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CASE MANAGEMENT: AN EVALUATION OF ITS IMPACT ON THE PRIMARY CAREGIVER

By

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ABSTRACT

CASE MANAGEMENT: AN EVALUATION OF ITS IMPACT ON THE PRIMARY CAREGIVER

BY

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The present study was an attempt to assess the degree to which case management has impacted the lives of the primary caregivers of frail elderly individuals. The sample consisted of 76 caregivers to frail elderly clients. A 20 to 30 minute telephone interview was administered which assessed six areas of the caregiver's life, which were as follows: social involvements, psychological health, physical health, the relationship between the caregiver and the care-receiver, stress the caregiver may be experiencing, and activities of caregiving. The case management group was compared to a control group of primary caregivers whose care-receiver received the information and referral condition. No differences were detected between the treatment and control groups. Step-wise regression procedures were performed and four scales (social, physical health, psychological health, and relationship) and two variables were found to be significant predictors. The results of this study indicate a need for future research to address the needs of caregivers to the frail elderly.

In Memory of my Grandmothers,

Helmi Anna Eleanora Moyryla Paulson
and
Helena Elizabeth Hukkala Helbacka

"Friendship is the shadow
of the evening,
which strengthens
with the setting sun of life".
-LaFontaine

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CHAPTER 1

Introduction

The notion of caregiving to aged parents is certainly not new. For example, in the 1900's, the care given to ailing aged parents was usually done by their adult children in their homes (Dahlin, 1980). Thus, the family bore full responsibility for the care of incapacitated relatives. Since the advent of nursing or convalescent homes and public funding, an argument has ensued which alleges that the elderly have been abandoned and dumped into institutions (Dahlin, 1980; Lasch, 1977; Sussman, 1976). Two equally persistent and pervasive contentions which have also been generated are: formal support systems, which refer to governmental and community services, provide the bulk of care received by the dependent elderly; and these services undermine the family's sense of responsibility and encourage the family to shirk those responsibilities (Brody, 1981). Brody (1981) has referred to these arguments as "the myth of family alienation". Shanas (1979) has made reference to them as a "hydra-headed monster" due to their permeating nature. Research over the past several decades has invalidated these myths and consistently documented the dominant role the family has in providing health care to impaired noninstitutionalized elderly (Branch & Jette, 1983; Brody, 1981; Brody, 1987; Cantor, 1983; Chatters, Taylor, &

Jackson, 1986; Kohen, 1983; Shanas, 1979; Solomon, 1982; Treas, 1977; Ward, 1984).

Caregiving involves at least a two-person dyad, the person receiving assistance, the care-receiver; and the individual providing care, the caregiver (Cantor, 1983). A primary caregiver is defined as someone principally responsible for providing personal care and/or coordinatining resources required by the impaired elderly individual (Zarit, Reever, & Peterson, 1980). An example of various types of services might include: household chores, transportation, meal preparation, and financial assistance.

A primary caregiver is part of or may be the only member of the informal support system which is available to the care-receiver. Informal support systems are defined as an elder's spouse, living children, siblings, other relatives, friends, and neighbors (U.S. Office of Management and Budget, 1980).

Within the informal support system, two patterns of familial network use have been recognized. First, a hierarchical, compensatory model in which kin, especially spouse and children, are preferred by care-receivers over friends and neighbors as the cornerstone of the support system (Cantor, 1983). When a crisis occurs, the elderly will turn to the immediate family first, then to other relatives, friends, neighbors, and finally formal supports (Cantor, 1979). When family members are not available, the role of friends and neighbors is more dominant. The existence of a hierarchy has been documented by various researchers studying caregiving (Chatters, Taylor, & Jackson, 1985; Kulys & Tobin, 1980; Stack, 1974).

An alternative model proposed by Shanas (1979) is the principle of substitution whereby general patterns of family support are available to support members, in serial progression. The individual selected for the primary caregiver role is done so by the nature of the kin relationship: spouses before children, children before siblings, siblings before other extended family members. This model emphasizes the primacy of spousal and filial support and only when this is not available, will the older member turn to distance kin and non-kin for support (Shanas, 1979). This model has been elaborated on by other researchers (Brody, 1981; Chatters et al., 1985; Johnson, 1983; Johnson & Catalano, 1981; Ward, 1978).

Both the hierarchical and the substitution model place caregiving responsibilities directly on immediate family members. The use of non-kin and formal support systems is generally less frequent by older individuals who are ill (Cantor, 1979; Chatters et al., 1986; Johnson & Catalano, 1981).

Research on Case Management

Over the past decade, discussions on caregiving have increased, but more research is needed on the consequences of long-term care on the primary caregiver (Crossman, London, & Barry, 1981; Marcus & Jaeger, 1984; Rakowski & Clark, 1985; Townsend & Poulshock, 1986). At this time, two questions arise which must be considered: how long can caregivers carry the heavy responsibilities associated with caregiving and what can be done to ease the burden of caregiving. By directing our attention towards the latter of the two, we may be able to eliminate the need to ask the first question.

What appears to be the overwhelming consensus among researchers is the need for more collaborative work between informal and formal support networks for the frail elderly (Biegel, Shore, & Gorden, 1984; Brody, 1981; Horowitz, 1985; Johnson, 1983; Jones & Vetter, 1984; Rakowski & Clark, 1985; Scott & Roberto, 1985; Stoller, 1982, 1983; Stoller & Earl, 1983). Clark and Rakowski (1983) and Zarit, Reever, and Peterson (1980) stated that alternative ways to reduce burden of home care have not been given sufficient attention.

Case management is one alternative which provides a supportive link between informal support networks and those of the community. It is a service that assists clients in identifying needs (physical, emotional, and economic), explores solutions, and provides a connection between informal and formal supports in order to achieve the highest level of independence for the at-risk elderly (Steinberg & Carter, 1983). Although components of case management programs vary, the core characteristics typically shared by all programs include:

1) Prescreening: preliminary assessment of potential clients to determine eligibility.
2) Assessment/Reassessment: multidimensional

assessment (physical, mental, and social evaluation) done at the initial phase of the program with periodic reassessments done every 60 to 90 days to determine client progress and highlight needed changes in service utilization.

3) Care Plan: a plan which documents needed services. Elements of the plan include information regarding the frequency, duration, and goals of services utilized by clients. It also documents meetings with the informal support system and various consultations with specialists and/or other members of the formal support system.

4) Coordination: contacting and contracting with a variety of providers to arrange for care plan implementation.

5) Monitoring: maintaining ongoing contact with the client between scheduled assessments to check on client progress and satisfaction. In addition, contact is also made with service providers to assure that the services prescribed in the care plan are being delivered.

A case manager is usually a registered nurse or a social worker and may be working individually or as part of a team comprised of several nurses and/or social workers. The primary objective of case management is to maintain the at-risk elderly person in his/her own home through coordination of in-home and community-based services, thus reducing premature institutionalization.

Institutionalization is considered premature when an individual is placed in an institution despite the fact that the individual could maintain him or herself in the community if they had supplemental assistant (Ward, 1984). Those individuals who cannot obtain special assistance or additional health care services are more likely to be admitted to an instititution (Wachtel, Fulton, & Goldfarb, 1987).

Institutionalization for the elderly has been referred to as a life-or-death issue (Ward, 1984). Coinciding with the growth of institutions has been the concern about the impact institutionalization has on the elderly. A number of studies have reported the consequences of being institutionalized which include: depersonalization, physical and other abuses, demoralization, relocation stress or transfer trauma, as well as the financial costs (Kimmel, 1980; Shanas & Maddox, 1976; Ward, 1984; Williams, 1985). Thus, the gravest decision that spouses, family members, and long-term care providers face involve recommending institutional placement.

The obvious benefits of case management for the formal support system are: containing long-term care costs, reducing service fragmentation, and eliminating service duplication (Steinberg & Carter, 1983). But more importantly, increased assistance from formal supports will reduce the burden on informal caregivers (Brill & Horowitz, 1984; Callahan & Stanley, 1981; Kodner, Mossey, & Dapello, 1984).

With Medicaid funding cuts pushing greater financial responsibility for care of the frail elderly on the family, the increase in the old-old (age 75+) rising rapidly, and a shortage of potential caregivers predicted in the future, case management has been looked upon as a viable solution to a possible crisis situation (Callahan & Stanley, 1981). Although the literature on case management is sparse, what does exist presents very promising outcomes.

Brill and Horowitz (1984) have assisted in implementing a project in New York City called Home Care Project (HCP). The project provides home care and other maintenance level services to homebound, frail elderly in four selected areas of New York City. Longitudinal data are being collected from a research sample of 504 HCP clients and 200 matched comparisons.

Preliminary results show a decrease in the length of stay per hospitalization by 29% and overall positive satisfaction with services provided expressed by caregivers. Kodner et al. (1984) reports similar results with another project in New York City called "Nursing Homes Without Walls". Clients and their families appear almost universally satisfied with the project. Data collected in the client interview survey indicate that the project has helped to foster an increase in informal supports and caregiving by family and friends.

Triage, a project directed to meet the needs of the frail elderly in Connecticut, was also an experiment in changing the service delivery mechanism for long-term care

(Quinn & Hodgson, 1984). This seven-year project showed a positive impact on caregivers through the use of counseling and supportive services to alleviate confusion, despair, and even crisis situations.

The South Carolina Community Long Term Care Project (CLTC) began accepting client referrals in July of 1980 (Brown & Learner, 1984). The control group of this project had 337 participants and the experimental group had 282 participants. The mean age of each group was 74.87 and 73.23 respectively. The majority of the clients (82%) were at nursing home levels of care and women represented 69% of the clients.

The preliminary findings in the CLTC study indicated that the experimental intervention, case management, was successful in providing community-based care for the frail elderly with chronic health conditions. The experimental group used significantly less nursing home days at an intermediate care facility (ICF) level than the control group. For ICF controls, 42% of the participation days were spent in nursing homes. In addition, among the patients who were intitially at nursing home care levels, a greater proportion of experimental patients remained in their homes than did the controls. Similar results have been reported with other projects by various researchers (Eggert & Brodows, 1984; Jette, Branch, Wentzel, Carney, Dennis, & Heist, 1981; Skellie, Favor, Tudor, & Strauss, 1984; Weiss & Sklar, 1984).

These findings, although optimistic, should be interpreted with some caution due to serious methodological limitations in some of the studies. For example, Eggert and Brodows (1984) used a nonequivalent control group design to analyze their data which was collected over a three year period. In addition, due to differences in research designs, data collection systems, and the populations served, generalizability from project to project is difficult.

For instance, none of the studies on case management randomly selected their participants from a general population, which places a limitation on external validity (Campbell & Stanley, 1968). Additionally, Brill and Horowitz (1984) evaluated their program impacts utilizing a quasi-experimental research design with no randomization. The researchers did attempt to use a matched comparison sample of 200 individuals, but their design was weakened by the extreme levels of disability found with in the treatment group as compared to the individuals in the comparison group who were significantly less impaired.

However, several researchers (Brown & Learner, 1984; Skellie et al., 1984; Weiss & Sklar, 1984) did utilize an experimental design with randomization of participants to experimental and control groups.

Clearly what is needed in this area is research which adheres to rigorous experimental methodology. Only then can the effects of the experimental innovation be accurately evaluated against what presently exists in the system

(Fairweather & Tornatzky, 1977). Finally, once this type of research design has been incorporated into the project, then the magnitude of the impact of case management on alleviating caregiver burden can then be assessed.

Research on the Effects of Caregiving

Along with the mounting evidence which supports the active involvement of the family in caregiving to the elderly, there is a growing awareness of the demands, risks, and costs associated with caregiving. These demands, risks, and costs have been labeled the "burden" of caregiving which the informal support network must cope with (Kraus, 1984; Poulshock & Deimling, 1984; Rokowski & Clark; 1985; Ward, 1984; Zarit et al., 1980). The toll of caregiving to the old-old, often referred to as the frail elderly when ill, is high in terms of physical, psychological, and financial resources (Clark & Rakowski, 1983; Lowenthal, Berkman, & Associates, 1967). Research has shown that family members go to great lengths to avoid institutionalization of frail, homebound elderly family members even to the detriment of their own health (Brody, 1981; Deimling & Bass, 1986; Rabowski & Clark, 1985; Shanas & Maddox, 1976).

