To the Graduate Council:

I am submitting herewith a dissertation written by Ruth Nelson Paton entitled "Geriatric Rehabilitation and Caregiver Perception of Burden: A Randomized Control Study." I have examined the final copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy, with a major in Social Work.

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We have read this dissertation
and recommend its acceptance:

Accepted for the Council:

Vice Provost
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GERIATRIC REHABILITATION AND CAREGIVER PERCEPTION OF BURDEN: A RANDOMIZED CONTROL STUDY

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ABSTRACT

This dissertation describes the results of a randomized controlled trial of caregivers whose frail elders were randomized to a Geriatric Assessment and Rehabilitation Unit (GARU) or to usual care in the community. Previous research has demonstrated that the functional status of elders contributes to caregivers' perception of burden. Other studies have demonstrated that GARU care improves elder patient function. The research questions were: Does locus of treatment effect caregiver perception of burden? Does change in elder functional status have an effect on caregiver perception of burden? (Variables of interest were elder ADL, bladder and bowel function, depressive symptomatology, and mental status.) Are elder and caregiver characteristics (age, race, gender, residence and relationship to elder) associated with caregiver perception of burden? A semi-structured telephone interview with caregivers was utilized to collect data on caregiver perception of burden. No significant difference in caregiver perception of burden was found between GARU caregivers and community caregivers. Change in total ADL function and change in depressive symptomatology were not associated with burden. Change in mental status and bladder and bowel function were associated with burden, but not in the expected direction. Additionally function on some individual ADL tasks was associated with burden. Finally, gender and relationship to elders were statistically related to caregiver perception of burden. Race was related to burden only in the community caregivers with white caregivers experiencing more burden.

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CHAPTER I

ELDER CAREGIVING

Introduction

American, cross-cultural and cross-national studies have documented family care of the elderly in amazingly consistent patterns (Rosow, 1965; Brody, 1967; Shanas, Townsend, Wedderburn, Friis, Milhoj & Stehouwer, 1968; Shanas, 1969; General Accounting Office, 1977). In spite of the replication and publication of these findings since at least the mid-sixties, many myths still exist about older people and their families.

One of the most pervasive and destructive is the myth of abandonment. That is that families today, unlike families in the good old days, abandon their elderly relatives, often dumping them in institutions, neglecting them both physically and psychologically (Brody, 1977; Shanas et al., 1968; Shanas, 1979). Neither the myth of the "good old days" nor that of abandonment is correct. Old age historians have substantiated Kent's 1965 statement that there has never been a "golden age" for the elderly. The nuclear family has always been the dominant mode of family life and when sharing of residence was necessary for economic or other reasons, adult children moved in with their parents. Additionally, the parents maintained their status as heads of households (Kent, 1965; Laslett, 1976; Nydegger, 1983). This presents a very different configuration from the

romantic ideal of the parent being cared for by a loving extended family (Simos, 1970; Fischer, 1978; Dahlin, 1980).

Current studies show that present day families do not abandon their elderly. Approximately 80% of all home health care services provided to elderly persons in this country are provided by members of their families (National Center for Health statistics, 1972; General Accounting Office, 1977). Furthermore, studies show that the presence or absence of a family caring unit is an important predictor of the placement of the chronically ill or disabled elderly and it is usually a crisis in the family, such as the illness or death of a family member, which precipitates institutional placement when it is made (Townsend, 1965; Maddox, 1975; Brody & Poulshock, 1978). Not only do families provide care, they do so at great cost to themselves. This cost, alternately referred to as stress, strain, or burden, provides the focus of the caregiver sub-study.

Problem Context

The Aging Family in Social Science Literature

Interest in the relationship between adult children and their aging parents (the aging family) is a recent phenomenon. In fact, the neglect of the aging family in social science literature has been widely documented (Beard, 1948; Shanas & Streib, 1965; Townsend, 1965; Troll, 1971; Berardo, 1972; Dahlin, 1980; Brody, 1985). When intergenerational research began, much of the focus was on family structure and its effect on behavior, with little or no attention to

affective quality of the relationship. Johnson and Bursk noted as recently as 1977 that an extensive review of the literature found only one study (Simos, 1970) on affective quality of the caregiving relationship and none which included both adult children and their parents.

A 1963 symposium sponsored by the Gerontological Society of America and Duke University, called to consider the relationships between adult children and their parents, made little if any attempt to examine the impact which elder caregiving had on the family (Brody, 1985). The conveners were primarily interested in the three-generation family and the persistence of the myths of abandonment and a golden era for the elderly referred to earlier. Family care of aging parents had been irrefutably established, yet these myths persisted.

Concerns About Aging Families

Growing Number of Elderly

The increasing number of older persons and the public and professional attention they have gained are probably partly responsible for the increase in studies in the past decade focusing on the aging family generally and on caregiving specifically. Certainly as the number and proportion of persons over 65 years of age has increased, concern for their care has also increased. Concern is exacerbated by the fact that the fastest growing segment of the population is the age group over 85 years of age and as age increases, use of services also increases.

Use and Quality of Services

Concern focuses on the delivery of services formally by agencies and institutions and informally by family and friends. Concern has also been expressed for the quality of health care provided to the elderly. Incomplete or inadequate health care results in inappropriate institutionalization (Williams, 1973).

Impact on Families

Families are caught in a double bind over the myth of abandonment. First, there is the psychological bind and its associated guilt when institutional placement becomes necessary. Second, it has been suggested that state regulations which may require families to assume financial responsibility for aged family members reflect the persistent belief that families are not doing their part in caring for aged family members (Brody, 1970). That is, policy makers who believe the myth of abandonment often look to family care as an alternative mechanism for reducing health care costs. Callahan (1985) notes, for instance, that 26 states have statutes that can require children to provide financial support for financially needy parents.

Social and demographic changes and the impact of caregiving also cause concern for the caregiving family. Caregivers are primarily female: spouses, daughters and daughters-in-law. At the same time that the number of older people is increasing, family size is increasing. Women are returning to the labor force in record numbers resulting in fewer females being available to provide care (Treas, 1977). Earlier marriage and child bearing means that we are dealing

for the first time in history with four and even five generation families. There are no role models for caregivers or their elders. Brody (1981) has referred to middle-aged caregivers as "women in the middle," facing demands of spouse and children on the one hand, and parents and possibly even demands of employment on the other. Still other caregivers may be 60 to 80 years of age, dealing with their own aging processes, which complicates and sometimes makes it impossible for them to provide care (Treas, 1977; Brody, 1981).

Caregiver Burden

The past decade has also seen a rapid increase in studies focusing on the impact care has upon caregivers and their families. As studies have developed, recognition has been given to the necessity for distinguishing between the objective impact of caregiving and the subjective response (Hoenig & Hamilton, 1966; Herz, Endicott & Spitzer, 1976; Thompson & Doll, 1982; Poulshock & Deimling, 1984). That is, while caregiving may have a significant impact on the lives of family caregivers, some define that care as burdensome while others do not. Different tasks increase anxiety in different caregivers. Thus, the perception of burden becomes a variable of interest.

Numerous researchers have documented that burden exists though findings are by no means unequivocal (Sanford, 1975; Reever Bach-Peterson, 1980; Vetter, Jones & Victor, 1981; Cantor, 1983; Horowitz & Shindelman, 1983; Jones & Vetter, 1984; Poulshock & Deimling, 1984; Brody, 1985;; Sanders, Pittman & Montgomery, 1986; Zarit, Todd & Zarit, 1986). Emotional and mental health problems (anxiety and

depression) and social restrictions are problems most consistently reported by caregivers. Correlates of burden, discussed more extensively in the literature review, have alternately been found to include functional status (Robinson & Thurner, 1979; Deimling & Bass, 1984; Jones & Vetter, 1984), incontinence (Vetter, Jones & Victor, 1981; Rabins, Mace & Lucas, 1982; Sanders, Pittman & Montgomery, 1986) mental health and mental status (Robinson & Thurner, 1979; Rabins, Mace & Lucas, 1982; George & Gwyther, 1986; Zarit, Todd & Zarit, 1986), health (Koopman-Boyden & Wells, 1979; Robinson & Thurner, 1979; Sanders, Pittman & Montgomery, 1986) and certain caregiver and patient characteristics (Johnson & Catalano, 1981; Cantor, 1983; Horowitz & Shindelman, 1983; Robinson, 1983; Jones & Vetter, 1984; Horowitz, 1985; George & Gwyther, 1986).

In general, these findings suggest that improvement in patient status has a potential impact on the caregiver's perception of burden. There is also research evidence, discussed in the rationale below, that elder patient status can be improved through specialized medical care.

Rationale

One of the earliest studies on the potential benefits of a specialized medical approach for geriatrics occurred in 1973 (Williams, Hill, Fairbank & Knox, 1973). Reporting on 332 patients who had been referred for nursing home placement, Williams et al. found that in 55% of the cases further diagnostic procedures, medical treatment, or rehabilitation were indicated before a final determination of nursing

home placement could be made. Additional treatment resulted in the following recommendations: 22.9% returned to their own home, 30.5% supervised boarding home; 34.9% nursing home, 8.2% health-related facility and 3.5% psychiatric hospital.

This early study raised serious questions about the adequacy of medical care and the resulting referral process to nursing homes for older persons. Specifically, it suggested that specialized medical care holds the potential for improvement in function for older persons. Studies of elder outpatient and inpatient assessment units, referred to as Geriatric Assessment Units (GAUs) or Geriatric Assessment and Rehabilitation Units (GARUs), have proliferated since this 1973 study and have been of increasing interest to researchers. A 1982 analytic review of fifteen descriptive studies (Rubenstein, Rhee & Kane, 1982) found that GAUs can have an important positive impact on health care for the elderly, including more thorough diagnosis, improved levels of physical and psychological functioning and better placement decisions.

Thus, we see from the earlier discussion that some research studies have found that elder functional status contributes to caregiver perception of burden. Additional studies have found that specialized medical care such as that provided on GARUs improves elder functional status. Would intervention designed to improve elder functional status affect caregiver perception of burden? This caregiver study was specifically designed to determine if elder treatment on a GARU would affect caregiver perception of burden.

The importance of the caregiver study is twofold. First, it builds on earlier research for which questions remain, specifically studies which examine the association between the caregiver's perception of burden and caregiver and elder characteristics. It also contributes to the more recent studies which recognize the multidimensional nature of burden. Second, it will be the first caregiver study which measures the impact of an intervention with elders upon their caregiver's perception of burden. This discussion leads to the following statement of problem and research questions for this caregiver study.

Statement of the Problem

Research studies have demonstrated, although not unequivocally, that functional status of the elderly contributes to caregiver burden. Other studies have demonstrated that treatment on a Geriatric Assessment and Rehabilitation Unit (GARU) improves patient function. Thus, the following three questions are posed:

1. Does locus of treatment affect caregiver perception of burden?
2. Does change in elder functional status have an effect on caregiver perception of burden?
3. Are caregiver and elder characteristics (age, gender, race, residence and relationship to each other) associated with the caregiver's perception of burden?

The major independent variable is treatment location (GARU vs. community). Elder mental status, depression and ADL functional status

are identified as intervening variables. Based on findings from previous studies, sex, race, age, residence, and relationship of the caregiver to the elder are also included as independent variables.

Summary

The increase in numbers and proportions of older persons has raised world-wide concern about the provision of services generally and health care services specifically for the elderly. The pervasive and persistent myths about the golden age when the extended family (i.e., adult children, their children, and their parents) lived happily together under one roof, creates serious problems for the elderly, their families, and society. The myth of abandonment (though soundly defeated in numerous research studies) suggests that families are not doing their part in care of the elderly. It has been well documented that in reality, families provide approximately 80% of all home health related services which the elderly receive in the United States. Further, studies document that families provide such services at considerable cost to themselves. These costs, sometimes perceived as burdensome by caregivers, seem to depend on elder functional status and certain elder and caregiver characteristics (age, race, sex, residence and relationship to each other).

Additional studies have demonstrated that treatment of elders on a GARU improves elder functional status. The caregiver study asks three questions: 1) does locus of treatment affect caregiver perception of burden? 2) does change in elder functional status have an effect on

caregiver perception of burden? and 3) are caregiver and elder characteristics (age, gender, race, residence and relationship to each other) associated with the caregiver perception of burden?

Overview of Remaining Chapters

Chapter II will cover the caregiving literature in more detail. Chapter III will focus specifically on caregiver burden. Chapters IV, V, and VI describe the methodology of this study and discuss the findings, implications, and suggestions for future research.

CHAPTER II

CAREGIVING AND ELDER RECIPIENTS OF CARE

Introduction

Although there has been an explosion of knowledge and research regarding elders and their families since the mix-sixties, some information has been available for centuries. Kastenbaum and Ross (1975) note that "people have been speaking of the state and needs of the aged for centuries . . . what is needed is more listeners." Family care of the aged has been documented since Biblical times. Freeman (1938) notes the serious interest in the study of aging since the earliest days. Griffin (1949) refers to the Bible as a sourcebook of history which students of gerontology cannot afford to ignore.

Even in primitive and Biblical times, however, ambivalence characterized family care of the aged. Two sets of mores are described pertaining to societal attitudes toward the aged. In one the aged were venerated and respected for their wisdom and counsel and viewed with affection and sympathy. Life in primitive times dealt with the grim necessity of survival and the second set of mores reflected this reality. The aged in times of hardship were seen as burdens, wasting the strength of society which was already weakened (Zeman, 1944). In times of famine, the elders were eaten; when burial was a problem, cannibalism was practiced as a means of sanitation. Suicide was seen as an honor at times, and family or friends sometimes assisted to

maintain the dignity of the aged (Freeman, 1938; Zeman, 1942; Zeman, 1944).

Reality is not the only thing which shapes societal responses to elders, however. Priorities, politics and as we have seen even myths are powerful shapers of such reactions. It has been suggested that apathy and ambivalence in recent years have allowed myth to cloud and even guide policy, programs and practice for the aged (Brody, 1985).

Ambivalence toward the aged comes from several sources. The first is the state of elders themselves: competent and incompetent, admirable and lamentable (Kastenbaum & Ross, 1975). Competition for available resources is suggested as the second source. As societal conditions improved, competition for resources decreased and the grim necessities described above disappeared (Kastenbaum and Ross, 1975). A third source of ambivalence is the position held by the aged between youth and death. Old age is better, they say, than death but hardly an ideal toward which one strives (Kastenbaum & Ross, 1975).

Even in times of prosperity, however, conditions for the elderly may not be good. Robert Butler in his 1975 Pulitzer Prize winning book, "Why Survive: Growing Old in America," suggests that conditions for the elderly in the United States are such that life is hardly worth living.

Additionally, societal conditions are not always stable. In times of prosperity, states can assume more responsibility. In times of crisis, individuals, families and other volunteers are an important and

necessary addition to the provision of social services. Such has been the change for elders and their families in Poland over the past two decades (Worach-Kardas, 1983).

While Kastenbaum and Ross note that some information on the state and needs of the aged has been available for centuries, the same cannot be said for literature and research on aging families. The aging family has held a less than prominent place in social science literature, especially prior to the 1970s. Troll (1971) states that books on family life devoted little if any space to the family of late life, not even references or indices. She also comments that her review of the family of late life was the first in the Journal of Marriage and the Family on that topic. The early literature, she notes further, was only available in specialized journals with select readership and in chapters in books, which slowed further the widespread development of an adequate knowledge base.

Empirical research on the family began in the mid-fifties (Townsend, 1965). Aging family research is a more recent phenomenon and caregiving research even more recent. Research findings on caregiving are not always consistent. A great deal of consistency has been found, however, in descriptions of caregivers and their elder recipients of care.

Caregivers

Descriptions of Caregivers

Caregivers are primarily female, usually daughters, daughters-in-law and spouses. Spouse caregivers, however, are almost equally

divided among males and females. Caregiver ages range from the mid-twenties to the mid-eighties. Caregivers are usually married and peers of elders receiving care. They have been found to have a moderate need for assistance themselves (Soldo & Myllyluoma, 1983). When there are no close relatives, more distant relatives become caregivers and friends and neighbors sometimes act as caregivers in the absence of family (Shanas, 1979; Cantor, 1983; Jones & Vetter, 1984).

Jones and Vetter (1984) generally substantiated Cantor's 1983 findings of caregivers' relationships: spouses comprised roughly 30% of their samples, children approximately 40%, other relatives roughly 20%, and friends and neighbors about 10%. Koopman-Boyden and Wells (1979) in their New Zealand studies of caregiver burden found that 45% of their caregivers were children and 29% spouses. Overall 88% of their caregivers were family members.

A 1975 national probability sample of a survey of noninstitutionalized persons 65 years of age and older found that spouses were the number one source of support for elder receivers of care. Children were the second source of support (Shanas, 1979).

Contact Between Elders and Caregivers

Horowitz (1985) found that the majority of caregivers either live with their elders (27%) or within a half hour's drive (over 60%). Daily telephone contact is maintained and at least weekly face-to-face contact. The probability sample reported above (Shanas, 1979) substantiated these findings. About 10% of the elders in her study had not seen their child in the last month. Only 13% of elders with living

children had seen neither a child nor a relative during the week before they were interviewed.

Caregivers of Centenarians

Sanders, Pittman, and Montgomery (1986) studied caregivers from 21 states who responded to a survey seeking information regarding centenarians and their caregivers. Confirmation of shared residence reported by Horowitz and Shindelman (1983) was also found in this study with 27% doing this. One-third lived within a short walk, 35% were within a 10-minute drive, and 97% within a 70-minute drive. Caregiver ages ranged from 30 to 87 with a mean of almost 68 years of age. Caregivers were primarily female and were children or spouses of children. Spouses comprised only 4% of the caregivers in this sample. Other relatives comprised just over 16%.

