are employed full-time; all seven of the professional women are in this group. Only 20% of the provider group is employed. The nature of her work influences the caregiver in several ways. The impact of income on options has already been discussed. Career commitment, more prevalent among women in positions highly valued by the society, provides a salient competing role to caregiving. The lawyers, physicians, and other professionals in the sample are clear that their work is important, and that caregiving must be fit in around it. "I am a lawyer, I had prepared all those cases. No one else could present them. I could not take off large amounts of time during the week. It was just impossible." This clarity in the importance of the occupational role enables the managers to dele-

gate parent-caring activities with little conflict. It did not occur to any of the professional women in the sample to give up their positions or to decrease their working hours.

In contrast, those providers who are working are not career oriented. Their occupational roles (secretarial, volunteer, housewife) are less valued by the society. Additionally, the salary provided by their work is not enough to purchase needed services for the parent. Providers become torn between their work and their feeling of obligation to their parent. In two cases, parent-caring provided an opportunity for the caregivers to resign from undesirable work situations.

An indirect benefit of higher socio-economic status is contact with a broad range of social supports. The networks of managers include lawyers, physicians, nurses, and social workers. As a result, knowledgeable professional advice is available to many managers "unofficially" and at no cost. A number of managers discussed specific assistance they received from friends:

> The social worker next door has been very helpful. Anytime I've had a question she has been right there. She came in the night Mom had the stroke and did an assessment. The next day she got a doctor from her hospital for Mom.

> I finally had to ask a friend, a doctor, to intervene. My questions only made the doctors and nurses irritated. He could say a few things and get results.

Providers, on the other hand, have significantly fewer social supports in general. None have unofficial connections with the health or legal systems. Providers make contact with these systems without the assistance of an "insider." Thus, ease of access and knowledge of options are limited.

Table 3
Distribution of the Caregivers' Scores
on the OMFAQ Social Resources Rating Scale

| Social Resources Rating | Providers # | Providers % | Managers # | Managers % | Total # | Total % |
|---|---|---|---|---|---|---|
| Excellent | 0 | 0.0 | 6 | 40.0 | 6 | 20.0 |
| Good | 5 | 33.3 | 8 | 53.3 | 13 | 43.3 |
| Mildly Impaired | 4 | 26.7 | 1 | 6.7 | 5 | 16.7 |
| Moderately Impaired | 6 | 40.0 | 0 | 0.0 | 6 | 20.0 |

Chi Square test: $p = 0.0023$

It is clear that higher socio-economic status, including income, education, and work is advantageous to caregivers. The income provides the money necessary to purchase services, the education provides the knowledge or process of obtaining the

knowledge of resources, the highly valued work role provides a source of personal self-esteem, income, and clarity in decisions about parent-caring, and the higher social status provides social supports of greater instrumental value.

Housing

Shared housing by the parent and caregiver influences the decision to provide or manage care. Shared housing is a characteristic of the providers (73.3%) more than managers (37.5%). Women who shared homes with their parent(s) prior to the parents' illness become providers in the initial phases of caregiving.

Previous Experience as a Caregiver

Qualitative analysis of the interview data suggests that a woman's successful and rewarding engagement in previous caregiving roles will facilitate her assumption of the provider role. Four of the providers had been caregivers in the past: two for their own mentally retarded children, one for an ill husband, and one for a series of extended family members. Although it is a very small percentage of the sample, it is interesting because previous positive experience with care-provision overrides socio-economic factors in determining caregiving modalities. The opportunity of caregiving to an ill parent is viewed by these women in a very positive light. Their previous experience in the role was satisfying and personally valued by them. Parent-caring added significance to their lives.

## Parent Characteristics Influencing the Decision to Provide or Manage Care

### Onset of Illness

The onset of parental illness is related to the initial decisions to provide or manage care. In general, illnesses with a slow onset are associated with a decision to provide care. An acute onset of illness in the parent is more likely to be associated with care management than care provision.

Slow onset. A slow, incremental onset and progression of illness and functional loss, as one sees in arthritis and mild congestive heart failure, often requires only minor support activities, such as lawn work, in the initial phase of illness. These services require a minimum of time and energy investment and are usually provided by the caregiver.

Rapid onset. A sudden onset of parental health failure, as one sees in a stroke, creates a situation in which deliberate and immediate decision-making about caregiving is necessary. Caregivers usually observe the sudden, dramatic loss of parental functional ability in the controlled environment of the hospital. Based on their observations in this setting, and other pre-existing factors (work, family responsibilities, the relationship with the parent, etc.), the caregivers decide how and where the parent will be cared for. Most women decide to manage care in the event of an acute onset of illness leading to severe functional impairment.

In summary, several factors influence the caregiver's decision to provide or manage care for her ill parent. Caregiver characteristics influencing the decision include: socio-economic status (including income, education, and occupation), pre-illness shared housing with the parent, and previous experience with caregiving. Parental characteristics influencing the decisions about caregiving are the degree of functional impairment and the nature of the illness onset.

The next section presents the characteristics of the provider and manager groups. Since the availability of community services determines, in part, the options open to caregivers, the final section describes the community resources in the study area.

## IV. Characteristics of the Providers, Managers, Parents, and Communities

The demographic, social, and health characteristics of the providers and managers and their parents are compared for similarities and differences. Those characteristics which influence the decision to provide or manage parent-caring (caregiver education, economic resources, housing, and social resources) appear in the section on Factors Influencing Caregiving Decisions. The characteristics of the study communities are described in terms of services available to caregivers.

### Caregiver Characteristics

Age. The mean age of providers (56.86 years) is greater than the mean age of the managers (51.06 years).

Marital status. Forty percent of both the provider and manager groups are married; 60% of both groups are single, divorced, or widowed. Nearly half of the manager group have always been single, as compared to 13.3% of the providers.

Table 4
Caregiver Marital Status

| Marital Status | Providers | | Managers | | Total | |
|---|---|---|---|---|---|---|
| | # | % | # | % | # | % |
| Single | 2 | 13.3 | 7 | 46.7 | 9 | 30.0 |
| Married | 6 | 40.0 | 6 | 40.0 | 12 | 40.0 |
| Widowed | 4 | 26.7 | 0 | 0.0 | 4 | 13.3 |
| Divorced | 3 | 20.0 | 2 | 13.3 | 5 | 16.7 |

Table 5
Caregiver Employment Status

| Employment Status | Providers | | Managers | | Total | |
|---|---|---|---|---|---|---|
| | # | % | # | % | # | % |
| Not Employed | 12 | 80.0 | 5 | 33.3 | 17 | 56.7 |
| Employed | 3 | 20.0 | 10 | 66.7 | 13 | 43.4 |

As noted in the previous section, caregiver career is a critical variable influencing decisions about care-provision or

management. A large majority of care-providers (80%) are not employed, whereas 67% of the managers are employed.

Table 6
Caregiver Retirement Status

| Retirement Status | Providers | | Managers | | Total | |
|---|---|---|---|---|---|---|
| | # | % | # | % | # | % |
| Not Retired | 8 | 53.3 | 15 | 100.0 | 23 | 76.7 |
| Retired | 7 | 46.7 | 0 | 0.0 | 7 | 23.3 |

A greater percentage of providers than managers were retired at the time of parental illness onset, and even more had retired by the time of the interviews. Retirement provided the women the "freedom" to assume the direct care-provider role.

Distribution of the Caregivers on the OMFAQ Rating Scales

Please see the section on influencing variables for the social and economic resource rating scales of the caregivers.

Table 7
Distribution of Caregivers' Scores
on the OMFAQ Mental Health Rating Scales

| Mental Health Rating | Providers # | Providers % | Managers # | Managers % | Total # | Total % |
|---|---|---|---|---|---|---|
| Excellent | 0 | 0.0 | 1 | 6.7 | 1 | 3.3 |
| Good | 8 | 53.3 | 10 | 66.7 | 18 | 60.0 |
| Mildly Impaired | 2 | 13.3 | 3 | 20.0 | 5 | 16.7 |
| Moderately Impaired | 5 | 33.3 | 1 | 6.7 | 6. | 20.0 |

Chi Square test: p = not significant

Table 8
Distribution of Caregivers' Scores
on the OMFAQ Physical Health Rating Scales

| Physical Health Rating | Providers # | Providers % | Managers # | Managers % | Total # | Total % |
|---|---|---|---|---|---|---|
| Excellent | 2 | 13.3 | 8 | 53.3 | 10 | 33.3 |
| Good | 9 | 60.0 | 7 | 46.7 | 16 | 53.3 |
| Mildly Impaired | 3 | 20.0 | 0 | 0.0 | 3 | 10.0 |
| Moderately Impaired | 1 | 6.7 | 0 | 0.0 | 1 | 3.3 |

Chi Square test: p = 0.0492

Low socio-economic status and increased age combine to increase the provider's risk for impairment in physical and mental health. The provider's ratings for physical health indicate

significantly more impairment than the ratings of the managers. Hypertension is the most commonly treated problem among providers.

Table 9
Distribution of Caregivers' Scores on the OMFAQ
Activity of Daily Living (ADL) Rating Scale

| ADL Rating | Providers | | Managers | | Total | |
|---|---|---|---|---|---|---|
| | # | % | # | % | # | % |
| Excellent | 11 | 73.3 | 14 | 93.3 | 25 | 83.3 |
| Good | 3 | 20.0 | 1 | 6.7 | 4 | 13.3 |
| Mildly Impaired | 1 | 6.7 | 0 | 0.0 | 1 | 3.3 |

Chi Square test: p = not significant

Cumulative impairment scores of caregivers. The cumulative impairment score represents the total of the five rating scores of the OARS (ratings for social and economic resources, mental and physical health, and activities of daily living functional capacity). In general, the higher the combined scores, the greater the functional impairment. The providers' mean CIS score is 12.00; the managers' mean CIS score is 7.7. Providers, as a group, are significantly more impaired than managers. Cumulative impairment scores below 10 indicate good functioning; scores from 10-18 indicate moderate impairment.

Table 10
Duration of Parent-Caring

| Duration of Parent-Caring (in years) | Providers # | Providers % | Managers # | Managers % | Total # | Total % |
|---|---|---|---|---|---|---|
| 0-1 | 2 | 13.3 | 4 | 26.6 | 6 | 20.0 |
| 1-2 | 2 | 13.3 | 1 | 6.6 | 3 | 10.0 |
| 2-5 | 1 | 6.6 | 7 | 46.6 | 8 | 53.3 |
| 5 and more | 10 | 66.6 | 3 | 20.0 | 13 | 43.3 |

The duration of parent-caring in the sample varied for providers and managers. Two-thirds of the providers have cared for their parent for 5 years or more; whereas, 80% of the managers have been involved in caregiving for less than five years. This may reflect the provider's limited economic resources, decreasing their options for care transfer. Duration and intensity of caregiving is one of the major causes of shifts in caregiving modalities (see Section VII).

Parent Characteristics

Age. The mean age of the parents of providers is 82.26 years; the mean age of the parents of managers is 81.56 years.

Table 11
Sex and Relationship to Caregiver

| Sex of Parent | Relationship to Caregiver: Parent # | Parent % | Parent-in-law # | Parent-in-law % | Total # | Total % |
|---|---|---|---|---|---|---|
| Male | 5 | 17.3 | 0 | 0.0 | 5 | 16.0 |
| Female | 24 | 82.7 | 2 | 100.0 | 26 | 84.0 |

Most of the parents in the sample (84%) are women; only 16% are men. In one of the sample families, both parents receive care from the caregiver; in all other families, the ill parent is widowed or divorced, or the spouse is unable to provide care.

Table 12
Distribution of Parents' Scores
on the OMFAQ Social Resources Rating Scale

| Social Resources Rating | Providers # | Providers % | Managers # | Managers % | Total # | Total % |
|---|---|---|---|---|---|---|
| Excellent | 5 | 33.3 | 6 | 37.5 | 11 | 35.5 |
| Good | 3 | 20.0 | 8 | 50.0 | 11 | 35.5 |
| Mildly Impaired | 3 | 20.0 | 1 | 6.3 | 4 | 12.9 |
| Severely Impaired | 4 | 26.7 | 1 | 6.3 | 5 | 16.1 |

Chi Square test: $p = 0.0023$

The differences between the parents of providers and managers in social resources are statistically significant. The parents of providers are more impaired than the parents of managers.

Table 13
Distribution of Parents' Scores
on the OMFAQ Economic Resources Rating Scale

| Economic Resources Rating | Providers # | Providers % | Managers # | Managers % | Total # | Total % |
|---|---|---|---|---|---|---|
| Excellent | 0 | 0.0 | 3 | 18.8 | 3 | 9.7 |
| Satisfactory | 4 | 26.7 | 6 | 37.8 | 10 | 32.3 |
| Mildly Impaired | 5 | 33.3 | 7 | 43.8 | 12 | 38.7 |
| Moderately Impaired | 4 | 26.7 | 0 | 0.0 | 4 | 12.9 |
| Severely Impaired | 2 | 13.3 | 0 | 0.0 | 2 | 6.5 |

Chi Square test: p = not significant

The economic resources of the managers' parents are greater than the economic resources of the provider's parents, although the difference is not statistically significant.

Table 14
Distribution of Parents' Scores
on the OMFAQ Mental Health Rating Scale

| Mental Health Rating | Providers # | Providers % | Managers # | Managers % | Total # | Total % |
|---|---|---|---|---|---|---|
| Excellent | 0 | 0.0 | 0 | 0.0 | 0 | 0.0 |
| Good | 5 | 33.3 | 3 | 18.8 | 8 | 25.8 |
| Mildly Impaired | 1 | 6.7 | 6 | 37.5 | 7 | 22.6 |
| Moderately Impaired | 2 | 13.3 | 5 | 31.3 | 7 | 22.6 |
| Severely Impaired | 5 | 33.3 | 1 | 6.3 | 6 | 19.4 |
| Completely Impaired | 2 | 13.3 | 1 | 6.3 | 3 | 9.7 |

Chi Square test: p = not significant

The differences between the mental health ratings of the providers' parents and the managers' parents is not significant. The mean score of the providers' parents on the Short Portable Mental Status Questionnaire (SPMSQ) is 5.26; the mean score of the managers' parents is 5.0. Scores of 5-7 on the SPMSQ indicate moderate intellectual impairment.

Table 15
Distribution of Parents' Scores
on the OMFAQ Physical Health Rating Scale

| Physical Health Rating | Providers # | Providers % | Managers # | Managers % | Total # | Total % |
|---|---|---|---|---|---|---|
| Mildly Impaired | 4 | 26.7 | 6 | 37.5 | 10 | 32.3 |
| Moderately Impaired | 3 | 20.0 | 4 | 25.0 | 7 | 22.6 |
| Severely Impaired | 7 | 46.7 | 6 | 37.5 | 13 | 41.9 |
| Totally Impaired | 1 | 6.7 | 0 | 0.0 | 1 | 3.2 |

Chi Square test: $p = 0.0492$

Differences in physical health ratings between the providers' parents and the managers' parents are significant. The parents of providers are more impaired than the parents of managers.

Table 16
Distribution of Parents' Scores on the OMFAQ
Activity of Daily Living (ADL) Rating Scale

| ADL Rating | Providers | | Managers | | Total | |
|---|---|---|---|---|---|---|
| | # | % | # | % | # | % |
| Mildly Impaired | 5 | 33.3 | 5 | 31.3 | 10 | 32.3 |
| Moderately Impaired | 2 | 13.3 | 6 | 37.5 | 8 | 25.8 |
| Severely Impaired | 5 | 33.3 | 4 | 25.0 | 9 | 29.0 |
| Completely Impaired | 3 | 20.0 | 1 | 6.3 | 4 | 12.9 |

Chi Square test: p = not significant

The differences in the scores of the parents of providers and managers on the activity of daily living ratings are not statistically significant.