Emotional and Physical Effects of Caregiving

Farkas (1980) examined the degree of burden associated with caring for a chronically ill spouse and reported the spousal caregivers often described themselves as physically and emotionally drained. Fengler and Goodrich (1979) reported loneliness, a sense of isolation, and role overload experienced by wives of elderly disabled men. Similar findings were reported by Crossman et al. (1981) while utilizing a Wives Support Group for the spouses caring for disabled men.

Those comprising the informal support network have expressed feelings of guilt and anger (Crossman et al., 1981; York & Calsyn, 1977) towards the care-receiver and other family members who are not involved with caregiving responsibilities. Additionally, caregivers often experience low morale and depression (Crossman et al., 1981; Fengler & Goodrich, 1979; Poulshock & Deimling, 1984). Family members and those making up the informal support network have been known to make personal sacrifices even to the point of giving up their jobs to care for the frail, elderly relative in need (Brocklehurst, Morris, Andrews, Richards, & Laycock, 1981; Robinson & Thurnher, 1979).

Several studies (Cantor, 1983; Fengler & Goodrich, 1979; Smith & Bengston, 1979) report that caregiving may be accompanied by a suspension or even abandonment of one's future plans. Rakowski and Clark (1985) investigated future outlook by contacting the care-receivers and primary caregivers and found restricted future outlook for both groups to be associated with situations of greater impairment, more extensive assistance, and greater stress. Although the authors report a cause-effect association cannot be identified due to cross-sectional data, they do hypothesize that a limited future outlook may in turn exacerbate feelings of stress.

Types of Caregivers

Mcauley, Jacobs, and Carr (1984) studied patterns of caregiving assistance in 389 older married couples. The couples were interviewed and asked if they had acted as a caregiver to anyone within the past six months, and if so, to describe the relationship between themselves and the care-receiver. It was found that wives are more likely to provide assistance outside of the marital relationship, whereas men are more likely to help their spouse.

Cantor (1983) researched the factors associated with stress among four types of informal caregivers: 33% were spouses (49% women), 36% were children (75% women), 19% were other relatives (86% women), and 12% were friends and neighbors (92% women). The results indicated that the amount of stress and disruption of daily lives of the caregiver is different for different groups of caregivers. Closer bonds make caregiving more stressful and the two groups of caregivers at highest risk of stress are spouses and children.

Virtually all of the literature substantiates the fact that women predominate as providers of direct services to the frail elderly (Brody, 1981; Cantor, 1983; Crossman et al., 1981; Horowitz, 1985; Johnson, 1983; Jones & Vetter, 1984; Perspective on Aging, 1985; Rakowski & Clark, 1985; Shanas, 1979; Stoller, 1982, 1983; Treas, 1977). However, the data do not reflect the lack of responsibility on the part of men as caregivers; rather, they represent the cultural assignment of gender-appropriate roles (Brody, 1981).

The sex of the adult child is one of the most important and consistent predictors of caregiving involvement (Horowitz, 1985). But due to increased involvement in the labor market by women, society may see different patterns of caregiving in the future as well as more equally distributed responsibility among male and female adult children and siblings (Horowitz, 1985). At this time, research supports the fact that adult daughters report considerably greater stress than adult sons when caring for an older parent (Horowitz, 1985). Numerous researchers have found this relationship between gender and caregiving stress (Brody, 1985; Cantor, 1983; Cicirelli, 1981; Johnson, 1983; Marcus & Jaeger, 1984; Robinson & Thurnher, 1979; Scharlach, 1987). Robinson and Thurnher (1979) have hypothesized that because of the more intimate emotional relationship which often exists between mothers and daughters, greater stress results. This hypothesis is strengthened by the research done by Cantor (1983) and the fact that elderly women are more likely than men to be in the position of the care-receiver over the age of 75 (Ward, 1984; Wingard, Jones, & Kaplan, 1987).

The association between female caregivers and greater reported stress is equally likely to be explained by what Brody (1981) has named "woman in the middle". Such women are in middle age, are middle generation, and are in the middle of competing demands on their time and energy. Added to their traditional roles as wives, homemakers, mothers, and grandmothers are roles such as paid workers, caregiving daughters, and daughter-in-laws. These multiple demands may explain why the experience is more stressful for women.

Bowling (1984) supports the work done by Brody in a study of the lives of 213 relatives who were caregivers to elderly widowed people. Sixty-nine percent of these caregivers were children of the widowed person and of these, 46% were daughters and 33% were sons. It was reported that daughters were more likely to suffer life restrictions before and after the death because of the care and support given to the deceased and surviving spouse. These women were also committed to full and part time work and most had their own families to support.

Recently, it has been assumed that women who are employed outside of the home reduce the amount of time spent as caregivers. Research on this issue has found that employment outside of the home is not a deterrent to the level of involvement by daughters as caregivers (Brody, Kleban, Johnson, Hoffman, & Schoonover, 1987). Instead of reducing the amount of time as caregivers, daughters give up their own free time and opportunities for socializing. A recent study reported that regardless of their work status (working or nonworking) daughters provided the most help to their dependent mothers (Brody & Schoonover, 1986).

Types of Caregiving Relationships

The degree of burden felt by caregivers is also affected by the relationship which exists between the caregiver and care-receiver (Kulys & Tobin, 1980). The long-term quality of their relationship, the degree of physical impairment of the care-receiver, and the individual personalities combine to affect the degree of burden experienced (Biegel et al., 1984).

Kulys and Tobin (1980) also report that a close affectionate bond between a child caregiver and a cared-for-parent is said to lessen the strain of caregiving. Supporting the work done by Cantor (1983), Kulys and Tobin (1980) also found that the intimate bonds established in a spouse caregiving relationship tends to heighten stress and perceived sense of burden. This finding may be explained by a number of factors which are unique to the spousal relationship and increase stress (Cantor, 1983; Crossman et al., 1981; Fitting, Rabins, Lucas, & Eastham, 1986; Gibson, 1982; Marcus & Jaeger, 1984). First, the spousal caregiver often provides care to a severely impaired individual who can no longer communicate verbally, thus depriving the caregiver of the companionship and support once derived from the confidant relationship they once enjoyed. Second, the spouse's sexual and affectional needs are frustrated due to the loss of psychological, physical, and mental capacities for interpersonal sensitivity and communication. Finally, the spouse must also adjust to issues of role reversal as he or she assumes both roles in order to maintain the household. Therefore, in addition to the demands and costs of caregiving experienced by caregivers, the spousal caregiver must also cope with the loss of a lifelong companion. Although the familiar body remains, the capacities to nurture a mutually satisfying relationship have deteriorated.

Zarit et al. (1980), while working with caregivers of persons with senile dementia, reported stress was not related to behavior problems of the care-receiver but associated with the social supports available. As the number of visits to the impaired elderly person increased from family members, the degree of burden experienced by the primary caregiver decreased. Marcus and Jaeger (1984) also found a "high" burden score to be associated with fewer visits to the household.

Gilleard, Gilleard, Gledhill, and Whittick (1984) investigated the relationship between the sex of the dependent person and the amount of stress and burden reported by the caregiver. Interviews were conducted with 129 caregivers of an elderly mentally infirmed relative. The results indicated that male dependents were perceived as being more stressful to live with than female dependents.

Several researchers working with dementia patients have drawn the connection between stress and the amount of support given throughout the caregiving relationship (Caserta, Lund, Wright, & Redburn, 1987; Zarit, Orr, & Zarit, 1985; Zarit, Todd, & Zarit, 1986). Their findings indicated that as the disease progressed, the dependence upon family resources for care also increased to proportions which are considered to be overwhelming. Thus, research has focused on the effects of planned interventions such as respite services and programs designed to improve coping with everyday problems. Preliminary results indicated that such programs do have a beneficial impact on caregivers by reducing the stress associated with caregiving (George & Gwyther, 1986; Zarit el al., 1986). But knowledge and access to services does not always lead to utilization because the presence of other informal support reduces the impact of providing home care to a level that the caregiver considers manageable (Caserta et al., 1987). The absence of additional informal support and the caregiver's feeling that he or she simply could not continue to provide 24-hour care needed are two major factors leading to institutional placement (Chenoweth & Spencer, 1986).

General Criticisms of Research on Caregiving

A variety of methodological weaknesses have been cited in the literature on caregiving (Clark & Rakowski, 1983). Many of the published articles are small-scale surveys, case studies, program reports, and narrative accounts of the practitioner's experience. Due to nonrandom sampling procedures employed in many of the studies and small sample sizes, the generalizability to populations outside of the sample used is restricted.

Another shortcoming in the caregiving literature is the range of definitions for burden; the effects of caregiving, and its measurement (Poulshock & Deimling, 1984). For example, the range of definitions for the concept burden have ranged from role strain, emotional costs, financial difficulties to disruption of the day-to-day life of the caregiver. Thus there exists no unified definition of burden and because burden has been defined and measured in various ways, cross-study comparisons are very difficult to make. Attempts to derive a specific measure from a concept with varying definitions creates a lack of consistency in the results making them difficult to interpret.

The effects of caregiving are detrimental to the primary caregiver psychologically, physically, and financially. The literature on caregiving has emphasized the need to increase the available support systems of the primary caregiver. Social support systems play a significant role in the lives of primary caregivers. Therefore, it is important to examine network theory as an aid to understanding the functioning of informal and formal social support networks and how they influence health. Due to the nature and content of this review, a comprehensive review of the material on social support networks will not be presented. 'For an all-inclusive review on this topic, the reader is referred to Leavy (1983).

Social Support Networks and Health

The past decade has seen the emergence of the term social support network which has been defined as that set of personal contacts through which the individual maintains his or her social identity and receives emotional support, material aid, services, new social contacts, and information (Pilisuk & Parks, 1981). Investigators have hypothesized about the link between an individual's social support network and his or her psychological state ever since Cassel (1974) noted that altered social ties affect the body's defense system, so that people became more susceptible to disease. The precise mechanism of action linking social support and health is still unknown (Minkler, 1981). But during the past 20 years, social support has been shown to be a mediator or buffer against the harmful effects of life events (Cobb, 1976; Gottlieb, 1981; Snow & Gordon, 1980; Thoits, 1982; Tolsdorf, 1976).

The buffering hypothesis asserts that the support provided by social networks increases coping ability. Thus, individuals are better able to cope with major life changes and this may increase the individuals resistance to disease (Minkler, 1981). In turn, a person with little or no social support network is more susceptible to negative effects from life changes.

Luke, Norton, and Denbigh (1981) compared psychologically impaired to psychologically healthy individuals. The sample consisted of 200 elderly individuals, with an age range of 80 to 104 years. Social isolation was reported markedly different in the psychologically impaired group and the results indicated that social interaction was the strongest predictor of psychological well-being in a multiple regression analysis that included physical health and socioeconomic variables. This finding suggests that by increasing the social interaction of primary caregivers, social isolation will decrease which will have a positive effect on the psychological well-being of the primary caregiver. This finding has been found by various researchers (Chatters et al., 1985; Marcus & Jaeger, 1984). For example, Zarit et al. (1980) studied primary caregivers of elderly individuals with senile dementia. When informal support was increased, the amount of burden experienced by the primary caregivers decreased.

An important influence on the literature concerning social support has been the work done by Caplan (1974, 1976). Caplan places a premium on the collaborative nature of the relationship between the professional and local citizens in working with support systems and community mental health. Focusing his research on how an individual responds to crisis in his or her life, Caplan has concluded that response to a crisis by an individual is dependent on three factors:

1. the nature and variation of stress
2. the present ego strength of the individual
3. the value of emotional support and task-oriented assistance which the individual's social support network is able to provide.

The results of the work done by Caplan indicated that the last factor is the most important.

Caplan has put forth the concept of mobilization, which refers to how potential supporters in a network become supporters in a stressful situation. It is important not only to examine the context in which mobilization takes place but also to examine the forces which inhibit the mobilization process from becoming activated. These forces can take many forms which are classified into two categories: subjective and objective, which are either rooted in the individual or the support network.

Subjective factors include beliefs which an individual may possess regarding when someone should be called on for help and who the helper might be. Objective factors include barriers affecting the ability to help someone, such as physical distance or levels of demand on the potential caregiver. Measuring levels of stress within the support network allows for a more concise understanding of the stress the individual is experiencing and gives one a complete overview for analyzing social support processes within the support network.