Elder Recipients of Care

Description of Elders

Cantor (1983) found the elders in her study were frail (73.9% white, 23.4% black, 0.9% Hispanic), over half of whom lived alone. One-third lived with spouse a and 14% resided with another relative or friend. The vast majority were female, most over 60 years of age. Approximately one-half were over 75 years of age. Seventy-three percent were rated as severely impaired on Townsend's Index of Functional Incapacity, 15% seriously impaired, and 12% suffering from some mild impairment. Jones and Vetter (1984) found that 27% of the elderly needed assistance at short notice throughout the day or night,

35% at least once a day, 22% less than once a day, and 16% less than once a week. The national probability sample referred to earlier showed that 7% of those interviewed were bedfast or housebound and an additional 7% were able to go out of doors only with difficulty (Shanas, 1979).

Johnson and Catalano (1981) in their eight-month follow-up of persons previously interviewed found that 32 of 167 (19.2%) elders had died. The mean age of their sample was 74.5 years with 43% being over age 75. Fifty-five percent were female. Of the 49% who were married, 66% were male and 33% female. Brody, et al. (1978) characterize their sample as ill, poor, and mostly women.

Functional Capacity

Poulshock and Deimling (1984) looked at their sample in terms of functional capacity on the Activities of Daily Living (ADL): bathing, dressing, toileting, mobility, incontinence, and eating. On the average the elders were dependent in three of five areas. Approximately 30% were dependent in five areas. On measures of mental impairment they found sufficient disability to "considerably increase the caregiver's burden."

Residence

Fifty percent of the centenarians in the sample described above resided in nursing homes. Approximately 5% lived alone, 14% lived with relatives not identified as caregiver, and 4% lived with friends or other persons (Sanders, et al., 1986).

Service Needs

Service needs of the centenarians (Sanders, et al., 1986) were extensive. Ninety-eight percent could no longer drive, over one-half needed help with bathing, walking and/or dressing and could not perform "solitary entertainment tasks, such as reading or watching TV." While the vast majority (84%) were able to converse, fewer than half could use the telephone or keep in touch with friends.

Health

Snyder and Keefe (1985) report that 45% of the disabled adults in their study had Alzheimer's Disease, 22% multiple sclerosis and 10% stroke. In the Fengler and Goodrich (1979) study of disabled husbands and their wives, 80% of the men suffered from cardiac disabilities which affected mobility, use of limbs, senses and in about 20% of the cases, communication (aphasia). Many had multiple afflictions, two were hemaplegics, one had multiple sclerosis and several suffered from arthritis, cancer and diabetes. In spite of limitations, health was rated as good for 32%, fair for 29% and poor for only 25%. Loss of hearing was the most common problem, followed closely by loss of vision. Only 31% reported incontinence of bladder and bowel. The foregoing description of elder recipients of care presents a picture of significant functional deficits, yet research has demonstrated a potential for improvement in this same population. As mentioned earlier, this improvement is often associated with treatment on GARUs.

Geriatric Assessment and Rehabilitation Units

Geriatric Assessment and Rehabilitation Units (GARUs), described as the "new technology of geriatrics" (Epstein, Hall, Besdine, Cumella, Feldstein, McNeil & Rowe, 1987), have produced encouraging results in terms of reducing the use of nursing home placement upon discharge from hospitals or specialized care units, reducing future need for both hospital and nursing home care and reducing the cost of health care per year of life lived (Applegate & Miller, 1984). More pertinent to this caregiver study, improved functioning has been found in Activities of Daily Living (bathing, dressing, personal care, toileting and ambulation) and both physical and mental health.

The seminal study of Geriatric Assessment Units was a 1979 study of 74 patients admitted during the first year of operation at the Sepulveda VA Medical Center GARU in California. This study found that due to their increased level of independence, 48.4% of the patients required less care at discharge than had been expected. Functional status was improved in two thirds of the patients who could have shown improvement. An average of almost four new treatable disorders per patient was diagnosed that had not been noted by previous physicians. The mean of daily drug dosages per patient was reduced by 32% and the total number of drug doses was reduced by 43% (Rubenstein, Abrass & Kane, 1981).

Rubenstein followed this descriptive study with a randomized control study in 1982. Frail, elderly patients at risk of long-term institutionalization were randomly assigned following stabilization of

acute illness to the GARU or to usual medical care. GARU patients had reduced mortality, were less likely to be discharged to a nursing home, less likely to spend time in a nursing home, less likely to be readmitted to a hospital, and spent fewer days in a hospital per year survived (Rubenstein, Josephson, Wieland, English, Sayre & Kane, 1984).

The Rubenstein study presents one example of the difficulties experienced in cross-study comparisons of caregiver burden research. The study utilized a sample of veterans whose health status may not be representative of the general population and whose gender status certainly is not. Nonetheless as findings from studies of select populations confirm findings from other studies, evidence mounts which is helpful in designing new studies.

In 1983 Applegate, Akins, Vanderzwagg, Thoni, and Baker reported results from data on 100 patients admitted during the first year and a half of operation on a GARU located at Baptist Regional Rehabilitation Center in Memphis, Tennessee. The GARU opened in 1979 with a goal of preventing institutionalization of frail, elderly persons at risk for nursing home placement. The average number of admitting diagnoses was 3.4. Ninety-one new diagnoses of treatable conditions were made. At discharge, 27% needed assistance with ambulation down from 81% at admission. At a six-month follow-up, this was reduced to 22%. Also improved were skills of dressing, housekeeping and toileting. A randomized control trial designed to follow this GARU descriptive study was completed in July 1988. This randomized control trial compares GARU patients to patients who were discharged from acute care hospitals

directly to usual care in the community. The caregivers of the elderly in the randomized controlled trial are the caregivers who comprise the subsample of the caregiver study.

The 1983 Applegate, et al. study is one of only a few which includes a specific report on changes in patterns of incontinence. Teasdale, Sherman, Snow, and Ludie (1983) also comment specifically on incontinence and report "striking examples of change in urinary and fecal incontinence" between GARU patients and patients who received care on a diagnostically similar unit. They also reported improvement in ADL function of GARU patients. While the number of studies is not large and findings are not in total agreement, there is consistency in findings of physical and mental improvement following treatment on a GARU.

Caregiving

Caregiving research has had a number of different foci. Quality of relationship between caregiver and elder, relationship of caregiver to elder, marital and employment status of caregiver, and social and demographic variables have all been studied.

Quality of Caregiving Relationship

Simos (1970) was perhaps the first researcher to look at the affective quality of relationships. One fourth of the referrals to a West Coast Jewish family agency involved a problem with an aging family member. Fifty caregivers from this agency provided the sample for this study. Simos found that where caregivers had been raised in an

environment which was warm, accepting, and responsive, they were able to reciprocate to parents in like manner. Not all environments provided this support and acceptance, however; some were hostile and abusive.

Simos notes the persistent belief that most elderly persons can find a comfortable haven in old age in the three-generation family. This belief, she comments, is especially prominent in the literature and popular belief about Jewish families. Her study, however, did not substantiate this belief. Unfortunately, Simos only interviewed caregivers. This study is important, however, not only for its contribution to the literature on the affective quality of elder and adult child relationships but also for its contribution to the growing number of studies attempting to add to the knowledge base regarding cultural differences in elder caregiving.

The Simos study is also important for its contribution of information about the realities of family life. Not all families are, nor have the capability of being, loving. This is a dilemma of aging family life which has rarely been accounted for in caregiving studies. In this extensive literature review on caregiving, it has been surprising to find few references to the potential for abuse in caregiving families. Elder abuse literature demonstrates clearly that abuse is a family affair. Eighty percent of abusers are family members and increasing dependency raises the potential for abuse. Thus, caregiving families are at risk for elder abuse.

Determinants of Quality of Care

Approximately seven years after the Simos study, Johnson and Bursk (1977) provided perhaps the first study on quality of caregiving relationship which included both the caregiver and the elder recipient of care. This study of 54 parent-child pairs was a Boston area convenience sample. The researchers were interested in examining the impact of four variables (health, attitude toward aging, finances and living environment) on the affective quality of relationships. Only two, health and attitude toward aging, were found to be significantly related to relationship quality. The better the parent's health and attitude toward aging, the better the relationship between parent and child. While some studies have found a difference between parent and adult child attitudes toward their relationship, this study found high agreement between the two ($r = .55$).

Horowitz and Shindelman (1983) looked at reciprocity and affection as determinants of patterns of caregiving. Reciprocity, the giving and receiving of help, was found to be positively correlated with the amount of help given. This study of 203 caregivers found that while relationships were primarily positive, caregiving could and did take place without such positive regard. This finding substantiates that of Simos (1970) discussed above.

The studies have provided only cross-sectional data. Robinson and Thurner (1979) provide longitudinal data on the quality of relationships between caregivers and their elder recipients of care. Baseline data found about equal proportions of caregivers describing

their relationship with their parents as predominantly positive, conveying neutrality, or showing ambivalence or resentment. Health status and activity level of the parent was associated with the level of appraisal. Those respondents who spoke positively of the relationship perceived their parents to be living self-directed and active lives. In other words, they saw their parents as aging successfully. This substantiates the Johnson and Bursk finding that the quality of relationship between caregivers and their elders was correlated with the attitude of the parents toward aging.

Caregivers from this study were interviewed again at 18 months and 5 years. When change in relationship was discussed, it was more likely to be a negative rather than a positive change. When caregivers and their elders resided in the same city, change in the relationship was more often negative. This may reflect other research findings that it is the restrictions of caregiving, not the tasks themselves, which create the greatest difficulty for caregivers (Jones & Vetter, 1984). This assumes that caregivers residing in the same city would be more inclined to feel restrictions than those in differing locales.

Johnson and Catalano (1983) also provide a longitudinal look at the quality of the dyadic caregiving relationship. In an eight month follow-up, they found that for caregivers whose elders had improved, the relationship was less strained. Caregivers, however, were less involved due to improved function, and elders felt more isolated due to this decreased involvement. For caregivers whose elders had

deteriorated, the relationship showed increased strain, had also generally deteriorated, and use of support services had increased.

Gender Differences in Caregiving

As indicated earlier, caregivers are usually female. Horowitz (1985) compared caregiving of sons and daughters for gender differences. She found that sons were more likely to become caregivers in the absence of females to assume the caregiving role. Males often turn the caregiving responsibility over to their female spouses. Sons provide fewer services than daughters and more instrumental assistance, that is financial assistance and concrete services, than emotional support. Even response rates to her survey were lower for males than females (58% vs. 78%).

Impact of Demographic and Social Variables

Demographic and social variables have also been studied for differences in caregiving. Cicirelli (1983) compared caregiving of adult children with intact and disrupted (divorce, widowed, and remarried) marriages. He found little difference in caregiving and the tasks performed between the three groups categorized as having disrupted marriages. Viewed as a total group, however, those with disrupted marriages gave fewer total care and less of 7 of 16 specific services. Caregivers with disrupted marriages perceived parental needs to be lower, felt less filial obligation and felt more limited in time available for caregiving. It is interesting to note, however, that this group recognized the need for emotional support and felt that this

was something they were able to provide to their elders. However, this group felt that they could not give up employment if caregiving responsibilities increased, presumably due to economic responsibilities of a single caregiver.

Childless Elderly

The childless elderly, though not often studies, comprise an interesting and important population and are estimated to be about 20% of the population over 65 years of age (Shanas, 1979; Johnson & Catalano, 1981). Today one-fifth of all women in the childbearing age are choosing not to have children resulting in smaller family size and increasing the likelihood of larger numbers of childless elderly in the future. Similar demographic and social patterns are reported in other countries. Japan (Maeda, 1983), Egypt (Fadel-Girgis, 1983), and China (Chow, 1983) are also experiencing increasing numbers of elderly and decreasing family size.

A small subsample of childless elderly recently discharged from the hospital was studied by Johnson and Catalano (1981). They found that the childless elderly clearly had fewer resources from which to draw but interestingly married childless had fewer resources than single childless. They found childless couples to be socially isolated and very interdependent. Such couples are not inclined to use services despite their frailty. They refer to this phenomenon as "social regression."

Some researchers have found the childless elders and those with no families to be more likely to be institutionalized (Townsend, 1963;

Brody, Poulshock & Masciocchi, 1978). Interestingly, in their larger study, Johnson and Catalano found no significant association between numbers and proximity of children and the occurrence of institutionalization. Johnson and Catalano also found that in the absence of spouse and children the elderly may receive perfunctory help from distant relatives. Also, in the absence of children, elders were more likely to have seen a sibling (Shanas, 1979). Jones and Vetter (1984) and Cantor (1983) confirmed these findings.

Attitudes Toward Aging

Brody, Johnsen, and Fulcomer (1984) utilized three generations of women to examine attitudes toward aging. This study of grandmothers, mothers and daughters found that the elders preferred adult children as providers of emotional support and financial management but not of income. This finding tends to confirm the "intimacy at a distance" of Rosenmayr and Kockeis (1963). The middle generation was least in favor of receiving financial support or instrumental support from children, preferring reliance upon formal services.

Intergenerational Differences

Brody, Johnsen, Fulcomer, and Lang (1983) studied the changing role of women to examine attitudes toward caregiving. In this earlier study grandmothers, mothers and daughters were interviewed. Grandmothers were found to be more amenable to help from formal services than granddaughters. This finding is in keeping with a preference for independence by the elderly found by other researchers

(Rosenmayr & Kockeis, 1963). It differs, however, from findings of Cicirelli (1981). All three generations agreed that older persons should be able to rely on their adult children for help. They concluded that family values regarding care of the aged have not eroded, despite social and demographic changes. This finding also disputes a 1944 study of attitudes of high school and college studies toward caring for the aged (Dinkel, 1944). He concluded that attitudes had changed, that younger generations were less favorably disposed toward care of the aged and that policy needed to reflect these changing attitudes.

Almost 30 years later Wake and Sporakowski (1972) attempted to replicate the Dinkel study. Utilizing the Dinkel questions and a high school and college student sample, they found, unlike Dinkel, that the younger generation had a stronger sense of filial responsibility than their aging counterparts. This finding is in agreement with Brody, et al. (1983).

Further information on intergenerational differences comes from Townsend and Poulshock (1986). They compared information and perceptions of caregivers with their elders on three variables: the person identified as primary caregiver, where and how decision-making occurs, and the extent of support that was available to elders. They found that information on primary caregivers and decision-making would be reliable obtained from the caregivers or their elders. Perception of support available differed between the two groups, however, with elders believing that fewer supports were available. Differences in perceptions about support availability has important implications for

provision of services and suggests that information from elders regarding support availability should be questioned.

Employment and Caregiving

Brody and Schoonover (1986) looked at employed daughters and their widowed mothers to examine the amount of caregiving. The employed caregivers did not give less care than unemployed caregivers, but some differences in task performance were noted. Caregivers who were employed more often shared responsibilities of personal care and meal preparation with others. The others were more often paid employees and to a lesser extent caregiver spouses and other family members. The increased income appeared to allow the employed caregiver to hire help while the unemployed caregiver could not. It is interesting to note that daughters were the primary caregivers whether employed or not. The second line of defense was paid help with minimal reliance on government programs. Some have expressed concern that availability of services might cause caregivers to decrease their provision of services, but this has not proved to be the case (Brody, 1970; Shanas, 1979, 1982; Bane, 1983).

Ethnicity and Culture

Researchers have recently begun to look at ethnicity and culture as variables which may have an impact on caregiving (Simos, 1970; Koopman-Boyden & Wells, 1979; Weeks & Cuellar, 1981; Fadel-Girgis, 1983; Little, 1983; Nydegger, 1983; Chow, 1983; Maeda, 1983; Fleishman & Shmueli, 1984; Strong, 1984). Only a few researchers have

compared caregiving burden by ethnic or cultural factors (Cantor, 1983; Strong, 1984; Moryca, 1985) but descriptive studies have confirmed that many of the same variables operate in caregiving burden regardless of the culture or country where the caregiving occurs (Simos, 1970; Weeks & Cuellar, 1981; Chow, 1983; Fadel-Girgis, 1983; Little, 1983; Maeda, 1983; Nydegger, 1983; Worach-Kardas, 1983; Fleishman & Shmueli, 1984). To be sure ethnic and cultural differences in attitudes toward elder relatives, characteristics of coping, factors resulting in a decision to institutionalize and use of services have been found (Cantor, 1983; Fadel-Girgis, 1983; Little, 1983; Maeda, 1983; Strong, 1984). Differences found are not always in keeping with popular belief, however. More striking have been the similarities across lines of ethnicity and culture (Jackson, 1982; Little, 1983). Factors such as education, socio-economic status and social class have been found to be more important predictors of family support than ethnicity and culture (Little, 1983).

Gelfand (1982) notes that researchers often overlooked race as a variable in their eagerness to identify the needs of "the" elderly. Unfortunately, this approach only perpetuates the myth that elderly persons are a homogeneous group. In fact, elders are a heterogeneous group and their needs are varied. To be of real benefit, true similarities and differences must be identified.

Summary

Caregivers are typically female, most likely to be in their late fifties to mid-seventies and the spouses, daughters or daughters-in-law

of the elder recipients of care. Spouses are probably the number one caregivers with adult children not too far behind. If the caregiver does not live with the elder, he or she is likely to live nearby and almost certainly within an hour's drive. There are likely to be frequent telephone contacts and regular face-to-face contacts.

The elder recipients of care are also likely to be female and have about a 50% chance of being over 75 years of age. With increasing age come increasing frailty and need for caregiving. About 7% are bedfast and another 7% have difficulty going out of doors. The quality of relationship may or may not be strained. This has little to do with feelings of closeness. In fact, feeling close may increase the strain. While there is great variance in caregiving situations, one thing is certain: employed or not, married or not, good relationship or not and location of residence not withstanding, caregivers continue to provide care. Females, however, will in all probability provide more care and have greater emotional involvement than males.

CHAPTER III

CAREGIVER BURDEN

Introduction

The previous chapters have demonstrated that most families are responsible when it comes to providing care for their elder family members. Families in this country as well as in other countries provide the overwhelming majority of services for elders. Further, they provide such care at great cost to themselves. This cost, as indicated earlier, is alternately referred to as stress, strain or burden. The cost may be physical, psychological, financial, social or any combination of the above. Impact upon caregivers is not always perceived as burdensome, however. The focus of this sub-study is caregiver perception of burden.