Cumulative impairment scores (CIS). The mean CIS score of the providers' parents is 19.40; the mean CIS score of the managers' parents is 16.56. CIS scores of 18 and over indicate that significant impairments exist in several areas of functioning. Scores of 10-18 indicate a moderate impairment in several areas of function. Although the differences between providers' and managers' parents on three of the individual rating scales are not statistically significant, each shows a trend toward more impairment for the provider group. These differences are accentuated when the scores are totaled. The parents of providers are more impaired in general than the parents of the managers.

Characteristics of the Study Communities

Subject families required support services in order to provide care for ill parents. This section discusses two key aspects of service delivery to parents and caregivers: 1) the availability and distribution of services and 2) information about and referral to appropriate services.

Community services for ill elderly. The chronically ill elderly in the sample have functional disabilities reflective of those found in the general population over 65 years of age except for cognitive impairment. The functional impairments range from the inability to do yard work and heavy housework to the inability to bathe or feed oneself. Thus, the supportive services required by the parents range from minor assistance (e.g., short term help with house maintenance and telephone checking) to major assistance (e.g., daily personal and nursing services, housekeeping, etc.).

While isolated support services do exist, the full range of services does not exist in the study community, or in the country as a whole. Services are usually developed either: 1) in response to a specifc need of a particular consumer group or 2) in response to private and public funding guidelines. Consequently, the ideal situation, in which a continuum of organized services is available to families, is far from a reality. Limitation in reimbursement guidelines for Medicare and Medical further decrease the service options available to families.

The location of the study is a large, progressive metropolitan area and its suburbs. The locale has a history of developing and supporting innovative public and voluntary social and health services. At the time of the study, however, public support for human services in general had diminished. Voluntary and public services used by sample subjects include: visiting nurse, home health aides, day care, and homemakers. The staff in the agencies used for obtaining the sample are increasingly frustrated, because they are unable to deliver needed services to their clients due to restrictions in the reimbursement guidelines and funding cutbacks.

The family is expected to provide the continuum of services required by its parent. Many families need help in providing services to their parent. Because help is decreasingly available through public and voluntary sources, the private sector responds with profit-making service systems. Five of the study families used private nursing and homemaking services. Unfortuantely, the cost of such services precludes their use by average families. Private services used by sample families include: private nursing services, homemakers, sitters, and ambulance transportation.

Community services for caregivers. Services for caregivers are even more limited than for ill parents. A major problem confronting caregivers is their isolation from each other. Caregivers represent a hidden, at risk population. They are not

visible to each other, or to professionals, except through their parent. The greater the functional impairment of the parent, the more homebound the caregiver is. Consequently, the most hidden population of caregivers is that with the greatest burden of caregiving.

Some of the voluntary agencies providing care to ill elderly recognize the need for support services for caregivers. Several of the study subjects report on the benefits of the support groups for caregivers established by the staff of day centers for the elderly. One family participated in the self-help group initated by family members of cognitively impaired adults. The subject found this group very helpful. All of the caregivers involved in caregiver-support groups valued the services.

Organization of the service network. The limitations of the public and voluntary services available to impaired elderly and their caregivers are severe. However, even when services do exist, information about them (specific services offered, eligibility requirements, funding policies) is difficult to obtain. Neither the sample families, nor the professionals in the agencies, have a clear idea of the range of services available in the communities, despite the publication of a local service directory. Several factors contribute to the lack of clarity of the service network: 1) Programs change rapidly in response to funding, interests and availability of staff, and client needs.

Therefore, knowledge obtained about services at one point in time might be inaccurate later. 2) The reimbursement policies and benefits of the federal and state insurance programs change and serve to limit service options. Brochures and policy statements about benefits are written at a level which is difficult for many older clients and family members to comprehend.

The result is a frustrating situation in which families must engage in a difficult community assessment to discover even partial information of the service network. The fortunate family makes contact with a knowledgeable professional early in their exploration phase. Although this does not guarantee that they will obtain complete information, it decreases their "leg work." "The social worker at the hospital told us about the home health agency--they have been real helpful." Once "hooked into" the service system, access to more information is facilitated. "I don't know what we would have done without Kathy [social worker at the day center]. She gave us the information on meals-on-wheels, homemaker services, and everything."

A second type of service "non-system" exists. Private nurses, housekeepers, and aides are available to care for the elderly on a fee-for-service basis. The sources of information about this type of help are: physicians, ministers and priests, newspapers, and registries. Few of the families in the sample could afford private services.

## V. Strategies

> The hardest physical job of the day was getting Cornelius up and dressed; it took patience and good humor, and in preparation for it she drank a second cup of coffee . . . ." (Sarton, 1970, p. 312)

It is clear that the tasks and problems encountered by providers and managers of care differ substantially. Providers require skills in individual assessment of functional ability and the planning and implementation of a method to assist the impaired person. Managers of care require skills in both individual and systems assessment, as well as in negotiation with the social system. The strategies used by caregivers impact on their own lives and the lives of the parent and other family members. In this section three types of strategies described by caregivers are discussed: 1) caregiving strategies, 2) strategies to manage their own reactions to parent-caring, and 3) strategies to manage the reaction of other family members to parent-caring.

### Strategies for Parental Problems

Whether a caregiver uses a provider or managerial style, the strategies for parent-caring fall into three categories--those which: 1) assist the parent with the activities of daily living, 2) manipulate the environment to decrease the problems encountered, and 3) modify the parent's behavior.

## Provider Strategies Which Assist the Parent with Problems of Daily Living

Predictably, women who provide services directly to the parent, rather than manage the service provision of others, are immersed in the daily routine required for meeting the parent's need for physical care. Their time and energy are devoted to the heavy physical labor involved in assisting an impaired person with the problems of daily living. A majority of this group list assistance with nursing care, bathing, toileting, feeding, food preparation, home maintenance, and housekeeping as the caregiving activities they regularly performed:

> I do everything for her, really. Bathing, dressing, cooking, getting her in and out of bed, onto the commode . . . .

> Every evening I clean her, change and bathe her and make her bed. Everyone looks to me as if it were my problem. We [husband and caregiver] do everything--banking, purchasing, taking care of the yard, everything.

> I prepare her food, do the bathing, lay out her clothes, put on pads for incontinence, watch her diet so she does not get loose bowels--everything.

Every small aspect of daily life is planned. The key tasks of eating, elimination, and sleep require concentrated planning to be accomplished smoothly. Food planning, for example, is done in relation to: 1) the functional capabilities of the parent in relation to self-feeding and swallowing, digestion and elimination, 2) parental food preferences, 3) budget, and 4) preparation time. Interestingly, provision of a variety of foods is not a consideration in planning. Once a food, for example oatmeal for breakfast, is found successfully to meet the criteria listed above, it is used consistently:

> He always liked soup, but now it is hard for him to eat it because of the shaking. He can manage really thick soups from a cup, so that's what I make everyday for lunch.

It often requires a lot of experimentation before a satisfactory procedure is worked out. Once it is established, therefore, it is rigidly adhered to.

Bowel management. All the providers identified strategies for maintaining regular bowel functioning in their parent. The strategies served two purposes: 1) to prevent constipation and 2) to prevent incontinence. Strategies vary in complexity, but usually involve the regular administration of prune juice, periodic laxatives, and/or enemas. The planning and implementation of bowel strategies are of major importance to all

the parents and caregivers. "Every night I give her a laxative. Then in the morning she has a cup of coffee and a glass of prune juice for breakfast. Then she sits on the toilet." This is a relatively straight forward management regime for constipation, but it requires thought and action several times a day. Problems in the area of bowel incontinence are particularly difficult for parents and caregivers. Accidents are a source of embarrassment and shame for the parent, and disgust for the caregiver. "Both our days are completely ruined if something goes wrong [parent is incontinent of feces]. It takes her a few days to recover."

Mobility management. Caregivers develop routines for technically difficult tasks like transferring the immobile parent from a bed to a chair. For example, one small caregiver assists a large parent in getting out of bed with a systematic series of manageable activities. The routine demonstrates that she had identified all the components of the transfer. She accomplishes each of the component acts individually. Both parent and caregiver know the 15 minute routine which involves: 1) clearing the area around the bed, 2) folding the covers in a particular way, 3) pulling a large chair close to the left side of the bed, 4) raising the head of the bed to a specific position, 5) pulling her legs over the side of the bed, 6) pulling the person to a sitting position, 7) putting on the parent's robe and slippers, 8) positioning the parent's feet on the floor, 9) resting, 10) assis-

ting the parent to a standing position, 11) placing the parent's right hand on the arm of the chair, 12) turning the parent, and 13) assisting the parent to sit gently. Another set of predictable behaviors follows this activity, and includes providing a warm covering, obtaining fluids for drinking, and turning of the television.

Rest management. Preparation for sleep is also an important ritual among parents. There is a great deal of individual variation in the specific behaviors involved. Behavioral sequences which, on the surface appear inconsequential, are essential for the parent to sleep. Care-providers become part of the ritual by carrying out associated tasks. "I have to sit next to Mom's bed every night while she drinks her tea. When I leave I turn the night light on and the big light off. This makes her feel secure."

Scheduling. The strategies used by providers also relate to the timing of tasks. For example, thought is given to what time of day is best for those activities which require uninterrupted blocks of time (e.g., bowel management, bathing, and meals). These tasks become the focal points of the parent's and care-provider's days. Other activities are discussed in relation to them.

> I can't leave the house until he's had a bowel movement. I'm sorry to talk about it, but it has

become very important. If it is late it throws off my whole day as well as his.

At first we took a bath in the morning after breakfast. She always did it that way. Then we would get interrupted--the priest always came in the middle [he comes once a week, but does not schedule his visit]--that was upsetting, because he would leave without seeing her. We decided to take the bath before breakfast.

Adherence to a rigid schedule is the main strategy used by providers. This functions to add predictability and a sense of control for both the caregiver and the parent. All the providers interviewed responded to the question "What is a typical day like for you?" with a specific time or function related schedule. For example:

I get up at 8am, shower and make coffee. By 8:30 I get her up, help her wash, then we have breakfast. The Day Center bus comes at 10. I clean the house, shop and do errands until she comes back at 2-2:30. We both take a nap. I get up at 5 to make dinner. We eat, then watch t.v. At 8 I get her ready for bed, that's when she moves her bowels and takes a bath.

Although the specifics of the schedules differ in relation to the timing of activities, each is based on meeting the basic needs of

the parent for food, rest, exercise, and elimination. A breakdown of the schedule is disturbing to both the caregiver and parent:

> The whole day is thrown off if she does not move her bowels by 9:30am. It happens about once every three months and completely disrupts everything. She gets upset, I get upset. It means that nothing runs smooth, everything else is late.

Unusual activities, such as an interview or a visit to the doctor, interrupt the routine. Although this is often viewed as a relief, it requires special planning and rearrangement of the schedule. In scheduling unusual events, like a doctor's appointment for example, the care-providers considered: 1) inflexible parental activities (meals, bathing, toileting, naps, and certain t.v. shows), 2) the length of interruption which could be tolerated on a given day, and 3) parental energy peaks. The juggling of these considerations is complicated, and a minor miscalculation can be upsetting. In some cases, unpredictable events intervene in even a well-planned schedule. For example, a provider scheduled a routine check-up for herself for mid-afternoon time, knowing that her mother would be napping. The day of the appointment, however, the mother fell in the bathroom. Although she was not injured, the fall upset both the parent and the caregiver sufficiently that the daughter canceled her appointment.

In summary, the development of strategies to manage specific functional problems of the parent and the scheduling of the management activities are key for understanding the care-provider's experience. Her life is centered on these activities, and they often expand with increasing functional limitations of the parent to fill her entire day.

Use of assistance from others. A smaller percentage of providers than managers have assistance in caring for their parents. Care-providers did not actively seek assistance. Rather, outside professionals in contact with the family (e.g., private physicians, discharge planners, social workers) referred the parent to specific agencies. Passive acceptance of help, rather than active seeking and management of assistance, characterizes the provider group. Primary sources of assistance identified by providers were the clinic where the parent received medical care and home health agencies.

Direct assistance. Some of the providers receive direct assistance in the provision of nursing and housekeeping services from employees of voluntary agencies. This assistance includes bathing, light housekeeping, and medically-related services (e.g., injections). Although limited, the direct assistance is very helpful to families. Many expressed the fear that the services would be discontinued because of funding limitations. "I don't know how long the nurses from home health will keep coming. The

Medicare runs out soon and we don't have enough to pay them. I don't know what we'll do if they don't come."

Advice from others. A number of providers use management strategies recommended by professionals or neighbors:

> The nurse taught me how to put the leg brace on and how to get her in and out of the car. Now that I know to have her sit down first, then bring her legs into the car it is much easier.

> Fran, next door, took care of her mother for a long time. She knew a lot about how to make things easier. She told me about an oil to put in the bath water to keep her skin soft, what kind of teas have vitamins in them.

The women who discussed the advice of others as a major management strategy are the ones who were experiencing the most difficulty in caregiving at the time of the interview. They are unable to prioritize or approach problems systematically. They are also the women with the fewest resources in terms of social supports, education, and money.

Environmental Manipulation by Providers

Caregivers from both the provider and the manager groups describe strategies for manipulation of the environment to facilitate caregiving. Members of the provider group decide more

frequently than managers to share a household with the ill parent. The decision is usually based on easing access to the parent so that observations and care activities can be done more conveniently. In this sense, the move is made for the caregiver's convenience:

> We brought her here so I could watch her more closely. It was too much of a hassle to always be going over there [to the parent's house] and too hard to keep up both places.

Shared residence facilitates the provision of physical care as suggested by the caregiver's statement. The decision is often made after a period of providing care in the parent's own home. The drain of the work involved in the maintenance of two separate houses adds to the strain of providing care to the parent:

> Mother never did her own shopping, banking, etc. Dad took care of these things until his death. I took over when he died, but she lived two hours away from me. I had to drive up every weekend and do everything. It was exhausting. Finally, I arranged with the local store to deliver groceries when Mom called them. I had to do everything else though. Eventually, I brought her here.

Care-providers devise strategies for ensuring privacy in light of a shared household. For example, one caregiver and her

husband extend their work day by the socially accepted method of taking public transportation from their suburban home to the city rather than driving. The bus schedule requires that they leave their home very early in the morning and return late in the evening. Although the strategy enables the couple to avoid contact with the parent, it is exhausting.

Four providers described specific modifications of the home environment they made to facilitate the parent's functioning. This strategy is more common among managers, however. One provider showed the investigator relatively minor changes in her mother's bathroom (a handgrip in the tub area and a bar next to the toilet) and kitchen (rearrangement of the location of articles on shelves and modification of the oven height) which enabled the mother to live alone.

Behavior Modification by Providers

Several of the providers describe strategies to modify intolerable parental behavior. The behavior requiring change is not unusual, for example, it includes crying after residential relocation:

> I had to harden Mother not to cry. At first when she moved in she cried all the time. She would say, "How can you make me do the dishes?" I had to get her to stop crying. I just told her to stop and would not pay attention to her.

In this, and other cases in which caregivers use behavior modification, the caregivers describe the historical and current interpersonal relationship between themselves and the parent as poor. Conflict arises from behavior which does not cause problems for most families.

Summary

In summary, providers use a variety of different strategies to handle the physical problems of their parent. The strategies include those which assist the parent in activities of daily living, those which manipulate the environment to decrease the problems in activities of daily living, and those which modify the parent's behavior. Providers are too burdened with the physical care of the parent to focus on other types of support. Provision of physical care takes over their lives. Adherence to the tight schedule required for meeting the parent's basic needs precludes attention to the parent's psychological or social well being. The questions eliciting information about strategies and types of assistance were worded to suggest responses in the areas of physical, psychological, and social support. Only with prompting were the providers able to identify any strategies for psychological or social support. They focus exclusively on strategies to manage physical and functional problems. When strategies for psychological and social support were requested directly, a few were identified, but little elaboration was given. For example, "I try to be cheerful around her."