The vast majority of research findings indicate that women have more supportive relationships than men. Elderly women report larger, more intimate network ties than same-aged men (Ward, 1984). They also are more likely to have confidant relationships, which appear to be crucial for adapting to old age (Lowenthal & Haven, 1968; Ward, 1984). The components of social support for men and women also differ between sexes. In a study of network characteristics done by Phillips (1981), male's happiness was best predicted by the size of the social network, whereas women's happiness was best predicted by the number of social activities in which they participated over the preceding three months. Phillips (1981) suggested the traditional sex-role stereotypes may explain these differences, with men more connected to non-kin relationships and women to kin and social activities. Other researchers have reported similar findings regarding relationships to sex roles (Holahan & Moos, 1981; House, 1981; Roy, 1978).

These findings may help to explain why women report a greater degree of stress associated with caregiving. Because of the sexual division of labor which exists in the care of elderly individuals, women provide more "hands-on" assistance such as personal care and household chores which limits their ability to maintain social involvements outside of the home (Brody et al., 1987; Horowitz, 1985; Stoller, 1983). Thus as the number of social involvements decrease, social isolation increases and as noted earlier, an increase in social isolation is associated with psychological impairment (Luke et al., 1981). The male role in caregiving is less involved with personal care tasks and tends to be geared towards financial management and dealing with bureaucratic organizations (Brody, 1981). Thus their social network is not altered since their social support network is traditionally connected with non-kin relationships (Phillips, 1981).

An important point to consider in addition to the amount and kind of support, is the quality of support. Not all ties are supportive and a small proportion of those that are provide significant support (Wellman, 1981). An overall theme which needs to be considered is the fit between one's ideal type of support and what type of support is actually available. Research indicates that individuals should take steps to unify what exists in the informal and formal networks and mobilize them in order to achieve the highest quality of support available to those in need of such support (Porritt, 1979).

Problems in the literature on social support parallel those problems found in the literature on caregiving. In their review of this topic, Rabkin and Streuning (1976) point out the psychometric weaknesses of measurement instruments. Currently, there is no assessment instrument which measures the components of social support with great precision (Leavy, 1983). Most support questionnaires are ad hoc measures with unknown reliability and validity. In addition, a lack of agreement exists on how to define social support.

In summary, social support networks can act as a buffer which minimizes the negative effects of life stressors. This increases coping ability which may increase an individuals resistance to disease (Minkler, 1981). As a result, increasing the informal and formal support networks of the primary caregiver may decrease the burden associated with caregiving.

At the present time, it is necessary to infix the current literature, which has just been reviewed, into the policy and demographic changes which are now taking place which affect caregiving. As a result, the global picture acquired will enable the reader to fully understand the extent of the present and future problems associated with caregiving to the elderly.

Background Research

Interaction with trusted others and supportive relationships with family and friends is essential for physical and emotional well-being throughout life (Ward, 1984). As we age, the importance of social support takes on even greater significance due to the effects of aging over time. The effects of aging and disease compound one another (Kimmel, 1980). While disease may be defined as a disorder of bodily functions that may occur within a broad age range; aging involves changes that are caused solely by the passage of time (Kimmel, 1980).

These changes may be described as a continuum of loss. Minute changes begin to occur around thirty years of age (Ward, 1984). But as aging continues, changes occurring in body functioning, sensory functioning, mental functioning, family and peer supports, income, self-image, self-esteem, control, and power begin to accelerate (Biegel et al., 1984).

If the changes an individual must cope with are perceived as threatening, potentially harmful, unpleasant, or overwhelming, they are said to be stressful. Stressful changes place pressure or strain on a system due to an imbalance which occurs between the perceived demand placed upon the individual and the perceived response capability (Ward, 1984).

Stress activates the body's entire mental and physiological systems, precipitating more than 1400 physiological changes. The physiologic response to stress involves the homeostatic regulatory mechanisms of the body. As aging continues, there is a decrease in the physiologic adaptability of the older individual. Thus, the lowered efficiency of the response mechanisms causes greater sensitivity to stress (Biegel et al., 1984; Kastenbaum, 1969).

At the present time, deaths attributed to diseases associated with stress account for over 75% of all deaths at ages 65 and over (Ward, 1984). Because of the changes in the leading causes of death; from infectious communicable diseases (e.g. tuberculosis, pneumonia) to chronic degenerative diseases (e.g. cancer, heart disease), there has been a marked increase in life expectancy (Ward, 1984). There have been only small increases in life expectancy at age 65; the declines in infant mortality have contributed most to the aging of the population. As life expectancy increases and the fertility rate decreases, the proportion of older individuals begins to rise. As a result, the nation's "fastest growing minority" are those 65 and older (Brotman, 1974).

Over 95% of Americans age 65 and over reside in the community, and even among those 80 and above, 7 of every 8 individuals live in their own homes (Shanas, 1979). About 8 to 10% of the noninstitutionalized elderly are as functionally impaired as those in institutions (Brody, 1981). Overall estimates of the proportion of the population who need supportive services hover about the one-third mark, or about 8 million people (Brody, 1981). Eighty percent of this long-term care is provided by family and friends (Brody, 1987; Shanas, 1979).

The likelihood of institutionalization increases with age. Only about 5% of persons age 65 and over are in institutions, but this proportion rises from 1% of those 65 to 74 to 6% of those 75 to 84, and to 20% among those 85 and over (Williams, 1985). Because men often marry women younger than they are, they are more likely to have a spouse to care for them. In addition, women have a longer life expectancy than men (Wingard, et al., 1987), thus women outnumber men in institutions in a ratio of about three to one (Brody, 1987). The fastest growing age group is comprised of the old-old; those aged 85 and above (Manton, Blazar, & Woodbury, 1987).

The increased risk of institutionalization is reflected in the dramatic increase in Medicaid expenditures in recent years. The number of nursing home patients in the United States has increased rapidly to 1.3 million in 1978 and is projected to approach 2 million by the year 2000 (Schneider, 1983). Almost 40% of total Medicaid expenditures and about 75% of Medicaid expenditures for the elderly are spent on nursing home care (Kane & Kane, 1981). The increase in Medicaid expenditures has sparked a debate about increasing the responsibility of the informal support network for the care of noninstitutionalized elderly (Branch & Jette, 1983; Brody, 1981; Callahan, Diamond, Giele, & Morris, 1980). An untested assumption that providing home care can influence the rate and timing of nursing home use has further fueled this debate (Branch & Jette, 1983).

As the need for informal support networks and the proportion of elderly who need home care continues to grow, the amount in federal funds for formal programs is decreasing (Stoller, 1983). At the same time, we are experiencing a decline in the number of available caregivers (Horowitz, 1985; Stoller, 1983; Stoller & Earl, 1983; Treas, 1977). There are several demographic trends which may be responsible for this decrease in available caregivers. First, an increasing proportion of women, ages 45 to 64, are participating in the labor market. This age group is most likely to provide caregiving to the elderly and now comprises 60% of the labor force (Brody, 1981; Horowitz, 1985). Secondly, among the old-old there is a disproportionate number of widows who must depend on someone other than their spouse for caregiving assistance (Stoller, 1983; Treas, 1977). This group is less likely to have living adult children due to declines in fertility rates during the depression (Treas, 1977). Finally, the adult women of this group; women in today's middle generation, are more likely to have married and have had children then their predecessors, thus creating a shortage of "maiden aunts" to devote themselves to aging parents and a reduction of the pool of potential caregiving adult children (Brody, 1981; Stoller, 1983; Treas, 1977). Combining these factors with a higher life expectancy markedly changes the dependency ratio. If these trends continue, there will be two older people for every three working Americans in the next century (Johnson & Catalano, 1981). In addition, the cumulation of these factors creates a tremendous sense of responsibility on present and future caregivers in meeting the needs of the frail elderly individual (Cantor, 1983).

Although the family has an active role in the care of their frail, elderly members, the toll of caregiving is high physically, psychologically, and financially on the primary caregiver. Thus, there is a growing need to identify ways to alleviate the burden of caregiving experienced by the caregiver. It is hypothesized that increasing informal and formal social supports will decrease the burden associated with caregiving. This investigation examined the effectiveness of case management as a means of alleviating the stress associated with caregiving to frail elderly individuals.

Specific Research Goals

The present study was an attempt to assess the impact case management had on the primary caregiver of the frail elderly individual in comparison to traditional services which were available in the community (i.e., information and referral). The purpose was to assess whether case management reduced the burden of the caregiver through the incorporation of formal supports into the informal support network.

The investigation was part of a larger research project, which is being conducted to evaluate case management in sites throughout Michigan. Five case management projects have been implemented throughout the state. The specific research objective is to evaluate case management in terms of:

1. nursing home and acute care utilization
2. community service utilization patterns
3. health care costs
4. client life satisfaction/quality of life.

The project is a longitudinal study which employs a true experimental design. This design should overcome some of the methodological flaws present in prior studies.

The present study utilized a subset of three of the five sites of the larger study in an attempt to assess whether case management is effective in reducing the stress associated with caregiving to the elderly.

Hypotheses

The following hypotheses were tested through use of a telephone interview which was implemented after completion of the twelve month follow-up interview from the larger project. The measurement instrument is located in Appendix E.

I. The quality of the relationship between the primary caregiver in the case management group will be significantly better than the comparable relationships of caregivers in the information and referral group.

II. The physical health status of the primary caregiver in the case management group will be significantly better than the primary caregiver in the information and referral group.

III. The emotional/psychological health of the primary caregiver in the case management group will be significantly better than that of the primary caregiver in the information and referral group as measured by negative emotional reactions (anger, frustration, helplessness, and guilt).

IV. The social contacts of the primary caregiver in the case management group will be significantly greater than those of the primary caregiver in the information and referral group as measured by interactions with friends, relatives, children, and other social activities not associated with caregiving activities.

V. The perceived sense of burden of the primary caregiver in the case management group will be significantly lower than that of the caregiver in the information and referral group.

VI. The number of informal and formal supports of the primary caregiver in the case management group will be significantly greater than those of the primary caregiver in the information and referral group.

CHAPTER II

Methods

Overview

This study was part of a larger ongoing longitudinal research project conducted at Michigan State University in collaboration with the Michigan Office of Services to the Aging (OSA) designed to evaluate case management with the frail elderly. The project consists of five sites throughout Michigan. Clients[1] are referred to the case management team from traditional sources. Such sources include: hospitals, community organizations, nursing homes, family members, friends, physicians, or themselves. Although research intake ended in July 1986, the case management program is still currently operating in the five demonstration sites.

Once referred, the client was evaluated by a pre-screening tool to determine whether he/she would be eligible for the program. If eligible, the client constituted part of the subject pool. Verbal and written consent was than obtained prior to the initial baseline interview. The

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[1] The term client refers to the elderly individual of the larger project in collaboration with OSA. The future use of the term participant makes reference to the individuals who participated in the caregiver study.

number of clients in the treatment and control groups were 328 and 324 respectively for a total of 652 clients.

Following the completion of the baseline interview, random assignment was exercised to assign the client to either the treatment or control group. The treatment group received case management which consisted of: staff members assessing client needs, creating a care plan and helping the client arrange services. The control group received information and referral which included providing the client with written information and/or information over telephone about how to obtain needed services. The client was responsible for contacting and arranging the services that he or she needed. These are services typically provided in the client's community.

A second and third follow-up interview was conducted at six and twelve months after the initial interview. Data collection procedures included self report and archival records. The five dependent variables were:

1. facility and service utilization
2. costs (health and other support services)
3. client life satisfaction/quality of life
4. client health (includes mortality)
5. informal support

To ensure adequate data collection, inter-rater reliability checks and retraining of interviewers was conducted periodically throughout the three data collection periods by the research evaluation team and the project managers.

Present Study

Subjects

Subjects for the study on caregiving were primary caregivers of the frail elderly clients of the larger project. Sampling occurred from September 1986 through March 1987. A total of 101 people were contacted and of these, 15 refused, 13 couldnot be contacted, and 6 were in nursing homes. Thus, a total of 76 people completed the interview. The sample consisted of individuals considered to be the primary person providing instrumental and emotional support to the frail elderly client. The primary caregiver was nominated by the elderly client during the twelve month follow-up interview.