Research studies of caregiver burden have burgeoned since the late seventies. Declining physical, mental, and functional status; incontinence in elders; and certain elder and caregiver characteristics (age, race, sex, residence and relationship of caregiver to elder) have all been identified as correlates of burden. Impact on caregivers has also been measured. Caregiving often causes anxiety and depression in caregivers and restricts them socially. Some caregivers also report changes in lifestyle, role overload and changes in health. There is some disagreement whether spouses, children, other relatives or non-relative caregivers feel the most stress. There is consensus that

females feel more stress, or at least report more, than male caregivers.

Correlates of Burden

Mental Health and Mental Status

Grad and Sainsbury (1963) provided one of the earliest studies of caregiver burden. This study was one of several investigating the burden experienced by family members caring for mentally ill relatives (Grad & Sainsbury, 1963; Hoenig & Hamilton, 1966; Endicott & Spitzer, 1976; Thompson & Doll, 1982). Interestingly, though the Grad and Sainsbury study was not primarily of elderly persons, findings indicated that caregiver burden was significantly increased when the recipients were older and particularly if they suffered from organic psychoses, symptoms of dementia (night wandering and confusion), gross thought disorder or were bedfast (Grad & Sainsbury, 1963). Other mental health problems found to be burdensome to caregivers included aggressive behavior, delusions, hallucinations, behavior that might be dangerous to self or others, and inability to care for oneself (Grad & Sainsbury, 1963; Hoenig & Hamilton, 1966).

Little attempt has been made to measure effect of patient intervention upon caregiver burden, however. Interestingly, one of the earliest and most frequently cited studies on caregiver burden is a British study of mental illness and family burden (Grad & Sainsbury, 1963). This study sought to determine whether treatment location of the patient, that is, community services or hospital services, had an

impact upon the burden experienced by their caregivers. In other words, its focus was the same as the current proposal addresses: does patient intervention reduce burden experienced by the caregiver? Grad and Sainsbury found that treatment location of the patient did not have a significant impact on caregiver perception of burden. It is interesting to note, however, that family members caring for elders over 65 years of age were the most severely burdened.

Caregiver perception of burden did not differ significantly in the two treatment groups of the Grad and Sainsbury study, but several cautions are in order. Organic disorders were the most troublesome for families and those were most successfully treated in the hospital setting. In the current randomized controlled trial, patients with severe organic disorders were not eligible for the trial, due to their inability to remember and follow directions. Both settings in the British study were mental health treatment programs, one hospital-based, the other community-based. In the current randomized controlled trial, discharge to the community is not to a treatment program. It is simply discharge to the patient's residence with the option of utilizing community-based services. Also programs were not age-specific in the British study.

Findings have varied regarding mental status (alternately referred to by researchers as "cognitive capacity") as a correlate of burden. Studies on burden in families caring for dementia patients have provided the majority of information on mental status. Rabins, Mace, and Lucas (1982) found memory disturbance in their sample of dementia

patients to be the second most common behavior problem reported by caregivers. It was also rank-ordered second as a cause of serious problems for caregivers. Not every researcher has found cognitive capacity to be correlated with burden, however.

Zarit, for instance, in a two year follow-up of caregivers found that scores on the Mental Status Questionnaire were correlated with burden but not in the expected direction (1984). That is, more correct scores on Mental Status Questionnaires, indicating better mental status, correlated with higher burden scores for caregivers. At least two researchers have found that caregivers of dementia patients tend to adjust or accommodate to the illness over time, tolerating stress better, thus showing less burden (Gilhooly, 1984; Zarit, Todd & Zarit, 1986).

It is important to recognize certain characteristics of the dementia caregiving situation. For some families true dementia fits the popular belief regarding elders. That is they grow old and forgetful, becoming progressively more feeble and forgetful over time, never to get well again. Other families, however, become appropriately alarmed at the changes which they are seeing and seek medical advice. The diagnosis of dementia, often Alzheimer's Disease or an Alzheimer's type dementia, confirms the worst fears of families. Sometimes it has taken several trips, many months, and sometimes even years to get a diagnosis. Other times the diagnosis of dementia is given very quickly. Some families accept the diagnosis, others deny. There is genuine cause for concern either way.

Clinical experience shows that about 20% of patients with a diagnosis of dementia have a pseudodementia, that is, an incorrect diagnosis of dementia and possibly a treatable problem (unlike dementia). Whether families have accepted or rejected the diagnosis, it is readily apparent why fluctuations in mental status have an unsettling effect on caregivers. Fluctuations in mental status would certainly be disconcerting when families have accepted a diagnosis, made a psychological adjustment to the disease and, in need of respite, are actually ready for placement of the relative.

It should be noted also that mental status can be variable, particularly in the elderly. Medications, illness, time of day and environment are all known to effect results of mental status exams. Whether families or indeed the persons giving the exams were cognizant of that is unknown.

Some researchers have not found level of impairment of dementia patients or mental status to be correlated with burden (Gilhooly, 1984; Deimling & Bass, 1986; Fitting, 1986; George & Gwyther, 1986). Deimling and Bass (1986), however, recognizing the complexity of burden, looked at two manifestations of dementia--disruptive behavior and impaired social function--and found these to be correlated with burden. While cognitive capacity was not significantly correlated to burden, disruptive behavior and impaired social function were significantly correlated. Thus cognitive capacity had an indirect effect on burden. It is quite likely, knowing the way other factors (physical and mental health, ADL, and social and economic resources)

interact in elderly persons that problems of direct and indirect effects have clouded findings in many research studies, leaving conclusions of dubious value.

Health

Robinson and Thurner (1979) found that both health and activity level were correlated with positive feelings about the caregiver/elder relationship. When health and activity were good, appraisals of relationship were positive and vice versa. Follow-up studies indicated that positive relationships deteriorated as health declined. This finding substantiates the study of Koopman-Boyden and Wells.

Koopman-Boyden and Wells (1979) studied physical and mental health and caregiver factors as correlates of burden. They found that physical health problems, while accounting for only two-fifths of the problems reported, accounted for almost 50% of the help needed by caregivers. Physical health problems in their study accounted for the largest proportion of all problems and the most help needed. Sanders, Pittman, and Montgomery (1986) in their study of centenarians also found that poorer elder health resulted in increased perception of burden by caregivers.

These findings are by no means universal, however. Many researchers have found no correlation between severity of illness and burden (Zarit, et al., 1980; Gilhooly, 1984; Fitting, et al., 1986; George & Gwyther, 1986). This is difficult to understand. Severity of illness certainly has an impact on elder functional status. Functional status has been found by some to be associated with burden.

Additionally, there is strong documentation of a relationship between social restrictions and burden. One would expect severity of illness and functional status to have an impact on caregiver social restrictions. Therefore, it is expected that the level of impairment would be associated with burden. The problem of interaction is again at the forefront of questions to be raised.

Functional Status

A 1984 Benjamin Rose Institute study of 614 impaired elders who resided with their family caregivers utilized four concepts (elder impairment, burden, impact and caregiver mental health) to examine caregiver burden. ADL impairment, sociability, disruptive behavior and cognitive incapacity were considered to be indicators of both elder impairment and burden. Negative impact on the elder-caregiver family (ECF) relationships and caregiver social activity restriction constituted the two impact measures. The fourth concept, caregiver mental health, was measured by scores on the Zung Depression Inventory. The data from this study indicate that the measures of elder mental impairment and the corresponding burden measures are substantially correlated with the negative impact on ECF relationships. The elders' ADL impairment and burden were more highly correlated with restrictions in caregivers' activities.

While the measures of impairment, burden and impact were correlated, they were clearly not representing single dimensions. Because other researchers have found the variables age, socio-economic status and physical and mental health to be potential indicators of

burden, Poulshock and Deimling (1986) included them in their analysis. Only the latter, caregiver's mental health measured as depression, displayed any consistent relationship. The dimension of depression was found to affect both burden and impact. It is quite possible that caregiver depression has been an intervening variable not accounted for in other studies. Poulshock and Deimling correctly point out that whether the depression is antecedent to caregiving or an effect of caregiving, it must be considered in measurement to preclude its confounding the analysis. This article represents the first attempt to conceptualize burden, impact and impairment as multidimensional constructs and represents an important addition to caregiver burden literature (Poulshock & Deimling, 1984).

Incontinence

When we speak of ADL function, bladder and bowel incontinence are generally included. For purposes of this caregiver study, however, the researcher has sought to look at them separately to determine their significance in burden. Several other researchers have also studied incontinence.

Sanders, et al. (1986) found that loss of bladder and/or bowel control was related to greater caregiver burden and greater experience of problems. Sanford (1975) found that 54% of his sample suffered bladder and/or bowel incontinence. Fecal (bowel) incontinence was tolerated very poorly by caregivers, whereas bladder incontinence was considered much less of a problem.

Vetter, Jones, and Victor (1981) found that incontinence was tied to anxiety and depression in their elder sample. They found that incontinence was common and that it greatly distressed caregivers, especially those who shared a residence with their elders. It is interesting to note that contact with domiciliary health providers increased for elders with incontinence. Frequency of contact also increased with increased incontinence. Contact with friends, however, decreased with incontinence.

Caregiver and Elder Characteristics

Cantor (1983) utilized two stepwise multiple regressions to analyze her data measuring impact of caring on the lives of the caregivers and to look at the presence of strain in their lives. Six demographic variables (sex, age, race, socio-economic status, marital status, and relationship to caregiver), five situational variables (health status of the care-receiver, geographic proximity of caregiver to their elders, work status of caregiver, caregiver's ability to manage financially and the amount of assistance provided by the caregiver); and three attitudinal variables (degree of worry, compatibility of relationship between caregiver and elders, and attitude of caregiver towards the importance and value of the family) were utilized.

The caregiver's relationship to the elders was by far the most important variable with respect to strain in this study, accounting for 37% of the total variance. The closer the bond, the greater the strain. Impact on life and strain in her model were correlated (r=.58)

but were two separate dimensions of the caring picture. The most important predictor variable in terms of impact was also the relationship of caregiver to elder, accounting for 28% of the total variance. Four other variables were found worthy of mention: degree to which caregiver worries, attitudes about the role of the family, sex of the caregiver, and the quality of the relationship between the parties in the caring situation. A small but significant amount of the variance in both the strain and impact model is found to be explained by race. Controlling the variables by social class might negate that relationship. We do not know if that was done.

Thompson and Doll (1982) and Zarit et al. (1980) found no relationship between race, sex, education and socioeconomic variables and perception of burden. Thompson and Doll found that burden was felt universally regardless of race or class. The one exception appeared in the lower socio-economic group. Financial strain was added to correlates of burden for this group. Only a few researchers find that caregivers report financial burden (Fengler & Goodrich, 1979; Baines, 1984; George & Gwyther, 1986). It must be remembered that we are talking about community-residing elderly. Families who do not qualify for Medicaid or who are just under or over the guidelines, but have a relative in need of nursing home care are likely to experience severe financial burden.

Impact on Caregivers

Anxiety, depression, and social restrictions are the effects of caregiving reported most consistently by caregivers. Additionally, a wide range of emotions are reported by caregivers including sadness, pity, anger, chronic fatigue, shame, guilt, fear, helplessness, self-blame, worry, isolation and loneliness (Fengler & Goldrich, 1979; Farkas, 1980-81; Rabins, Mace & Lucas, 1982; Goldman & Luchins, 1984; Jones & Vetter, 1984; Snyder & Keefe, 1985).

Impact on Mental Health

George and Gwyther (1986) found that caregivers report three times the number of stress-related symptoms reported by non-caregivers. George and Gwyther conceptualize burden at the negative end of a well-being continuum. Physical and mental health, and social and economic resources are considered indicators of well-being. Burden is the absence of some or all of those. They utilized scales of well-being with caregivers of dementia patients and compared the findings with the general population. Not only did they find significantly more symptoms of stress but also substantially greater use of psychotropic medication, 28% versus 19% in the non-caregiver population.

Social Restrictions

Social restrictions have been found by many researchers to be a very serious problem for caregivers (Simos, 1970; Sanford, 1975; Robinson & Thurner, 1979; Rabins, et al., 1982; Poulshock & Deimling, 1984; Noelker & Wallace, 1985; Deimling & Bass, 1986). Simos (1970)

found that social problems of their parents created considerable distress for caregivers. It is interesting that even when elders did not consider social restrictions a problem for them, caregivers still found them a real threat. If parents complained, either directly or indirectly, for instance about being lonely, caregivers reported that it angered them more than any other problem. It may be that caregivers see such comments or complaints as a reflection on their skills or perhaps an infringement upon their time and space. There is some indication that caregivers' fear of their own aging process is exacerbated by their parents' problems (Johnson & Bursk, 1977).

Robinson and Thurner (1979) confirm the importance of social restrictions for caregivers. Negative appraisals of the relationships between caregivers and elders were most likely to occur when the caregiver viewed the caretaking situation as confining or restrictive. Many caregivers reported that social restrictions created their most severe problems. Many had not taken a vacation for years, had given up friends and hobbies and sometimes employment (Rabins, et al., 1982; Sanford, 1975; Brody, 1985). These researchers have reported directly on the impact of social restrictions. There are indirect confirmations of these findings as well.

The 1980 Zarit, Reever, and Bach-Peterson study for instance, found that the only variable which correlated significantly with burden was visits by family members. As the number of visits increased, burden decreased. Not only do social restrictions cause burden, visits to the home decrease burden. Or it may be that those who have less

burden visit more often. Noelker and Wallace (1985) and Zarit, Todd, and Zarit (1986) also confirm these findings. Caregivers (N=29) who came to a training and research center that provides counseling and memory training for older persons comprised the 1980 sample of Zarit, et al. This is a very select sample who have involved themselves in a program of support and for whom supportive services have been sought, raising concern about a biased sample. One cannot, however, ignore the replication of thee findings in numerous other studies. Indeed it appears that social restrictions are the most serious problem faced by caregivers.

Studies of shared residence by caregivers and their elders suggest further confirmation of the importance of social restrictions for caregivers. These studies have found that the burden is increased when caregivers and elders share a residence (Stoller, 1985; George & Gwyther, 1986). It would seem that shared residence would also be more socially restricting for caregivers. Since social restrictions have been demonstrated to be a problem for so many caregivers, it would be interesting to know whether researchers have controlled for social restrictions in measuring the burden of shared residence.

Additional information on social restrictions comes from a study of disabled husbands and their wives which found that activity and friendship patterns had been disrupted by the husband's disability. Wives stated that they had never considered that their lives might end this way. Life satisfaction scores were lower for the wives in this study than comparable scores from a national study on life satisfaction

conducted by Harris (1975). Communication and sharing decreased for those with lower satisfaction. It is not clear which came first, the lower satisfaction or the decreased communication. Increased confinement and time spent with the disabled spouse often meant increased isolation and reduced time spent in meaningful activities. Visits from friends and relatives decreased the isolation felt by wives in this study (Fengler & Goodrich, 1979).

Lifestyle Change and Role Overload

Changes in lifestyle and role overload are reported by many spouses and daughters (Hoenig & Hamilton, 1966; Thompson & Doll, 1982). Daughters particularly have competing demands for their time from spouses, children and increasingly from employers as well. As age of the caregiver increases, the number of hours of caregiving also increases causing some relatives to give up employment due to the caregiving role thus increasing the potential for feelings of isolation. Curtailment of social life distresses some caregivers more than the tasks that they perform, demonstrating the importance for caregivers of contact with other persons (Fengler & Goodrich, 1979; Rabins, Mace & Lucas, 1982; Jones & Vetter, 1984; Brody, 1985).

Snyder and Keefe found that some lifestyle changes were reported to have a negative impact on health problems. Their 1985 study describes two categories of caregiver health problems: physical "ailments" and lifestyle changes which have a negative impact on health, for example, inability to get regular exercise, inability to plan for the future, loss of time for oneself, loss of interest in

activities including their sex life and the loss of friends. Other health problems mentioned were hernias, pulled muscles, allergies, headaches, diabetes, bladder and liver trouble and cancer. It is interesting to note possible indicators of depression (loss of interest in activities) in the lifestyle changes and possible stress-related disorders. Allergies, headaches, bladder trouble and some forms of cancer occur following stress.

Who Feels the Most Stress?

There is some disagreement as to which caregivers feel the most stress. Jones and Vetter (1984) found that daughters seemed to suffer more than spouses. Horowitz (1985) compared daughters to sons and found that daughters feel more stressed. Fitting, Rabins, Lucas, and Eastham (1986) also found that females feel more distress than males. They also found that younger caregivers were lonelier and more resentful of their roles than older caregivers. Cantor (1983) on the other hand found that spouses felt the most strain both physically and financially. Horowitz and Shindelman (1983) also found spouses to be more at risk. This finding was particularly interesting because as dependency increased, the caregivers felt closer to their care recipients; however, they enjoyed time spent with them less. There is the suggestion of a contradiction in findings in this study because they also found an inverse relationship between affection and level of stress. The earlier finding, feeling closer but enjoying time with them less, seems to be in agreement with the findings below.

Cantor (1983) found an inverse relationship between closeness and ability to get along. That is, closer relationships made it more difficult to get along. On the contrary, Johnson and Catalano (1983) reported more stress for distant relatives than for close relatives who provided more consistent care and demanding services. They conclude that stress for distant relatives may be secondary to the feelings of ambivalence they report. Care for distant relatives was outside their expectations.

Issues in Measurement of Burden

Several issues in measurement of burden are of concern. First many, though certainly not all, of the samples reported here are small purposive samples. This makes generalization and cross-study comparisons difficult if not impossible. This researcher is aware of only one effort to replicate another researcher's study. Wake and Sporakowski (1972) replicated Dinkel's 1944 study of high school and college students' attitudes toward caring for the aged, utilizing the same questionnaire and a matching sample. While there are a few longitudinal studies, most are cross-sectional with no control group. There have been no experimental studies. Few studies have included both caregivers and elders in their studies. Samples have at times been biased by self-selection as in the Zarit, et al. (1980) study referred to earlier. Some researchers make note of such problems; others do not.

Other problems also bear mention. Early studies (and some recent ones, as well) measured burden as a uni-dimensional variable. Findings of no association may have been clouded by this fact. Burden, as has been indicated in a variety of ways throughout these chapters, may be economic, physical, psychological, or social or any combination of those. If burden is experienced in one or more of these sub-categories, but not in others, a true picture of burden is not obtained by a total burden score or a means test for the sample.