Manager Strategies Which Assist
the Parent with Problems of Daily Living

Obtaining and retaining services. In contrast to the strategies used by the provider group, the managers focus on strategies to organize services to meet the needs of the parent. Obviously, the skills required to perform this activity are very different from those required by direct care provision. The managers provide for the functional needs of the parent by obtaining professional or non-professional services for those tasks which they do not want, or are unable to do. Obtaining reliable nursing, housekeeping, and home maintenance services requires a knowledge of the parent's health problems, a knowledge of community resources, an ability to negotiate, and adequate financial resources. Many of the managers describe the initial phases of caregiving as a frustrating period of endless phone calls and interviews to accomplish the assessment of community resources prerequisite for setting up an effective means of meeting parental needs. Several strategies are successful: 1) substitute caregivers (paid professional and non-professional caregivers), 2) persons hired to perform specific tasks (nurses and housekeepers), 3) services to provide care out of the home for limited periods of time (Day Care Centers), and 4) collaborative caregiving with other relatives.

Community assessment. None of the managers were familiar with the services available in the community for parent-caring until their own parent required them. The initial assessment of the community and the evaluation of available services is time consuming and difficult. It requires the caregiver to increase her knowledge in the areas of: the impact of illness on the parent's functional abilities, services available, funding and public policy, medicine, and the law.

> It was terrifying to me that the hospital staff made so many mistakes. The doctor, the nurses, the social service worker all ignored Mother despite the progressive signs. Finally I called a friend of a friend, a doctor, who gave Mother adequate attention and admitted her to the critical care unit. I really thought that they should have known what they were doing, it was the best hospital in the area. I did all the negotiating around medical and legal matters. Arranging the bank conservatorship, etc. You can't trust the bank conservators to attend to details, they forgot to pay the insurance premiums.

> At first the main problem was finding people to care for her and interact with her. The whole social service thing took days on the phone.

> The main problems were caused by battling the social service system and filling out the forms. It required days on the phone. Mom never saw this--she did not know how much "behind the scenes" work I did. It was hard for both of us. She wanted me to spend more time with her, and was not grateful for the work I did because she did not see it.

In addition to describing the problems encountered when dealing with the health and social systems, these quotes suggest consequences of assuming the role of manager. The impact on their own careers and the lack of gratitude from the parent are disturbing to the caregivers and will be discussed in the next chapter.

Care-managers take great care in the delegation of tasks to others, seeking reliable and sensitive help. In one case, for example, a caregiver preferentially hired a nurse from the Philippines. "I think that will make things easier. Mother needs to overprotect father, and I think a nurse from the Philippines will understand these things. She will also take directions from the man."

Consultation as a strategy. One care-manager described her process of problem solving when confronted with the need to obtain help for her mother after a stroke. It involved consultation with family, friends, and professionals:

> When she became quite ill I first tried to get a relative to come and stay with her. I had to go to work and was afraid to leave her alone for fear she would become confused and wander. I offered to pay their airfare down, they could stay with her during the day and be able to vacation in the evening. They were skeptical that I was not being honest with them about her physical condition. At that time she was healthy except for confusion. None of them wanted to come, it was the last minute and they have their own lives. Next I tried agencies, but I talked with friends with similar experiences and everyone said not to do that [hire help through an agency]. The people are often unreliable, they drink, they are irresponsible, they come on time, but then leave before you get back, or they are not qualified. Last I tried asking a social worker, she recommended Board and Care. Now I am checking out Board and Care facilities in the area. They are really "cottage industries." [Next she described in detail her accurate and thorough assessment of board and care facilities in the area.]

Many of the managers describe a similar process, although they did not approach resources in the same order. Family,

friends, and professionals are engaged in discussions of the problem. Data are collected which lead to the generation of a series of options for care provision. These options are then evaluated by the manager for congruence with the parent's need, reliability, convenience, expense, etc. Since resources in the community are limited, time is spent on assessment activities that could be eliminated if knowledgeable professionals were available to offer guidance at this point. Unfortunately, the experience of many managers with professionals during this stage was not positive. Inadequate and inaccurate information from health and social workers complicated the process in some cases.

Cultivation of the caregiving system. After obtaining the services needed by the parent, the managers devote varying amounts of time and energy to the maintenance of the caregiving system. This requires a range of activities including: building an interpersonal relationship with the providers of the service, purchasing gifts for caregivers, and volunteering on the boards of service agencies.

> The roommates I get to stay with mother both help with the rent payments and watch her. They use my things without asking, but I don't say anything. I really need them to stay with her. Also, the homemaker did not clean the bathroom floor well. I wasn't sure what to do because I was afraid if I said anything she would stop coming.

> I get gifts for the house cleaners and the nurse. I want them to be happy and enjoy it here. I really need them.

> I joined the board of the Day Center and the Easter Seal Society where Mom goes. It is very interesting to me, and I can influence the programs a bit.

Alternatives to purchased services. Some of the managers elect to perform certain physical care activities themselves. They approach the task with thought and organization. One caregiver decided not to transfer cooking activities to her housekeeper or nurse. She maintains a well-organized system to facilitate meal preparation. Every month she purchases large quantities of food. Before freezing the meats she cut them into small pieces appropriate for the stir fried cooking she and her parents enjoy. Every weekend she cooks several meals so they are ready for heating in a microwave oven on evenings when she is tired or gets home late from work. This manager is a physician who is particularly skilled at problem solving and has the resources necessary to obtain the equipment and services required to implement her ideas.

Another strategy for organizing parent-care used by two of the managers is the development of self-help groups. Women with

similar parent-caring problems get together to provide relief and respite services for each other in an informal manner. The systems work on an exchange of services, rather than a fee-for-service basis. This makes it economically feasible for group members to have time away from their parent, but to provide quality service at the same time.

Social/Psychological Support

By managing rather than personally providing physical care and housekeeping services, the managers are freer to direct their attention to other types of support. This group places more emphasis on strategies to meet the parent's psychological and social needs than do the providers. The strategies they use fall into three categories--those which: 1) promote interaction and contact with family, friends, and the larger society, 2) provide pleasurable activities for the parent, and 3) avoid activities which might be disturbing to the parent.

Interaction with family and friends. Managers promote interaction with the family through regular activities. "The primary thrust of social support for Mom is getting her together with the grandchildren. I usually have her up for dinner at least once a week when my husband is working." Another care-manager described her strategy for keeping her mother in touch with old friends. "I forced her to call friends from church every weekend. She is glad she did it but would not do it on her own. I also

watch the obituaries and help her write sympathy cards when her friends and acquaintances die." Several of the managers read the newspaper or a news magazine to their parent, or discuss the news with them on a regular basis. Maintenance of integration in the larger social system through contact with friends and knowledge of news is important to the parents interviewed. It gives them a basis of interacting with others. Their ability to discuss current events is valued by other family members and friends.

Provision of pleasurable activities. Managers devise activities for the parent's enjoyment. The nature of the activities depends on the parent's functional status, likes, and dislikes. The activities include: 1) taking the parent on drives, to the hairdresser, out to dinner or church, 2) giving birthday parties for him or her, 3) bringing visitors to the parent, and 4) purchasing large screen televisions. The managers give a lot of thought to these activities and are able to discuss the strategies in detail.

Engagement in activities to promote psychological and social well being among the parents is one of the major differences between the provider and manager groups. This activity provides the managers with a sense of satisfaction.

Avoidance of disturbing activities. Managers also develop strategies to decrease or prevent parental contact with unpleasant stimuli. The screening of television shows involving violence is

an example of this phenomenon. Other well meaning censorship activities were not appreciated by the parents. Limitation of contact with young grandchildren or great grandchildren is done by some managers in an attempt to prevent fatigue in the ill parent. This is resented by the parents involved who feel that the trade-off for fatigue is worth it in this case.

Environmental Manipulation by Managers

Major environmental manipulation is a possibility for the wealthier care-managers. One purchased a large house designed to accommodate herself and her parents. The layout of the structure facilitates safe mobility for the impaired parent. This manager also purchased head phones so that she could listen to her stereo while her parents watch television.

Another care-manager, who lives separately from her mother, purchased duplicates of products needed for her own daily routine (make up, curlers, hairdryers, bathrobe, etc.). This enables her to move freely between her own home and her mother's without the inconvenience of packing.

Environmental Manipulation and Behavioral Modification

A different strategy for managing the physical care of the less impaired parent involves combining environmental manipulation with behavior modification. This enables the parent to perform complex tasks unassisted. In two cases, this strategy enabled parents to remain in their own homes without outside help and with

minimal intrusion on the care-manager's life. In both cases the managers are nurses:

> I set up the kitchen for a person with one hand [the parent had hemiparesis]. You have to think of things like loosening the tops on jars, etc.

> Initially [after the mother's stroke] I lived with her for six weeks. That way I could see the problems she ran into. We got button-up or zipper-up the front dresses so she can dress herself. We could not figure how she could be independent in putting on her bra. Finally I had a flash that she should not unhook it, but pull it on and off over her head. We figured out things by trial and error--what foods to purchase that she could get into on her own . . . .

Few care-managers have the knowledge base to enable them to assess, manage, and teach the parent with a moderate functional impairment to be independent. The managers employing this strategy are nurses, experienced in the assessment of functionally impaired adults and the development of intervention strategies.

Summary

Managers devote a great deal of time and energy to the development of care systems for their parent. This activity requires skill in the acquisition of new knowledge and negotiating

with the social system. Maintenance of the care system, once established, requires constant attention. If the management is effective, the caregiver is freer than the provider to consider the psychological and social needs of the parent. Strategies described by this group reflect the focus on social and psychological support.

## Strategies Used by Caregivers for Their Own Reactions to Caregiving

### Providers

Ventilation to friends. Despite the difficulties experienced by providers, few identify strategies which help them in coping with their own problems. Ventilation to friends and professionals is the primary strategy used by this group. Guilt, anger, and constant irritation are common reactions to the caregiving situation. These emotions are disturbing to the care-providers. Discussions with friends and professionals help in dealing with these reactions:

> My confidants are in the Friday night prayer group. It is really like therapy. I can say anything there. Anything. I say many things I would not be able to say to my husband. For example, I really did not want to take care of his mother. I felt it was not my problem. I was angry. I could talk about this with the prayer group and the other women were very understanding.

Providers use religion more as a social support than a spiritual support.

Ventilation to professionals. Another subject uses her psychiatrist for ventilation. "I see him once a week. That is not really enough. He is treating me for anxiety attacks. I talk with him a lot about my problem with my mother. It helps, but it is not enough."

One provider arranged for the transfer of the care of her demented mother to a nursing home during the data collection period. She feels extremely guilty about this and discussed her feelings at length. "I did not realize that anything was wrong. I just thought she wanted to irritate me. I really resented her. Then I realized she was sick and thought of all the times I was short and nasty with her. I was terrible." This provider discussed her guilt with nurses and her minister. "Nurses are very helpful in relieving guilt. They said 'just do what you can.' The pastor was also helpful."

Assignment of meaning to caregiving activities. Another means of coping among the provider group is to find meaning in the caregiving activities. Four providers engaged in caregiving as their primary role for years prior to the illness of their parent. Previous experience with mentally retarded children or ill relatives established their identity as providers, and gave meaning to their lives. The role of caregiver makes them feel important.

Managers

Ventilation--friends as instrumental assistance. Managers use a wider array of strategies than providers for dealing with their own problems associated with caregiving. Ventilation to family, friends, and professionals plays an important role for this group as well as for providers. The social support systems of the managers are much broader than those of the providers. Consequently, they have more opportunity to discuss their situation and get support and advice on problem management unofficially from persons with professional backgrounds. Thus, advice from friends often includes advice from doctors, nurses, lawyers, and social workers. "When Mom had the stroke I called the nurse down the block. She came over and assessed her language and reasoning ability. She called a doctor she knows at the hospital where she works. We took Mom there the next day."

Self-help groups. A few care-managers use self-help groups to discuss strategies for dealing with their own problems as well as for exchange of caregiving services:

> A group of us caretakers met while bringing our parents [and husbands] to Day Care. We talked a lot, and realized that we should plan a meeting time to share our experiences. The social worker at the Center took care of organizing it. We meet twice a month. Sometimes we have people talk about services available. Other times we just talk among ourselves.

Organization of time. All the managers discuss the organization of their time as a strategy which enables them to accomplish the things that are important to them. Unlike the providers, who discuss a daily schedule based on the parent's needs, the managers discuss the planning necessary to meet their own needs and those of the parent. The descriptions center on balancing highly valued activities with the care management and rest.

> You would be amazed at how much you can get done if you have to. I work full time, go to school and help Mom. I'll give you an example of how it works. The day before Christmas I had to go shopping for Christmas dinner. You know how crowded the stores are. I took my nephews with me. I made each of them a list for a particular section of the store. Each of us got the things from our section and met at the check out counter. It was great.

Religion: finding meaning in the experience. Finally, religion is useful to many of the managers in coping with their own reactions to caregiving. "I am a Christian Scientist, and this has been most helpful in coping with the problems I have had, including this one . . . . I would probably have reacted entirely differently to this problem with my mother if it had not been for Christian Science." A personal belief system and sense of meaning

in the experience is more common in the managers than is participation in organized religion. "I think everything that happens, even the things that are hard, has a purpose, but that it might not be obvious. That is faith. It does not mean that things are easier, but that they are easier to view because you know somehow there is a reason." Meeting the challenge of providing care, in this view, gives the caregivers a sense of satisfaction.

Strategies for Dealing with the Problems of Other Family Members

Caregiving to an ill parent has a great impact on family relations in general, and particularly on the dyadic relationship between the caregiver and her spouse. The married caregivers discuss the problems created by the caregiving situation (see Section VI). Interestingly, most of the married providers attempt to "protect" their husband (or avoid painful communication) by not discussing caregiving problems or by hiding aspects of caregiving (incontinence). This strategy is generally unsuccessful. One provider had to "convince" her family and husband to assume the care of her mother. Her argument was based on the loss of inheritable income should the mother's savings be depleted with nursing home care. Fear of loss of inheritance is an unusual motivating factor for care provision in this sample. It led to a family situation in which no one discusses anything about the mother, or the impact she has on the family.

Both daughters-in-law in the sample are providers. In this situation, the husband is indebted to the care-provider and gives her support. None of the daughters receive help in the care of their parent. Spouse tolerance of the situation is the most positive level reached. The author assumed that the presence of a spouse would serve as a support to the caregiver. In a sense, the opposite was true in the sample studied. The competing demands of spouse and parent (and sometimes children) are difficult for the caregiver to manage.

Managers consider and use a variety of strategies to handle the problems of other family members. The strategies are more active than those of the provider group and include: 1) discussion of divorce to protect the husband from increasing care demands, 2) arranging for marriage counseling, and 3) scheduling time with the parent while the husband is at work. The last two strategies are successful according to the managers' assessment.

Married managers are more clear than providers that the dyadic marital relationship takes priority over the relationship with the parent. They feel a responsibility for the parent, but keep it in second place.

Most of the children of caregivers in the sample are grown and live independently from their parents. With very few exceptions, caregivers did not identify them as a major source of assistance or problems in caregiving. In the two families in

which young children live with the caregiver, the children clearly took priority over parent-caring activities.

Summary

In summary, both providers and managers become inundated with the activities of caregiving. The involvement is qualitatively different for the two groups. Providers become directly involved in the heavy physical work of nursing care and assistance with activities of daily living. Their lives become rigidly scheduled according to the parent's need for care. Providers receive assistance in caregiving activities, but do not themselves "delegate" activity. Finally, the time and energy expended by providers on physical care of the parent leaves little time for focusing on his/her psychological and social needs.

Managers, in contrast, devote a great deal of time to obtaining and retaining appropriate service systems for their parent. This requires skills in the assessment of the parent's functional capacity, assessment of community resources, and cultivation of the caregiving system once it is established. Managers devote more thought than providers to the psychological and social needs of their parents.