All of the participants resided in the Grand Rapids, Flint, and Southfield Michigan areas. Their mean age was 57.01 with a range of 23 to 93 years (See Table 1). Consistent with the literature on caregiving, women predominated as caregivers. Seventy-five percent of the sample was women. Whites comprised 84.2% of the sample, slightly over 10% of the sample was Black, and the remaining 5% represented other races.

The majority of the participants were married (71.1%) and stated that they had children (86.8%) with the most frequently reported number of children being three (26.3%). The income levels reported by the participants were well distributed throughout the income scale (See Table 1). Twenty-two point five percent of the participants reported incomes between $5,000 to $9,999 and another 22.5% reported incomes falling in the $30,000 or above category. In addition, 21.1% fell within the $15,000 to $24,999 range.

Spouses (28.9%) and children (31.6%) dominated as caregivers in this sample. Other relatives made up the next largest percentage (18.4%). Somewhat surprising is the low percentage of siblings who acted as caregivers, only 1.3% of the sample.

A little over one-third of the participants were employed (35.5%). This finding is somewhat low when compared to other studies which report employment figures over 60%. Of those that reported the number of hours worked, the most frequently reported number of hours was 40. When asked how many months that the participant had been working, 24 months was reported most often. However, there was a wide variation in the number of hours caregivers spent working as can be depicted by the range of work hours (See Table 1). With respect to living status, 53.9% of the participants stated that they lived with the individual they were caring for (See Table 1).

The participants were also divided into a treatment group (case management) and a control group (information and referral). Forty-one participants were in the case management group. Thirty-five were in the information and referral group. Case management provides for the coordination of health care services into the informal support system, by the case manager. Information and referral refers to those services which are typically available in the client's community. Thus, this study

Table 1

Demographics

Demographic		Adjusted Percent
Age:	Mean = 57.01	
	Range = 23 to 93	
	(n=73)	
Sex:	Female	75.0
	Male	25.0
	(n=76)	
Race:	White	84.2
	Black	10.5
	Other	5.3
	(n=76)	
Marital Status:	Married	71.1
	Widowed	10.5
	Divorced	13.2
	Never married	5.3
	(n=76)	
Children:	Yes	86.8
	No	13.2
	(n=76)	
Number of Children:	One	13.2
	Two	18.4
	Three	26.3
	Four	10.5
	Five or more	18.4
	Missing	13.2
	(n=76)	
Income:	0 to 4,999	12.7
	5,000 to 9,999	22.5
	10,000 to 14,999	9.9
	15,000 to 19,999	14.1
	20,000 to 24,999	7.0
	25,000 to 29,999	11.3
	30,000 or above	22.5
	(n=71)	

Table 1 con'd

Demograhic		Adjusted Percent
Relationship:	Spouse	28.9
	Child	31.6
	Sibling	1.3
	Other relative	18.4
	Neighbor or friend	14.5
	Paid helper	5.3
	(n=76)	
Work:	Yes	35.5
	No	64.5
	(n=76)	
Number of Work Hours:	Four to 20	9.3
	25 to 35	4.0
	40	16.0
	42 to 60	5.2
	Missing	65.5
	(n=26)	
Number of Working months:	one to 12	8.1
	24 to 36	8.1
	66 to 660	16.9
	Missing	66.2
	(n=74)	
Living Status:	Yes	53.9
	No	46.1
	(n=76)	
Program Status:	Case Management	53.9
	Information and Referral	46.1
	(n=76)	

compared the effects of a experimental intervention to treatment as usual.

Procedure

During the twelve month follow-up interview associated with the larger project, each elderly client was asked to nominate the one person who he/she considered to provide the most help and support throughout the day. (See Appendix A for a copy of the question format). Once the primary caregiver was identified, the client was presented a consent form which was read and clarified by the interviewer. The elderly client was then asked for permission to contact the nominated primary caregiver. If the client agreed, the client signed the consent form and the primary caregiver's address and phone number were obtained. (See Appendix B for a copy of the consent form).

Once verbal and written permission were obtained from the elderly client, the primary caregiver was then contacted by letter, which informed him/her of the nature of the study, how his/her name was obtained, and what his/her involvement would entail if he/she agreed to participate, i.e., would be called by the research staff in approximately one week. (See Appendix C for the letter). In addition, two copies of a consent form were sent; one copy was for the caregiver and the second copy was for the project's records. A self-addressed stamped envelope was enclosed for the purpose of the caregiver returning the latter copy to the project staff. (See Appendix D for the consent form).

Approximately one week after the letter was sent to the caregiver, a telephone call was placed to the caregiver to explain the study, and to see if the caregiver was interested in participating. It was explained that written permission to contact him/her was obtained from the elderly client of the larger project. In addition to describing the study to the caregiver, the time commitment and the nature of the questions were specified so that the caregiver had a complete understanding of what participation in the study would entail. The caregiver was free to ask questions about the study. The caregiver was also assured of anonymity, confidentiality, and the right to stop at any time while the interview was in process.

During this telephone conversation the caregiver was asked if it was a convenient time to talk and if so, the telephone interview was conducted. The interview took approximately 45 minutes. If it was not a convenient time for the caregiver, an interview day and time was set up and the interview was conducted at that future time. In those instances when the caregiver refused to participate, the caregiver's right to refuse was respected.

The interview began with a section entitled "opening the interview". This section is a brief introduction paraphrased by the interviewer which explains the interviewing process to the caregiver. (See Appendix E).

Interviewers maintained a call record on each of the participants, which kept track of the date and time of each contact, whether or not the interview was completed, if the participant refused to participate, and a future appointment date if necessary. The call record can be found on page 89 of the interview.

The participant identification sheet can be found on page 90 of the interview. All pertinent information necessary to contact the caregiver was compiled in this section for future use. This sheet was a record of the participant's identification number, site location, the interviewer, interview date, the participant's name, address, phone number, the elderly client's status in the program (case management or information and referral), the beginning and ending time of the interview, and whether or not the participant was currently living with the elderly client. In addition, how the twelve month follow-up interview from the larger project was completed (with a proxy or the combination of the elderly client and a significant other) was recorded along with the elderly client's name and address only if the information was necessary.

When the interview was completed, the interviewer followed the standard closing procedure specified in the section entitled "closing the interview" found on page 100 in the interview. This was an important final step in the interviewing process for two reasons: (1) The caregiver may have been upset by the nature of some of the questions; therefore it was important for the interviewer to try to assess and if necessary, address such concerns. (2) It was equally important to reassure the caregiver of anonymity and confidentiality following the interview in case he/she may have been feeling some regrets for sharing some of the personal information that he/she disclosed during the course of the interview. The reassurance may have enabled him/her to feel more comfortable about discussing issues relating to the care-receiver.

Part of the closing procedure involved offering the caregiver a summary of the final report. If the caregiver expressed an interest in obtaining the report, his/her name was taken down and added to the master list of names for future mailing. At this time, the interviewer determined whether or not the caregiver was living with the elderly care-receiver, if not already ascertained. Finally, the interviewer thanked the caregiver for his/her time, allowed the caregiver to ask any additional questions, and closed the interview. The completion time of the interview was then recorded.

Instrument

The measuring instrument was designed to assess the caregiver's life to determine which areas may have been negatively affected by caregiving responsibilities.

The structured interview consisted of 47 questions with five fixed response alternatives. The questions were divided into seven categories:

1. the quality of the relationship between the primary caregiver and the care-receiver
2. the physical health of the caregiver

3. the emotional and psychological health of the caregiver
4. the number of social involvements of the caregiver
5. the perceived sense of burden of the caregiver
6. the number of additional informal and formal support people assisting the caregiver
7. demographic information

The interview is located in Appendix E and provides quantitative indices of the effects of case management on reducing stress associated with caregiving.

The items which comprise the interview were rationally derived after an extensive review of the literature on caregiving to the elderly, and reviewing previously designed instruments used with caregivers (e.g., Horowitz (1984), Kane and Kane (1981), Robinson (1983), and Zarit et al. (1980)). The work done by Zung (1967, 1972) and Yesavage, Adey, and Werner (1981) on depression was also reviewed to generate items relating to depression and psychological health.

Section A of the interview was comprised of questions which regard the relationship between the caregiver and the care-receiver. Section A begins on page 91 of Appendix E. These six questions assessed how the caregiver and the care-receiver spent their time together. For instance, how often did they spend time together in conversation, watching television, and/or laughing. Several items assessed the underlying feelings the caregiver may or may not have towards the care-receiver. Thus, the questions focused on both positive and negative aspects of the relationship. All six questions utilized a response category of five alternatives: 1-never, 2-rarely, 3-sometimes, 4-quite frequently, 5-always.

Section B consisted of six questions which focused on the caregiver's physical health. An indirect way of assessing the effects of stressful situations is by measuring changes which may have occurred in the health of an individual. Therefore these six questions were directed towards: 1) changes in the caregiver's sleeping habits, 2) appetite changes, 3) how quickly he/she tires, 4) whether or not he/she feels overwhelmed with responsibility, 5) general mood state upon waking in the morning, and 6) if he/she experiences feeling restless during the day. The six questions in this section use the same five point response scale as the previous section. Section B is found in Appendix E.

Questions which asked about the caregiver's emotional and psychological health are found in Section C of Appendix E. These six questions utilize the same response alternatives as the previous two sections of the interview. The overall theme of this section was to discover what type of emotional feelings the caregiver may or may not be experiencing during the time spent assisting the care-receiver. Thus, the questions revolve around emotional feelings which have been frequently stated in the literature as common feelings shared by caregivers. Feelings such as anger, guilt, fear about the future which exists for the care-receiver, feeling happy around the care-receiver, and whether or not the caregiver considers his/her life to be interesting were asked. Again, these questions attempted to reveal the positive and negative feelings which the caregiver may or may not be experiencing.

The next section concerned the social involvements of the caregiver, and how often he/she engaged in activities which were purely for personal pleasure (e.g., a hobby). The first four questions determined how many times a week the caregiver spent socializing with friends, participated in activities such as hobbies, being with his/her children or other family members, and how many hours a day were spent caring for the care-receiver. The first three questions had five response alternatives which were: 1-daily, 2-3 to 4 times a week, 3-at least twice a week, 4-at least once a week, 5-less than once a week. The fourth question concerning the number of hours spent caring for the care-receiver used the following response alternatives: 1-less than 5 hours, 2-6 to 10 hours, 3-11 to 15 hours, 4-16 to 20 hours, 5-more than 20 hours. The fifth question asked how satisfied the caregiver felt about the amount of contact he/she had with friends and relatives for social purposes in the past month. A five point Likert scale was used with "1" representing very dissatisfied and "5" representing very dissatisfied. The last question asked how often the caregiver attended meetings sponsored by various organizations such as: social groups, clubs, churches, or civic groups. The following five response alternatives were used: 1-never, 2-rarely, 3-sometimes, 4-occasionally, 5-regularly.

The caregiver's perceived sense of stress was the theme for the next six questions. These questions attempted to assess the feeling of stress associated with the caregiver's role and responsibilities. Six stressors were the basis for the next set of questions: physical strain, family adjustments or changes to the caregiver's lifestyle, feeling stressed, financial strain, feeling the care-receiver is demanding, and the convenience of caregiving. All the questions used the same 5 point scale: 1-never, 2-rarely, 3-sometimes, 4-quite frequently, 5-always.

Section F examined the amount of additional support which was available to the caregiver (See Appendix E). Two questions asked how many people from the informal network were helping the caregiver with caregiving responsibilities and how much time did he/she spend helping, on the average, per visit. Another set of questions asked about the formal service providers that were coming into the home to assist the caregiver.

The last section of the interview collected demographic information on the caregivers. This section included items on age, sex, race, marital status, the number of children the caregiver has, socioeconomic status, the caregiver's relationship to the care-receiver, and work status.

Interviewers

All of the interviews in the Grand Rapids and Southfield sites were conducted by the project director. An interviewer from the larger project was recruited to conduct interviews in the Flint site. Because intake was based on the completion time of the twelve month interviews of the larger project, the rate of intake was moderate and therefore no other additional staff members were needed.

Because of the extensive experience the interviewer had with in-person interviews, telephone interviews and data collection procedures, the interviewer only needed minimal training regarding interviewing procedures.