George and Gwyther (1986) have recently pointed to another significant measurement issue. Studies are automatically biased when the researcher sets out to measure burden. They suggest utilization of well-being scales in the measurement process. These scales can be used for caregivers and non-caregivers allowing for a more accurate measurement and interesting comparison of caregiver burden. It is encouraging to note that with all of the problems mentioned, large studies with probability samples and the well-being study of George and Gwyther (1986) mentioned above have validated many of the findings of the smaller studies.

Additionally, and this has been mentioned earlier, most researchers have made no attempt to distinguish between direct and indirect effects of variables. Interactions of physical, mental, ADL, social and economic resources are so common in elderly persons that research simply must take these into account if findings are to be of assistance in the development of a knowledge base. Other interactions are also likely. Females report more burden than males. Co-residence

is also reported to increase burden. Do these findings hold when controlled for social restrictions, for instance? These questions have not always been considered.

Some comments about this caregiver study are in order in this discussion. Like others, this is a small, purposive sample. Data are cross-sectional. A strong advantage, however, is provided by randomization, giving true experimental and control groups. This caregiver study also includes interviews with both elders and caregivers.

Another advantage is that the CCI utilized to measure caregiver perception of burden not only yields a total burden score but five sub-categories. While the caregiver data are cross-sectional, elder data collected at admission and six-week follow-up allow for assessment of change in elder functional status. Additionally, extensive data on elders allows for examination of a large number of variables as potential correlates of burden.

Expectations

This caregiver study is among the first to look at the effectiveness of efforts to alleviate burden. It seems that a logical way to reduce the impact of caregiving is to reduce the amount of care required by elders, but negative stereotypes about elders mitigate against this approach. Elders, family members and professionals have accepted the view that to be old and especially frail and elderly is synonymous with not being treatable. There is ignorance, even among

professionals, regarding the ability of a very ill and frail older person to respond to treatment. The older the person, the stronger the bias is likely to be. Consequently, an active treatment approach is likely to be the last approach considered. Researchers have found, however, that such an approach does improve function. An additional benefit is likely to be increased self-esteem of the older person due to the decreased dependence. This often results in the older person being able to remain in his or her own home or requiring less care. The expectation is that increased elder independence would reduce caregiver perception of burden.

Based on the literature review and clinical experience, this researcher expects to find that the perception of burden will be less in caregivers of the experimental group than in those of the control group. It is anticipated that mental status, functional status, depression, and bowel and bladder incontinence will be improved sufficiently in the experimental group that the perception of burden will be altered for GARU caregivers. Additionally, it is anticipated that variables which contribute to the variance of caregiver perception of burden in this sample will be identified. Further, it is expected that change in functional status will have an impact on perception of burden. Greater positive change is expected in the experimental group.

Chapter III completes the review of the literature, statement of the problem and presentation of the research questions which have guided this caregiver study. The summary presents the critical points of the first three chapters as they relate to this caregiver study.

Summary

The first three chapters of this caregiver study have provided an extensive review of the literature which has documented the following:

- The growing number of older persons world-wide has increased concern about the provision of services for this group.
- A great deal of this concern focuses on families of older persons, with two opposing viewpoints. There are those who believe that families abandon their elders and are not doing their part to provide care and those who recognize that families are already providing 80% of home health related services for elders and do so at great cost to themselves.
- Care is not always perceived as burdensome, however substantial caregiving burden has been documented.
- Correlates of burden, although not unequivocal, have been found to include elder functional status and certain elder/caregiver characteristics.
- Additionally, research studies focusing on specialized medical care for the elderly (GARUs) have documented, rather impressively, that elder functional status can be improved.

This caregiver study seeks to pool the information from the caregiving research studies and GARU research studies which say:

1. Caregiving burden exists, and elder functional status seems to be a contributing factor and
2. Elder functional status can be improved on GARUs.

The questions which this caregiver study seeks to answer then are:

1. Does locus of treatment effect caregiver perception of burden?
2. Does change in elder functional status have an affect on caregiver perception of burden? and
3. Are caregiver and elder characteristics (age, sex, race, residence and relationship to each other) associated with the caregivers perception of burden?

Chapter IV will describe this caregiver study's research methods and data collection techniques and introduce data analysis. Chapter V describes the sample and presents data analysis techniques, findings and discussion of those findings for the research questions. Chapter VI discusses implications for practice, research and policy. The reader should note that two samples are involved in the research described in the following chapters: (1) The sample for the primary study, the GARU randomized controlled trial and (2) the sample for the caregiver study, which is a sub-study to the GARU trial and the primary focus of this research. For purposes of clarity, the primary study will be referred to as the "randomized controlled trial" and the caregiver sub-study will be referred to as the "caregiver study."

CHAPTER IV

RESEARCH METHODOLOGY

Introduction

Caregivers of frail elderly patients involved in the randomized controlled trial at Baptist Regional Rehabilitation Center in Memphis, Tennessee provide the sample for this caregiver study. A brief explanation about the elders involved in the randomized controlled trial and their caregivers is found below. A description of the trial, randomization process, data collection techniques and an introduction to data analysis complete the chapter.

Sampling Methodology

Elders involved in the GARU randomized controlled trial came through the routine referral process for the GARU with the exception of the randomization process which is described below. The sample for the caregiver study comprises caregivers of elderly patients participating in the randomized controlled trial. Both samples are described in detail in Chapter V.

Description of the Randomized Controlled Trial

The Geriatric Assessment and Rehabilitation Unit (GARU) at Baptist Regional Rehabilitation Center began operation in October, 1979. Results from a descriptive study of the first year and a half of

operation have been published elsewhere (Applegate, Akins, Vanderzwagg, Thoni & Baker, 1983) and described briefly in Chapter I of this caregiver study. Based on findings from this descriptive study, a randomized controlled trial, funded by the Robert Wood Johnson Foundation, admitted its first patient in July of 1985. The last patient was admitted in July of 1987. The randomized controlled trial concluded in July of 1988 following the one year follow-up for the last patient.

Elder rehabilitation candidates have been referred to the GARU since its opening in 1979. Referrals come from area hospitals, nursing homes, family members and others in the community. The change to a randomized trial, however, meant that referrals now had only a 50% chance of being treated on the GARU. A variety of considerations and constraints led to a limitation of referral sources for the GARU during the trial. Baptist Central and East Hospitals, The Med (Memphis City Hospital) and William F. Bowld (University of Tennessee Hospital) were selected to participate in the randomized controlled trial. Every effort was made to inform hospital physicians, social and liaison workers, discharge planners, nurses, physical therapists and other staff who assisted in the referral process. Staff were contacted personally, both formally and informally. Additionally, letters were mailed several times during the two-year recruitment period to physicians who were most likely to have patients needing rehabilitation.

An individual over 65 years of age was considered for the GARU if at the time of referral he or she was a patient at one of the participating hospitals, had experienced acute loss of more than one of Katz's Activities of Daily Living functions, did not have any of the exclusions listed below and his or her physician agreed to resume care of the patient at discharge. If the patient met the above requirements (s)he was seen for assessment to determine eligibility for treatment on the GARU as described above. The patient was eligible if he or she met the following 5 criteria: (1) The patient's medical problems was stable (but could require continuing care and monitoring); (2) the patient could not be judged to be possibly terminal in the next six months; (3) the patient might be acutely confused but not chronically confused; (4) the patient had acute functional loss requiring assistance in more than one ADL; (5) the combination of clinical and functional problems were severe enough to negate home physical therapy as an immediate option (Applegate & Miller, 1984).

Upon referral, patients were seen by a GARU physician to determine their eligibility for rehabilitation. If the patient was eligible for the GARU, the study was explained and the patient told that he or she had an equal chance of going to the GARU (experimental group) or simply returning to his or her residence upon discharge from the hospital (control group). Control patients were free to utilize any community services when they were discharged from the hospital. Patients who agreed to participate were then seen by a trained interviewer for a comprehensive assessment of mental status, social supports, depressive

symptomatology, economic resources, health perception, and functional status. The assessment process is described in the data collection section later in this chapter. Randomization occurred following the initial assessment. That process is described below.

Randomization Process

The randomization process, though essential, was very difficult. Some physicians quit referring and staff and family members alike tried to circumvent the system. Such efforts were rigorously avoided, however. Occasionally patients who were assigned to the control group were later referred to General or Stroke Rehabilitation Units. In spite of careful explanation about randomization and the 50-50 odds, patients or their families sometimes refused to participate when assignment to the control group occurred. Additionally, it was difficult for staff to interview patients who obviously needed rehabilitation and for whom the GARU seemed to be the last hope, only to have them assigned to the control group.

Every conceivable effort was made to give eligible patients in the participating hospitals an opportunity for referral. There is no way of knowing, however, how many patients in the participating hospitals who were eligible for rehabilitation were not referred. A GARU physician saw 278 patients, of those, 118 (42.3%) were not eligible for the GARU. Of the remaining 160, 5 had to be dropped from the trial. This left 155 elders eligible for the trial. Table I shows the reasons for ineligibility.

Table I

Reasons for Ineligibility of GARU Referrals

Reason	Number	Percent of Ineligibles	Percent of Total
Medically Unstable	17	14.4	6.1
Terminally Ill	7	5.9	2.5
Cognitively Impaired	34	28.8	12.2
Functioning Too Well	12	10.2	4.3
Too Ill	5	4.2	1.8
Refused[a]	18	15.3	6.5
Nursing Home[b]	8	6.8	2.9
Other	9	6.8	2.9
Not Rehab. Candidate (reason unknown)	8	6.8	2.9
Total			

[a]Refused rehabilitation, trial or both.

[b]Since this was a trial on cost effectiveness of geriatric rehabilitation, patients who were going to nursing homes regardless of outcome were excluded from the trial.

Treatment Location

Treatment location was determined by blind random assignment. The random assignments were made and placed in double-sealed envelopes before the trial began. Once the elders agreed to participate in the trial, understanding that there was a 50-50 chance of going to the GARU or returning to the community, they were assessed to determine eligibility for rehabilitation. If they were eligible, a comprehensive assessment was completed by a trained interviewer after which randomization occurred. The interviewer called the secretary (not associated with the GARU), who had the sealed envelopes. She took the next envelope in sequence, opened it and told the interviewer the result.

Definition of Variables

Caregiver perception of burden is the dependent variable. Location of treatment, that is care on the GARU or discharge to home (Community care) is one independent variable of interest. Based on findings from other studies, caregiver gender, age, race, relationship to elder and residence (that is, do elders and caregivers live together) are included in the analysis as independent variables. Depression, Activities of Daily Living (ADL) functional status, mental status, and bladder and bowel incontinence of the elderly patient are intervening variables.

Caregivers

Caregivers are the primary persons to whom the elders turn when assistance is needed. The caregivers may be relatives or friends but need not reside with their elders. Caregivers and elders must agree, however, that the identified person is the primary person who provides care when assistance is needed. Verification of agreement is made by the interviewer at the time of the caregiver interview. Agency staff or paid employees are not considered caregivers for this caregiver study.

Burden and Perception of Burden

Burden is defined as the impact or effect (physical, psychological, social, and economic) which caring for the elder person has on the caregiver and his or her family. Caregiver burden studies sometimes distinguish between objective and subjective burden. The focus of this caregiver study is caregiver perception of burden which is measured by a modified version of the Kosberg Cost of Care Index (CCI). Cost refers to the total impact which care has upon the family (Kosberg, 1986). Perception of burden is measured in five areas: (1) personal and social restrictions (Questions 4, 11-13 & 15), (2) physical and emotional health (Questions 6, 14, 16, 18, 20, 22 & 23), (3) values (Questions 3, 17, 21 & 24), (4) patient as provocateur (Questions 12 & 22); and (5) economics (Question 19). These five sub-categories were selected by Kosberg based on empirical research findings on elder, child and spouse abuse and family conflict. A total burden score (range = 14-56) is obtained. The sub-categorization

allows for a more accurate analysis of burden and its impact on caregivers. Low scores indicate high burden. A copy of the Caregiver Questionnaire is found in Appendix A.

Comprehensive Assessment

Elder comprehensive assessment includes basic demographic information, medical information, the Folstein Mini-Mental Examination, measures of social support, depressive symptomatology, health perception, financial information, a measure of ADL functional status and timed function. Individual components of the assessment are defined below. This assessment is completed at admission to the randomized controlled trial, prior to randomization (T1) and at six-weeks (T2), six-months (T3) and one-year follow-ups (T4). The complete GARU Assessment Form is found in Appendix B.

Functional Capacity

Functional capacity refers to an individual's ability to conduct Activities of Daily Living (ADL). Such activities include bathing, dressing, toileting, grooming, and ambulation. The Framingham ADL Scale is being utilized to measure ADL functional status. This scale is an eight-item scale with each item containing three sub-items (see pages 14-17 of the GARU Assessment). Scores range from 8 (no help needed on any item) to 80 (maximum assistance needed and great difficulty accomplishing all activities) (Jette & Branch, 1981). Further, this caregiver study defines functional status more broadly to include depressive symptomatology (CESD as defined below), mental status and bladder and bowel function.

Depression

The Center for Epidemiological Studies Scale (CES-D Scale) (Radloff, 1977) was utilized for measuring depression in this randomized controlled trial. The CES-D Scale was designed to measure current level of depressive symptomatology and was not intended as a clinical diagnostic tool. The scale was designed to identify high risk groups and (of particular interest to this caregiver study) to study the relationship between depressive symptoms and other variables. The scale has been tested extensively and found to have high internal consistency, acceptable test-retest stability, excellent concurrent validity by clinical and self-report criteria, and substantial evidence of construct validity. These properties hold for the general population and for subgroups studied. The CES-D Scale is a 20-item Likert scale (see pages 8-10) of the GARU Assessment Form. Scores range from 32 (little or no symptomatology) to 68 (significant symptomatology) (Radloff, 1977).

Mental Status

Mental status is measured using the Folstein Mini-Mental State Examination and includes orientation in three spheres (time, place, and person), short and long term memory, naming of simple objects, and attention and calculation (see page 3 of the GARU Assessment). This widely utilized instrument contains 11 items. Scoring per item varies from 1 to 5 points with a total possible score of 30. High scores indicate better cognition than low scores (Folstein, Folstein & McHugh, 1975).

Bladder and Bowel

Bladder and bowel incontinence is defined as the inability to control one's bladder and/or bowels. The measure of incontinence is a self-report question included in the physical health assessment (see page 10 of the GARU Assessment).

Data Collection

Elder comprehensive assessments were completed in the GARU randomized controlled trial at admission to the trial (prior to randomization), and at six weeks, six months, and one-year follow-ups. Data collected at admission (T1) and six week follow-up (T2) only, are being utilized for this caregiver study. The semi-structured interview was conducted by a trained interviewer.

Caregiver perception of burden was measured in a telephone interview with the caregiver at approximately the same time as the elder six-week assessment. The semi-structured interview, conducted by the researcher, utilizes a modified version of the Kosberg Cost of Care Index (CCI) (Kosberg & Cairl, 1986) which was described earlier. A copy of the Caregiver Questionnaire is found in Appendix A.

Research design may have introduced bias into the data for the caregiver study. George and Gwyther (1986) recently stated that once a researcher has indicated to a caregiver that (s)he is measuring burden, the study is biased. This researcher quickly found that "burden" is not a neutral term and caregivers react to it strongly. The introductory statement to the caregiver interview was changed and every

effort was made to be consistent in the introduction to avoid further bias. Nonetheless, bias was probably introduced.

Additionally, caregivers varied in their responses to the interviews. Some respondents were guarded, others were interested in the caregiver study and eager to share; some were openly angry about their situations and eager to talk about their problems, while others were apologetic; some appeared burdened but played the martyr role and some seemed genuinely pleased to be doing what they were doing. It was not felt that the instrument was a particular problem, but rather that a more general approach such as well-being measures suggested by George and Gwyther (1986) would help avoid bias.

Additionally, it was noted during the data analysis process that there were several family members who had been designated as the primary caregiver when there was a spouse present in the home. It may be that the designated person was the true caregiver; however, it is also possible that some bias may have been introduced in that way.

Introduction to Data Analysis

Cost of Care Index

Kosberg and Cairl (1986) found in their early use of the CCI that several questions had low factor loadings. Those items were subsequently dropped from their questionnaire. In order to determine whether individual questions were correlated with the whole, Pearson's product-moment correlation was used in this caregiver study's version of the CCI. These results are shown in Table II. No single question

Table II

Correlation of Individual Questions with Total Burden

Variable	r =	Sub-Category
Anxious	0.7058	PsyEmo[a]
Family Relations	0.6966	PsyEmo
Social Relations	0.6645	PerSoc[b]
Physical Health	0.6225	PsyEmo
Time for Self	0.6160	PsyEmo
Family Stress	0.6037	PsyEmo[c]
Disrupts Freedom	0.5918	PerSoc
Restricts Freedom	0.5918	PerSoc
Caregiver Mood	0.5783	PsyEmo
Patient Demanding	0.5159	PerSoc[c]
Patient Grateful	0.4333	Value
Economic Necessity	0.4246	Eco[d]
Meet Daily Needs	0.3672	Value
Meet Health Needs	0.3500	Value

[a]Psycho-Emotional.

[b]Personal Social.

[c]Also included in Patient as Provacateur sub-category.

[d]Economic.

was found to have so weak an association with the total burden score that it should be eliminated from the caregiver study. The five burden sub-categories were also correlated with the total questionnaire and these data are reported in Table III.

In the data set produced by the caregiver questionnaire, seven questions were refused by one caregiver (13, 14, 15 and 19) and three of these were refused by two caregivers (12, 17 and 21). Thus, there were ten missing values. Rather than a particular problem with these questions, it seemed that an occasional question was not applicable to a particular caregiving situation. In fact, in one or two cases the caregiver simply refused to comment. There were four missing values in the GARU caregiver responses and six in the Community caregivers. The difference in number of missing values between the two groups was not significant. Median values for individual questions were inserted for the missing values. This procedure, of course, reduces the variance of burden; however, since the number of missing values was so small, less than 1% (0.00566) of the total, it is unlikely that outcome was significantly effected.