Providers primarily use ventilation to friends and professionals to cope with their own reactions to caregiving. Managers use ventilation, but also develop a range of strategies to deal with their own reactions to caregiving, including: self-

help groups, organization of time around their own interests, and the use of religion (in finding existential meaning in the caregiving situation).

Finally, providers "protect" their husbands from the caregiving situation, whereas, managers manipulate their time schedules and engage in marital counseling to handle the problems arising in the marital relationship as a result of caregiving.

The next section analyzes the consequences of caregiving to providers and managers in general, and the consequences of the use of specific strategies for parent-caring.

## VI. Consequences of Parent-Caring

> At supper I would cut my father's food up for him and wheel him into the living room where I would read to him for an hour. And then it would be time to get him ready for bed. The slow, long business of dying tired him daily. It is impossible to explain to anyone how long it takes to do the most ordinary things for an invalid. The whole day goes into the needs of a dying animal. And as with each new stroke he was able to do less for himself, the days were filled and I grew dull. I slept whenever he slept. Sometimes he slept most of the day. (Gordon, 1978, p. 4)

Any social interaction involves costs and benefits to the interactants. In the complex interactions of parent-caring the

costs and benefits are often subtle, indirect, and difficult to calculate. This section addresses the consequences of caregiving. The data analyzed are the caregiver's perception of the consequences at a single point in time and the researcher's observations. The analysis will be treated as static for the purpose of discussion. The reader must keep in mind that the process of parent-caring is influenced by time, changes in functional status, family structure, community services, etc. These factors affect the cost/benefit equation and call for constant reassessment of changes in the ratio.

Benefits of Caregiving

Providers. Half of the providers could not identify any benefits of caregiving. Responses to questions in this area elicited comments reflecting sad resignation, tired frustration, and hostility toward the parent. "Who could benefit from this?" "I used to get some satisfaction. But five years, day in, day out. There are no benefits." These comments are typical for caregivers who have been worn down by years of caring for severely impaired parents.

Table 17
Benefits of Parent Caring Identified
by Providers and Managers

| Caregivers | Benefits* | | | | | | |
|---|---|---|---|---|---|---|---|
| | None | Satisfaction | Money | Increased Knowledge Self | Aging | Improved Parent/Child Relationship | Existential Meaning in Situation |
| Providers | 53.3% | 26.6% | 26.6% | 0.0% | 0.0% | 0.0% | 0.0% |
| Managers | 0.0% | 33.3% | 0.0% | 40.0% | 20.0% | 20.0% | 20.0% |

* Categories are not mutually exclusive.

A quarter of the care-providers, on the other hand, feel a sense of satisfaction in their role. "She will die at home, peacefully. I get a sense of satisfaction from that," or "I get a feeling of reward for doing what I think is best for her." Finally, 25% of the caregivers received some financial benefits from care-provision which are important to them. "There is more money with her social security check, it helps with the rent," and "I can keep this apartment. Financially I would not be able to without her income. Because I'm paid for caring for her I have saved enough to keep the apartment on my own." One care-provider spoke of the rationale for keeping her mother in her home rather than placing her in an institution. "Her assets would be drained if she would go into a home. That is all we have; my husband and I raised eight kids, we have no savings."

The provider's responses to inquiries about benefits of caregiving were terse. The women did not elaborate in this area in the same way the managers were able to. It is clear that the providers are strong women who had endured years of great emotional and physical duress. They are trapped in a situation of diminishing benefits and increasing costs. The end of the process could not be predicted; most of the parents are chronically ill, with conditions which are debilitating but not fatal. Forecasting an indeterminant continuation of their life situation makes identification of benefits nearly impossible.

Managers. Managers identified many and more diverse benefits from parent-caring than did providers. Experience with the ill parent is associated with increased knowledge about the self, the aged, and chronically ill in general. "I have more strength and tolerance than I thought," and "It's a learning process. I'm glad I'm going through it; I just wish it weren't so hard . . . ." are typical remarks from the manager group. An interesting consequence of involvement in parent-caring is the change in career focus on the part of 20% of the managers. "I'm more interested in voluntary organization work with the elderly [previous work had been with pregnancy prevention]. It's been an enriching experience. I have more knowledge and empathy for the disabled." Another manager states "I am painfully sensitive to older people. I am very sensitive to their loneliness. I might change my career to work with older people. I have grown in compassion and become more conscious of what happens when you age."

Improvement in the parent/child relationship is noted by a minority of subjects as a benefit of care-management. This is in stark contrast to the experience of the care-providers, most of whom experienced a worsening of the relationship. "Historically Mother and I were close, but never physically affectionate. Now she likes more physical expression of affection, and so do I. There is more bonding." After a long period of thought, another

care-manager said, "Many problems are cleared [colloquialism meaning resolved]. I have 'cleared' more stuff with my mother than people who left home when they were young."

Many of the managers were able to find some meaning in the caregiving situation. Recall the statements suggesting that all things that happen have a purpose, it might not be apparent at the time (see pages 86 and 87). Assigning a higher meaning to caregiving activities was of benefit for the managers, who found this interpretation helpful in increasing their self-esteem and motivation.

Costs of Parent-Caring

Predictably, most of the costs of parent-caring differ qualitatively and quantitatively with management style. Both managers and providers are engaged in a difficult, time consuming process which cannot be fit into their lives without strain. Both providers and managers experience problems in marital and sibling relationships. Other costs identified by caregivers reflect the impact of the specific caregiving activities in which they are engaged. The primary categories of costs identified by the providers are: decreased freedom, a lack of privacy, constant daily irritation, and guilt. Managers experience some of the same costs, but with different salience. Time limitations, career interruption, financial problems, and guilt are the problems identified most frequently by the manager group.

## Impact of Parent-Caring on the Family Relationships of Providers and Managers

Marital relationships. Parent-caring is a strain on the marital relationship of the caregiver regardless of the caregiving style employed. The time and energy required by caregiving activities exacts a toll on the caregiver which is felt by her spouse and other family members. "There is more conflict with Dan [husband], he is under a lot of stress. It changes things to have a third person to consider. I am not 'there' for him as much."

Caregivers feel torn between their wish to continue to relate to the spouse as before and to meet the demands of their increasingly dependent parent. During critical periods, the marital relationship suffers significantly. The caregiver's fatigue and anxiety lead to disinterest in intimacy with the spouse. This is perceived as rejection by the husband, who becomes angry and resentful. He increases his demands on the wife, and a cycle is set into motion which causes distress to both. Although this period is universally stressful, couples with strong relationships retrospectively assess it as valuable. "When you go through hard times together you come out stronger."

Couples with a history of a problematic relationship by their own assessment experience more difficulties with caregiving. In one family, the husband and mother-in-law never got along. She

did not think he was good enough for her daughter (some of the daughter's comments indicate that she agreed with her mother). The mother was brought into the couple's home following an illness. Soon the situation became intolerable, the mother criticizing the husband, the husband expressing hostility toward the mother. The daughter placed herself in the middle of the two angry factions. During the interview period, the couple decided to obtain marital therapy for the second time in their relationship.

In the study sample, couples with pre-existent strong dyadic relationships were stressed but not overwhelmed by parent-caring. For couples with a history of significant problems in the dyadic relationship, parent-caring created a substantial threat to the relationship.

Resistance of the spouse to parent-caring is expressed to the caregiver. "My husband was opposed to caring for her. At first he was upset and gloomy. Now he's resigned to it." None of the caregivers received any physical or emotional assistance from her spouse in caring for her own mother. When a daughter-in-law cares for a parent-in-law, however, the husband is more helpful. "Steve is more helpful around the house now. He does some of the housekeeping and all of the shopping. He understands it's a strain and feels bad that I have to care for his mother."

Siblings. Perceived inequities in the distribution of parent-caring activities creates sibling conflicts. Generally, one sibling is the "caregiver." She inevitably feels the heavy responsibility of caregiving more than other siblings, even if the others are involved in some caregiving activities. As with the marital relationship, historically good sibling relationships tolerate the stress of parental illness better than problematic ones. "My brother purchased a house in a town quite far away a couple of weeks before Mom's stroke. Immediately afterwards he realized that he should not have moved so far away. But it was too late. He hasn't been much help. At first I felt resentment, but now I understand his position and do not expect more."

Siblings are exempted from parent-caring responsibility if they have a recognized "excuse." "My sister gave birth to a mentally retarded child a few years ago and has been busy taking care of her. Also she has been ill." However, without an excuse, the lack of support from a sibling is criticized by the primary caregiver. "I resent it that my brother does not visit her," and "Everyone is isolated in their own world. It was always like that in our family. The boys just pretend there is nothing to do."

It is especially painful for the caregiver when the parent does not appreciate her caregiving because another sibling(s) is favored. "Despite all I do for her, what she really wants is them [brothers]. Last Christmas I saved to get her a jacket she really

wanted. It was a sacrifice because I have so little money. My brothers did not even call that day. She was totally depressed. The jacket didn't make any difference. She only wants them."

Although less common, shared sibling responsibility for parent-caring is successful in some families. This was seen in the manager group only. Two sisters, both nurses, share the parent-caring tasks equally. Their mother is relatively independent except for requiring transportation, assistance with major housekeeping, and communication with the social system (she has aphasia). The sisters cooperatively worked out a schedule for the provision of needed services and visiting. The entire family is clear on their own responsibilities and expectations of others.

In another family, siblings provide respite for the primary caregiver by spending their vacations (6 weeks per year) caring for their parents. "I know I can count on my sisters. I am not sure about the boys. There is no sibling conflict in the family. We are all cooperative, I know they will help me." In both families in which sibling cooperation and sharing is effective, the parent does not require personal physical care from the offspring. It is either purchased or unnecessary.

In summary, there are two categories of sibling behavior in relation to parent-caring: 1) non-participation (excused or not excused) and 2) cooperation. The nature of the sibling relationship prior to the parent's illness appears to determine,

or at least influence, the quality of the relationship after the stress of parent-caring has been imposed.

Costs to Providers

Loss of freedom. The most common, and most severe, cost to the provider of care is the lack of freedom. This has two components: the loss of freedom on a daily basis and the loss of freedom in a larger sense, e.g., to make long range life plans.

All the providers suffer from the loss of daily freedom. Some of the parents cannot be left alone. "I have more responsibility, it is hard to get away. It is hard to be alone. I feel like an old maid." Even when other family members share the responsibility there are severe limitations. "It has really limited us from going out except when our son is home. He can watch her in the evening, but he cannot prepare her for bed [diaper and change her] so we have to be back at nine." The presence of other family members, even those with minimal involvement, alleviates some of the strain on the caregiver. Unfortunately, most of the providers interviewed are single women and have no respite from caregiving activities. "I can only be out of the house for an hour. That is really limiting. I always have to be here." This constant entrapment in a house with the parent is extremely taxing. When added to the necessity of providing physical assistance it is even more disturbing. "I cannot plan time ahead. There is no time for myself. I get last

priority. I can't leave him alone in case something happens. Then every two hours there is something to do: fix a meal, help him dress, bath, clean the catheter, clean the house. There's always something."

Specific questioning about the impact of loss of freedom yielded interesting responses. "I have completely lost the ability to carry through on plans. I missed two antique shows after carefully arranging to have my aunt come and stay with Mom that day. At the last minute she said she couldn't make it." Most caregivers experience a complete termination of spontaneous activities, "I hesitate to ask people to stop in because you never know what she [mother] will be like," and "I used to like to go shopping with girl friends on the spur of the moment. Of course that's out now."

When the parent requires constant supervision, the providers must approach even routine activities of daily living with considerable planning. An hour shopping trip for groceries means the parent will be alone. The providers are anxious that "something will happen" when they are out of the house, "I'm most afraid that she will fall and injure herself when I am gone." The providers developed tactics to minimize risk in this case, "I only go out when she is taking a nap. She is in bed with the side rails up. She has never gotten hurt, but you never know. Each time when I come back to the house my heart stands still for a minute until I know she is OK."

Even when substantial assistance from an agency (e.g., Day Care Center) is available to the care-provider, their poverty, depression, and the fact that relief time is not in their control prevent them from enjoying or utilizing the "freedom":

> "There is not much time left for me during the day, not enough for me to take a job. The hours available are from 11am-2pm. I just sit. Sometimes I write letters to two friends. For a while it was self-fulfilling [the role of parent-caring], then it was hard. Now it's drudgery. It has brought on anxiety attacks. There is no place to go, no one to do anything with. I can't even go to a movie because it gets out too late. I am very frustrated and lonely. Now I don't even want to go out."

The limitations of freedom extend into the future. Moves, retirement plans, vacations, etc., all are affected. "We have no freedom. We had to give up the move to our house in the country because she's here in San Francisco and needs our help. For years we have been planning to move as soon as our youngest left. Now we are panicked. We built that house for our retirement--she could live for another 10 years." In addition to the physical limitation on geographic mobility imposed by caregiving, this family could not sell their home in the city until they move to the country. All their equity is tied up in real estate. The

taxes on both houses are more than their retirement income can absorb. The family has dreamt of moving to their country home through long years of unsatisfying manual labor in a factory and for the city. The indefinite postponement of their dream causes frustration and resentment and the fear that time is running out for them.

Privacy. A second area of impact on the caregiver's life--especially problematic in cases of shared households--is privacy. "I am never alone. She is always around. She even follows me around sometimes. It drives me crazy." Intrusion on personal space is particularly difficult for the families. "This is example number one for your research. This clutter is what happens when you are working plus taking care of a parent, plus all squeezed into a small space." Another provider states, "Obviously, space is a problem. Two children, a grandmother, and my fiance all in a two bedroom house. It's too much. I have to get out a lot just to keep my sanity.

As in any situation in which people live closely together, differences in attitudes and values create difficulties between the caregiver and the parent. "We have a problem living together. Mother feels she is sick and does not want to do anything. I feel you have to do something to live, there is always conflict. She does not want to help with the gardening, she complains about the weather . . . her pain. I just can't stand it." Historical data

suggests that this family, and others experiencing similar problems, have long standing interpersonal relationship problems which are accentuated by proximity.

Parental cognitive impairment amplifies the usual problems of shared housing. "I get frustrated when she makes a mess. She takes dirty clothes and folds them up to put them in her bed." Irritating habits are particularly difficult for caregivers and families. "The most annoying thing is that Granny won't admit a mistake. She was always secretive about herself." Another provider complains, "One annoying habit she has is whistling. All day the same song. I try to ignore it. That's the best thing to do."

There is, of course, an objective loss of privacy in most cases. However, the situation is often more complicated than it appears on the surface. "There is a loss of privacy in the larger sense. I have to tell her where I am going, how long I'll be gone, why I leave the car out, etc. She says, 'If something happens to you, what will happen to me?'" Parental anxiety and dependence on the caregiver are sometimes expressed in a manner which is perceived by the caregiver as restricting her privacy and freedom. The caregiver is accustomed to being free to come and go at will. She has not had to answer to anyone about her activities since childhood. The parent is afraid that her only source of support and contact with the outside world will desert her. Par-

ental anxiety increases when the provider leaves. The anxiety is expressed in questions about the caregiver's plans. These questions increase the caregiver's resentment because they are interpreted as controlling and as an invasion of privacy. Each question increases the caregiver's frustration and feeling of entrapment. The real issue of trust between caregiver and parent is never addressed directly.

Daily irritation. The proximity required by care-provision can lead to chronic daily irritation. Small things, which seem on the surface to be of little consequence, take on disproportionate significance. They become the focus for all the frustrations experienced by the caregiver. "Everyday she complains about the weather here. I never asked her to come to San Francisco. It drives me crazy when she complains about the fog." This type of irritation is greatly increased with shared households, and often arises from conflicting lifestyles. The fundamental issues confronting the caregiver and parent: resentment, anger, and frustration at the overall situation, are so threatening that they are not dealt with directly, except for the most secure families. The seemingly small issues become the targets permitting expression of the feelings. In this way, these "brush fires" serve to decrease the overall tension of an extremely difficutly situation which is perceived as insoluble. Systematic problem solving about the specific target issues is resisted probably because of the larger function served by its existence.