Training was conducted at the Flint site, and consisted of one three hour session. The project, the interview process, and data collection procedures pertinent to this study were reviewed. Issues of anonymity of the participants and confidentiality were also discussed.

The consent forms from Flint were processed by the project director and copies of the consent forms and the interviews were sent to the interviewer in Flint. The completed interviews were returned to the project director through the mail for processing.

Weekly contact was made with the interviewer by phone to check on the completion time of interviews and to problem solve with the interviewer when needed. In person meetings were conducted when necessary. Because the interviewer volunteered to conduct interviews, the interviewer did not receive a set fee for completing interviews.

Scale construction

Because this was an exploratory procedure with no preset notion of how the variables should go together, scale construction set out to detect patterns of variables which make conceptual sense and to possibly reduce the data. The analysis of the data obtained was done in several steps utilizing the SPSS9 Statisical Program. First, a principal factoring method was done on 32 variables (excluding the demographics and variables 32 and 34 which asked how many minutes the informal and formal care provider spent assisting the caregiver respectively). Principal factoring without iteration was performed followed by a varimax rotation. This data-reduction procedure allows one to see whether there are underlying pattern of relationships among the data which can be rearranged into a smaller set of components accounting for the observed interrelations in the data. Using Cattell's Scree Criteria, rationality, and independence, a four factor solution was used. The variables making up factor one asked about the social involvements of the caregivers life and was therefore called social (variables 19, 20, 23, and 24). Variables 11, 14, 16, and 18 were later dropped from the scale called social because they did not make conceptual sense within the scale. Variables 11, 14, and 16 were used later in two different scales called psychological health and physical health (See Table 4). Variable 18 (how often have you felt afraid about what the future holds for _________?) was left as a single item.

Factor two was comprised of variables which focused on stress and its effect on the caregiver. The name relationship was given to factor three which was made up of variables which regard the relationship between the caregiver and the care-receiver. Factor four was called caregiving. These variables looked at how the caregiver's time was spent with the care-receiver. The four factor solution is reported in Tables 2 and 3.

Second, once the number of factors was determined and the variables which made up those factors examined by setting a cut-off factor loading of .50 for inclusion in a scale, the items were combined to create a scale based on the factor solution. If an item did not make conceptual sense with in the context of the other items, it was taken out of the scale and retained for later use. Thus, the next step was to test each scale to determine how homogeneous they were by computing Cronbach's alpha.

Social Scale. The scale social was made up of variables 19, 20, 23, and 24. The content of these variables were as follows: variable 19) how often did you spend time socializing with friends; variable 20) how often did you have time to do things you like to do; variable 23) how satisfied have you been with the amount of contact with friends and relatives for social purposes; and variable 24) how often have you attended meetings of social groups, clubs, churches, or civic groups. These variables focused on the social involvements of the caregiver and time spent engaging in pleasurable activities. Cronbach's alpha = .74 (See Table 4).

Table 2

Factor Analysis Summary

Factor	Eigenvalue	Percent Variance
1	7.57	23.7
2	2.67	8.3
3	2.16	6.8
4	1.91	6.0
5	1.66	5.2
6	1.42	4.4
7	1.40	4.4
8	1.25	3.9
9	1.14	3.6
10	1.04	3.2
11	.99	3.1
12	.89	2.8
13	.82	2.6
14	.74	2.3
15	.67	2.1
16	.66	2.1
17	.57	1.8
18	.51	1.6
19	.47	1.5
20	.44	1.4
21	.42	1.3
22	.40	1.3
23	.36	1.1
24	.33	1.0
25	.32	1.0
26	.23	.7
27	.22	.7
28	.19	.6
29	.18	.6
30	.15	.5
31	.12	.4

Table 3

Factor Analysis Summary

Variable	Factor 1	Factor 2	Factor 3	Factor 4	h^2
Name	Social	Stress	Relationship	Caregiving	
1	-.21	.34	-.09	.64	.58
2	-.11	-.09	.77	-.17	.64
3	-.28	-.10	.13	.60	.47
5	.27	.00	.76	-.09	.66
6	-.31	.29	-.67	.17	.66
10	.00	-.57	.15	-.05	.35
11	.59	-.29	.15	.30	.55
12	-.17	.58	-.12	-.19	.42
13	.24	.01	.55	.16	.39
14	.63	.02	.41	.13	.58
15	-.10	.60	.04	-.01	.37
16	.58	-.08	.47	.22	.61
19	-.72	.19	-.04	.14	.57
20	-.68	.15	.01	.11	.49
21	-.27	-.07	-.36	.53	.49
22	-.29	.23	-.08	.78	.75
23	.57	-.35	.08	-.15	.49
24	.54	-.05	.01	-.28	.37
26	.11	-.64	.34	-.37	.68
27	-.29	.72	-.21	.09	.66
28	.52	.01	.17	-.34	.42

Stress Scale. Five variables (10, 12, 15, 26, and and 27) made up the next scale which was called stress and the content of these variables were as follows: 10) how often were there times when you didnot feel overwhelmed by responsibility; 12) how often do you find yourself restless; 15) how often do you find yourself angry with other relatives and friends; 26) how often have you been able to avoid having to make family adjustments due to your caregiving role; and 27) how often have you felt stressed while caring for the care-receiver. Cronbach's alpha was .73 (See Table 4).

Relationship Scale. The relationship between the caregiver and care-receiver was the content of the next scale named relationship. The scale was comprised of questions (2, 5, 6, 13) which asked how often the caregiver: 2) spent time enjoying conversation with the care-receiver; 5) spent time laughing with the care-receiver; 6) felt that he/she couldnot cope with the care-receiver; and 13) felt happy around the care-receiver. Cronbach's alpha was .76 (See Table 4).

Caregiving Scale. An alpha of .73 was reported for the last scale, caregiving, which was made up of variables 1, 3, 21, and 22. These questions focused on how the caregiver's time was spent with the care-receiver and the amount of time spent as a caregiver. The content of these four questions were as follows: variable 1, how often have you felt that the care-receiver was dependent upon you; variable 3, how often have you and the care-receiver spent time together watching television; variable 21, how often have you spent time with children and/or other family members; and variable 22, in the past day how many hours per day were spent caring for the care-receiver. (See Table 4).

The remaining variables were then examined to determine if any other scales existed. A reliability procedure was run on these variables and a factor analysis procedure, as described previously, which resulted in two additional scales called psychological health and physical health.

Psychological Health Scale. The variables in the scale psychological health were as follows: 14, 16, 29, 30. This scale tapped the caregiver's outlook on life in relation to his/her attitude towards caregiving. The content of these variables were as follows: 14) how often have you felt that your life is full of things that keep you interested, 16) how often have you felt satisfied with life, 29) how often have you felt that the care-receiver asks for more help than he/she really needs, and 30) how often would you say that you have felt that caring for the care-receiver is an inconvenience. Cronbach's alpha was .60. (See Table 4).

Physical Health Scale. The variables in the physical health scale are: 7, 8, 9, 11, 25. The nature of these questions revolve around physical health: question 7 asks if the caregiver has trouble getting to sleep, question 8 asks if how often the caregiver would say his/her appetite was good, and question 9 concerns how often the caregiver feels tired after little or no strenous activity. Questions 11 and 25 ask how often the caregiver feels fresh and rested in the morning and how often he/she has experienced physical strain while caring for the care-receiver respectively. The reported alpha for this scale was .68. (See Table 4).

The fourth step in the data analysis process, was an attempt to address the issue of independence of the measure. Each of the six scales were correlated against one another using the Pearson project-moment correlation coefficient (r). The scale social correlated with the scale stress, -.40; relationship, .28; caregiving, -.44; physical health, -.47; and psychological health; -.48. The scale stress correlated with the scale relationship, -.38; caregiving, .29; physical health, .58; and psychological health, .46. The relationship scale correlated with the caregiving scale, -.26; with the physical health scale, -.36; and the psychological health scale, -.51. Caregiving correlated with the scales physical and psychological health .31 and .18, respectively. Finally, physical health and psychological health correlated .38. The results of this procedure were somewhat disappointing. It was hoped that the scales would be as independent from one another as possible with each scale measuring its own unique construct. Thus, a cut-off level for the correlation between the scales was set at .30 and below. As Table 5 indicates, some of the scales correlated above the cut-off point which can

Table 4

Scale Reliability Summary

Variable	Corrected r	Alpha
Social Scale		.74
19	.54573	
20	.57640	
23	.49260	
24	.53449	
Stress Scale		.73
10	.43869	
12	.47583	
15	.46235	
26	.52677	
27	.59280	
Relationship Scale		.76
2	.53977	
5	.66178	
6	.58062	
13	.44676	
Caregiving Scale		.73
1	.51804	
3	.52320	
21	.47286	
22	.66980	
Psychological Health Scale		.60
14	.30747	
16	.45437	
29	.29433	
30	.48390	
Physical Health Scale		.68
7	.40480	
8	.45260	
9	.44950	
11	.40726	
25	.47381	

Table 5

Pearson Product-Moment Correlations

Between Scales

	Social	Stress	Relship	Cargiv	Physheal	Psycheal
Social		-.40	.28	-.44	-.47	-.48
Stress			-.38	.29	.58	.46
Relship				-.26	-.36	-.51
Cargiv					.38	.18
Physheal						.38

be taken as an indication that those scales shared a relationship between one another and may be measuring the same construct.

CHAPTER III

Results

This section presents the results of the statistical analysis of the data to test the seven hypotheses. The purpose of the study was to determine if case management was effective in reducing the stress associated with caregiving to the frail elderly through the incorporation of formal supports into the informal support system. The study was a post test design and data was collected using a telephone questionnaire.

The first statistical procedure tested the assumption of homogeneity of variance which was then followed by a multivariate analysis of variance (MANOVA) procedure which entered all of the six scales as dependent variables to test the hypotheses about the relationship between the set of interrelated dependent variables and one grouping variable, program status.

Each of the seven hypotheses were tested using a one-way analysis of variance (ANOVA) procedure which uses the F-ratio to determine whether or not two variances differ significantly from one another. In addition, regression procedures were employed to assess the relationship between the dependent variable stress; and several independent variables to determine indicators of stress in a caregiving relationship.

Homogeneity of Variance

Because the F test is not robust to violations of the homogeneity of variance assumption when the sample sizes are not the same, the assumption of equal variances was tested. Each of the six following scales were tested univariately: social, stress, relationship, caregiving, physical health, and psycholgical health. The results of the Bartlett-box and Cochran's C tests indicate the assumption was not violated. The results of these two tests are presented in Table 6.

Manova

A one by six multivariate analysis of variance (MANOVA) utilizing a full factorial design was performed on the six dependent variables: social, stress, relationship, caregiving, physical health, and psychological health. The independent variable was the experimental condition. This analysis was done to test the hypothesis that there is an univariate difference on the six scales in two experimental groups of individuals (case management and information and referral) and to possibly reveal differences in the data not shown in separate ANOVA procedures.

The MANOVA procedure was performed using SPSS9, and the effect was tested at the $p<.05$ level for a two-tailed test. Seventy-six cases were used. Wilk's Lambda was used to determine if there was a main effect, and if so, to find a measure of the strength of association between the independent effect and the combination of the dependent variables. There was no main effect detected (Lambda=

Table 6

Univariate Homogeneity of Variance Summary

Variable	DF	F	P
Social Scale			
Cochran's C	37/2	.55120	.535 (Approx.)
Bartlett-Box	1/16142	.38430	.535
Stress Scale			
Cochran's C	37/2	.52889	.727 (Approx.)
Bartlett-Box	1/16142	.12084	.728
Relationship Scale			
Cochran's C	37/2	.58883	.279 (Approx.)
Bartlett-Box	1/16142	1.17446	.279
Caregiving Scale			
Cochran's C	37/2	.53232	.696 (Approx.)
Bartlett-Box	1/16142	.15240	.696
Physical Health Scale			
Cochran's C	37/2	.50031	.997 (Approx.)
Bartlett-Box	1/16142	.00001	.997
Psychological Health Scale			
Cochran's C	37/2	.57001	.395 (Approx.)
Bartlett-Box	1/16142	.72346	.395

.96355, F=.43497, significance of F=.85306). (See Table 7). Although there was no main effect detected, each of the dependent variables was tested individually, since the nature of the study was exploratory.