Statistical Analysis

As a general rule, researchers strive to avoid Type I errors. In this caregiver study, however, the null hypotheses hold that: (1) There is no difference in the perception of caregiver burden between caregivers of the experimental and control groups, (2) that elder depression, mental status, ADL, bladder and bowel functional status make no difference in caregiver perception of burden, and (3)

Table III

Correlation of Sub-Categories with Total Burden

Sub-Category	r =
Psycho-Emotional	0.9090
Personal Social	0.8297
Patient as Provocateur	0.7462
Value	0.5178
Economic	0.4246

that elder/characteristics (age, race, gender, residence and relationship to each other) make no difference in caregiver perception of burden. If these null hypotheses are true, a Type I error (rejection of null when it is true) is not the error of primary concern. Rather, failing to reject the null when the alternative is true is the error of greatest concern for this caregiver study. Thus a trade-off has been made. The α level has been increased to .10, decreasing the ß level to reduce the possibility of a Type II error.

Data Adjustments

Elders residing beyond a 50-mile radius of Memphis were interviewed by telephone. This necessitated an adjustment in the mental status scores. For telephone interviews the maximum score was 22 rather than 30. Mental status scores, therefore, are reported as a ratio of correct score to possible score.

Caregiver relationship to elder was collected as one of seven categories (see Appendix A, page 1). The "sibling" category, usually subsumed in the "other relative" category, was of particular interest in this caregiver study. Therefore, that category was maintained for information for future research. However, for certain data analysis we collapsed the "sibling" and "other relative" categories and combined all non-relative categories (significant other, friend and other). It is not felt that when it is utilized this adjustment compromises findings, because the categories of primary interest are "spouse," "child," "other relative" and "non-relative." Also, this categorization is consistent with that found in the literature.

Originally, residential status was categorized as the following four categories: (1) Caregivers who live with the elder for whom they provide care, (2) caregivers who live in the same town as their elders but not in the same house, (3) caregivers who live in different towns, and (4) caregivers whose elders reside in an institutional setting. Because of the small number of caregivers who lived in different towns, the residential category was collapsed to the following 3 categories: (1) Caregivers who lived with elders, (2) caregivers who did not live in the same house with elders, and (3) caregivers whose elders were in institutions.

For purposes of clarity, data analysis techniques utilized for examination of each research question are incorporated in the presentation and discussion of findings of the individual research questions in Chapter V.

CHAPTER V

DESCRIPTION OF SAMPLE AND FINDINGS

Introduction

This chapter begins by describing the sample of elders involved in the GARU randomized controlled trial followed by several comparisons in tabular form of elders by experimental (GARU) and control (community) group. The sample for the caregiver study is also described and tabular presentations are given of data on GARU caregivers and community caregivers. A statement of each research question is followed by the data analysis techniques, findings and discussion of findings for that question.

Description of Elders

There were 155 elders involved in the randomized controlled trial on the cost effectiveness of geriatric rehabilitation (78 in the experimental group and 77 in the control group). Elders can be described as primarily white, female, in their late seventies and requiring at least moderate assistance with ADLs. Fractures comprised the largest percentage of primary diagnoses (33.6%). Diagnosis involving the circulatory system was the second largest category (26.4%). The next most common problem was with the musculoskeletal system (8.8%). Tables IV-X give more detailed baseline information with comparison of elders by experimental and control group.

Table IV

Mean and Standard Deviation of Age for Elders by Discharge Group

Age[a]	GARU[b]	Community
Mean	79.4	78.1
Standard Deviation	7.0	7.2
(N)	(67)	(59)

[a]Ages ranged from 64 to 100 years.

[b]Geriatric Assessment and Rehabilitation Unit.

Table V

Elder Gender by Discharge Group

Gender	GARU[a]		Community		Totals	
Female	56	(83.6)	41	(69.5)	97	(77.0)
Male	11	(16.4)	18	(30.5)	29	(23.0)
Totals	67	(100.0)	59	(100.0)	126	(100.0)

[a]Geriatric Assessment and Rehabilitation Unit.

Table VI

Elder Race by Discharge Group

Race	GARU[a]		Community		Totals	
White	56	(83.6)	50	(84.7)	106	(84.1)
Black	11	(16.4)	9	(15.3)	20	(15.9)
Totals	67	(100.0)	59	(100.0)	126	(100.0)

[a]Geriatric Assessment and Rehabilitation Unit.

Table VII

Education of Elders by Discharge Group

Years Completed	GARU[a]		Community		Totals	
0-4	6	(9.0)	3	(5.1)	9	(7.1)
5-8	16	(23.9)	9	(15.3)	25	(19.8)
9-11	11	(16.4)	10	(16.9)	21	(16.7)
12	11	(16.4)	15	(25.4)	26	(20.6)
13-15	13	(19.4)	15	(25.4)	28	(22.2)
16	6	(9.0)	5	(8.5)	11	(8.7)
16+	4	(5.9)	2	(3.4)	6	(4.8)
Totals	67	(100.0)	59	(100.0)	126	(100.0)

[a]Geriatric Assessment and Rehabilitation Unit.

Table VIII

Annual Income of Elders by Discharge Group

Annual Income	GARU[a]		Community		Totals[b]	
$0-2,999	1	(1.6)	2	(4.3)	3	(2.7)
$3,000-4,999	18	(29.0)	16	(33.3)	34	(30.9)
$5,000-6,999	16	(25.8)	5	(10.4)	21	(19.1)
$7,000-9,999	7	(11.3)	5	(10.4)	12	(10.9)
$10,000-14,999	9	(14.5)	6	(12.5)	15	(13.6)
$15,000-19,000	0		5	(10.4)	5	(4.6)
$20,000-29,000	8	(12.9)	4	(8.3)	12	(10.9)
$30,000+	3	(4.9)	5	(10.4)	8	(7.3)
Totals	62	(100.0)	48	(100.0)	110	(100.0)

[a]Geriatric Assessment and Rehabilitation Unit.

[b]7.5% of the GARU elders and 18.6% of the community elders did not report their income.

Table IX

Elder Marital Status by Discharge Group

Marital Status	GARU[a]		Community		Totals	
Married	14	(20.9)	16	(27.1)	30	(23.8)
Widowed	43	(64.2)	34	(57.6)	77	(61.1)
Separated/Divorced	5	(7.5)	6	(10.2)	11	(8.7)
Never Married	5	(7.5)	5	(8.5)	10	(7.9)
Totals	67	(100.0)	59	(100.0)	126	(100.0)

[a]Geriatric Assessment and Rehabilitation Unit.

Table X

Elders with Living Children by Discharge Group

Number of Living Children	GARU[a]		Community		Totals	
0	27	(40.3)	14	(24.6)	41	(41.3)
1-2	25	(37.3)	29	(50.9)	54	(42.9)
3-4	11	(16.4)	12	(21.1)	23	(18.3)
5+	4	(6.0)	4	(7.0)	8	(6.4)
Totals	67	(100.0)	59	(100.0)	126	(100.0)

[a]Geriatric Assessment and Rehabilitation Unit.

The largest proportion of elders (27.0%) had eight or fewer years of education; however, 22.2% also had professional training or some college. Additionally, 11.9% were college graduates and 16.7% attended graduate school. Table VII presents a more detailed report of educational status by group.

Elders were less hesitant to report income than their caregivers (87.3% of the elders reporting versus 70.6% of the caregivers). Many elders had annual incomes below the poverty level. Almost half (49.3%) had annual incomes less than $7,000 and 30.1% had annual incomes below $5,000. Table VIII also gives a detailed report by group.

Over 60% of elders were widowed and more than 29% lived alone. Almost 79% (78.6%) lived in private homes. The last two percentages may be surprising to some due to the advanced age and somewhat frail condition of these elders.

Description of Caregivers

Caregivers of the elders described above are the primary focus of this study. Nineteen of the elders in the randomized controlled trial died prior to the start of the caregiver study (six weeks following admission) or had no caregiver. Thus there were 136 elder-caregiver pairs who could have participated in the caregiver study. It was not possible to interview four of the caregivers due to their refusal or the refusal of the elders to release their names. Of the remaining 132 caregivers, 126 were actually interviewed for an overall response rate of 92.6%. Lack of response to the caregiver interview was 10.2% for

GARU caregivers versus 3% for community caregivers. No difference was found between the study participants and non-participants between the GARU (experimental) and community (control) groups. Participants and non-participants did not differ by age, race or gender. Thus it appears that no bias was introduced due to loss of elders from the study.

Of the 126 participating caregivers, 67 had elders who were treated on the Geriatric Assessment and Rehabilitation Unit (referred to as GARU caregivers) and 59 had elders who were discharged directly to homes in the community (referred to as community caregivers). Caregivers, like their elder counterparts, can also be characterized as primarily white and female. They are primarily in their late fifties and in good health. Caregivers are well educated, many having college degrees and graduate educations. The majority have annual incomes in excess of $30,000. Tables XI-XVI give more detailed information and a group comparison of major demographic variables. This sample is not representative of Memphis elders or their caregivers or those in the larger Memphis metropolitan area, therefore inferences beyond this sample are not possible.

The bar graph, Figure 1, presents a much more interesting visual image of caregiver ages. Clearly this sample, like those of other research studies, indicates that a substantial portion of the caregivers are at an age where they may be dealing with significant aspects of their own aging processes.

Table XI

Means and Standard Deviations of Caregiver Age by Discharge Group

Age[a]	GARU[b]	Community
Mean	57.9	58.2
Standard Deviation	14.7	14.2
(N)	(67)	(59)

[a]Ages ranged from 27 to 90 years.

[b]Geriatric Assessment and Rehabilitation Unit.

Table XII

Caregiver Race by Discharge Group

Race	GARU[a]	Community	Totals
White	56 (83.6)	50 (84.7)	106 (84.1)
Black	11 (16.4)	9 (15.3)	20 (15.9)
Totals	67 (100.0)	59 (100.0)	126 (100.0)

[a]Geriatric Assessment and Rehabilitation Unit.

Table XIII

Caregiver Gender by Discharge Group

Gender	GARU[a]		Community		Totals	
Female	48	(71.6)	39	(66.1)	87	(68.9)
Male	19	(28.4)	20	(33.9)	39	(31.0)
Totals	67	(100.0)	59	(100.0)	126	(100.0)

[a]Geriatric Assessment and Rehabilitation Unit.

Table XIV

Caregiver Education by Discharge Group

Years Completed	GARU[a]		Community		Totals	
0-4	3	(4.5)	0		87	(2.4)
5-8	2	(3.0)	2	(3.4)	4	(3.2)
9-11	8	(11.9)	5	(8.5)	13	(10.3)
12	19	(28.4)	17	(28.8)	36	(28.6)
13-15	21	(31.3)	13	(22.0)	34	(27.0)
16	6	(9.0)	9	(15.3)	15	(11.9)
16+	8	(11.9)	13	(22.0)	21	(16.7)
Totals	67	(100.0)	59	(100.0)	126	(100.0)

[a]Geriatric Assessment and Rehabilitation Unit.

Table XV

Caregiver Income by Discharge Group

Annual Income	GARU[a]		Community		Totals[b]	
$0-2,999	2	(4.3)	2	(4.7)	4	(4.5)
$3,000-4,999	3	(6.5)	5	(11.6)	8	(9.0)
$5,000-6,999	1	(2.2)	1	(2.3)	2	(2.2)
$7,000-9,999	2	(4.3)	0		2	(2.2)
$10,000-14,999	9	(19.6)	6	(14.0)	15	(16.9)
$15,000-19,000	5	(10.9)	5	(11.6)	10	(11.2)
$20,000-29,000	5	(10.9)	8	(18.6)	13	(14.6)
$30,000+	19	(41.3)	16	(37.2)	35	(39.3)
Totals	46	(100.0)	43	(100.0)	89	(100.0)

[a]Geriatric Assessment and Rehabilitation Unit.

[b]31.3% of the GARU caregivers and 27.1% of the community caregivers did not report their income.

Table XVI

Caregiver Health by Discharge Group

Health Rating	GARU*	Community	Totals
Excellent	17 (25.8)	20 (33.9)	37 (29.6)
Good	26 (30.9)	28 (47.5)	54 (43.2)
Fair	18 (27.3)	8 (13.6)	26 (20.8)
Poor	4 (6.1)	0	4 (3.2)
Very Poor	1 (1.5)	3 (5.1)	4 (3.2)
Totals	66 (98.5)	59 (100.0)	125 (99.2)

*Geriatric Assessment and Rehabilitation Unit

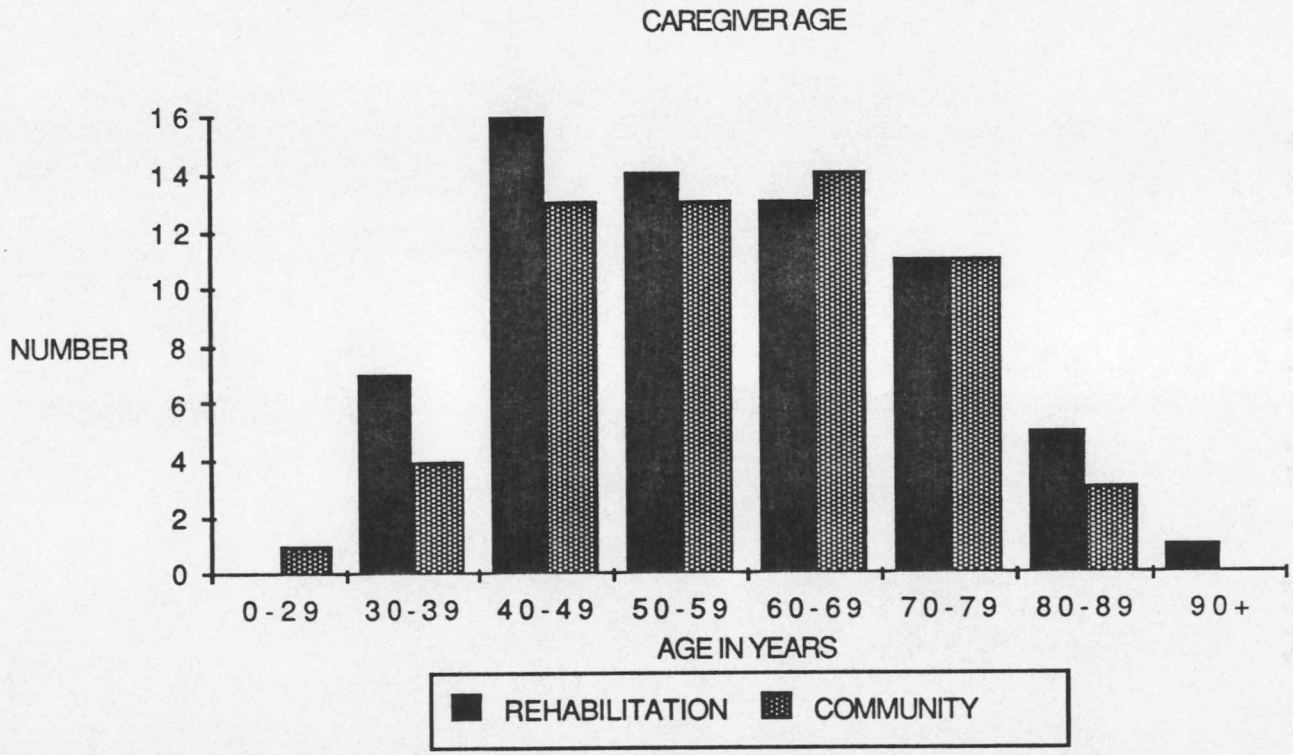


Figure 1. Caregiver Age

While caregivers were well educated, there was a wide range in years of education. Five GARU caregivers and three community caregivers had eight or fewer years of education. A substantial number, however, also had college and graduate educations (Table XIV).

More than one-half of the caregivers who were willing to report their annual income had incomes in excess of $30,000 annually. There was, however, economic diversity; 2 caregivers in each group had incomes under $3,000 annually and 6 in each group had incomes between $3,000 and $10,000. Several caregivers reported severe financial burden, 4.5% of the GARU caregivers and 1.7% of the community caregivers.

Caregivers by and large considered their health to be good or excellent, 65.2% in the GARU and 81.4% community, respectively (Table XVI).

As reported in Chapter IV, it was necessary for some data analysis purposes to reduce the number of relative categories in this study from seven to four. Combination numbers and percentages are found in Table XVII. Family caregivers comprise 92% of this sample, a figure which is only slightly higher than other studies have reported.

Relationship of Caregiver to Elder

Table XVII shows the relationship of caregivers to elders. These percentages are similar to those found by Cantor (1983) and Jones and Vetter (1984). In those studies, however, spouses were the second largest group of caregivers with other relatives following at third. National probability samples have shown spouses to be the primary

Table XVII

Caregiver Relationship to Elder

Relationship to Elder	GARU Caregiver		Community Caregiver		Totals	
Child	25	(37.3)	23	(39.0)	48	(38.1)
Other Relative[a]	22	(32.8)	14	(23.7)	36	(28.6)
Spouse	9	(13.4)	13	(22.0)	22	(17.5)
Sibling[a]	6	(9.0)	4	(6.8)	10	(7.9)
Significant Other[b]	1	(1.5)	0		1	(0.8)
Friend[b]	2	(3.0)	4	(6.8)	6	(4.8)
Other[b]	2	(3.0)	1	(1.7)	3	(2.24)
Total	67	(100.0)	59	(100.0)	126	(100.0)

[a]Combined Other Relative: GARU 28 (41.8%), Community 18 (30.5%).

[b]Combined Non-Relatives: GARU 5 (7.5%), Community 5 (8.5%).

source of caregiving followed by children as the secondary source (Shanas, 1979).

Table XVIII presents the sample by caregiver relationship and gender. The predominance of female caregivers in this study is the same as in previous research. This predominance is most outstanding, however, among the other relatives (35.6% female and 15.4% male). Among spouses, males and females are more equally represented (25.6% male versus 14.9% female), with males predominating. In spite of the female predominance in the sample, all categories except other relatives and siblings have a higher percentage of males.