Guilt. Guilt is prevalent among care-providers. In general, providers' guilt is related to: 1) the past life of the parent or 2) the caregiver's anger about the caregiving situation.

Guilt occurs when the caregiver perceives that the parent suffered in his/her younger years; especially when the suffering was for the care-provider's benefit. "I feel guilt, sympathy, and empathy that she never had anything and that she worked so hard for her kids. That is why I care for her now." Predictably, this feeling is often accompanied by anger, "I did not ask her to do it. No one should give up so much for another person. It makes them feel guilty." Caregiving is always complicated by the perception of the historical relationship between the caregiver and receiver. In this case, guilt became the primary motivation for caregiving.

A more common source of guilt is resentment for the burden of caregiving. "I feel awful that I resent it so much. After all, she is my mother, and I love her." Daughters-in-law are less likely to feel the "obligation" or filial piety aspect of the relationship with the parent. "I feel guilty because I do not want to do this. I really have to fight it. I feel as if it is not my problem."

Costs to Managers

Time. The managers in the sample are younger and more engaged in the larger society through career and social activities

than the providers. It is predictable, therefore, that the most problematic sequella of caregiving for them is the invasion of their time by caregiving activities. The impact is felt first in personal and family time, then time with friends, and last in work time. "I really lost all my own time. Time for myself. I gave up practicing the piano, dancing lessons, and reading. I haven't read a novel in one and a half years." Another caregiver states, "I gave up all time to 'pull things together.' It used to be easy to do things and accept invitations, now I need lead time. There is no spontaneity in my life."

Eventually, there is encroachment on family time. "It's a problem, though. My husband and I rarely have time alone together. I bring Mom home on weekends because the Day Center is closed and she has no structured activities on those days." Caregiving causes severe stress on the marital relationship. Competition between the parent and spouse for the caregiver's time is often a crucial issue. "We have not figured out a way to get time together [caregiver and husband] for ourselves. Only at night just before bed. By then we are tired and irritable. It has completely destroyed our sex life."

All caregivers give up social activities with friends. This is true of both providers and managers, but the loss is more problematic for the managers. "I have no time with my friends. I feel I have to come home early every evening. I used to entertain

at least every week. I never invite friends anymore." Another care-manager stated, "We have no social life now. Only church. We used to do things with friends every Friday night. No more though." Another caregiver expresses similar concerns, "I gave up inviting friends for dinner every week. I love to cook so this is really a sacrifice. I gave up the opera, also. Since I do not feel comfortable leaving them [parents] alone in the evening, I do not go out anymore either." Their decreased involvement in social activities leads to social isolation among caregivers. "People stop inviting you if you do not reciprocate. They say they understand, but it is hard." "I'm not going to have any friends when my mother dies. We gave up having people over to the house three years ago." Exhaustion also interferes with the desire to engage in social activities. "I used to like to travel. Now I no longer dream about travel. Last night I went out for the first time in weeks. Now I don't go out, I get tired before we go; it's probably psychological."

The one type of social activity that continues in the face of intensive caregiving is church. Caregivers do not feel ambivalent about leaving the parent to attend church, and parents do not infringe on religious activities.

Career. During peak periods, care-managing activities spill over into work time. This is the last area to be affected. Women in positions of higher status are able, by virtue of their more

flexible work schedule, to incorporate caregiving activities with minimal disruption in their work. A physician, for example, could take off an afternoon without repercussion. The secretary received a negative evaluation from her boss because she made too many personal calls on work time.

Decreased geographic mobility secondary to caregiving affects both the caregiver's and her spouse's career. A young caregiver stated, "I thought of divorcing my husband, even though we have a good relationship, so I could take care of Mom and not be a burden to him. He's a researcher and has a new position. For him to advance he has to be mobile. Obviously we can't move because we can't leave Mother. This county has excellent services compared to most."

Certain trade-offs are necessary to enable the professional woman to manage parent-caring. One teacher of pre-school children, for example, never attends the national convention because it is held on weekends. She hired a woman to care for her parent during the week, but cannot afford to hire other people for the weekend. A physician and professor is willing to do less reading and writing so that she can be with her parents. This decision may well infringe on her professional advancement.

Finally, the timing of parental illness influences its impact on careers. One care-manager was in between positions when her mother suffered a stroke. Her "freedom" enabled her to make a

career of caregiving. "I had not been working for some time and was really ready to throw myself into a new job or school. I had completed the applications for a special course in organizing the day I heard about Mom's stroke. I flew to be with her immediately and stayed with her for several months. It was the first time my husband and I had been separated."

Financial. The expenses incurred by care-managers are great. Personal services (nursing and housekeeping) are not only difficult to locate, but costly. Only a small percentage of families can afford to purchase caregiving for long periods of time. Even the professional women in the sample had little left at the end of the month after paying for housing, food, and services. Other miscellaneous expenses occur periodically in connection with the parent's illness. For example, one of the caregivers had to fly to the East Coast twice to arrange for her mother's move to the West Coast. This family was marginally able to make the payments on their small house before the mother's illness. Traveling costs created a debt which the family is not able to eliminate. Another caregiver said, "I have learned a lot about money, especially insurance. It [caregiving] is expensive. If we sell the house, one third of it will go for taxes on capital gains. Things would be better if I could work."

Guilt. In contrast to the providers, the guilt experienced by managers is related to the lack of time and energy to meet the

competing demands of parent, family, and work. "I just can't do everything. I stay on top of Mom's care and my husband suffers, I keep up with work and everything else falls apart. Even though I do my best, I feel guilty toward everyone." Fewer managers (20%) than providers (60%) discuss guilt as a major cost of caregiving.

Summary

In summary, both providers and managers identify costs and benefits related to parent-caring. Fewer providers identified benefits than managers. Providers focused on a sense of satisfaction and financial gain as the positive consequences of caregiving. All managers identified benefits from parent-caring. The benefits include: satisfaction, increased knowledge about self and aging, improvement in the parent-child relationship, and a sense of meaning in the experience.

Both providers and managers experienced difficulties in their marital relationship and sibling relationships. Other costs experienced related to the specific activities in which they engaged. Care-providers identified decreased freedom, a lack of privacy, constant daily irritation, and guilt as the major costs of caregiving. Managers focused on time limitations, career interruption, financial problems, and guilt as the major costs of parent-caring.

## VII. Shifts in Caregiving Modalities--
## Crises in the Caregiving Process

The previous sections described the structural variables present in caregiving situations. Caregiving, however, is a process which occurs over time and which is modified by changes in the environment and individuals. The process of caregiving involves a constant re-evaluation of the costs and benefits of caregiving and shifts in caregiving modalities in response to change in: 1) the functional capacity of the parent, 2) the functional capacity of the caregiver, and/or 3) one or more of the "influencing variables" (socio-economic status, career, etc.). The shifts in caregiving modalities represent crisis periods for caregivers and parents. For some families, the sustained stress of caregiving is interrupted with a series of consecutive crises, as the parent's functional status changes rapidly, or the caregiver's health fails. This section focuses on the process of caregiving by analyzing: 1) the major shifts in caregiving modalities experienced by the sample during the year prior to the interviews, and 2) a case in which caregiving shifts occur. The focus on caregiving shifts serves three purposes: 1) It examines the complex interrelationships among the structural components of caregiving. 2) It demonstrates the changes in caregiving with time. 3) It allows for a discussion of individualistic caregiving experiences.

Several shifts in caregiving modalities are theoretically possible: from provider to manager or transferor, from manager to provider or transferor, and from transferor to provider or manager. Three of the six possible shifts are seen among the study subjects during the year prior to interview: 1) from provider to manager (n=5), 2) from transferor to provider (n=2), and 3) from manager to provider (n=1). Sample selection processes ruled out any caregivers who shifted from provider or manager to transferor. A brief description of the relationship of key structural variables to caregiving shifts in the sample as a whole follows.

Provider to manager. Two factors lead to a shift from the provider to the manager role: 1) decreased functional capacity of the parent and 2) failing health of the caregiver. Typically, the woman assumes the role of provider when the parent's limitations are minimal. She automatically performs the weekly shopping and yard work for the parent, these activities are not time consuming and can be fit into her schedule without much disruption. With increasing parental functional impairment, the caregiver becomes more involved in caregiving. Rarely, however, are conscious evaluations and decisions about careprovision made until the time and energy required for the activities is overwhelming. At an identifiable point in time, the caregiver realizes that caregiving has negative consequences for herself, her family, and her career.

At this point she begins managing parent-caring activities, but the change is not easy. A mutual set of expectations has been established for her behavior in relation to the parent. Although it is impossible to meet the expectations without a heavy toll, she feels guilty when she pulls back from her involvement. "You know, one day I realized I am spending four hours a day over there [in the parent's house]. It was taking all of my time for myself. I was cranky and irritable at home. But how can you say to your mother that you cannot come as much anymore. It was really hard."

Some shifts from provider to manager are caused by decreasing functional capacity of the caregiver. Older providers are confronted with the problems of providing the taxing physical care to parents in the face of their own diminishing strength. Eventually, the frail care-provider must consider the option of managing or transfering her parent's care.

Transferor to provider. Two women reported that they became providers when they took their parent home after institutionalization. In one case the mother became too impaired to qualify for board and care. The state inspector indicated that the parent had to be transferred to a skilled nursing facility. The caregiver knew that the cost for good skilled care would significantly diminish the mother's assets and decided to provide care herself.

The second woman stated that the quality of institutional care available in the area was unacceptable to her. Her mother was unhappy and became increasingly disoriented in the nursing home. When the daughter retired from her position in a large firm, she assumed care-provider activities.

Manager to provider. Only one woman reported changing her caregiving style from managerial to provisional. When she retired from her job with the phone company she accepted the offer of the welfare department to pay her for assuming the responsibility for providing care for her mother.

Critical periods necessitating a re-evaluation of caregiving arise in all caregiving situations. Shifts in caregiving modalities create crisis and disequilibrium in the caregiving unit. At these times social supports are called upon, old coping strategies are tried, and unresolved conflictual material resurfaces, as the individuals re-establish equilibrium in their lives.

Crisis periods in caregiving allow the observer to see family strengths and weaknesses, resolved and unresolved conflicts. The family members describe their feelings with less inhibition than during non-critical periods. The key issues of dependence/ independence, the threat of loss of a significant love object, and the fear of one's own aging and death confront the caregiver at these times. Emotionally charged memories and past traumas color

perceptions of the current caregiving situation. Each subject rewrites history when asked to analyze life events retrospectively. Although the specific historical events differ from family to family, all of the subjects explain their current situation in light of past events and relationships.

Case Study

The following case demonstrates the interaction between and among caregiving variables by focusing on critical periods in a caregiving career. The caregiver is a 54 year old single professional woman; the mother is a 93 year old widow who suffers from mild cognitive impairment and instability leading to falls and fractures. Both women are successful in their social relationships, both are intelligent, open, and introspective. Although it is not a "typical" family in some ways, the daughter's and mother's unusual capacity for introspection and ability to articulate feelings make theirs a valuable case for analysis.

During the time of the interviews the family was in a period of disorganization and crisis. Three factors contributed to the stress of the situation: 1) The mother's functional capacity diminished markedly in the month prior to the interview. 2) The caregiving system broke down. 3) The mother's functional capacity was difficult to evaluate because of an overlay of anxiety caused by her fear of institutionalization. Both the mother and daughter experienced stress at this time and felt the need to regain equilibrium in their lives.

A crisis paradigm serves to organize the case analysis.

Perception of the event. Neither the daughter nor the mother have a clear perception of the current crisis. For the daughter the situation resurrected old feelings of ambivalence toward her mother which she attributed to the mother's dependent, manipulative behavior when she was a child. The daughter's overwhelming preoccupation with past painful events distorts her perception of the current situation. She interprets the mother's illness as manipulative behavior directed at controlling her. This distortion makes it difficult for the daughter accurately to appraise the mother's objectively decreasing functional capacity.

Likewise, the mother's perceptions of the current crisis are colored by her past experiences. During the interviews her preoccupation with feelings of childhood abandonment, her unsatisfactory marriage and premarital sexual relationships were evident. Her anxiety about her daughter's willingness to continue management activities is great. She articulates fear of institutionalization (abandonment by the daughter in her eyes) and illness (punishment in her view).

Social supports. In part, the current crisis was triggered by a breakdown of social supports. The mother's caregiving system depended on the reliability of 1) day services, 2) homemaker services, 3) transportation services, and 4) a roommate and night companion. As the mother's functional status decreased following

another fracture, hospitalization, and increasing cognitive impairment, reliability of the system was absolutely essential for her to remain at home. Immediately prior to the study interviews, the homemaker service discontinued sending a consistent person to the home. A new woman appeared each week. This disruption in the routine was disturbing to the mother and increased her confusion. In addition, the roommate, a college student whose purpose is to help with the rent payments as well as serve as a companion to the mother at night, became overwhelmed by the responsibility for the increasingly impaired mother. She decided to leave. Finally, the transportation system responsible for taking the mother to day care was unreliable on two occasions. The family functioned on a very delicate balance. A problem with one piece of the caregiving system created stress which had a rippling effect, increasing the mother's confusion and the daughter's involvement with management activities.

The mother and daughter have traditionally served as a support system for each other. They are the only surviving members of their family. Consequently, they are especially important to each other. The realization that the mother's health is failing is extremely threatening to the daughter. "If she dies, who will there be?" The mother is objectively dependent on the daughter. She is grateful for the daughter's interventions on her behalf and hesitant to voice criticism or even divergent

opinions. The relationship is so important to her that she cannot risk losing it. Additionally, the daughter's management of her care enables her to remain in her home. Without this assistance she would need to move to a more protected environment. She is afraid of "abandonment" of her primary source of support.

At the time of interview the daughter experienced increasing difficulty in maintaining the caregiving system. The mother is afraid that she may require institutionalization if her daughter cannot continue care-management. The threat of loss in the primary support relationship placed both the mother and daughter in a vulnerable position.

Adequate coping mechanisms. The family's history reflects a good ability to deal with the earlier crisis created by the decreasing functional impairment of the mother. A brief review of caregiving crisis resolutions is presented here.

Crisis I--1973--The mother's health became mildly impaired with slight instability, fatigue, and falls. Both the caregiver and mother are from a relatively high socio-economic status. They shared a household at this time. The caregiver was involved in a highly valued professional career and in graduate school. The mother's illness onset was slow with minor functional deficits.

Crisis resolution. The daughter provided the care needed by the mother at this time. It involved shopping and performing major housework, in addition to social and psychological support.

The tasks of initial care provision limited the daughter's time, freedom, and privacy to a small but tolerable degree.

Crisis II--1977--The mother's functional capacity markedly decreased over the period of a year because of increasing instability leading to a series of falls and fractures. Each acute episode required a re-thinking and a re-organization of the caregiving system. The mother's increasing dependency placed greater demands on the daughter's time, freedom, and privacy which could not be balanced with the daughter's other highly valued roles (professional and academic).

Crisis resolution. The daughter shifted from a provider to a manager role. The management activities involved obtaining and retaining an effective caregiving system for the mother. The system established included: 1) day services, 2) homemaker services, 3) a roommate to be with the mother at night. At this time the daughter moved out from the apartment shared by her and her mother so there would be room for the roommate. The daughter experienced relief from the demands of care provision on her time, freedom, and privacy, but an increase in guilt.

Crisis III--the current crisis described on page 116.

Crisis resolution. In a post-interview phone call initated by the daughter, the investigator learned that both the daughter and mother now feel that a move to a more protected environment is desirable. Together they are exploring the appropriate facilities

in the area and will make a joint decision regarding a transfer of care.

In summary, the case presentation demonstrates a process of caregiving, involving a series of changes in the functional status of the parent and caregiving systems which lead to shifts in caregiving modalities. The case is typical in that the family has resolved a number of crises in caregiving. The occurrence of serial crises in caregiving suggests the need for longitudinal research in this area.