Hypothesis One

The first hypothesis stated that the quality of the relationship between the primary caregiver in the case management group would be significantly better than the primary caregiver in the information and referral group. The scale relationship was entered as the dependent variable. Program status defined whether the client was in the case management group or in the information and referral group. The item program status was the independent variable. There was no significant difference between the two groups (F=.064, DF=1 p<.801). (See Table 8).

Hypothesis Two

The second hypothesis stated that the physical health status of the primary caregivers in the case management group would be significantly better that than caregivers in the information and referral group. The scale physical health was entered into the ANOVA procedure as the dependent variable and program status was the independent variable. The results of the ANOVA procedure were not significant (F=.495, DF=1 p<.484) therefore, the null hypothesis cannot be discarded. (See Table 8).

Hypothesis Three

The next ANOVA procedure tested the third hypothesis; the emotional/psychological health of the primary caregiver in the case management group would be significantly better than the primary caregiver in the information and referral group. The independent variable was program status. The results were not significant (F=.020, DF=1 p<.887), therefore, the null hypothesis that there would be a difference between conditions on emotional/psychological health cannot be rejected. (See Table 8).

Hypothesis Four

The following hypothesis addressed the social contacts of the primary caregivers; the social contacts of the primary caregivers in the case management group would be significantly greater that those of the primary caregivers in the information and referral group. No significant difference was found between the two groups when using the scale social as the dependent variable as compared to program status (F=1.528, DF=1 p<.220). (See Table 8).

Hypothesis Five

The next analysis was run to test the hypothesis; the perceived sense of burden of the primary caregiver in the case management group would be significantly lower than the primary caregiver in the information and referral group. The scale stress was entered as the dependent variable and program status was the independent variable. The mean score for the case management group on the stress scale was 14.93 and the mean for the information and referral group was 15.17. The results of the ANOVA were non significant, (F=.058, DF=1 p<.811), the null hypothesis that there would be a difference between the conditions cannot be rejected. (See Table 8).

Hypothesis Six

The following hypothesis focused on the number of informal and formal supports of the caregivers; the number of informal and formal supports of the primary caregiver in the case management group would be significantly greater than those of the primary caregiver in the control group. There was no significant effect between the two groups using variable 31, which asked the caregiver how many additional family members or friends were assisting with caregiving responsibilities, as the dependent variable for informal supports and program status as the independent variable (F=.040, DF=1 p<.841) and variable 33, which asked for the number of formal service providers who were coming into the home, as the dependent variable for formal supports and program status as the independent variable (F=2.958, DF=1 p<.090). (See Table 8).

In summary, none of the six hypotheses could be confirmed by the either the multivariate or univariate analysis of variance procedures. Thus, there was no significant treatment effect and none of the six null hypotheses could be rejected.

Regression Analysis

Four separate regression procedures were done to assess the relationships between the scale stress and various

Table 7

Multivariate Summary

Test Name	DF	Value	F	Sig. of F
Wilk's Lambda	6/69	.96355	.43497	.85306

Table 8

ANOVA Summary

Source of Variation	DF	MS	F	Sig. of F
Relationship Scale	1/75	.668	.064	.801
Physical Health Scale	1/75	8.878	.495	.484
Psychological Health Scale	1/75	.195	.020	.887
Social Scale	1/75	28.209	1.528	.220
Stress Scale	1/75	1.130	.058	.811
Variable 31 (additional informal supports)	1/75	.238	.040	.841
Variable 33 (additional formal supports)	1/75	2.121	2.958	.090

independent variables to determine whether or not they might be predictors of stress. All four procedures were stepwise regression with forward inclusion.

In the literature on caregiving, various demographic variables have been found to be significant predictors of stress, such as the sex of the caregiver and socioeconomic status, therefore the first procedure regression procedure were was done to confirm the hypothesis that the demographics, variables: living status, program status, the five scales and the remaining variables 4, 17, 18, 28, 31, and 33 could be indicators of stress. The scale stress was entered as the dependent variable and the demographics, living status, and program status were entered as the predictors. Listwise deletion was used to handle missing data therefore; only sixty-seven cases were included in this analysis. The variable living status was significant with a significance value =.005, R square =.11709, and simple R = .34219. (See Table 9). According to this result, if the caregiver lived with the care-receiver, there was an increase in stress reported by the caregiver. This makes rational sense since living with another individual involves more opportunities for contact between individuals. Increased contact can mean increased stress in the relationship if one of the individuals perceives the relationship as restricting and the responsibilities associated with the relationship overwhelming (Cantor, 1983; Crossman et al., 1981; Rakowski & Clark, 1985; Robinson & Thurnher, 1979).

In the equation, living status correlated with relationship (r =.50) which indicated that if you lived with the person you were caring for, you were more likely to be a relative e.g., spouse, child, other relative. This finding is consistent with the literature which has documented the role of the family in providing care for noninstitutionalized elderly (Brody, 1981; Cantor, 1983; Treas, 1977). In addition, those caregivers who had a frail elderly member living with them also reported lower incomes (r =-.47).

The next regression procedure was done with stress as the dependent variable and the five scales as predictors. Seventy-six cases were used in this procedure. Four of the scales were significant; social, physical health, relationship, and psychological health. The significance values were: .000, .007, .006, and .025, respectively. (See Table 10). The R square values were: social = .15609, Physical health =.23616, relationship =.31275, and psychological health =.35984. Simple R values were as follows: social =-.39508, physical health =.34582, relationship =-.37535, and psychological health =.14598.

These results indicate that as caregivers reported more physical strain related to caregiving, stress scores increased. Similarly, as psychological health scores increased, indicating negative effects on psychological health, stress scores increased. Parallel results have been found in the literature on the physical and emotional costs of caregiving (Clark & Rakowski, 1983). Thus, stress has a detrimental effect on the physical and psychological health of the caregiver.

Stress is also heightened by a decrease in social involvements and a decrease in satisfaction with the caregiving relationship. It could be explained that the caregiver becomes more and more dissatisfied with the caregiving relationship because it means lack of social involvements. The two scales were correlated (r =.28) which indicated as social isolation increased, dissatisfaction increased. Similar results have been found by various researchers examining the relationship between social isolation and psychological well-being (Chatters et al., 1985; Fengler & Goodrich, 1979; Marcus & Jaeger, 1984).

The variables which were retained after the factor analysis procedures and which did not fit into any of the scales were combined and utilized in a regression procedure. Since stepwise regression can be viewed as a model-building procedure, this procedure was done to find a subset of independent variables that were most useful in predicting the dependent variable, and to eliminate those independent variables that did not provide additional prediction. Seventy-six cases were used in this procedure. The variables used as predictors were: V4, how often have you felt you should be doing more for the care-receiver; V17, how often have you been bothered by feelings of guilt; V18, how often have you felt afraid about what the future holds for the care-receiver; V28, how often have you felt that you have enough money to care for the care-receiver in

Table 9

Regression Summary

Variable	Significance	R Square	Simple R
Living Status	.005	.11709	.34219

Table 10

Regression Summary

Variable	Significance	R Square	Simple R
Social	.000	.15609	-.39508
Physical Health	.007	.23616	.34582
Relationship	.006	.31275	-.37535
Psychological Health	.025	.35984	.14598

addition to your other expenses; V31, how many additional family members or friends have helped the care-receiver to take care of him/herself or have done things around the house for the care-receiver; V33, how many formal service providers (i.e., nurses, therapists, chore workers) have come to the care-receiver's home, on the average. Once again, the dependent variable was the scale stress. Of these variables, three were significant, which are: V18, V4, and V31. Corresponding significance values are: .004, .019, .074. R Square values were: .10881, .17436, and .21030 respectively. Simple R values were as follows: -.32987, .28325, and -.21586 respectively. (See Table 11).

These results indicated that there were additional variables which were important indicators of stress based on the responses given by the caregivers in this sample. Question 18 refers to the fear caregivers often express about the future of the care-receiver. This fear is related to such issues as possibly institutionalizing the care-receiver, especially if something would happen to the caregiver. Fear is often mentioned in regards to the care-receiver's safety and future deterioration of the care-receiver's physical and mental health (Cantor, 1983). This variable did not correlate significantly with any of the other variables in this equation.

The second significant variable was number four which asks "how often have you felt you should be doing more for care-receiver?" This variable correlated with variable 17 (how often have you been bothered by feelings of guilt) in this equation (r =.28) which is not unusual since most caregivers feel their "job" is never done and feel they they should be doing more, whether it is motivated by love or a sense of obligation (Brody, 1981; Shanas & Maddox, 1976).

The last variable in this equation was number 31 which asked about the number of additional informal supports (family members and friends) who may be assisting with caregiving responsibilities. This variable correlated with stress r =-.22, which indicated that as informal assistance increased, stress decreased. This variable did not correlate with any of the other variables significantly.

The final regression procedure combined the variables found to be significant indicators in the previous procedures and entering them as predictors with the scale stress as the dependent variable. Seventy-six cases were utilized in this procedure. The variables found to be significant were the scale social, variable 4; how often have you felt you should be doing more for the care-receiver, the scales physical health, psychological health, and relationship, and variable 18; how often have you felt afraid about what the future holds for the care-receiver. The corresponding significance levels were .000, .005, .009, .013, .013, .036. (See Table 12). R Square values were: .15609, .24467, .31402, .37094, .42400, and .45975, respectively. The Simple R values associated with each of the variables were: -.39508, .28325, .34582, .14598, -.37535, and -.32987. These results indicated that

Table 11

Regression Summary

Variable	Significance	R Square	Simple R
Variable 18	.004	.10881	-.32987
Variable 4	.019	.17436	.28325
Variable 31	.074	.21030	-.21586

Table 12

Regression Summary

Variable	Significance	R Square	Simple R
Social Scale	.000	.15609	-.39508
Variable 4	.005	.24467	.28325
Physical Health Scale	.009	.31402	.34582
Psychological Health Scale	.013	.37094	.14598
Relationship Scale	.013	.42400	-.37535
Variable 18	.036	.45975	-.32987
Adjusted R^2		.10212	

living with the care-receiver results in decrease social involvement, more physical health problems, decreased satisfaction in the caregiving relationship, and increased fear regarding the care-receiver's future. Once again, increased social involvements correlated relationship with the care-receiver (r =.28) and the social scale correlated with variable 18 (r =.27) indicating decreased fear regarding the care-receiver's future associated with increased social involvement. Finally, a correlation between variable 4 and the relationship scale (r =-.22) indicated as the caregiver felt he/she should be doing more for the care-receiver, satisfaction in the relationship decreases.

Because R square tends to overestimate in the positive direction, the value obtained from the SPSS9 procedure, which utilizes the Wherry Formula, was entered into the Cattin Formula which is more advantegeous to use when sample sizes are small (Tabachnick & Fidell, 1983). Adjusted R square =.10212 and is reported in Table 12.

CHAPTER IV

Discussion

The purpose of the present study was to examine the effect case management had on primary caregivers in hopes of identifying a means to reduce the stress associated with caregiving to the elderly. In this study, case management was compared to a service normally available in the community called information and referral through the responses given by caregivers utilizing a telephone interview.

The consequences of caregiving have been shown to be deterimental to the psychological and physical health of the caregiver (Brody, 1985). Therefore, of major interest was the relationship between stress and several aspects of the caregiver's life. These included: social involvements, physical health, psychological health, the relationship with the care-receiver, and caregiving itself. The experimental analyses, MANOVA and ANOVA, used to examined these relationships found no significant effects by the treatment case management. Several possible explanations arise which might account for these results. Let us now take a look at what has been presented regarding case management, what we have learned from the present study, and examine some of the explanations associated with the failure of the present study to detect any treatment effects.

An Evaluation of the Treatment

First, case management as a treatment provides for the coordination of available services to assist the frail elderly to remain as independent as possible in their own homes, thus reducing the nursing home usage. This study found no significant difference between the control and experimental groups regarding the number of formal service providers. Since a core part of case management is the coordination of formal services into the informal network, this may explain why case management, as a treatment, did not significantly impact the caregivers in this study. In a preliminary study based on the larger project associated with this study, it was found that a problem did exist regarding implementation of services throughout the five sites (Bornstein, 1986). This study questioned the effectiveness of case management which may have been insufficient to produce the expected outcomes because case management teams were found to be restricted in their ability to broker services into the client's home. This was due to the lack of medicaid and medicare waivers which were not available to enable the treatment teams to purchase services for their clients. In addition, the treatment group did not differ significantly from the control group in formal service levels.