Residence

The most common family size in both groups of caregivers was two, usually caregiver and spouse. Families of three and four were also common. Some caregivers lived alone (13.6% in the GARU caregivers and 10.2% in the community caregivers). Residential patterns vis-a-vis caregivers and elders who live together were remarkably similar in the groups, as shown in Table XIX.

Findings

Question 1: Does locus of treatment effect caregiver perception of burden?

The t-test for independent means was utilized to compare means of the perception of burden for GARU and community caregivers. The means of the burden scores were 40.5 (s.d. = 6.5) for GARU caregivers and 39.1 (s.d. = 6.7) for community caregivers. The difference in

Table XVIII

Caregiver Relationship to Elder by Gender

Relationship	Female		Male		Totals	
Other Relative[a]	31	(35.6)	6	(15.4)	37	(29.4)
Child	30	(34.5)	17	(43.6)	47	(37.3)
Spouse	13	(14.9)	10	(25.6)	23	(18.3)
Sibling[a]	7	(8.1)	2	(5.1)	9	(7.1)
Friend[b]	4	(4.6)	2	(5.1)	6	(4.8)
Other[b]	2	(2.3)	1	(2.6)	3	(2.4)
Significant Other[b]	0		1	(2.6)	1	(0.8)
Total	87	(100.0)	39	(100.0)	126	(100.0)

[a]Combined Other Relative: Female 38 (43.65%), Male 8 (20.5%).

[b]Combined Non-Relative: Female 7 (8.0%), Male 4 (10.3%).

Table XIX

Residential Status of Caregivers and Elders[a]

Residence	GARU[b]		Community[b]		Totals	
Live with Elders	27	(40.9)	24	(41.4)	51	(41.1)
Live in Same Town	33	(50.0)	19	(32.8)	52	(41.9)
Live in Different Town	2	(3.0)	3	(5.2)	5	(4.0)
Elder in Institution	4	(6.1)	12	(20.7)[c]	16	(12.9)
Totals	66	(100.0)	58	(100.0)	124	(100.0)

[a]At six week interview.

[b]CG denotes caregiver.

[c]Statistically significant, $p < 0.10$.

perception of burden between GARU caregivers and community caregivers was not statistically significant. Caregivers in this study, like those in previous studies, are experiencing their primary burden in the psycho-emotional and personal/social aspects of their lives with the greatest burden experienced psycho-emotionally (see Table II, page 63, and Table III, page 65).

While burden scores had a potential range from 14 to 56, burden scores for GARU caregivers ranged from 29 to 56 and from 23 to 56 for Community caregivers. No caregiver had a burden score below 20. Almost 63% (62.7) of the community caregivers and 59.8% of the GARU caregivers had scores indicating a moderate perception of burden, however. Only community caregivers experienced severe burden (5.1%). It is worth noting that while the difference in burden between GARU and community caregivers was not statistically significant, there was a sub-group of individuals for whom the GARU did make a difference. These were caregivers whose elders were institutionalized. Thus in the area where the GARU made its greatest impact, nursing home utilization, the GARU did have an impact on caregiver perception of burden.

Question 2: Does change in elder functional status have an effect on caregiver perception of burden? Variables of interest were elder ADL, bladder and bowel functional status, depressive symptomatology, and mental status.

Change in functional status (T1-T2) was measured for ADL, CESD, mental status and bladder and bowel function. The association of change with caregiver perception of burden was measured using Pearson's product-moment correlation.

Activities of Daily Living (ADL)

Change in ADL function was not found to be associated with burden. This finding is surprising and is made even more interesting by the additional ADL findings discussed below.

Interest in ADL, CESD and mental status and bladder and bowel function went beyond change scores for these variables, however. There was also interest in the association of elder function on each of these variables with caregiver perception of burden.

Individual ADL tasks (T1 and T2) and total ADL functional capacity were examined for association with caregiver perception of burden. Therefore, the scores of the eight individual tasks and the ADL sum scores at T1 and T2 were included in the correlation analysis. The ADL sum score is the sum of the eight individual ADL tasks found in section (a) of questions 101-108 (Appendix B).

Six of the eight individual ADL tasks at T1 (dressing, bathing, walking, eating, getting from bed to chair and using the toilet) were associated with caregiver burden. The association, however, was not in the expected direction. That is, elders who reported requiring no help with dressing (or other tasks) increased caregiver perception of burden.

At least two factors may be involved with this finding. First, in dealing with a frail older person, doing things for them is easier, quicker and less frustrating than having them do things for themselves. The tendency is to do for them or at least to want to do for them, whether as a function of time or as a function of caring. Elders at T1

would have been particularly slow in completing tasks due to their need for rehabilitation.

Second, the ADL measures were self-report measures, taken at admission to the randomized controlled trial and at six weeks into the trial. While the question given to elders is stated "at the present time do you need help with . . .," it is possible that elders were over-rating their ADL capacity, particularly on admission. That is, they may have been more likely to respond based on previous functional capacity than present capacity. The literature on elder health substantiates elder overrating on health self-reports. This interpretation is strengthened by the fact that none of the individual ADL tasks at T2 was associated with caregiver perception of burden. In other words, when elders reported needing "no help" at T1 and their function was weakest, that report was associated with burden. At T2, when elders reported needing "no help" and they were functionally improved, there was no association with burden.

Two of the individual ADL tasks associated with caregiver burden at T1 (dressing and walking) were included in the regression model. This model comes from the researcher's interest in explaining the variance in caregiver perception of burden and is discussed later in this section.

The ADL sum scores at T1 and T2 were not associated with burden. The T2 finding is consistent with that on individual tasks. Thus it seems that it was not the elders' total functional status at T1 which had an effect on caregiver perception of burden. This is probably due

to the fact that some of the individual ADL tasks contributed more to caregiver perception of burden than others and two of the tasks were not associated with burden at all. Therefore, the effect of the stronger variables is lost when totaled with those that have a weaker association or no association with burden. Thus, if researchers have only a total score for ADL functional status and expect that to relate to burden, the association is likely to be missed.

Bladder and Bowel

The change scores for both bladder and bowel were associated with caregiver burden in the Pearson's product-moment correlation (bladder, $r = -.01397$, $p = 0.063$; bowel, $r = -0.1426$, $p = 0.059$). The association is not in the direction expected, however. That is, improvement of bladder and bowel function was associated with an increase in caregiver perception of burden. This finding is not in keeping with previous research on incontinence; however, Zarit, Todd, and Zarit (1986) found that improvement in mental status was associated with increased caregiver burden.

Improvement does not necessarily mean going from incontinent to continent. Thus, it may be that improvement without a "cure" is anxiety producing for caregivers. Perhaps caregivers had hoped for more. On the other hand, Dr. Eric Pfeiffer, nationally known Geriatric Psychiatrist, warns that when we treat older persons, we may have to teach family members that the elders may get well, an outcome which they may not expect. Thus it may be that psychologically some

caregivers expect deterioration and are prepared to handle that but are not prepared to handle improvement.

Bladder and bowel function at T1 and T2 were also included in the correlation analysis. While both change scores were associated with burden, only bowel function at T1 was associated with burden ($r = -0.1211$, $p = .093$). There was also a trend for bowel function at T2 to be associated with burden. Not so for bladder function, however. Since change in bladder and bowel function is the stronger association with burden, perhaps it is change itself and not whether a person is continent or incontinent which creates greater burden for caregivers.

Depressive Symptomatology (CESD)

Changes in CESD scores were not found to be associated with burden. Additionally, further inclusion of CESD scores was not possible. Missing data due to elder deaths reduced the number of cases in the correlational analysis and also artificially elevated the r square values.

Mental Status

Change in mental status was found to be associated with burden ($r = -0.1388$, $p = 0.071$). This association also is not in the expected direction. That is caregiver perception of burden increased with improvement in elder mental status. This finding is consistent with the 1986 study of Zarit, et al. referred to above.

Other research studies on mental status and caregiver burden have varied in their findings. An earlier study (Zarit, Reever &

Bach-Peterson, 1980) found no association between mental status and caregiver perception of burden. Poulshock and Deimling, however, found that behaviors associated with impaired mental status were correlated with burden, thus they found an indirect association between mental status and perception of burden. Still other researchers have found that caregivers of dementia patients report that burden does not increase over time. It appears that caregivers become adjusted to the condition, possibly preventing an acceleration of burden. In this caregiver study, however, patients were neither chronically nor severely mentally impaired. Again perhaps looking at further comparisons of mental status with burden in this sample is helpful.

Mental status at T1 was not associated with burden but mental status at T2 was ($r = .2094$, $p = .009$). This association is in the expected direction, contrary to that of the mental status change score. This again raises the question whether it is the change in mental status which created the problem for caregivers. Improvement in mental status, like improvement in bladder and bowel function, does not mean "cured." Sometimes the status quo may be easier to handle than some change even if the change is in a positive direction.

The finding of a difference in perception of burden with variables at T1 and T2 continues to be very interesting. The finding may suggest that caregiver burden is a delayed response to certain types of elder dysfunction. In the case of mental status, however, that was not the case since it was mental status at T2, the same time that burden was measured, which was associated with burden. The finding of a

difference in variables at T1 and T2 with caregiver perception of burden may explain why some cross-sectional studies have found no association with burden and functional status. This finding also seems to suggest that timing of the measurement of burden may be particularly important. One wonders if burden would have been associated with elder ADL functional status at T2 if perception of burden had been measured again six weeks later (T3). If this were the case, measurement of caregiver perception burden secondary to the GARU intervention might have been more effective later in the trial.

Question 3: Are elder and caregiver characteristics (age, race, gender, residence and relationship to elder) associated with caregiver perception of burden?

Age

Neither caregiver nor elder age was found to be associated with caregiver perception of burden.

Race

Race was found to be associated with burden experienced by community caregivers, however, not by GARU caregivers (Fisher's Exact, 2-tail, $p = 0.025$). That is, among GARU caregivers there was no difference in the perception of burden experienced by blacks or whites. On the contrary among community caregivers, white caregivers experienced more moderate burden. This finding may be due to the small number of blacks (9) among the community caregivers. Another possibility to be explored would be the differential use of services

among black and white elders and whether elder use of services has an effect on caregiver perception of burden.

There is a body of literature on differential use of services. Mindel, Wright, and Starrett (1966) utilizing the national probability sample from the Cleveland well-being study, found remarkably similar patterns of use among black and white elders, with one exception. Black elders utilized those services to a significantly greater extent. We do not know if that pattern had an effect on caregiver burden in that study, nor if those findings are generalizable.

Residence

A general linear model procedure was also utilized to assess caregiver perception of burden by residential status. Unlike some previous research, living with or in separate housing from elders made no difference in caregiver burden. There was an interesting finding, however. There was a statistically significant difference in caregiver perception of burden between GARU and community caregivers for those who had elders in nursing homes with community caregivers experiencing greater burden ($p = .065$). The mean burden for GARU caregivers was 46.0 (standard error = 3.33). For community caregivers the mean burden was 38.8 (standard error = 1.92).

It is important to note that these were new institutional placements for both groups. That is, these were not elders who had resided in institutions prior to enrollment in the trial and then went back to the institution following treatment. Elders who would have

been placed in an institution regardless of outcome were excluded from the trial.

Intuitively, one expects an association between functional status and use of nursing home, but that was not the case in this sample. There was a statistically significant difference in ADL help required by the two groups, but the difference was not great enough to explain the difference in institutional use. Actually, the finding of institutional use, somewhat irrespective of functional status, also substantiates previous studies. The literature has shown that for each bedfast elder in nursing homes, there are two or three in the community who are equally impaired (Shanas, 1978).

The finding of greater burden among community caregivers for those whose elders were institutionalized probably relates to the GARU finding that there was a statistically significant difference in nursing home utilization between the two groups. These two findings go to the very essence of GARU intervention. A comparison of the difference in the intervention groups is important in understanding these findings. The GARU team in general, and the social worker in particular, work closely with elders and their families to work out elder living arrangements following discharge from the GARU. The GARU team is very community oriented with respect to elders, and nursing homes are less likely to be utilized for elders treated on the GARU. The advantage of GARUs in general, and this one in particular, is an understanding of an elder's rehabilitation potential regardless of age. GARUs maximize that potential through active treatment and by utilizing

available resources to assist elders and their families, providing family training where necessary and encouraging and assisting them to keep elders in the community.

Additionally, when an institutional placement is needed, GARU families are given assistance with both physical arrangements and emotional support. Families, understanding the thrust of the GARU treatment toward elder independence, recognize that there is no alternative when a decision is made to institutionalize. Community caregivers have neither advantage. It is likely that burden for community caregivers has to do with both the decision-making and application process without the benefit of GARU professional involvement. The net result is an increase in the use of nursing homes and an increase in burden.

There is substantiation for this in the literature. Grad and Sainsbury (1968), in a two year follow-up of their burden study, found that caregiver burden was less when there was intensive social work involvement with caregiving families. A follow-up study of schizophrenics also found that professional involvement, in this case home visits from nurses, reduced the stress experienced by families.

Gender and Relationship of Caregiver to Elder

Gender and relationship of caregiver to elder were both found to be statistically significant in their association with caregiver perception of burden. The mean burden for males was 41.44 and for females was 39.13. This difference was statistically significant ($p = 0.07$). Relationship was also found to be associated with

caregiver perception of burden ($p = 0.023$). Mean burden scores by gender and relationship can be found in Table XX. The importance of gender in caregiver perception of burden is highlighted in Table XXI.

Variance in Caregiver Burden

This researcher was also interested in knowing which of the variables in this study contributed most to the explanation of variance in caregiver perception of burden. Several regressions were run adding and deleting variables among those found to be associated with burden in the Pearson product-moment correlation analysis. Dressing or bathing status at T1 was always the first variable included in a forward regression regardless of other variables included. The association between bathing and dressing was strong; therefore, inclusion of one meant exclusion of the other in the forward selection and in the final model, dressing was selected for inclusion. Walking also was selected for inclusion.

Four elder characteristics and situational variables were also of interest for inclusion: age, residence, marital status and length of hospital stay. Residence and marital status were associated with burden in the Pearson product-moment correlation but neither was included in the final model. Both of these variables were associated with the caregiver relative variable, however, and each thus has an indirect association in the model.

Caregiver relationship, caregiver health and caregiver sex were all associated with caregiver burden. Caregiver relationship and caregiver sex were included in the final model. While caregiver health

Table XX

Least Square Means of Burden by Relationship and Gender

Gender/Relationship	N	Least Square Means
Female Spouse	13	32.13
Female Sibling	7	35.08
Female Child	30	37.87
Male Spouse	10	38.18
Female Other Relative	31	40.52
Male Other Relative	6	42.86
Male Child	17	45.94
Male Friend	2	50.89
Female Friend	4	51.17
Male Sibling	2	56.65
Other Relative (Male & Female)	3	*
Significant Other (Male)	1	*

*Where any cell contained a number less than two, the male/female comparison did not run.

Table XXI

Explained Variance in Caregiver Perception of Burden

Variable	B	Cumulative R^2	Significance
Dressing T1[a]	.40906	.08964	.0000
Relative	.40181	.19561	.0000
CgSex[b]	-.27871	.26448	.0003
Bowel T1[a]	-.20450	.30546	.0067
Walking T1[a]	.15382	.3254	.0681

[a]T1 = admission.

[b]Cg refers to caregiver.

was not in the final model, there was an association between caregiver health and both caregiver relationship and caregiver sex; therefore, there is an indirect effect of caregiver health in the model. While inference from this sample cannot be made, these variables will definitely be included in future studies by this researcher.

This model indicates that the greatest contribution to caregiver perception of burden was the elder's reported ability to dress him/herself at admission to the GARU randomized controlled trial. As stated and discussed above, elders reporting that they required no help created more burden than those who reported requiring assistance.

Caregiver/elder relationship and caregiver gender were also important contributors to the variance of burden with female spouses experiencing the most burden. The more distant the relationship, the less contribution to burden. Elders who were incontinent of bowel and elders reporting no need for assistance in walking at admission to the trial complete the contribution to the explanation of the variance of caregiver perception of burden in this model. In other words, a female spouse caregiver whose elder husband was incontinent of bowel at admission and reported that he required no help with dressing or walking at admission, experienced the greatest burden. Male caregivers who were not related to elder, and male caregiver relatives other than spouses felt less burden even if their elders reported that they required assistance with dressing and walking.

Additional Discussion

While this study did not consider elder survival in terms of caregiver perception of burden, those comparisons are interesting, particularly in the discussion of the importance of gender in the caregiver study and the GARU randomized controlled trial. Survival rates at six weeks were not statistically different between groups (96.15% for the GARU and 93.51% for the Community group). Survival by gender, however, is interesting. Slightly over 81% (81.3%) of the GARU males and 100% of the Community males were alive at six weeks. This difference is statistically significant ($p = .0212$). Females, on the other hand, did better in the GARU, 100% survival versus 91.2% in the Community group ($p = .009$).

This caregiver study had the advantage of being associated with a true randomized controlled trial, an advantage few caregiver burden studies have enjoyed. It also has the disadvantage of being a cross-sectional study, something most other studies have shared. Thus, some findings will have to wait for other studies to provide confirmation before it will be known whether they have significance for the larger population. The specific places where this has been a problem have been elucidated in the text. Timing is important for every research study. This caregiver study, however, as stated earlier, suggests that timing may be particularly important in the measurement of caregiver perception of burden.

Finally, in retrospect it is not felt that the modified Cost of Care Index (CCI) was the best measure of burden, at least for purposes

of this study. This study sought to measure the impact of GARU intervention with elders on their caregivers' perception of burden. GARU intervention would not be expected to have an impact on economic burden nor burden experienced due to values, yet several of the CCI questions measure burden in those areas. This points simply to a poor fit between the instrument and this study.