# Chapter V

## Conclusions and Recommendations

In this section, the clinical and research implications of the study are presented.

### Clinical Implications

Caregivers engage in an extended process of meeting the increasing dependency needs of an older parent. Caregiving creates problems for caregivers which are amenable to clinical intervention: physical and emotional exhaustion, decreased personal time and freedom, and disruption of marital and social relationships. Three categories of clinical interventions are suggested: 1) services for the parent to relieve caregivers of some caregiving activities, 2) services for the caregiver, and 3) services for the family unit. Services for the parent are critically important; they include: a full range of home support in personal care, nursing care, and homemaking, as well as options for institutional care, such as day and respite care. Services needed by caregivers include those to: 1) help in the care of the parent (e.g., assistance in strategy development, facilitation of information acquisition and service evaluation) and 2) help the caregiver with her own problems (e.g., provision of emotional and social supports and treatment for health problems). Finally, recommendations for the family unit as a whole are made.

Services for the parent. Assistance with the care of the parent is the most significant of the recommended interventions. Assistance in direct care-provision serves several functions for the caregiver: 1) it provides relief from the taxing physical activities of caregiving; 2) it increases the caregiver's time and freedom; and 3) it frees the caregiver to engage in other highly valued activities (e.g., rest, work, social interaction).

Doherty, Rieck, and Hicks (1975), in a report prepared for the White House Conference on Aging, found that the system of care for the elderly in this country is underdeveloped and uncoordinated. The authors identified four major problem areas: 1) inadequate coordination of services, 2) limited alternatives to institutionalization, 3) a frustrating maze of office locations, application procedures, and financial requirements, and 4) limited income, forcing a majority of elderly to accept only those services which are reimbursed. Although the data for this report were collected in 1971, the problems identified still exist and are even more acute today.

It is clear from an examination of the range of functional limitations experienced by older persons that a continuum of care and services is required to meet the needs of this group. This is not a new idea. For years, clinicians and researchers have discussed the need for an "organized delivery system" based on client needs. The range of services must extend from the commu-

nity support necessary to enable the minimally impaired elderly to live independently (telephone contact, companion, chore services) to institutions for the elderly where severely limited, ill elderly can receive skilled nursing services (Doherty, Segal, & Hicks, 1978; Kamerman, 1976; Kaplan, 1979). The vast "middle ground"--services for the frail elderly in the community (personal services, day care, respite care, home nursing, and homemaker services)--is most needed by the sample population. A comparison of providers and managers demonstrates that inequitable distribution of services is a major problem in the home health care of the aged. Managers, from a higher socio-economic status, can purchase needed services. Providers must "make do" with those services which are reimbursable by the major insurers of the elderly (Medicare and Medicaid). The option for care management should be made available to providers through changes in public policies.

Assistance with home care of the elderly. Caregivers need assistance in the provision of nursing and personal care for their parent. Professionals, skilled in the assessment, and delivery, of services to older chronically ill persons, significantly reduce the physical and emotional burden of caregiving to caregivers. The expertise provided by a skilled person (e.g., visiting nurse) in the management of problems of daily living and treatment regimens simplifies strategy development and shortens the time

necessitated by a trial and error approach to caregiving. Caregivers identify periodic professional assessment and sustained "helper" or companion assistance as the most valuable assistance in parent-caring.

Companions and helpers are persons who spend blocks of time with the ill parent and are skilled in meeting his/her needs for personal care and homemaking services. Companions and helpers provide complete relief for the caregiver; live-in helpers are particularly effective in providing relief and freedom for caregivers. The service must be available for long blocks of time. Unfortunately, lack of services, public policies, and funding restrictions limit the number of hours of homemaking and nurse's aides assistance available to most parents.

Three types of out-of-home services are discussed: 1) day care, 2) respite care, and 3) collective sitting services.

Day care services are programs designed for ill elderly for one or more of the following purposes: restorative care, maintenance care, and/or psychological support. Secondarily, day care offers complete relief from parent-caring activities for caregivers for the period the parent is in the center. The elderly participants are transported to a central location in which services are provided. The services usually include: nursing, social services, physical and occupational therapy, and counseling. In addition to providing professional services, these

programs foster social interaction among otherwise isolated persons. The availability of day care is very limited. The development of more low cost day care is needed in the study communities.

Respite care is the term applied to brief and temporary institutionalization of a parent to provide relief for the caregiver. Respite care takes several forms: 1) intermittent hospitalization, 2) holiday hospitalization, and 3) floating beds (Remnet, 1979). In principle, the three types of respite care are similar. An institution (hospital, skilled nursing facility, nursing home, etc.) provides for the temporary admission of an older person--not based on his/her physical condition, but on the provision of relief for the caregiver. This system is well-developed in England, but institutional policies and insurance restrictions preclude its widespread use in the United States. Both care-providers and managers identified this strategy as one which would allow them freedom and mobility, enabling them to continue parent-caring activities refreshed.

Collective parent-caring by informal social support groups unattached to the traditional health care delivery system is a potentially effective strategy for relieving caregivers for brief periods of time. This strategy was observed on a small scale in the study population. Caregivers who met each other through a day care center arranged to trade parent-sitting services for each

other on an individual basis. Theoretically, this strategy could work for small groups of parents. At a time of decreasing federal and state support for services, the informal social support model is a logical alternative to fee-for-service based programs.

Services for caregivers. Caregivers require: 1) assistance in strategy development for the management of caregiving problems, 2) acquisition and evaluation of information about community services, 3) surrogate management services, 4) social and psychological support, and 5) treatment for their own health problems.

Commonalities in strategies to manage nourishment, elimination, activity, and rest problems suggest that a skilled teacher of strategies would simplify the development of a workable routine for caregiving. Several methods could be used to provide assistance in this area: 1) individual assistance, 2) educational groups run by professionals, and 3) self-help groups.

Both providers and managers require knowledge and skills in strategy development. Individual assistance in strategy development can be provided by anyone with special skills and knowledge in the area and an ability to communicate--visiting nurses, experienced lay caregivers, nurse aides, etc. Community health nurses are particularly skilled in the development of strategies to manage the problems encountered by impaired persons in the activities of daily living. The nurse's education and

contact with other individuals who have solved similar problems make her an ideal assistant to the ill parent and caregiver. By assisting in the problem-solving process, the nurse can decrease the time spent in trial and error strategy development.

Appropriate content can also be taught in an educational group situation. Concrete information about aging, illness, services, insurance, conservatorships, nursing care, available equipment, etc., is needed by caregivers prior to and during strategy formation. Brief courses (similar to child birth information classes), taught by professional and knowledgeable lay caregivers, can be offered through public health departments, clinics, schools, or voluntary agencies. In addition to providing the content, the course would provide participants with contact with other caregivers. This would foster the sharing of successful strategies, as well as allow for group support.

Self-help groups of caregivers are difficult to organize because of the isolation of the members of this population. Service settings provide a meeting place for caregivers. Self-help groups serve as a basis for information and service exchange, psychological support, and political activity and are controlled by the caregivers themselves, rather than by professionals. Both educational groups and self-help groups are useful in providing a forum for the sharing of successful strategies for parent-caring.

Acquisition and evaluation of community services. The main problems experienced by managers are related to the process of identifying community resources and negotiating for services. The identification and evaluation of community resources would be facilitated immeasurably if knowledgeable, highly visible counselors were available in communities with current, accurate information about services, referral procedures, eligibility requirements, etc. The counselors could be professionals (nurses, social service workers, etc.) or lay counselors from self-help groups. In addition to being knowledgeable about resources, the counselors must be skilled in dealing with the bureaucracies of Medicare, Supplementary Security Income, and Medicaid.

The guidebooks available to caregivers (Percy, 1974; Silverstone & Hymen, 1975) offer lists of the state area agencies for aging, as well as a list of voluntary and official agencies usually found in communities in the United States. However, variation among communities is great, and few local guides provide adequate information on which to base decisions about a program. Information and referral services for the elderly, a recent Title II Old Age Assistance priority, can serve as a resource to families.

Another function which could be performed by a visiting nurse or advocate is the surrogate management of parent-caring. At the moment, transference of parent-caring can only be done to an

institution (congregate housing with services, nursing home, etc.). Theoretically, the management of services could be done, and actually facilitated, by an "expert manager" who is familiar with the services, personnel, disability requirements, funding sources, and reimbursement policies of the system.

Support for Caregivers

Caregivers are subjected to the prolonged, inordinant physical and psychological stresses of parent-caring during late middle-age or old age. The stresses impact their physical and mental health. Health care workers in general and nurses in particular should be aware of this hidden, at risk population. Caregivers report delaying or not seeking help for their own health problems because: 1) they are afraid that something serious will be found ("and who would take care of Mom if something happens to me?"); or 2) it is difficult to schedule a physician's visit because of inflexible time schedules related to caregiving activities. The identified problems would be greatly reduced by professional caretaking and/or respite care.

Physicians and nurses can be useful in the assessment of the caregiver's health and in treatment of health problems. The age and lower socio-economic status of the providers place them at higher risk for chronic physical and emotional problems. Preventive and secondary treatment of such problems as hypertension and obesity (common among providers) can decrease

their risk for other chronic illness. Visiting nurses are in a particularly good position to perform the assessment and treatment of caregivers, since they visit in the home, and can observe the caregivers physical-emotional condition, stresses, environmental situation, and behavior of family members.

Caregivers are often isolated from traditional social supports. As noted earlier, single and married women decrease their contact with friends and relatives because of caregiving. Caregivers experience feelings of anger, guilt, and hostility toward the parent. These emotions complicate the caregiving process. Support for caregivers is particularly necessary during times of crisis in the caregiving process (shifts in caregiving modalities, a change in the parent's condition, etc.). Social and psychological support can be provided through professional counseling and self-help groups. Professionals in contact with the parent can provide non-threatening support for caregivers. Self-help groups of caregivers or women who meet regularly at churches or other institutions are useful for the subjects engaged in them. Finally, for caregivers with particularly complex problems in the psychological management of caregiving or during "crisis" periods of caregiving (e.g., modality shifts), the services of professional psychological counseling are helpful.

Services for the Family

For selected families, intergenerational family group sessions would provide an opportunity to discuss issues which

confront family members. Expression of old, unresolved sibling and parent-child conflicts as well as current conflicts releases much of the anger and frustration experienced by family members, freeing them to deal more creatively with the parent's care needs. Realistic discussion of expectations and needs of all family members is difficult, but can be productive for some families.

Distribution of Services

The prerequisites for needed service delivery to chronically ill elderly are: 1) the existence of the needed services in the community, 2) adequate numbers of prepared professional and non-professional workers to provide the services, 3) effective information and referral services, 4) an organized access process, 5) non-restrictive eligibility requirements, and 6) adequate, sustained funding for the service. Distribution problems arise in each area. In the study communities for example, some of the needed services do not exist or are not large enough to serve the population in need. Respite services are totally unavailable to subjects. Day care is available only to a few. Home health services are decreasingly available because of funding limits. The lack of information and referral services has been discussed as a major problem for caregivers in the study community. Care managers identify the complicated and frustrating application procedure required by insurers and services as one of the most distressing parts of parent-caring. Finally, funding, or lack of

funding, for services determines their distribution. Medicare and Medicaid, the primary insurers of the elderly, are based on acute care needs. Their reimbursement schedules are inappropriate for the needs of the chronically ill, mildly to moderately functionally impaired elderly. For example, home care expenditures constitute less than 1% of both the Medicare and Medicaid budgets (Dougherty, Segal, & Hicks, 1978). Considering that 95-96% of the elderly in this country are living in their homes, this percentage is totally inadequate.

Institutional barriers to the delivery of needed services to the elderly in the form of eligibility requirements and reimbursement policies prevent an equitable distribution of existing services and, at the same time, serve as a disincentive for service development. Recommendations for policy research in the area of health care and the aged will be discussed in the next section.

Summary of Clinical Implications

The clinical implications of the study results relate to 1) the development of needed services for parents, caregivers, and families, and 2) the distribution of existing services. As suggested in the literature, services required by chronically ill elderly extend from the minimal community support of telephone contact to the intensive skilled nursing services provided in institutional settings. Elderly whose needs fall at either end of

the care continuum generally receive the needed services. The vast middle ground of support for the home bound frail elderly (homemakers, personal services, day care, home nursing, etc.) is less well distributed in the society.

Care-providers identify decreased freedom, decreased privacy, and daily irritation as most problematic in parent-caring. Recommendations related to the relief of these problems include the development of in-home and out-of-home services for the parent. Companion and homemaker services, day care, respite care, and collective parent-sitting are approaches to the most pressing problems of care-providers.

In-home nursing services are useful to caregivers in parent caring in three ways; 1) direct assistance in care activities, 2) assistance in strategy development, and 3) provision information and referral information. Additionally, home nurses can serve caregivers directly in 1) monitoring their health and 2) counseling them about primary and secondary prevention of health problems. Group programs are potentially useful for caregivers. Group strategies include: 1) educational, 2) self-help, and 3) intergenerational family groups.

Finally, policy questions related to the distribution of services are briefly presented. The distribution of service is directly related to income. In this situation, parents and caregivers, who are most vulnerable by virtue of low socio-economic

status, are the least served. Further analysis of and lowering of the institutional barriers to service delivery is critical for the study population.

Implications for Further Research

The results of the study suggest several areas for further clinical and policy research. Serendipitous findings also indicate directions for further investigation.

Clinical Research Suggested by the Findings

Basic research to:

1. Determine the number of women involved in caregiving and the extent of their involvement.

2. Compare systematically persons electing to engage in caregiving activities with persons electing not to engage in caregiving to identify the social, psychological, and cultural characteristics of each group.

3. Analyze the differential and cumulative impact on parents, caregivers, and family members of specific parental health problems (stroke, heart disease, cancer) and/or functional losses (mobility, speech, cognition, etc.).

4. Analyze the process of caregiving in families in longitudinal studies focusing on changes over time, development of coping strategies, critical periods for caregivers, etc.

5. Analyze the influence of social networks of caregivers and parents on the caregiving process and outcomes.

Tool development to:

1. Develop specific measures and weightings of the costs and benefits of parent-caring.

2. Devise meaningful outcome criteria on which to evaluate specific intervention strategies.

Evaluation research to:

1. Measure the effectiveness of specific intervention strategies in terms of:

   a. their appropriateness of specific client groups;

   b. the impact on the parent, caregiver, and family; and

   c. cost effectiveness.

2. Compare alternative interventions for specific problems and/or categories of needs (e.g., individual counseling or group support for caregivers in specific situations).

Ethics and policy research to:

1. Analyze the competing rights and obligations of individuals (parent/caregiver/other family members) in the situation of parent-caring.

2. Analyze the barriers to service provision to parents and caregivers created by social policies (eligibility requirements, reimbursement policies, etc.).

3. Analyze the allocation of resources to caregivers and frail elderly in terms of distributive justice.

4. Analyze the ethical issues raised by an intensive interviewing methodology in which one asks individuals to analyze their experiences so that their view of them may change.

Serendipitous findings. Several areas of research were suggested by serendipitous study findings:

1. Childless caregivers of mothers were more preoccupied with early mother-child conflicts than caregivers with children (for a more detailed analysis, see Archbold, 1979). This suggests that women with children have had an opportunity to resolve early mother-child conflicts (an analysis suggested by Bibring, 1959) and/or have learned to cope with the limitations imposed by dependents. Further investigation of this area might be fruitful.

2. The investigator had the opportunity to interview caregivers and parents in alternative family forms (kibbutzim and convents). Changing social norms in both arenas have placed the elderly in a particularly vulnerable position. For example, until recently, joining a religious order meant leaving the family of origin as a primary social group and embracing the order as the family. Over the past 15 years, a new emphasis has been placed on the nun's responsibility to her family of origin. The nuns spend holidays with their families, provide parent-caring to their own

parents, etc. Older nuns--who left their family of origin, figuratively and literally, are trapped. Ill older nuns are left alone on Christmas and feel deserted by "their family," the order. For a detailed analysis of changes on the kibbutzim leading to vulnerability of elderly members, see Archbold (1980). Further research on the impact of rapid social change in small communities on the aged would be interesting.

