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RELIEVING STRAIN IN INFORMAL CAREGIVERS OF THE ELDERLY

A Thesis

Presented to the

Faculty of

California State

University, San Bernardino

In Partial Fulfillment of the Requirements for the Degree

Master of Arts

in

Psychology

by

Roberta Louise Babbage

August 1989

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ABSTRACT

The purpose of this study was to explore the possible mediating effect of participation in a support group on strain experienced by caregivers of the elderly. Participants in the study consisted of nine caregivers who attended nine, two-hour support group sessions and nine caregivers who did not attend the group sessions. All 18 caregivers were assessed for level of strain, self-efficacy, life satisfaction, and activities of daily living, in a pre-test/posttest design. Group participants learned skills in behavioral management and problem-solving, received resource information pertaining to available supportive services, and were encouraged to participate in open discussions regarding their caregiving situations. Contrary to expectations, the results suggested no evidence that reduced perceived strain increased self-efficacy as a function of participation in the support group. However, although not significant, results for both groups suggested a negative correlation between caregiver life satisfaction and level of strain.

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INTRODUCTION

During the last ten years, the average life expectancy in the United States has increased dramatically, with the fastest growing segment of the population being those aged eighty-five and over (Smyer, 1984). As the population ages and more people live to old age, the number of people developing chronic illness is increasing.

Research of the past decade lends support to the important role played by family and other informal support systems in the care of frail and chronically ill elderly individuals. The family support system provides a higher level of assistance than do formal organizations; and without the care given by families, many more elderly would probably be forced to leave their homes and enter institutions (Brody, 1981; Cantor, 1983; Shanas, 1979). Studies show that families offer support to approximately 95% of the elderly who live outside long-term care facilities (Cohen, 1983). Thus, more people are spending a part of their lives as caregivers to impaired older relatives, and the caregiving role has now become so common as to be considered a normal, predictable life-course experience (Brody, Johnson, & Fulcomer, 1985).

Informal caregivers have long been a neglected and invisible group who are only now becoming the focus of research because of their new roles. The present study is an attempt to focus on the complex needs of these caregivers and to investigate the methods that may be successful in relieving the strain they experience as a result of being in the caregiving role. It is hoped that the identification of mediating variables of

caregiver strain will contribute to the development of programs and/or services designed to reduce the strain experienced by caregivers and allow them to continue caring for their aged care-receiver as long as possible.

Informal Caregivers of the Frail Elderly

Caregiving involves at least a two-person dyad: the person receiving care, and the individual providing care. Those providing informal care have been found to be a spouse, an adult child, or occasionally a close friend (Cantor, 1983). Regardless of whether the caregiver is a spouse, adult child, or friend, caregiving is an arduous task that produces feelings of stress and burden.

Spousal caregivers. The impact of caregiving may be most severe on spousal caregivers since they live in the same house as the person in need. The major adjustment of spousal caregivers is the personal restriction involving the giving up of preferred activities to provide the time to care for or to socialize with the homebound older person. George and Gwyther (1986) looked at the well-being of family caregivers of older memory-impaired adults in four dimensions: physical health, mental health, financial resources and social participation. Results showed that spousal caregivers exhibited lower levels of well-being than either adult-child caregivers or other-relative caregivers and that they reported lower levels of life satisfaction. In a similar study, Cantor (1983) found that the advanced age of spousal caregivers predisposed them to poor health, with over 84% rating their perceived health as fair or poor. Spousal caregivers have been found to be primarily women who also report the

greatest degree of physical and financial strain (Brody, 1981). Women usually marry men older than themselves and live longer than their husbands. Therefore they are more likely to assume the caregiving role than their husbands. From an early age men are taught to play down their nurturing instincts and learn that success is predicated on career-related activities. Hence men tend not to assume the role as caregiver; and when they do, it is to take on responsibilities for managing finances or home repairs (Wood, 1987).

Adult children. Adult children are often in the "grandparent" generation themselves and may be caught between generations. First, they may be expected to be the major source of social support for their parents; second, they may be taking on the role of "parent" to their own parents while still playing the role of parent to their own offspring; and third, they may be experiencing some of the stresses associated with their own aging (e.g., retirement, lessened income, and perhaps health problems). These adult children who are caregivers of elderly parents are predominantly married women with families (Brody, 1981; Cantor, 1983; Shanas, 1980). Brody (1981) characterized the dilemma of the caregiving daughter as the "woman in the middle". Such women are in middle age, in the middle from a generational standpoint, and in the middle in that the demands of their various roles compete for their time and energy. In addition to their traditional roles as wife, homemaker, mother, and grandmother, women now assume roles as paid worker and as caregiving daughter to dependent older parents. Robinson and Thurnher (1979) found that responsibility for the care of the aged parent

was perceived by caregiving daughters to occur at an inconvenient time. Some women in the study had looked forward to freedom from worries after their last child left home, and there was a general awareness among subjects that the time to make up for missed gratifications was limited. Recent studies have reinforced the fact that caregiving of older parents is a "women's issue" on a par with child care and pay inequity (Brozan, 1987; Hirsch & Rapkin, 1986; Scharlach, 1987).