On a more general level, however, on the last caregiver interview that was done, the researcher had a caregiver who was admitting to great burden and to the questions "I feel that caring for _____ has caused me and my family much stress" and "I feel that caring for _____ has caused me to become anxious" she responded "strongly agree." The balance of the questions, however, did not accurately portray this caregiver's experience of burden. Therefore, the total burden score indicated low burden for a caregiver who had just verbalized great burden. This is another example of the specifics of burden being lost in measurement of the whole. Perhaps the early modifications of this instrument would have best served this study if questions had been selected with a view to the GARU and the intent of its intervention. This seems particularly pertinent since the GARU had a significant impact in terms of reducing burden for those caregivers whose elders were discharged to nursing homes.

Summary

This caregiver study has documented that substantial perception of burden existed among caregivers. While the GARU was not effective in a

significant reduction in burden for the total caregiver sample, it was effective in reducing burden among the caregivers of elders who were institutionalized.

Additionally, there was a statistically significant difference in the change of elders ADL functional status between the experimental and control groups. Bowel function and need for help with dressing and walking at admission were associated with caregiver perception of burden, albeit not in the expected direction. Gender and relationship of elders to caregivers were also associated with caregiver perception of burden. Whether elders and caregivers shared a house was not associated with burden. There was a finding of association of race with burden among community caregivers only, with white caregivers experiencing more burden. Perhaps the GARU had the positive effect of preventing a differential experience of burden due to race.

Some elder functional deficits seem to be tolerated well by caregivers creating a lag time in their being experienced as burdensome by caregivers. While total functional status may not be associated with burden, individual functional tasks are associated with caregiver perception of burden.

Thus the measurement of caregiver perception of burden must allow for a great deal of specificity in measurement of both elder and caregiver characteristics. Global measures will be likely to result in erroneous conclusions of no association between perception of burden and characteristics of elders and their caregivers.

CHAPTER VI

DISCUSSION OF IMPLICATIONS AND FUTURE RESEARCH

Introduction

Donald Kent has been quoted as saying, "Research, policy and practice are . . . not the same, but . . . they are not unrelated . . . policy that is not informed by knowledge may be worse than worthless; it may be dangerous" (Brody, 1985). The statement applies equally to practice, research and policy. Yet this paper has indicated that much myth and misinformation continues to inform thought, work and probably even policy concerning the aging family. This caregiver study adds to the developing knowledge base on caregiving burden in aging families.

Implications

Implications for Practice

The GARU was effective in reducing the perception of burden for caregivers whose elders required institutional placement. As suggested earlier in the discussion, there are four factors which distinguish GARU intervention with elders and their families from the norm: (1) an active treatment program for elders regardless of age and frailty; (2) knowledge (and a belief) that elders can get better; (3) a commitment not to over-protect, thus encouraging independence to the greatest possible extent; and (4) involvement of family members in the plan of care. It is inferred that these distinguishing characteristics have

decreased caregiver perception of burden and nursing home utilization in this trial. They also provide a model for social work intervention with aging families and in the development of aging programs.

Unfortunately, clinical experience and the literature substantiate that work with frail elders and their families (if families are involved) is characterized by few of these. Families provide the majority of home health care services to older people in this country. Social work with elderly persons must be social work with family units. Social workers in hospitals, community and state agencies and in nursing homes are involved in the decision-making and planning process of institutional placement. It is true that nursing homes are essential for some elders and may even be the residence of choice for others. The model of treatment outlined above is suggested in the belief that it prevents those elders who neither want nor need nursing home care from going there by default.

The GARU was effective in reducing use of nursing homes. There is a suggestion in the finding of decreased nursing home utilization of cost effectiveness of GARU treatment (that is a decrease in health care costs per year of life lived, secondary to the GARU), but the documentation of that is yet to come. Thus development and utilization of GARUs could benefit caregivers and their elders by reducing the necessity for nursing home placement. Social workers in health care settings are often in a position to facilitate the use of GARUs when they are available and GARU development when they are not.

This caregiver study substantiates significant burden among caregivers in this sample. Among Community caregivers 5.1% experienced severe burden and 62.7% experienced moderate burden. Among GARU caregivers 59.7% experienced moderate burden. Caregivers experienced the primary burden psycho-socially. Thus, there is great need for social work intervention to facilitate reduction in burden. While this caregiver study did not look at abuse, the serious potential for elder abuse in these families must be noted. Families commit 80% of elder abuse As elder dependency and caregiver stress increase, potential for abuse also increases. Intervention to reduce burden is essential. Group work with caregivers would be an excellent beginning.

Caregivers are primarily female and females experience greater burden. In an age when self-help groups are in vogue, such groups would be a wonderful mechanism for increasing socialization, which studies have indicated reduces caregiver perception of burden. Groups would, of course, not be gender restricted. Such groups could quite naturally begin when elders are hospitalized.

Implications for Future Research

This caregiver study did not have several variables which this researcher believes are important and should be incorporated in future research. First would be a measure of caregiver depression. There was not even a variable in this caregiver study which might have acted as a marker of depression. This researcher's sense is that some caregivers were depressed. The extent and importance of that is obviously unknown. Second, a measure is needed of the quality of the

elder/caregiver relationship historically. This view should include perceptions of both elder and caregiver. Third, an estimate is needed of the time spent in caregiving and the tasks performed. Fourth, there should be a measure of the length of the caregiving relationship.

Ideally, samples would be large enough to allow for meaningful sub-category analysis. For instance, this sample sought to examine siblings as a relational category separate from other relatives. There were enough siblings to determine that they experience considerable burden. There were not enough to allow for between-group comparisons or comparisons by gender. Siblings and spouses are the same age cohort as elders, and there is potential for an increased need for services among elder caregivers. There were also insufficient males and blacks in this sample for anything other than the most rudimentary analysis.

This caregiver study substantiates the need for longitudinal studies. Few longitudinal studies have been conducted. The longitudinal study of Johnson and Catalano (1983) suggests (not surprisingly) that caregiver/elder relationships change over time. Some studies have found that relationships deteriorate over time (Robinson & Thurner, 1979). Others indicate that burden does not increase with time. More longitudinal studies are needed to aid in understanding this process. Such studies, to be most effective in developing a knowledge base, should measure elder status over time, caregiver well-being over time and the covariation of these.

Additionally, based on the contradictory findings on mental status and caregiver perception of burden, much work remains to be done in

this area. The findings of increased caregiver burden being associated with improvement of elder function raises the question of caregiver expectations vis-a-vis elder potential for improvement and the association of expectation with caregiver burden. This caregiver study has demonstrated the importance of research studies which reflect the complexity of burden. It has also demonstrated that global measures may obscure variance, thus causing erroneous conclusions to be drawn.

Finally, studies on the effectiveness of interventions in reducing burden are needed. Actually, little is known about interventions which are being utilized to alleviate burden. Descriptive studies may be an important place to begin.

Implications for Policy

The primary policy recommendation growing out of this caregiver burden study is for informed social work and professional involvement in the development of policy at the local, state and federal levels. Policy must reflect not only the increasing number of older persons but also the substantial involvement of families in providing care, the extent of their burden and the diversity of their needs and those of their elders. There are no easy or global solutions.

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APPENDICES

APPENDIX A

C A R E G I V E R Q U E S T I O N N A I R E

Patient Study ID _____ ___ ___ ___ ___
1 2 3 4

Date _____ Interviewer_____

Test Period: 6 weeks, 1 year ____
5

Name of Caregiver _____

Address_____

Telephone_____

1. Caregiver Sex: male = 1; female = 2 ____
27

2. Caregiver Race:

   1. White
   2. Black
   3. Other _____
      Specify

____
28

3. Date of Birth: ___/___/___ Age_____ ___ ___ ___
29 30 31

4. How far did you go in school?

   1. 0 - 4 years
   2. 5 - 8 years
   3. High school incomplete
   4. High school complete
   5. Post high school business or trade school
   6. 1 - 3 years college
   7. 4 years college completed
   8. Post graduate college

____
32

5. Please look at this card and tell me the amount that comes closest to your family income last year, from all sources put together (Show Card).

____
33

6. How are you related to _____?
Patient's name

1. Spouse
2. Child
3. Sibling
4. Other relative (specify) _____
5. Non-spouse significant other
6. Friend
7. Other _____

34

7. Who lives at home with you?

Age	Relationship to Caregiver
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

Total: 35 36

8. Would you say that in general, for your age your health is:

1. Excellent
2. Good
3. Fair
4. Poor
5. Very poor

37

9. Would you say you are as healthy as your friends? (Yes = 1, No = 2)

38

10. Have you had to change or had to give us your job because of _____'s illness? (yes = 1, no = 2)

39

11. I feel that caring for _____ restricts my freedom to come and go.

_____ Strongly Agree (1)
_____ Agree (2)
_____ Disagree (3)
_____ Strongly Disagree (4)

40

12. I feel that _____ is an overly demanding person to care for.

_____ Strongly Agree (1)
_____ Agree (2)
_____ Disagree (3)
_____ Strongly Disagree (4)

_____
41

13. I feel that caring for _____ has NOT interferred with my or my family's social relationships.

_____ Strongly Agree (4)
_____ Agree (2)
_____ Disagree (3)
_____ Strongly Disagree (1)

_____
42

14. I feel that caring for _____ has NOT caused me to become moody.

_____ Strongly Agree (4)
_____ Agree (3)
_____ Disagree (2)
_____ Strongly Disagree (1)

_____
43

15. I feel that caring for _____ disrupts my routine in my home.

_____ Strongly Agree (1)
_____ Agree (2)
_____ Disagree (3)
_____ Strongly Disagree (4)

_____
44

16. I feel that caring for _____ puts a strain on family relationships.

_____ Strongly Agree (1)
_____ Agree (2)
_____ Disagree (3)
_____ Strongly Disagree (4)

_____
45

17. I feel that meeting the health needs of _____ is worth the effort.

_____ Strongly Agree (4)
_____ Agree (3)
_____ Disagree (2)
_____ Strongly Disagree (1)

_____
46

18. I feel that as a result of caring for _____ I do NOT have enough time for myself.

_____ Strongly Agree (1)
_____ Agree (2)
_____ Disagree (3)
_____ Strongly Disagree (4)

47

19. I feel that I and my family must forego necessities because of the expense to care for _____.

_____ Strongly Agree (1)
_____ Agree (2)
_____ Disagree (3)
_____ Strongly Disagree (4)

48

20. I feel that caring for _____ has negatively affected my or my family's physical health.

_____ Strongly Agree (1)
_____ Agree (2)
_____ Disagree (3)
_____ Strongly Disagree (4)

49

21. I feel that meeting the daily needs of _____ is worth the effort.

_____ Strongly Agree (4)
_____ Agree (3)
_____ Disagree (2)
_____ Strongly Disagree (1)

50

22. I feel that caring for _____ has caused me and my family much stress.

_____ Strongly Agree (1)
_____ Agree (2)
_____ Disagree (3)
_____ Strongly Disagree (4)

51

23. I feel that caring for _____ has caused me to become anxious.

_____ Strongly Agree (1)
_____ Agree (2)
_____ Disagree (3)
_____ Strongly Disagree (4)

52

24. I feel that _____ is grateful for the care I provide.

_____ Strongly Agree (4)
_____ Agree (3)
_____ Disagree (2)
_____ Strongly Disagree (1)

53

APPENDIX B

GARU Assessment Form

Start time _____am/pm End time _____am/pm

Patient ID# _____ 1-4

Test Period: Admission, 6 weeks, 6 mths, 1 year _____ 5

Is patient 1. Living 2. Dead 3. Other _____ 6

Sex of patient:
1. Male
2. Female _____ 7

Race of patient:
1. White
2. Black
3. Other _____ 8

Patient Name_____

Patient Address_____

_____

Zip code _____ 9-13

Patient Phone #(____) _____-_____

Contact Person _____ (other than spouse)

Address _____

_____

Zip code _____

Phone # _____

Interviewer _____

Date of Interview _____/_____/_____

Place of interview _____

Informant used 1. Yes 2. No _____ 14

Informant's Name _____

Relationship to patient _____

Telephone interview 1. Yes 2. No _____ 15

Medical Information for Hospitalized Patients

Patient ID# _____

Patient Name _____

3. Date of birth ___ ___ / ___ ___ / ___ ___ (16 - 17 / 18 - 19 / 20-21)

4. Age _____ (22-24)

Admission # _____ (the number in the blue box)

Medicare # _____

Date admitted to hospital ___/___/___

Date discharged from hospital ___/___/___

Length of stay, hospitalization _____ (25-27)

Principal diagnosis - DRG class

_____ (28-30)

Comorbid diagnosis - DRG class (x2) _____ (31-33)

_____ (34-36)

_____ BLANK (37)

#Active meds (at discharge from hospital) _____ (38-39)

#Prn meds (at discharged from hospital) _____ (40-41)

Serum albumin ___/___/___ _____ (42-44)

Hematocrit % ___/___/___ _____ (45-47)

Additional Notes:

_____

_____

_____

_____

MINI-MENTAL STATE EXAMINATION

		Maximum Score	Score
Orientation			
1.	What is the (year) (season) (day of week) (date) (month)? Give one point for each correct answer.	5	____/48
2.	Where are we (state) (county) (city) (hospital) (floor)? Give one point for each correct answer.	5	____/49
Registration			
3.	Repeat these objects: **Chair, Tree, Cigarette.** One second to say each. Then ask the patient all three after you have said them. Give one point for each correct answer. Repeat them until he learns all three. Count trials and record number. Number of trials _____	3	____/50
Attention and Calculation			
4.	Begin with 100 and count backwards by 7 (stop patient after five answers). One point for each correct response. Alternatively, spell "WORLD" backwards. 100 93 86 79 72	5	____/51
	R e c a l l		
5.	Ask for three objects repeated above. Give one point for each correct answer.	3	____/52
	L a n g u a g e		
6.	Show a pencil and a watch and ask patient to name them. Give one point for each correct answer.	2	____/53
7.	Repeat the following: **No if's, and's, or but's**	1	____/54
8.	A three-stage command, **"Take a paper in your right hand; fold it in half and put it on the floor."** Give one point for each action performed.	3	____/55
9.	Read and obey the following: (show patient the written item). **CLOSE YOUR EYES.**	1	____/56
10.	Write a sentence. **SEE THE DOG RUN.**	1	____/57
11.	Copy a design (**Complex Polygon** as in Bender-Gestalt).	1	____/58
	Total Score		____/59-60

SOCIAL SUPPORT

12. How far did you go in school?
    1. 0-4 years
    2. 5-8 years
    3. High school incomplete
    4. High school complete
    5. Post High School business or trade school
    6. 1-3 years college
    7. 4 years college completed
    8. Post graduate college

    61

13. Who lives with you?
    1. No one
    2. Husband or wife
    3. Other relative (s)
    4. Friend
    5. Non related paid helper
    6. Institution

    62

14. What type of residence do you live in? (Prior to admission)
    1. Private home - house or apartment
    2. Apartments for elderly (no meals)
    3. Apartments for elderly (meals provided)
    4. Board and care
    5. Skilled nursing home
    6. Regular Nursing home

    63

15. Are you now married, widowed, divorced, separated, or have you never married?
    1. Married
    2. Widowed
    3. Divorced
    4. Separated
    5. Never Married

    64

16. How many living children do you have? (if none go to #24)

    65-66

17. How many of your children live within an hour of you?

    67-68

18. How many of your children do you see at least once a week?

    69-70

19. How many of your children do you talk to on the phone or correspond with at least once a week?

    71-72

20. ASK PARTICIPANT ONLY:
    How many of your children do you feel very close to?

    73-74

21. ASK PARTICIPANT ONLY:
    Would you like to see your children
    1. more often, 2. about the same, or 3. less often
    than you do now?

    75

CARD 1

80

Patient ID# _____ 1-4

Test Period: Admission, 6 weeks, 6 mths, 1 year _____ 5

22. Do you help your child/children in any of the following ways? Do you.....(Read activities. Do not include help to grandchildren. If asked about time frame, say: "Within the last year." For part "e", if there are no grandchildren mark "NA not applicable.

a.	Give gifts	1. Yes	2. No	6
b.	Help out with money?	1. Yes	2. No	7
c.	Help out when someone is ill?	1. Yes	2. No	8
d.	Help keep house or fix things around the house?	1. Yes	2. No	9
e.	Take care of grand-children or babysit for a while when parents are out?	1. Yes	2. No	10

23. Now, I would like to know if your child helps/children help you in any of the following ways? Do they/Does he or she... (Read activities. Do not include help from grandchildren.) CHILD HELPS PARENT:

A.	Help you when you are ill (or when your husband/wife is ill)	1. Yes	2. No	11
B.	Give you gifts?	1. Yes	2. No	12
C.	Shop or run errands?	1. Yes	2. No	13
D.	Help keep house or fix things around the house?	1. Yes	2. No	14
E.	Help out with money?	1. Yes	2. No	15
F.	Prepare meals for you?	1. Yes	2. No	16
G.	Drive you places, such as the doctor, shopping, or church?	1. Yes	2. No	17

24a. ASK PARTICIPANT ONLY:
Is there any one special person you know that you feel very close and intimate with - someone you share confidences and feelings with, someone you feel you can depend on? (This can be spouse, child, relative, friends, or anyone else.)

1. Yes
2. No

_____ 18

24b. How often do you get together with this person?
1. Daily
2. Weekly
3. Monthly
4. Several times a year
5. Once a year or less

19

c. How often do you talk on the telephone with him/her?
1. Daily
2. Weekly
3. Monthly
4. Several times a year
5. Once a year or less

20

25a. ASK PARTICIPANT ONLY:
When you need some extra help, can you count on anyone to help you with daily tasks like grocery shopping, cooking, telephoning, or giving you a ride?

1. Yes
2. No
3. I don't need help (go to 26a)

21

b. In the last year could you have used more help with daily tasks than you received? Would you say that you could have used a lot more help, some more help, a little more help, or that you received sufficient help?
1. A lot
2. Some
3. A little
4. Received sufficient help

22

26a. ASK PARTICIPANT ONLY:

Can you count on anyone to provide you with emotional support? (Talking over problems or helping you make difficult decisions.)
1. Yes
2. No
3. I didn't need help

23

b. In the last year could you have used more emotional support than you received? Would you say that you could have used 1. a lot more emotional support, 2. some more support, 3. a little more support, or 4. that you received sufficient emotional support.

24

27a. ASK PARTICIPANT ONLY.