3. The literature and discussions with nurses from other cultures suggest that significant differences exist in the phenomenon of parent-caring in different cultures. These differences are based on the culture's general view of dependence/interdependence/independence, as well as variations in expectations of filial piety. Cross cultural studies of parent-caring, as well as appropriate nursing interventions for families of different cultural backgrounds, is indicated.

Summary

Two caregiving modalities were studied by the investigator: 1) care provision, the performance of care activities for the parent by the caregiver; and 2) care management, the delegation and management of caregiving activities for the parent by others. The social and behavioral precedents of the decision to provide care to a parent include: 1) the caregiver's lower socio-economic background, shared housing with the parent prior to parental illness, and previous satisfying experience in a caregiving role;

and 2) the parent's slow, progressive illness onset. Social and behavioral precedents of the decision to manage parent-caring include: 1) the caregiver's higher socio-economic background (income, career commitment), and 2) the parent's rapid illness onset with sudden loss of major functional abilities.

Once the decision to provide or manage care is made, the caregiver must develop strategies for dealing with the problems of the parent, herself, and her family. Provider strategies for handling the parent's problems can be placed in three categories--those which: 1) directly assist the parent with his/her activities of daily living, 2) manipulate the environment to decrease the problems encountered by the parent in activities of daily living, and 3) modify the parent's behavior. Manager's strategies include: 1) obtaining and retaining the services of others to assist the parent with activities of daily living, 2) providing psychological and social support directly, 3) major environmental manipulation, and 4) parent education to facilitate independent performance of tasks.

The strategy used by providers to cope with their own problems related to parent-caring is ventilation to others. Managers also use ventilation to friends, family, and professionals. In addition, managers use self-help groups, the restructuring of their time to meet their own needs, and finding meaning in the experience of parent-caring to help with their own

reactions to caregiving. Finally, the providers attempted to "protect" their spouse and family from the impact of parent-caring; the managers manipulated their schedules to spend time with their families and parent separately and engaged in marital counseling to cope with their family's problems with caregiving.

Parent-caring has different consequences depending on the caregiving style employed. Few providers see any benefits to parent-caring. Managers identified a sense of satisfaction, increased knowledge about themselves and aging, improvement in the parent-child relationship, and a sense of meaning in the caregiving as benefits of parent-caring.

Both providers and managers experience difficulties in their marital and sibling relationships secondary to caregiving. Other "costs" to caregivers relate to the care modality they use. Providers report their main problems as decreased freedom, a lack of privacy, constant daily irritation, and guilt. Managers report that time restrictions, career interruption, financial problems, and guilt are the major costs of parent-caring.

Shifts in caregiving modalities occur with time, increasing functional limitations of parent or caregiver, changes in family dynamics, etc. The periods before and during the shifts are often times of crisis for the individual and family. At these points, expression of the complex intrapsychic and interpersonal correlates of caregiving is less inhibited.

Women who care for chronically ill elderly parents are an at risk and underserved population group. They often live under extreme stress which could be decreased with adequate support services including: 1) direct assistance with parent-caring activities, 2) help with the caregivers own problems related to parent-caring, and 3) services to the family unit as a whole. Areas of basic research on parent-caring, evaluative research on program impact and ethics, and policy research are suggested by the study's findings.

References

Adams, B. Isolation, function and beyond: American kinship of the 1960s. Journal of Marriage and the Family, 1970, 32, 575-597.

Adams, B. N. The middle-class adult and his widowed or still-married mother. Social Problems, 1968, 16(1), 50-60.

Adams, M. Older Patients and Their Care: Interactions with Families and Public Health Nurses. Paper presented at the meeting of the 4th Nursing Research Conference, March 1969.

Aguilera, D. C., & Messick, J. M. Crisis Intervention Theory and Methodology. Saint Louis: The C. V. Mosby Company, 1974.

Akhtar, A. J., Broe, A. C., McLean, W. M. R., Andrews, G. R., & Caird, F. I. Disability and dependence in the elderly at home. Age and Aging, 1973, 2, 102-110.

Alam, S. E. The aging parent and the adult child. Journal of Home Economics, 1978, 70(4), 26-28.

American Red Cross. Home Nursing Text. New York: Doubleday and Company, 1963.

Anderson, O. Reflections on the sick role and helping systems. In B. Neugarten & R. Havighurst (Eds.), Social Policy, Social Ethics and the Aging Society. Washington, D.C.: U. S. Government Printing Office, 1976, pp. 89-95.

Archbold, P. Resurgence of Unresolved Parent-Child Conflicts in Childless Parent-Carers. Paper presented at the American Nurses' Association Clinical and Scientific Sessions, Nashville, Tennessee, November 8-11, 1979.

Archbold, P. Impact of parent caring on middle-aged offspring. Journal of Gerontological Nursing, 1980a, 6(2), 78-85.

Archbold, P. Dependency needs of the aged on kibbutzim. Unpublished manuscript, University of California, San Francisco, 1980b.

Barnett, R., & Baruch, G. K. Women in the middle years: A critique of research and theory. Psychology of Women, 1978, 3(2), 187-197.

Barron, F. Personal soundness in university graduate students. In Creativity and Psychological Health. Princeton: N. J. D. Van Nostrand Co., 1963.

Bart, P. Depression in middle-aged women. In V. Gornick & B. K. Moran (Eds.), Women in Sexist Society. New York: New American Library, 1972, pp. 163-186.

Baumert, G. Changes in the family and position of older persons in Germany. In C. Tibbitts & W. Donahue (Eds.), Social and Psychological Aspects of Aging. New York: Columbia University Press, 1962.

Bell, M. J. Attitudes Toward the Female Role, Life Expectations and Problems of the Older Woman. Paper presented at the 32nd Annual Scientific Meeting of the Gerontological Society, Washington, D.C., November 1979.

Beresford, J. C., & Rivlin, A. The multigenerational family. In Living in the Multigenerational Family. Michigan: University of Michigan, Institute of Gerontology, 1969.

Berezin, M. H. The psychiatrist and the geriatric patient: Partial grief in family members and others who care for the elderly patient. Journal of Geriatric Psychiatry, 1970, 4(1), 53-64.

Bibring, G. L. Some considerations of the psychological processes in pregnancy. Psychoanalytic Study of the Child, 1959, 14, 113-121.

Black, K. D., & Bengston, V. L. The Measure of Solidarity in Intergenerational Analysis. Paper presented at the national meetings of the American Psychiatric Association, 1973.

Blenkner, M. Social work and family relationships with some thoughts on filial maturity. In E. Shanas & G. Streib (Eds.), Social Structure and the Family: Generational Relations. Englewood Cliffs, N.J.: Prentice-Hall, 1965, pp. 46-59.

Block, N. R., Davidson, J. L., Grambs, D., & Serock, K. E. Uncharted Territory: Issues and Concerns of Women Over 40. College Park, Maryland: University of Maryland Press, 1978.

Bott, E. Family and Social Networks. London: Tavistock Publishing, Ltd., 1957.

Brody, E. M. Aging and family personality: A developmental view. Family Process, 1974, 13(1), 23-37.

Brody, E. M. Long-Term Care of Older People: A Practical Guide. New York: Human Sciences Press, 1977.

Brody, E. M., Davis, L. J., Fulcomer, M., & Johnsen. Three Generations of Women: Comparisons of Attitudes and Preferences

for Service Providers. Paper presented at the 32nd Annual Meeting of the Gerontological Society, Washington, D.C., November 25-29, 1979.

Brody, E. M., Kleban, M., Woldow, A., & Freeman, L. Survival and death in the mentally impaired aged. Journal of Chronic Disease, 1975, 28, 389-399.

Brody, S. J., Poolshock, W, & Masciocchi, C. F. The family caring unit: A major consideration in the long-term support system. The Gerontologist, 1978, 18(6), 556-561.

Brown, G. W., Bhrolchaim, M. N., & Harris, T. Social class and psychiatric disturbance among women in an urban population. Sociology, 1975, 9, 225-254.

Brown, R. G. Family structure and social isolation of older persons. The Journal of Gerontology, 1960, 15(2), 170-174.

Busse, E. W. Social forces influencing the care and health of the elderly. In J. C. McKinnon & F. T. deVyver (Eds.), Aging and Social Policy. New York: Appleton-Century-Crofts, Inc., 1966.

Calkins, K. Shouldering a burden. Omega, 1972, 3(2), 23-36.

Caplan, G. Principles of Preventive Psychiatry. New York: Basic Books Publishers, Inc., 1964.

Caplan, G. Support systems. In G. Caplan (Ed.), Support Systems and Community Mental Health. New York: Behavioral Publications, 1974, pp. 1-40.

Cath, S. H. The geriatric patient and his family: The institutionalization of a parent--A nadir of life. Journal of Geriatric Psychiatry, 1972, 5(1), 25-46.

Cavan, E. Family life and family substitution in old age. American Sociological Review, 1959, 14, 71-84.

Christopherson, V. A. Family reactions to illness. In Living in the Multigenerational Family. Michigan: University of Michigan, Institute of Gerontology, 1969.

Clark, M., & Anderson, B. Culture and Aging. Springfield, Illinois: Charles Thomas, 1967.

Danis, B. G. Stress Factors in Families Caring for Ill Elders. Paper presented at the 11th International Congress of Gerontology, Tokyo, Japan, August 20-25, 1978.

Danis, B., & Noelker, L. The World of the Never Married Older Woman. Paper presented at the 32nd Annual Scientific Meetings of the Gerontological Society, Washington, D.C., November 25-29, 1979.

Doherty, N., & Hicks, B. The use of cost-effectiveness analysis in geriatric day care. The Gerontologist, 1975, 15, 412-417.

Doherty, N., Segal, J., & Hicks, B. Alternatives to institutionalization for the aged: Viability and cost effectiveness. Aged Care and Services Review, 1978, 1(1), 1-16.

Donahue, W. Living in the four-generational family. In Living in the Multigenerational Family. Michigan: University of Michigan, Institute of Gerontology, 1969.

Eggert, C., Granger, V., Morris, R., & Pendleton, S. F. Caring for the patient with a long-term disability. Geriatrics, 1977, 32, 107.

Fengler, A., & Goodrich, N. Wives of elderly disabled men: The hidden patients. The Gerontologist, 1979, 19(2), 175-183.

Fennell, V. I. Age relations and rapid change in a small town. The Gerontologist, 1977, 17(5), 405-411.

Frieze, I. H. Women's expectations for and causal attributions of success and failure. In M. Mednik, S. Tangri, & L. Hoffman (Eds.), Women and Achievement: Social and Motivational Analysis. New York: John Wiley and Sons, 1975.

Glaser, B. G. Advances in the methodology of grounded theory. In Theoretical Sensitivity. Mill Valley, California: The Sociology Press, 1978.

Glaser, B. G., & Strauss, A. L. The Discovery of Grounded Theory: Strategies for Qualitative Research. Chicago: Aldine Publishing Company, 1967.

Goldfarb, A. I. Psychodynamics of the three-generational family. In E. Shanas & G. Streib (Eds.), Social Structure and the Family. New Jersey: Prentice Hall, Inc., 1965.

Gordon, M. Final Payments. New York: Ballantine Books, 1978.

Gould, R. L. The phases of adult life: A study of developmental psychology. American Journal of Psychology, 1972, 129(5), 521-531.

Greenberg, R. M. Older Women: The Meaning of Involvement in Support Systems. Paper presented at the 32nd Annual Meeting of the Gerontological Society, Washington, D.C., November 28, 1979.

Greenfield, S. M. Industrialization and the family in sociological theory. American Sociological Review, 1961, 47, 312-322.

Hirschfeld, M. J. Families Living with Senile Brain Disease. Paper presented at the XII International Congress of Gerontology, Tokyo, Japan, August 21-25, 1978.

Isaacs, B. Geriatric patients: Do their families care? British Medical Journal, 1971, 4, 282-286.

Isaacs, B, Livingstone, M., & Neville, I. Survival of the Unfittest. London: Routledge and Kegan Paul, 1972.

Johnson, C. Family Support Systems of Elderly Italian Americans. Paper presented at the meetings of the American Anthropology Association, Washington, D.C., November 1978.

Johnson, E. S. "Good" relationships between older mothers and their daughters: A causal model. The Gerontologist, 1978, 18(3), 301-306.

Johnson, E. S., & Bursk, B. J. Relationships between the elderly and their adult children. The Gerontologist, 1977, 17, 90-96.

Kane, R. L., & Kane, R. A. Long Term Care in 6 Countries: Implications for the U. S. (Fogarty International Center Proceedings #33, DHEW Publication #[NIH] 76-1207). Washington, D.C.: U.S. Government Printing Office, 1976.

Kaplan, B. H. An overview of interventions to meet the needs of aging parents and their families. In P. Ragan (Ed.), Aging Parents. California: The University of Southern California Press, 1979, pp. 190-205.

Kaplan, J. The family in aging. The Gerontologist, 1975, 15(5), 385.

Kawabata, Y. The Sound of the Mountain. New York: Berkley Publishing Corporation, 1970.

Kiernat, J. M. Geriatric day hospitals: A golden opportunity for therapists. American Journal of Occupational Therapy, 1976, 30, 285.

Klein, R., Dean, A., & Bogdonoff, M. The impact of illness upon the spouse. Journal of Chronic Disease, 1967, 20, 241-248.

Komorovsky, M. Blue Collar Marriage. New York: Random House, 1962.

Kraus, A. S., Spasoff, R. A., Beattie, E. J., Holden, D. E. W., Lawson, J. S., Rodenburg, M., & Woodcock, G. M. Elderly applicants to long term care institutions. I. Their characteristics, health problems and state of mind. Journal of the American Geriatrics Society, 1976, 24(4), 117-125.

Kraus, A. S., Spasoff, R. A., Beattie, E. J., Holden, D. E. W., Lawson, J. S., Rodenburg, M., & Woodcock, G. M. Elderly applicants to long-term care institutions. II. The application process, placement and care needs. Journal of the American Geriatrics Society, 1976, 24(4), 165-172.

Laurie, W. F. Multi-dimensional functional assessment: The Duke OARS methodology basic research and practical application. Center Reports on Advances in Research, 1977, 1(2).

L'Engle, M. The Summer of the Great-Grandmother. New York: Farrar, Strauss and Giroux, 1972.

Litman, T. Health care and the family: A three generational analysis. Medical Care, 1971, 9(1), 67-81.

Lofland, J. Analyzing Social Settings. Belmont, California: Wadsworth Publishing Company, Inc., 1971.

Lopata, H. Z. Contributions of extended families and the support system of metropolitan widows: Limitations of the modified kin network. Journal of Marriage and the Family, 1978, 40, 355-364.

Lowenthal, M. F., Thurnher, M., Chiriboga, D., and Associates. Four Stages of Life. San Francisco: Jossey-Bass, 1975.

Matthews, M. A. On the psychology of the aging woman, depression in late midlife: Change or repetition? Another chance for working through. Journal of Geriatric Psychiatry, 1979, 12(1), 37-55.

Merton, R. F., Fiske, M., & Kendall, P. The Focused Interview. Glencoe, Illinois: The Free Press, 1956.

Nadelson, C. On the psychology of the aging woman, discussion of mid-life marital issues: Renewal or regression. Journal of Geriatric Psychiatry, 1979, 12(1), 57-70.

National Council for the Single Woman and Her Dependents. The dynamics of Informal Caring. Unpublished manuscript, London, 1979b.

National Council for the Single Woman and Her Dependents. The impact of caring on the single woman with elderly dependents. Unpublished manuscript, London, 1978b.

National Council for the Single Woman and Her Dependents. The loving trap. Unpublished manuscript, London, 1979a.

National Council for the Single Woman and Her Dependents. The single woman: Bereavement and associated depression. Unpublished manuscript, London, 1976.