Although the target group of case management was the frail elderly, it was hypothesized that increased assistance to the frail elderly client would have an indirect effect on the caregiver by easing some of the responsibilities of caregiving. This would in turn, reduce the stress the caregiver was experiencing. This hypothesis was not found to be true. It could be that even though a caregiver may not be providing instrumental support as often because of increased formal assistance, he/she is still psychologically involved. Psychologically, it is difficult to separate oneself completely from someone you care about even if you aren't there physically. Horowitz and Dobrof (1982) found that psychologically related problems were most often cited by caregivers when asked questions which determined the consequences of caregiving based on the relationship of the caregiver (spouse, children, relative) to the care-receiver. In addition, family supports continued to remain actively involved despite the addition of formal services into their network (Brody, 1986). Thus, there is a need for future research which focuses on programs that are aimed solely for the caregiver such as respite services and coping strategy education (Miller, Gulle, & McCue, 1986).

Methodological Considerations

The Measuring Instrument

The second possible explanation for the results obtained is that the measuring instrument may not have been sensitive enough to detect differences which may have occurred as a result of the intervention. Since the measuring instrument was newly designed, there was no previous reliability and validity data on it. Moderate reliability was reported for each of the six scales. Future efforts should include examining the psychometric properties of this instrument further, the use of instruments with established reliability and validity data, in the framework of longitudinal research which utilizes a true experimental design.

The Prescreening Tool

The question arises about the sample whether it was appropriate for the study. The caregivers who participated were based on a sample of frail elderly individuals who were involved in the study on case management. The elderly participants were selected based the use of a prescreening instrument which has unknown reliability and validity data. Just as in other studies on case management which has questioned whether they were actually targeting the high risk group in fear of institutionalization (Capitman, 1986), this study has also questioned the use of a instrument which has not been shown to actually target the group it is intended to due to lack of consistency in its use and the degree of "clinical judgement" associated with it. Thus, its effectiveness as a measuring instrument is questionable.

The Role of the Caregivers

The final explanation regards the sense of commitment many of the caregivers felt for the individual they were caring for. If a spouse could do what a paid helper could do, then he/she would do it. So the problem also exists concerning how to get certain types of caregivers to utilize services which they are eligible for. In this study, many family members could not afford to pay for services or they preferred, as the elderly care-receiver did, a family member to assist them instead of a formal helper. Thus, it is was not surprising that spouses and children were willing to do whatever was necessary out of a sense of familial responsibility regardless of possible adverse consequences which may occur over time. This result has been found consistently in the literature on caregiving to the elderly by family members (Deimling & Bass, 1986; Rabowski & Clark, 1985). Spouses had a deep sense of commitment to a husband or wife and were willing to accept what life brought to them whether it was good or bad. On the other hand, children stated that their parents had taken care of them and now it was their turn to reciprocate. Children felt indebted to their parents with a feeling of affection and love towards them. They cared for their parents because "it was the thing to do and you did not ask why, you just did it". Most children stated that they did not want to institutionalize their parents and would only consider it if they were physically unable to continue providing assistance. Thus, these individuals were providing the care necessary and managing sufficiently. They found no need for assistance from outside even when it was available to them because they were able to respond to the needs of the elderly sooner and were more flexible than the formal system. Thus they were willing to make the adjustments in their lifestyles that were necessary in order to care for their frail relative.

Final Considerations

As we move into a era in which the trend is to keep the frail elderly at home as long as possible, what this actually means is that there is an informal person(s) who is actively involved with keeping that person at home. The effects of caregiving need to be taken into consideration when implementing programs designed to reduce the costs associated with providing health care to the elderly. The current trend in this country is to look for alternatives to the rising costs of providing institutionalized care (Capitman, 1986). Are we attempting to substitute the institution for the family in an attempt to reduce expenditures for health care or because it benefits the frail elderly population? What is the motivating force behind the push for case management? Whatever that force may be, we must not ignore those who have been called the "hidden victims", the caregivers who continue to make sacrifices and do the best they can to cope with the loneliness, isolation, frustration, anger and depression that accompanies caregiving to the frail elderly. As attempts are made to modify the health care system, what seems to be overlooked is that if you change or modify one part of a system, you affect all other parts of that system (Miller, 1979). On one hand, we may be helping the elderly, but we could also be creating another problem. Because there is a lack of family-oriented services to support caregivers, they are at risk of experiencing a negative impact on their mental and physical health (Brody, 1986). If we do not recognize it, we will soon be creating another agency to deal with the health problems individuals are experiencing associated with caregiving and spending millions of dollars to fund it, thus defeating the purpose of what care management was meant to do; save money.

Case management has been shown to have some positive effects on caregivers in previous studies (Quinn & Hodgson, 1984), thus it should not be cast off as ineffective. But, it does need to be evaluated in a more stringent manner in regards to both its influence on the lives of the frail elderly and its possible effects on caregivers. From the policy maker's perspective, reducing or controlling hospital and/or nursing home costs is the primary objective. This objective is going to become even more important in the future as our elderly population continues to grow. But we also need to incorporate some additional characteristics into programs designed for the elderly, such as case management, which take into account the changes which effect the caregivers as a result of implementing these programs into the health care system. At the present time, social policy in the U.S. typically ignores the needs of the families providing home care (Brody, 1986).

Before considering widespread implementation of case management, policy makers facing the decision regarding implementation, such as the State of Michigan, need to consider not only the financial aspects of case management programs but also the social implications of incorporating these programs into the health care system. A balance is needed between what the formal support system can do and what the informal support system can provide. Each of these systems are a vital part of the social support network.

Ideally, the two system should complement one another, not increase the responsibilities on one of the systems, such as the informal system, until it can longer accept the heavy burden of care and the system itself begins to dissipate.

We must begin to take a hard look at the present and future results of the evaluations of case management programs for the elderly and the impact these programs may have on caregivers for several reasons. First, it is our tax money which funds these programs. If they are not effective, then we should look at other alternatives otherwise, it is just another example of wasteful government spending. Second, someday you may be in the position of being a caregiver to a relative or a friend. If this occurs in your life time, wouldn't you want support programs which actually worked or would you be willing to accept the help from a program which did not meet your needs? Finally, as you read this now, you are aging. Unfortunately, we are never in a position to know what our later years will be like; for instance, you do not know if you will be financially secure or if you will having surviving family members to help you. Therefore, if you reached old age, wouldn't it be more comforting to know that you can rely on an effective program to assist you regardless of the type of assistance you needed and whether or not you already had informal supports readily available to you?

As in other areas of life, we must be informed consumers relating to services being offered in the area of health care to the elderly. And as aging individuals, we all have an vested interest in seeing that the present and future elderly receive the best services possible.

APPENDICES

APPENDIX A

E11. PRIMARY CAREGIVER

TODAY, WE'VE TALKED ABOUT SOME PEOPLE WHO HELP YOU. OF THE FRIENDS, RELATIVES, AND NEIGHBORS THAT YOU HAVE MENTIONED TO ME, WHO DO YOU FEEL USUALLY PROVIDES YOU WITH THE MOST HELP AND SUPPORT?

SITE (01-02) ___ ___
CLIENT (03-05) ___ ___ ___
BLANK (06) BLANK

NAME: ______________________ RELATIONSHIP ______________________

(07-10) ___ ___ ___ ___

BLANK (11-78) BLANK
CARD (79-80) 50

APPENDIX B

Primary Caregiver Study Consent Form

During this interview, you gave us the name of __________ as the person who provides you with the most help and support throughout your day.

In order to determine how caregiving affects __________ life, we would like to talk to him/her about:

1. Age, employment, and income etc.
2. Relationship with you.
3. Health.
4. Social activities and who she/he talks to.
5. Things that may trouble __________.
6. Other people who help __________ care for you.

This should take about 20 to 30 minutes and we will be talking to __________ over the phone.

May we have permission to contact __________?

By allowing the research team to contact __________(primary caregiver's name), I understand that:

1. I am willingly granting my permission for the research team to contact my primary caregiver.
2. My decision to withdraw from this study will not affect my health care, support services, or benefits in any way.
3. My participation is voluntary and I may discontinue my involvement with this project at any time.
4. All information disclosed between my primary caregiver and the research team will be kept strictly confidential.
5. In no way can any information disclosed be used against me.
6. My name will not be associated with the information my primary caregiver may give and will not be included in any of the research findings.
7. I have a right to a summary of the research report that is a product of this study.

8. The reason for why my permission was needed was fully explained to me and the purpose of the study was also explained.

____
Signature

____
Witness

____
Date

<u>Primary Caregiver Address</u>

____
Full Name

____
Street

____
City State Zip

Telephone Number ( ) ______-__________

APPENDIX C

Date

Caregiver's name
Street address
City, State, Zip

Dear (Caregivers name),

I am writing to you about our study which is interested in learning about how caring for an older individual influences a person's life. We have been given permission by ______________ to contact you about your role as a caregiver. We are interested in your opinions about how helping and caring for ____________ has affected your life.

The study consists of a brief 20 to 30 minute telephone interview which will be arranged with you at your convenience. All the answers you give will be strictly confidential and anonymous. In addition, you will be free to skip any questions or stop at anytime throughout the interview. Therefore, your participation in this study is completely voluntary.

You will find two copies of a consent form with this letter. One copy is yours to keep, the other copy is for you to sign and return in the self-addressed stamped envelope, should you choose to participate.

I will be contacting you, or one of my staff members, in the next two weeks to talk with you and answer any questions you may have about the study. At that time, we could also conduct the interview if it is a convenient time for you.

I look forward to talking with you very soon.

Sincerely,

Susan Paulson
Project Director

APPENDIX D

Primary Caregiver Study

Client Consent Form

Currently, a study is being conducted at Michigan State University which is interested in learning about how caring for an older individual affects a person's life.

In hopes of learning more about this process, we have been given permission by __________ to contact you. If you agree to participate, we would like to talk with you for 20 to 30 minutes. We would like your opinions about how helping and caring for ___________ affects your life. In addition, we are interested in your point of view concerning the needs of primary caregivers.

We would like to talk to you about the following areas:

1. Age, employment, and work etc.
2. Your relationship with __________.
3. Your health.
4. Your social activities and who you enjoy talking with.
5. The things that may trouble you in your life.
6. The other people who may be helping you care for __________.

Would you like to participate?

Once the interview is over, your participation in the study has been completed. I understand that by participating in this research:

1. My participation is voluntary and I may discontinue at any time during the interview.
2. My decision to withdraw from this project will not affect my health care, support services, or benefits in any way.
3. All information disclosed will be kept strictly confidential.
4. My name will not be associated with the information and will not be included in any of the study's findings.

5. I can skip any questions I do not want to answer.
6. I have a right to request a summary of the report that is a product of this study.
7. In no way will the information disclosed be used against me.
8. The study has been explained to me and I have had an opportunity to ask questions about the study.

____
Participant's Signature

____
Witness

____
Date

APPENDIX E

CAREGIVER TELEPHONE INTERVIEW

Opening the Interview

Hello, my name is ________________. I am a interviewer with a research team at Michigan State University which is interested in talking with people who care for older individuals in their homes. This study is being done to better understand how caregiving to an older individual influences the life of the caregiver.

Your name has been given to us by ________________, who has identified you as the one person who provides him/her with the most help and support throughout his/her day. Therefore, you were sent a letter explaining the study and notifying you that someone would be calling you. Have you received that letter? Do you have any questions about the letter or the study that I might answer for you at this time?

At this time, I would like to give you some information about the interview. The interview will be conducted over the telephone and will take about 20 to 30 minutes to complete. The questions will concern your overall health, the number of your social involvements and informal/formal supports, your relationship with __________, and the amount of stress you may or may not be experiencing as a caregiver. All the answers you give will be strictly confidential. No one but the research team will have access to your answers and they will be anonymous. In addition, you will be free to skip any questions or stop at anytime throughout the interview. Do you have any questions you might like to ask at this time?