When you need some extra help financially, can you count on anyone to help you--that is, by paying bills, housing costs, hospital visits or providing you with food or clothes?
1. Yes
2. No
3. Offered (but would not accept)
4. I do not need help (go to Q# 28)

25

b. In the last year could you have used more financial assistance than you received? Would you say that you could have used a lot more, some more, a little more, or that you received sufficient financial assistance?

1. A lot
2. Some
3. A little
4. Received sufficient assistance

26

ECONOMIC RESOURCES

28. What type of work have you done?
1. Yes
2. No
3. Housewife

27

description: _____

29. Did your husband/wife work?
1. Yes
2. No
3. Housewife
4. Never married

28

description: _____

30. Do you receive income presently from any of these sources?
1. Employment (Wages, salaries, or business) ___29
2. Rental, investments, c.d., savings etc.) ___30
3. Social Security (disability payments) ___31
4. V.A. benefits such as G.I. ___32
5. Disability not covered by S.S. or G.I. ___33
6. Retirement pension ___34
7. Regular assistance from children ___35
8. SSI payments ___36
9. Welfare ___37

(SHOW PATIENT RANGES OF TOTAL INCOMES AND ASK THEM TO CHOOSE ONE)

Total Income: _____ 38

31. Are your assets and financial resources sufficient to meet emergencies?
1. Yes
2. No
3. Not answered

39

32. Are your expenses so heavy that you cannot meet the payments, or can you barely meet the payments, or are your payments no problem to you?
1. Subject cannot meet payments
2. Subject can barely meet payments
3. Payments are no problem
4. Not answered

40

33. Is your financial situation such that you feel you need financial assistance or help beyond what you are already getting?
1. Yes
2. No
3. No answered

41

34. Do you pay for your own food or do you get any regular help at all with th cost of food?
    1. Subject pays for food himself
    2. Subject gets help
    3. Not answered

42

35. Do you usually have enough to buy those little "extras"; that is small luxuries?
    1. Yes
    2. No

43

36. What type of insurance coverage do you have?
    1. Medicare A only
    2. Medicare A and B
    3. Medicare plus private insurance
    4. Medicaid
    5. VA

44

INTERVIEWER: Give participant response sheet.

"Now I have some questions about your feelings during the past week. For each of the following statements, please tell if you felt that way: Rarely or none of the time; some of the time; much of the time; most or all of the time."

	Rarely or non of the time	Some of the time	Much of the time	Most or all of the time	
37a. During the past week I was bothered by things that usually don't bother me. Did you feel that way...	_1	_2	_3	_4	45
b. During the past week, I did not feel like eating: my appetite was poor. Did you feel that way...	_1	_2	_3	_4	46
38. During the past week, I felt that I could not shake off the blues even with help from my family and friend. Did you feel that way....	_1	_2	_3	_4	47
39. I felt that I was just as good as other people. Did you feel that way...	_4	_3	_2	_1	48
40. I had trouble keeping my mind on what I was doing. Did you feel that way...	_1	_2	_3	_4	49

	Rarely or non of the time	Some of the time	Much of the time	Most or all of the time	
41. During the past week I felt depressed. Did you feel that way...	_1	_2	_3	_4	____ 50
42. I felt that everything I did was an effort. Did you feel that way...	_1	_2	_3	_4	____ 51
43. I felt hopeful about the future. Did you feel that way...	_4	_3	_2	_1	____ 52
44. During the past week, I thought my life had been a failure. Did you feel that way...	_1	_2	_3	_4	____ 53
45. I felt fearful. Did you feel that way...	_1	_2	_3	_4	____ 54
46. My sleep was restless. Did you feel that way...	_1	_2	_3	_4	____ 55
47. During the past week, I was happy. Did you feel that way...	-4	-3	-2	-1	____ 56
48. It seemed that I talked less than usual. Did you feel that way...	-1	-2	-3	-4	____ 57
49. I felt lonely. Did you feel that way...	-1	-2	-3	-4	____ 58
50. During the past week, people were unfriendly. Did you feel that way	-1	-2	-3	-4	____ 59
51. I enjoyed life. Did you feel that way...	-4	-3	-2	-1	____ 60
52. I had crying spells. Did you feel that way...	-1	-2	-3	-4	____ 61
53. During the past week, I felt sad. Did you feel that way...	-1	-2	-3	-4	____ 62

	Rarely or non of the time	Some of the time	Much of the time	Most or all of the time	
54. I felt that people disliked me. Did you feel that way...	-1	-2	-3	-4	63
55. I could not get going. Did you feel that way...	-1	-2	-3	-4	64
56. Total score	___	___	___	___	65-66

Note: Sum the scores in each of the 1st four columns. Add the four subtotals together to obtain the total score.

Physical Health

57. How many hospital stays have you had in the last _____months? 67

58. How many days have you been in the hospital in the last ____months? 68-70

59. Have you been a patient in a nursing home in the _____months?
    1. Yes
    2. No 71

60. Do you have any problems controlling your bladder?
    1. Never or infrequently
    2. Occasionally
    3. Frequently
    4. Catheterized 72

61. Do you have any problems controlling your bowels? (soiling yourself)
    1. Never or very infrequently
    2. Occasionally
    3. Frequently
    4. Ostomy 73

62. About how many times would you say that you have fallen to the floor or ground for no obvious reason in the past three months?
    1. None
    2. Once
    3. Twice
    4. Three times 74

63. Did you have any injury from those falls that required doctor's attention?
    1. Yes
    2. No 75

Describe injury:_____

64. For your age, would you say, in general, that your health is excellent, good, fair, poor, or bad?
    1. Excellent
    2. Good
    3. Fair
    4. Poor
    5. Bad

    ____ 76

65. Is it better, worse, or about the same compared to _____ months ago?
    1. Better
    2. Worse
    3. About the same

    ____ 77

66. How do you feel about life as a whole? Would you say that you feel delighted,pleased, mostly satisfied, mixed, mostly dissatisfied, unhappy, or terrible?
    1. Delighted
    2. Pleased
    3. Mostly satisfied
    4. Mixed
    5. Mostly dissatisfied
    6. Unhappy
    7. Terrible

    ____ 78

67. Taking all things together, how would you say things are these days? Would you say that you are very happy, pretty happy, or not too happy these days?
    1. Very happy
    2. Pretty happy
    3. Not too happy

    ____ 79

    2
    ____ 80

CARD

PLEASE LISTEN TO EACH OF THE FOLLOWING STATEMENTS ABOUT YOUR OWN HEALTH, AND THEN TELL ME WHETHER THE STATEMENT IS TRUE OR FALSE FOR YOU.

>>>> **There are no RIGHT or WRONG answers** <<<<

SOME OF THE STATEMENTS MAY SOUND OR SEEM LIKE OTHERS, BUT EACH STATEMENT IS DIFFERENT, AND SHOULD BE RATED BY ITSELF

ID#_____ 1-4

TP_____ 5

NOW I'M GOING TO READ SOME STATEMENTS, AND YOU TELL ME WHETHER THEY ARE:

	Definitely True	Mostly True	Don't know	Mostly False	Definitely False	
68. According to the doctor's I've seen, my health is now excellent....	-1	-2	-3	-4	-5	____ 6

	Definitely True	Mostly True	Don't know	Mostly False	Definitely False	
69. I try to avoid letting illness interfere with my life.....	-1	-2	-3	-4	-5	7
70. I seem to get sick a little easier than other people	-1	-2	-3	-4	-5	8
71. I feel better now than I ever have before.....	-1	-2	-3	-4	-5	9
72. I will probably be sick a lot in the future.....	-1	-2	-3	-4	-5	10
73. I never worry about my health	-1	-2	-3	-4	-5	11
74. Most people get sick a little easier than I do	-1	-2	-3	-4	-5	12
75. I don't like to go to the doctor	-1	-2	-3	-4	-5	13
76. I am somewhat ill	-1	-2	-3	-4	-5	14
77. In the future, I expect to have better health than other people I know	-1	-2	-3	-4	-5	15
78. I was so sick once I thought I might die.....	-1	-2	-3	-4	-5	16
79. I'm not as healthy now as I used to be	-1	-2	-3	-4	-5	17
80. I worry about my health more than other people worry about their health	-1	-2	-3	-4	-5	18
81. When I'm sick I try to just keep going as usual	-1	-2	-3	-4	-5	19
82. My body seems to resist illness very well	-1	-2	-3	-4	-5	20

	Definitely True	Mostly True	Don't know	Mostly False	Definitely False	
83. Getting sick once in a while is a part of my life	-1	-2	-3	-4	-5	21
84. I'm as healthy as anybody I know	-1	-2	-3	-4	-5	22
85. I think my health will be worse in the future than it is now	-1	-2	-3	-4	-5	23
86. I've never had an illness that lasted a long period of time	-1	-2	-3	-4	-5	24
87. Others seem more concerned about their health than I am about mine	-1	-2	-3	-4	-5	25
88. When I'm sick I try to keep it to myself	-1	-2	-3	-4	-5	26
89. My health is excellent	-1	-2	-3	-4	-5	27
90. I expect to have a very healthy life	-1	-2	-3	-4	-5	28
91. My health is a concern in my life	-1	-2	-3	-4	-5	29
92. I accept that sometimes I'm just going to be sick	-1	-2	-3	-4	-5	30
93. I have been feeling bad lately	-1	-2	-3	-4	-5	31
94. It doesn't bother me to go to a doctor	-1	-2	-3	-4	-5	32
95. I have never been seriously ill	-1	-2	-3	-4	-5	33
96. When there is something going around, I usually catch it	-1	-2	-3	-4	-5	34
97. Doctors say that I am now in poor health	-1	-2	-3	-4	-5	35

	Definitely True	Mostly True	Don't know	Mostly False	Definitely False	
98. When I think I am getting sick, I fight it	-1	-2	-3	-4	-5	36
99. I feel about as good now as I ever have	-1	-2	-3	-4	-5	37

100. WHISPER SOMETHING TO SUBJECT AND ASK THEM TO REPEAT IT.
e.g.: **The sky is blue**

1. Repeated
2. Unable

38

RECORD VISUAL ACUITY: (Test both eyes with glasses on at the same time)

BINOCULAR ACUITY 20 / 39-41

AT THE PRESENT TIME, DO YOU NEED HELP FROM ANOTHER PERSON OR SPECIAL EQUIPMENT FOR...

101. a. Walking across a small room

No help	___1	
Help	___2	
Unable to do	___3	42

b. Is this help from another person, from special equipment or both?

Person only	___1	
Equipment only	___2	
Both	___3	43

c. How much difficulty, on the average, do you have doing this? Would you say that you have...(say the response)

No difficulty at all	___1	
A little difficulty	___2	
Some difficulty	___3	
A lot of difficulty	___4	44

102. a. Do you need help from another person or from special equipment for bathing--either a sponge bath, tub bath, or shower?

No help	___1	
Help	___2	
Unable to do	___3	45

b. Is this help from another person, from special equipment or both?

Person only	___1	
Equipment	___2	
Both	___3	___

46

c. How much difficulty, on the average, do you have doing this? Would you say that you have....(say the response)

No difficulty at all	____1	
A little difficulty	____2	
Some difficulty	____3	
A lot of difficulty	____4	47

103. a. Administering medicines

No help	____1	
Help	____2	
Unable to do	____3	48

b. Is this help from another person, from special equipment or both?

Person only	____1	
Equipment only	____2	
Both	____3	49

c. How much difficulty, on the average, do you have doing this? Would you say that you have....(say the response)

No difficulty at all	____1	
A little difficulty	____2	
Some difficulty	____3	
A lot of difficulty	____4	50

104. a. Do you need help for personal grooming, like brushing hair, brushing teeth, or washing face?

No help	____1	
Help	____2	
Unable to do	____3	51

b. Is this help from another person, from special equipment or both?

Person only	____1	
Equipment only	____2	
Both	____3	52

c. How much difficulty, on the average, do you have doing this? Would you say that you have.....(say the response)

No difficulty at all	____1	
A little difficulty	____2	
Some difficulty	____3	
A lot of difficulty	____4	53

105. a. Do you need help for dressing, like putting on a shirt, buttoning and zipping, or putting on shoes?

No help	____1	
Help	____2	
Unable to do	____3	54

b. Is this help from another person, from special equipment or both?

Person only	____1	
Equipment only	____2	
Both	____3	55

c. How much difficulty, on the average, do you have doing this? Would you say that you have....(say the response)

No difficulty at all	____1	
A little difficulty	____2	
Some difficulty	____3	
A lot of difficulty	____4	56

106. a. Do you need help for eating, like holding a fork, cutting food, or drinking from a glass?

No help	____1	
Help	____2	
Unable to do	____3	57

b. Is this help from another person, from special equipment or both?

Person only	____1	
Equipment only	____2	
Both	____3	58

c. How much difficulty, on the average, do you have doing this? Would you say that you have....(say the response)

No difficulty at all	____1	
A little difficulty	____2	
Some difficulty	____3	
A lot of difficulty	____4	59

107. a. Do you need help getting from bed to a chair?

No help	____1	
Help	____2	
Unable to do	____3	60

b. Is this help from another person, from special equipment or both?

Person only	____1	
Equipment only	____2	
Both	____3	61

c. How much difficulty, on the average, do you have doing this? Would you say that you have....(say the response)

No difficulty at all	____1	
A little difficulty	____2	
Some difficulty	____3	
A lot of difficulty	____4	62

108. a. Do you need help using the toilet?

No help	____1	
Help	____2	
Unable to do	____3	63

b. Is this help from another person, from special equipment or both?

Person only	____1	
Equipment only	____2	
Both	____3	64

c. How much difficulty, on the average, do you have doing this? Would you say that you have....(say the response)

No difficulty at all	____1	
A little difficulty	____2	
Some difficulty	____3	
A lot of difficulty	____4	65

109. Are you able to do heavy work around the house, like washing windows, walls or floors without help?
(PROBE: Could you do it if you needed to?)

Yes	____1	
No	____2	66

110. Are you able to walk up and down stairs to the second floor without help?
(PROBE: Could you do it if you needed to?)

Yes	____1	
No	____2	67

111. Are you able to walk a mile **without help**? That's about 8 ordinary blocks.
(PROBE: Could you do it if you needed to?)

Yes	____1	
No	____2	68

NOW I'M GOING TO ASK YOU ABOUT HOW DIFFICULT IT IS, ON THE AVERAGE, FOR YOU TO DO CERTAIN KINDS OF ACTIVITIES

112. To begin, how much difficulty, if any, do you have pulling or pushing large objects like a living room chair? Would you say you have...

No difficulty at all	___1	
A little difficulty	___2	
Some difficulty	___3	
A lot of difficulty	___4	
Just unable to do it	___5	69

113. What about stooping, crouching, or kneeling? Do you have....

No difficulty at all	___1	
A little difficulty	___2	
Some difficulty	___3	
A lot of difficulty	___4	
Just unable to do it	___5	70

114. Would you be able to carry a bag under 10 lbs., like a bag of potatoes? Do you have...	No difficulty at all	___1	
	A little difficulty	___2	
	Some difficulty	___3	
	A lot of difficulty	___4	
	Just unable to do it	___5	71
115. Reaching or extending arms above shoulder level? Do you have?.....	No difficulty at all	___1	
	A little difficulty	___2	
	Some difficulty	___3	
	A lot of difficulty	___4	
	Just unable to do it	___5	72
116. Either writing or handling small objects? Do you have...	No difficulty at all	___1	
	A little difficulty	___2	
	Some difficulty	___3	
	A lot of difficulty	___4	
	Just unable to do it	___5	73

3
80

NOW I'M GOING TO READ A LIST OF THINGS PEOPLE DO IN THEIR FREE TIME. IN THE LAST MONTH, HOW OFTEN HAVE YOU DONE EACH OF THESE--OFTEN, SOMETIMES, OR NEVER"

ID _____ 1-4

TP _____ 5

	Often	some times	Never	
117. Active sports or swimming	-1	-2	-3	6
118. Take walks	-1	-2	-3	7
119. Work in the garden/yard	-1	-2	-3	8
120. Do physical exercises	-1	-2	-3	9
121. Prepare your meals	-1	-2	-3	10
122. Work at a hobby	-1	-2	-3	11
123. Go out and do some shopping	-1	-2	-3	12
124. Go out to a movie, restaurant, or sporting event	-1	-2	-3	13
125. Read books, magazines, newspapers	-1	-2	-3	14
126. Watch television	-1	-2	-3	15
127. Go on day trips, or overnight trips	-1	-2	-3	16
128. Unpaid community or volunteer work	-1	-2	-3	17
129. Paid community work	-1	-2	-3	18
130. Regularly play cards, games, or bingo	-1	-2	-3	19
131. Any other activities Specify _____	-1	-2	-3	20

TEST	PHYSICAL FUNCTION FUNCTION TESTS TIME UNABLE 999	INDP EQUIP PERS
SIMULATED EATING:		
DOMINATE HAND:	21-23	24
NON-DOMINATE HAND:	25-27	28
PHONE (PUSH BUTTON):	29-31	32
SHIRT BUTTON:	33-35	36
IN/OUT: BED/CHAIR:	37-39	40
BED/DOOR WALK:	41-43	44
DOOR/BED WALK:	45-47	48
WALK 25 FT.:	49-51	52
STERNAL PUSH NUMBER OF STEPS BACK:		53

VITA

Ruth Nelson Paton was born in Hartwell, Georgia, on August 19, 1933. She attended Georgia public schools and graduated from A. L. Miller Senior High for Girls in Macon, Georgia in 1952. She attended Mercer University and Maryville College in Maryville, Tennessee, graduating from Maryville with a Bachelor of Arts degree in Sociology in June of 1956.

After several years of experience as a social worker, Ms. Paton entered the College of Social Work at The University of Tennessee, Knoxville, in 1973. She graduated from The University of Tennessee, Knoxville with a Master of Science degree in Social Work in 1975.

In 1984 Ms. Paton enrolled in the Doctor of Philosophy in Social Work program at The University of Tennessee, Knoxville, having spent nine years practicing primarily in gerontological social work in a variety of health care settings. She received the Ph.D. degree in December of 1988.

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