National Council for the Single Woman and Her Dependents. Single women caring for their dependents. Unpublished manuscript, London, 1978a.

Newman, S. Housing Adjustments of Older People. A Report of Findings from the Second Phase. Michigan: University of Michigan, Institute for Social Research, 1976.

O'Brien, C. L. Exploring geriatric day care: An alternative to institutionalization? Journal of Gerontological Nursing, 1977, 3(5), 26-28.

Olsen, T. Tell Me a Riddle. New York: Dell Publishing Co., Inc., 1956.

Parsons, T., & Fox, R. Illness, therapy, and the modern urban American family. Journal of Social Issues, 1952, 8, 31-44.

Percy, C. H. Growing Old in the Country of the Young--With a Practical Resource Guide for the Aged and Their Families. New York: McGraw Hill Book Company, 1974.

Pfeiffer, E. A short portable mental status questionnaire for the assessment of organic brain deficit in elderly patients. Journal of the American Geriatrics Society, 1975, 23(10), 433-439.

Pfeiffer, E. (Ed.). Multidimensional Functional Assessment: The OARS Methodology. Durham, North Carolina: Center for Aging and Human Development, 1976.

Plath, D. W. Japanese psychology through Japanese literature. Journal of Nervous and Mental Diseases, 1973, 157(5), 346-357.

President's Commission on Mental Health. Report of the Task Panels on Women and Aging. Washington, D.C.: U.S. Government Printing Office, 1978, pp. 1022-1155.

Rathbone-McCuan, E. Geriatric day care. The Gerontologist, 1976, 16(6), 517-521.

Remnet, V. L. Alternatives in health care services. In P. Ragan (Ed.), Aging Parents. California: The University of Southern California Press, 1979, pp. 206-220.

Rice, D. Charts and Tables for Projection and Analysis of Health Status Trends. Paper presented at the 106th Annual Meeting of the American Public Health Associations, Los Angeles, California, October 17, 1978.

Robinson, B., & Thurnher, M. Parental Care-Taking: A Family-Cycle Transition. Paper presented at the 29th Annual Scientific Meeting of the Gerontological Society, New York, October 13-17, 1976.

Rosenmayer, L. Family relations of the elderly. Journal of Marriage and the Family, 1968, 30(4), 672-680.

Sainsbury, P., & Grad de Alacron, J. The effects of community care on the family. Journal of Geriatric Psychiatry, 1970, 1, 23-41.

Sanford, J. R. A. Tolerance of debility in elderly dependents by supporters at home: Its significance for hospital practice. British Medical Journal, August 23, 1975, pp. 471-473.

Sarton, M. Kinds of Love. New York: W. W. Norton and Company, 1970.

Segilman, M. Depression and learned helplessness. In R. J. Friedman & M. Katz (Eds.), The Psychology of Depression: Contemporary Theory and Research. Washington, D. C.: Winston, 1974.

Seiden, A. M. Overview: Research on the psychology of women. II. Women in families, work and psychotherapy. American Journal of Psychiatry, 1976, 133(10), 1111-1123.

Seltzer, M. The older woman. Research on Aging, 1979, 1(2), 139-154.

Shanas, E. The family as a social support system in old age. The Gerontologist, 1979b, 19(2), 169-174.

Shanas, E. Family help patterns and social class in three countries. Journal of Marriage and the Family, 1969, 29(2), 257-266.

Shanas, E. Family-kin networks and aging in cross-cultural perspective. Journal of Marriage and the Family, 1973, 17, 492-499.

Shanas, E. The Health of Older People. Cambridge, Massachusetts: Harvard University Press, 1962.

Shanas, E. Social myth as hypothesis: The case of the family relations of old people. The Gerontologist, 1979a, 19(1), 3-8.

Shanas, E., & Streib, G. Social Structure and the Family. New Jersey: Prentice Hall, Inc., 1965.

Sheeton, J. H. The Social Medicine of Old Age: Report of an Inquiry in Wolverhampton. London: Oxford University Press, 1948.

Silverstone, B., & Hyman, H. K. You and Your Aging Parents. New York: Pantheon Books, 1976.

Smith, H. E. Family interaction patterns of the aged: A review. In A. Rose (Ed.), Older People and Their Social World. Philadelphia: F. A. Davis, 1965.

Smith, K., & Bengston, V. L. Positive consequences of institutionalization: Solidarity between elderly parents and their middle-aged children. The Gerontologist, 1979, 19(5), 438-447.

Stehaurer, J. Relations between generations and the three-generational household in Denmark. In E. Shanas & G. Streib (Eds.), Social Structure and the Family. New Jersey: Prentice Hall, Inc., 1965.

Sussman, M. Relations of adult children with their parents in the United States. In E. Shanas & G. Streib (Eds.), Social Structure and the Family. New Jersey: Prentice Hall, Inc., 1965.

Sussman, M. B., Cates, J. H., & Smith, D. T. The Family Inheritance. New York: Russell Sage Foundation, 1970.

Sussman, M. B. The family life of older people. In R. H. Binstock & E. Shanas (Eds.), Handbook of Aging and the Social Sciences. New York: N. J. D. Van Nostrand Reinhold Co., 1976, pp. 218-243.

Thurnher, M. Becoming old: Perspectives on women and marriage. In Socialization to Become an Old Woman. Symposium presented at the meeting of the American Psychological Association, August 1977.

Townsend, P. The Family Life of Old People. London: Routledge and Kegan Paul, 1957.

Townsend, P. The effects of family structure on the likelihood of admission to an institution in old age. In E. Shanas & G. Streib (Eds.), Social Structure and the Family: Generational Relations. New Jersey: Prentice Hall, 1965.

Treas, J. Family support systems for the aged: Some social and demographic considerations. The Gerontologist, 1977, 17(6), 486-505.

Troll, L. E. The family of later life: A decade review. Journal of Marriage and the Family, 1971, 32(2), 187-214.

Troll, L. E., Miller, S. J., & Atchley, R. C. The Family in Later Life. Belmont, California: Wadsworth Publishing Co., Inc., 1979.

U.S. Department of Health, Education, and Welfare, Public Health Service. Home Care for Persons 55 and Over in the United States: July 1966-1968. Series 10 #73.

White, P. The Eye of the Storm. New York: Avon Books, 1973.

Appendix I

CONSENT FORM

| | |
|---|---|
| INVESTIGATION: Impact of parent-caring on women | INVESTIGATOR: Pat Archbold<br>PHONE: (415) 666-4771 |

Pat Archbold, a nurse and graduate student at the School of Nursing, University of California, is doing a study to find out more about: 1) the lives of women caring for ill parents, 2) the problems of daily living encountered by the caregivers, 3) the ways in which caregivers handle their problems and those of their parent and other family members, and 4) the problems and benefits of parental caregiving.

If we agree to participate in this study the following will happen: 1) the parent will answer questions in one or two interview sessions requiring approximately two hours in total; 2) the daughter or daughter-in-law will answer questions in two interview sessions requiring approximately three or four hours over a two-week period. The interviews will be recorded in writing. The recordings will be handled in a manner to ensure confidentiality. Any publications resulting from this study will include the necessary precautions to protect the identity of the respondent.

Sharing our thoughts and feelings with Ms. Archbold may not provide any comfort to us directly, and there may be no benefit to us personally. Some of the questions may touch on painful experiences which may be upsetting to us. We may refuse to answer individual questions or may terminate the interview at any time. The findings of this study may be of benefit to families in the future.

If we have any comments about participation in this study we should first talk with the investigator. If for some reason we do not wish to do this, we may contact the Committee on Human Research, which is concerned with the protection of volunteers in research projects. We may reach the Committee between 8:00am and 5:00pm, Monday through Friday, by calling (415) 666-1814, or by writing them at: Committee on Human Research, University of California, San Francisco, California, 94143.

| | |
|---|---|
| Date | Signature of Parent |
| Date | Signature of Daughter or Daughter-in-law |

Appendix II

Code #_____

Date _____

Description of interview setting:

Tell me about your parent:

What kinds of help do you provide for your parent?

WHAT DOES IT MEAN TO YOU TO CARE FOR YOUR PARENT?

What are the benefits to you?

What are the costs to you?

WHAT CHANGES HAVE YOU MADE IN YOUR LIFE SINCE THE ASSUMPTION OF CAREGIVING ACTIVITIES?

1. Leisure activities

2. Income and expenditures

3. Community activities

4. Other

HOW DO YOU FEEL ABOUT THESE CHANGES?

RELATIONSHIP WITH ILL PARENT

| | | | | |
|---|---|---|---|---|
| Prior to illness | ___Excellent | ___Good | ___Fair | ___Poor |
| Current | ___Excellent | ___Good | ___Fair | ___Poor |

Explain:

CHILDREN

| Names | Sex | Age | Educ. | Occup. | Mar. Status | Prox. Time | # Children |
|---|---|---|---|---|---|---|---|
| | | | | | | | |
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| SIBLINGS | | | | | | | |
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RELIGION _____

ATTENDENCE AT RELIGIOUS MEETINGS ___Weekly ___Monthly ___Occas. ___None

SELF DEFINITION AS A RELIGIOUS PERSON ___Yes ___No

CHANGE IN EMPLOYMENT STATUS SINCE ONSET OF CAREGIVING ACTIVITIES:

Explain

CHECK LIST OF CHANGE IN ROLE RELATIONSHIPS SINCE PARENT'S ILLNESS

| | Change in Relationship | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | Closeness | | | Conflict | | | Contact | | |
| | More | Same | Less | More | Same | Less | More | Same | Less |
| Spouse | ____ | ____ | ____ | ____ | ____ | ____ | ____ | ____ | ____ |
| Father | ____ | ____ | ____ | ____ | ____ | ____ | ____ | ____ | ____ |
| Mother | ____ | ____ | ____ | ____ | ____ | ____ | ____ | ____ | ____ |
| Siblings 1 | ____ | ____ | ____ | ____ | ____ | ____ | ____ | ____ | ____ |
| 2 | ____ | ____ | ____ | ____ | ____ | ____ | ____ | ____ | ____ |
| 3 | ____ | ____ | ____ | ____ | ____ | ____ | ____ | ____ | ____ |
| 4 | ____ | ____ | ____ | ____ | ____ | ____ | ____ | ____ | ____ |
| Children | ____ | ____ | ____ | ____ | ____ | ____ | ____ | ____ | ____ |
| Other relatives | ____ | ____ | ____ | ____ | ____ | ____ | ____ | ____ | ____ |
| Friends | ____ | ____ | ____ | ____ | ____ | ____ | ____ | ____ | ____ |
| Co-workers | ____ | ____ | ____ | ____ | ____ | ____ | ____ | ____ | ____ |
| Neighbors | ____ | ____ | ____ | ____ | ____ | ____ | ____ | ____ | ____ |

Probe:

All of us react to these problems (parent's health) differently. Have your recent concerns affected you in the following:

| | very much | somewhat | not at all |
|---|---|---|---|
| Sleep habits | _____ | _____ | _____ |
| Difference in appetite | _____ | _____ | _____ |
| Drinking habits | _____ | _____ | _____ |
| Smoking | _____ | _____ | _____ |
| Your health | _____ | _____ | _____ |
| Your mood | _____ | _____ | _____ |
| Your outlook on the world | _____ | _____ | _____ |
| Your energy level | _____ | _____ | _____ |
| Weight gain or loss | _____ | _____ | _____ |

Probe:

Has this changed since your parent was first hospitalized?

Generally, how has it changed your outlook on the world and how you get along with others?

PAST FAMILY SUPPORTS:

Has there been a time in the past when the family needed to rally around a member? Explain.

Have you or your husband ever been ill? If so, what arrangements were made? Who helped you?

When a financial crisis comes up, could you call on your family or relations? If so, what can you expect?

Some people feel that in time of stress, it is better to let off steam and show their emotions. Others prefer to keep their feelings to themselves. How would you categorize yourself?

How do your family and other relatives react?

In a crisis, is your family likely to turn to: _____the nuclear family, _____relatives, _____friends, _____professionals

DECISION MAKING WITHIN THE FAMILY ABOUT CAREGIVING

| Relation | | Involved | Not Involved | Satisfied | Not Satisfied |
|---|---|---|---|---|---|
| Ill parent | | | | | |
| Spouse | | | | | |
| Caregiver | | | | | |
| Spouse of Caregiver | | | | | |
| Siblings | 1 | | | | |
| | 2 | | | | |
| | 3 | | | | |
| | 4 | | | | |
| Children | 1 | | | | |
| | 2 | | | | |
| | 3 | | | | |
| | 4 | | | | |
| Physician | | | | | |
| Lawyer | | | | | |
| SSW | | | | | |
| Nurse | | | | | |
| Priest/Rabbi | | | | | |
| Other | | | | | |

ALTERNATIVES CONSIDERED OR CHOSEN

1. Long term care facilities _____
2. Board and Care homes _____
3. Senior citizens housing _____
4. Present residence with supportive community services and family _____
5. New, more efficient residence _____
6. Residence with family member _____
7. Other, explain _____

Describe in detail the informant's evaluation of these alternatives and what role the respondent and other family members will play.

PARENTAL OBLIGATIONS

What kinds of things have your parents expected from you over the years?

How was this instilled? Did they talk about it?

What is the motivation for the obligation? (repayment, love and gratitude, responsibility, etc.)

What kinds of responsibilities to your parents do you have now?

financial _____
chauffering _____
advice _____
other _____

frequent visits _____
services _____
respect _____

Probe:

How would you feel if either your parent(s) or your in-laws come to live in your home? What kinds of problems might arise?

How do you feel about your parent(s) having to go to a nursing home?

SANFORD'S TOLERANCE OF DISABILITY

Does your parent have any of the following problems? If so, how difficult is it for you to live with?

| Problem | Occur. | No Problem | Manageable | Difficult | Intoler. |
|---|---|---|---|---|---|
| Sleep disturbance | | | | | |
| Incontinence - F | | | | | |
| Incontinence - U | | | | | |
| Falls | | | | | |
| Inability to get out of bed | | | | | |
| Inability to get off commode | | | | | |
| Dangerous behavior | | | | | |
| Inability to walk | | | | | |
| Personality conflict | | | | | |
| Physically aggressive | | | | | |
| Inability to dress | | | | | |
| Inability to wash | | | | | |
| Inability to commu. | | | | | |
| Daytime wandering | | | | | |
| Inability to climb stairs | | | | | |
| Inability to feed self | | | | | |

How do you manage these problems? What advice would you give others experiencing the same problem?

Have you any problems limiting your own ability to provide care for your parent?

| Problem | Manageable | Difficult | Intolerable | No Problem |
|---|---|---|---|---|
| Anxiety/depression | | | | |
| Personality conflict | | | | |
| Insufficient physical strength | | | | |
| Arthritis | | | | |
| Back strain | | | | |
| Bronchitis | | | | |
| Embarrassment | | | | |
| Other (explain) | | | | |

What help do you receive in providing care for your parent?

What help do you need, but are not receiving?

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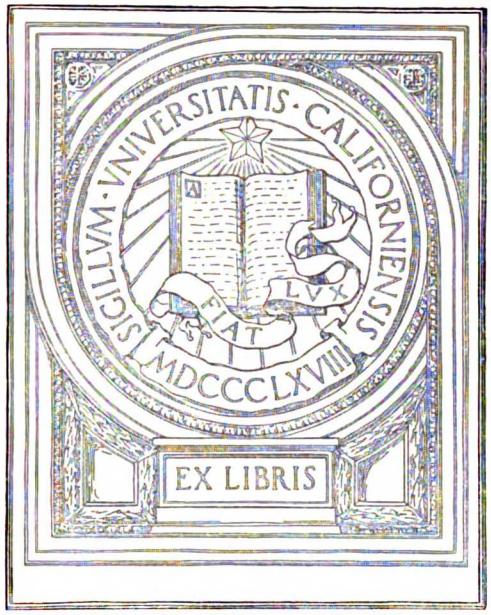


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