Would this be a good time for you to answer some questions about yourself and your role as a caregiver? [IF YES, THANK THE CAREGIVER USING HIS/HER NAME AND PRECEDE TO THE INTERVIEW. IF NO, ASK THE CAREGIVER IF YOU CAN ANSWER ANY QUESTIONS HE OR SHE MAY HAVE CONCERNING THE INTERVIEW, HIS OR HER INVOLVEMENT, CONFIDENTIALITY, OR HOW THE INFORMATION WILL BE USED. IF AFTER TALKING WITH THE CAREGIVER, HE OR SHE AGREES TO PARTICIPATE, THANK HIM OR HER USING HIS OR HER NAME AND PRECEDE WITH THE INTERVIEW. IF HE OR SHE REFUSES, THANK THE CAREGIVER FOR HIS OR HER TIME AND ASK IF WE COULD CALL ON ANOTHER DAY. IF YES, TRY TO SET UP A DAY OR TELL HIM OR HER YOU WILL CALL IN A FEW DAYS. IF NO, THANK THE CAREGIVER FOR HIS OR HER TIME AND CLOSE THE INTERVIEW BY EXTENDING THE WISH FOR THE CAREGIVER TO HAVE A GOOD DAY OR EVENING WHICH EVER IS APPROPRIATE].

NOTE: Before beginning the interview, inform the caregiver that he or she is free to ask questions if he or she doesnot understand something. In addition, remind the caregiver to return the consent form in the self-addressed stamped envelope.

CALL RECORD

DATE CALL IS MADE	TIME	COMPLETED: YES/NO (BUSY, NOT IN, NO ANSWER)	REFUSED	FUTURE CALL DATE

CLIENT IDENTIFICATION SHEET

Client ID Number ________________

Interviewer _____________________

Site Location ___________________

Interview Date __________________

Client Name _______________________________________

Address ____

____

Home Telephone ____________________________________

*** Is the caregiver currently living with the care-receiver?? YES or NO

Status in the study:

1. Case Management

2. Information and Referral

Time of Interview:

1. Beginning Time _____________

2. End Time ___________________

Information Source from the Parent Project:

1. Proxy

2. Combination

3. Client

Client of Parent Project for reference in interview:

____

Address, only if needed:

____

___ ___ ___ ___

(01-04)
Client I.D. Number

A. QUALITY OF THE RELATIONSHIP BETWEEN THE PRIMARY CAREGIVER AND THE CARE-RECEIVER

The first group of questions concern your relationship to ______________. I would like to ask some questions regarding you relationship and how the two of you spend your time together. The first question is:

1. In the past month, how often have you felt that ______________ is dependent upon you?

   1. never 2. rarely 3. sometimes

   4. quite frequently 5. always 6. refusal

(05)____

2. In the past month, how often have you and ______________ spent time enjoying conversation together?

   1. never 2. rarely 3. sometimes

   4. quite frequently 5. always 6. refusal

06)____

3. In the past month, how often have you and ______________ spent time together watching T.V.?

   1. never 2. rarely 3. sometimes

   4. quite frequently 5. always 6. refusal

(07)____

4. In the past month, how often have you felt you should be doing more for ______________?

   1. never 2. rarely 3. sometimes

   4. quite frequently 5. always 6. refusal

(08)____

5. In the past month, how often have you and _____________ spent time together laughing?

   1. never 2. rarely 3. sometimes

   4. quite frequently 5. always 6. refusal

(09)____

6. In the past month, how often have you felt that you cannot cope at all with _____________?

   1. never 2. rarely 3. sometimes

   4. quite frequently 5. always 6. refusal

(10)____

B. PHYSICAL HEALTH

The next few qestions are about your physical health. The first question is:

1. In the past month, how often have you had trouble getting to sleep or staying asleep?

   1. never 2. rarely 3. sometimes

   4. quite frequently 5. always 6. refusal

(11)____

2. In the past month, how often would you say your appetite was good?

   1. never 2. rarely 3. sometimes

   4. quite frequently 5. always 6. refusal

(12)____

3. In the past month, how often have you felt tired after little or no strenous activity?

   1. never 2. rarely 3. sometimes

   4. quite frequently 5. always 6. refusal

(13)____

4. In the past month, how often were there times when you didnot feel overwhelmed by responsibility?

    1. never 2. rarely 3. sometimes

    4. quite frequently 5. always 6. refusal

(14)____

5. In the past month, how often have you felt fresh and rested when you awoke in the morning?

    1. never 2. rarely 3. sometimes

    4. quite frequently 5. always 6. refusal

(15)____

6. In the past month, how often do you find yourself restless where you cannot sit still for very long?

    1. never 2. rarely 3. sometimes

    4. quite frequently 5. always 6. refusal

(16)____

C. EMOTIONAL/PSYCHOLOGICAL HEALTH

The next group of questions are about feelings you may have at one time or another as you care for _____________ and go about your day.

1. In the past month, how often have you felt happy when you are around _____________?

    1. never 2. rarely 3. sometimes

    4. quite frequently 5. always 6. refusal

(17)____

2. In the past month, how often have you felt that your life is full of things that keep you interested?

    1. never 2. rarely 3. sometimes

    4. quite frequently 5. always 6. refusal

(18)____

3. In the past month, how often do you find yourself angry with other relative and friends?

   1. never 2. rarely 3. sometimes

   4. quite frequently 5. always 6. refusal

(19)____

4. In the past month, how often have you felt satisfied with life?

   1. never 2. rarely 3. sometimes

   4. quite frequently 5. always 6. refusal

(20)____

5. In the past month, how often have you been bothered by feelings of guilt?

   1. never 2. rarely 3. sometimes

   4. quite frequently 5. always 6. refusal

(21)____

6. In the past month, how often have you felt afraid about what the future holds for ____________?

   1. never 2. rarely 3. sometimes

   4. quite frequently 5. always 6. refusal

(22)____

D. SOCIAL INVOLVEMENT

The next few questions are about your social involvements. This group of questions concern how often you are with other people or are doing things you like to do, for example, a hobby. The first question is:

1. In the past month, how often did you spend time socializing with friends? (i.e., being with other people for enjoyment)

   1. daily 2. 3-4 times a week 3. at least twice a week
   4. at least once a week 5. less than once a week 6. refusal

(23)____

2. In the past month, how often did you have time to do things you like to do? (i.e., hobbies, going for drives, reading, or going to the movies)

1. daily 2. 3-4 times a week 3. at least twice a week

4. at least once a week 5. less than once a week 6. refusal

(24)___

3. In the past month, how often did you spend time with children and/or other family members?

1. daily 2. 3-4 times a week 3. at least twice a week

4. at least once a week 5. less than once a week 6. refusal

(25)____

4. In the past day, how many hours were spent caring for ______________?

1. less than 5 2. 6-10 3. 11-15 4. 16-20

5. more than 20 6. refusal

(26)____

5. In the past month, how satisfied have you been with the amount of contact you have had with friends and relatives for social purposes?

1. very dissatisfied 2. dissatisfied 3. neutral

4. satisfied 5. very satisfied 6. refusal

(27)____

6. In the past month, how often have you attended meetings of social groups, clubs, churches, or civic groups?

1. never 2. rarely 3. sometimes

4. occasionally 5. regularly 6. refusal

(28)____

E. PERCEIVED SENSE OF STRESS

The next group of questions concern your perception i.e., your feeling of stress associated with your caregiving role and responsibilities.

1. In the past month, how often have you experienced physical strain (i.e., because of lifting) while caring for _____________?

   1. never 2. rarely 3. sometimes

   4. quite frequently 5. always 6. refusal

   (29)____

2. In the past month, how often have you been able to avoid having to make family adjustments due to your caregiving role (i.e., sense of privacy lost, disruption of daily routines)?

   1. never 2. rarely 3. sometimes

   4. quite frequently 5. always 6. refusal

   (30)____

3. In the past month, how often have you felt stressed while caring for _____________?

   1. never 2. rarely 3. sometimes

   4. quite frequently 5. always 6. refusal

   (31)____

4. In the past month, how often have you felt that you have enough money to care for _____________ in addition to your other expenses?

   1. never 2. rarely 3. sometimes

   4. quite frequently 5. always 6. refusal

   (32)____

5. In the past month, how often have you felt that ______________ asks for more help than he/she really needs?

   1. never   2. rarely   3. sometimes

   4. quite frequently   5. always   6. refusal

(33)____

6. In the past month, how often would you say that you have felt that caring for ______________ is an inconvenience? (i.e., because helping takes so much time)

   1. never   2. rarely   3. sometimes

   4. quite frequently   5. always   6. refusal

(34)____

F. AMOUNT OF ADDITIONAL SUPPORT

This group of questions is about those people who may or may not be helping you with your caregiving responsibilities. The first question is:

1. In the past month, how many additional family members or friends have helped ______________ to take care of him/herself or have done things around the house for ______________?

   number of informal care provider ________

   code 66 for refusal / code 99 for nonapplicable

(35-36) ____ ____

2. In the past month, if you have had an additional informal care provider helping you care for ______________, how much time did he or she spend helping you, on the average?

   number of minutes ________

   code 6666 for refusal / code 9999 for nonapplicable

(37-40) ____ ____ ____ ____

3. In the past month, how many formal service providers (i.e., nurses, therapists, chore workers) have come to ______________'s home, on the average?

number of formal service providers _______

code 66 for refusal / code 99 for nonapplicable

(41-42) ____ ____

4. In the past month, if you have had an additional formal care provider helping you care for _____________, how much time did he or she spend helping you, on the average?

number of minutes _______

code 6666 for refusal / code 9999 for nonapplicable

(43-46) ____ ____ ____ ____

G. DEMOGRAPHIC INFORMATION

The last group of questions is about background information on the caregivers that we are talking to. The first question is:

1. Would you mind telling me how old you are? _______

(47-48) ____ ____

2. Sex (only if not distinguishable) 1. Male 2. Female

(49) ____

3. The third question concerns race. Could you tell me which category you consider yourself in?

1. White 2. Black (50) ____

3. Indian 4. Hispanic 5. Other

4. Are you currently:

1. Married 2. Widowed 3. Divorced

4. Separated 5. Have never been married

(51) ____

5. Do you have children? 1. Yes 2. No

(52) ____

If yes, the number of children ________

(53-54) ____ ____

6. For purposes of the interview, we need a rough indication of your total income. Would you mind giving me an estimate of your yearly income?

1. below $5,000 a year _______
2. $5,000 to 9,999 a year _______
3. $10,000 to 14,999 a year _______ (55) ____
4. $15,000 to 19,999 a year ________
5. $20,000 to 24,999 a year ________
6. $25,000 to 29,999 a year ________
7. Above $30,000 a year ________

7. Could you please tell me what your relationship is to _____________ from the following categories?

1. Husband/Wife _______
2. Child _______
3. Sister/Brother _______ (56) ____
4. Other relative _______
5. Neighbor/Friend _______
6. Paid helper _______

8. The last question regards whether or not you have a job in addition to your being a caregiver. Could you please tell me if you are working and if so, how many hours per week and how long have you been working?

1. Yes _______ 2. No _______ (57) ____

If yes, how many hours per week ____ (58-59) ____

If yes, how long have you been working?

Number of months ____

(60-62) ____ ____ ____

NOTE: Code 9's for nonapplicable

Interviewer, code Living Status and Program Status as follows:

Program Status:

1. Case Management
2. Information and Referral

(63) ____

Caregiver lives with the care-receiver:

1. Yes ____ 2. No ____

(64) ____

Closing the Interview

I would like to thank you for participating in this interview. Are there any questions you may have that I could answer for you at this time? Hopefully, by your answers and the answers of other caregivers, we'll be able to determine what the needs and concerns of primary caregivers are and how caring for another individual affects the caregiver's life.

I would like to mention to you again that your responses to the questions that were asked are confidential and no one but the research team will have access to them. In addition, you also have a right to a copy of a summary of the final report that is a product of this study. If

you would like a copy of this report, I will be happy to send you a copy. YES or NO

Again, I would like to say how very much I appreciate the time you spent with me today. Do you have any questions or comments at this time? If not, close the interview by saying, thank you again for making this study possible and have a nice day or evening whichever is appropriate.

**** If you have not already done so, determine if the caregiver is living with the care-receiver.

COMPLETION TIME OF INTERVIEW ____________

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