Friends. Research that has looked at caregiving friends is limited. Cantor (1983) found that caregiving friends were almost all women living in the neighborhood and that the group was divided between younger persons and those aged 60 and over. These caregivers reported less emotional and physical strain than family caregivers; and they reported a better state of mind and tended more often to obtain outside assistance with caregiving duties. Cantor (1983) also found that caregiving friends reported a higher quality of relationship with their care-receiver than either spouse or adult child caregivers (i.e., care-receiver and caregiver get along very well; and care-receiver treats caregiver very well).

As we have seen, informal caregivers are comprised of 1) spousal caregivers who may be experiencing stress related to older age, poor health, financial strain and stress related to co-residing with their impaired spouse; 2) caregiving adult children who may be caught in the middle between the demands and needs of their own children and those of their aging parents; and 3) caregiving friends who may be experiencing strain from the demands of caregiving as well as from the

loss of a previous active relationship. There is therefore a need to consider these three groups when looking at caregiver strain.

Caregiver Strain

The demands, risks, and costs associated with caregiving, especially in regard to the stress experienced by the caregiver, are many. "Stressor" and "strain," often used interchangably in the literature (e.g., Pearlin & Schooler, 1978; Robinson & Thurnher, 1983), are defined as a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and as endangering his or her well-being. The toll which stress produces in the caregiver appears to be very high, and it can affect the emotional, physical, and mental health of the caregiver.

Sometimes with little or no warning, the caregiver role is thrust upon the family or friend who must provide service twenty-four hours a day, usually without benefit of formal training or support systems (Norris, 1988). The task of helping the aging or infirm elder person to maintain some degree of independence in his or her own home can involve most or all of the activities of daily living including food preparation, feeding, monitoring medications, exercise, toileting, transfer, laundry, and arrangements for social contacts (Shanas, 1980). If the aged care-receiver lives independently, the caretaker's provision of this help necessitates frequent visits, shopping, transportation, and advocacy (Shanas, 1980). The caregiver must also become an expert faced with the necessity of recognizing the signs that predict medical emergencies and of understanding the side-effects of medications (Zimmer & Mellor,

1988). The range of activity can become a full-time pursuit for the caregiver.

The demand for constant attention to caregiving duties intrudes on the caregiver's privacy and sense of self as an individual who has needs. The constant demands often create feelings of isolation and despair in the caregiver--especially when the task stretches out over months and years.

It is not unusual for caregivers to have difficulty in setting limits on caregiving. The dedicated caregiver has a tendency to take on too much for too long and to sublimate his or her own needs (Beckwith, 1988). Caregivers frequently feel guilty that they are not doing enough for their impaired friend or relative, particularly if they put their own personal needs above those of the one they care for. However, when the caregiver ignores his or her own personal needs, the result is often feelings of resentment toward the care-receiver. Setting limits may be particularly difficult for women, the predominant caregivers in our society, who often have strong self-expectations for nurturance and self-sacrifice without a balancing expectation for self-care (Norris, 1988).

Caring for an aged parent brings to the fore emotions and feelings connected to family roles. A caregiving child must redefine his or her role in relationship to the aged parent and must come to terms with the adjusted role (Zimmer & Mellor, 1988). Contradictory feelings are also present. For example, there may be jealousy of the primary caregiver by other siblings over the bond that develops between the caregiving sibling and the parent receiving care. On the other hand, the caregiver may

resent the lack of support of siblings and other family members who do not assist with caregiving tasks (Silverstone & Hyman, 1988). In extreme cases, the tension put on family relationships may cause the destruction and disintegration of family ties (Chenoweth & Spencer, 1986).

It is not uncommon for family members to give up their jobs to care for the ill relative and for their own health to deteriorate because of the strain related to caregiving. Exhaustion and fatigue are sure symptoms of stress (Zimmer & Mellor, 1988). When the aged relative co-resides with the caregiver, the caregiver may have no sense of rest, even upon awakening, because listening in the night, disturbed sleeping arrangements, conflicts in schedule, and other changes in their normal routine can cause caregivers to feel abnormally tired. Caregivers often describe themselves as physically and emotionally drained (Zarit, Orr, & Zarit, 1985). Exhaustion from endless nights of interrupted sleep may eventually deplete the caregiver's resources for coping with the care needs of the care-receiver. Often the caregiver is unable to shake a cold and is subject to flare-ups of chronic illness, headaches, gastrointestinal disorders, depression, and weight loss or weight gain, and may be vulnerable to chemical abuse (Beckwith, 1988).

In a study of 510 caregivers of memory-impaired elderly, it was found that caregivers were more likely to experience problems with mental health and experienced three times as many symptoms of stress as the control group (George & Gwyther, 1986). Often what emerges from the process of care are dual clients--the aged person and the family that has provided care (Kermis, Bellos, & Schmidtke, 1986).

Research also shows that family members will go to great lengths to avoid institutionalization of an impaired elderly parent or relative--many times at a great cost to their own health and to the family's well-being (Zarit et al., 1985). However, overly burdened caregivers may reach a breaking point in which they feel they can no longer cope, and they determine that institutional placement of the elderly family member is the only answer. The decision to institutionalize has been found to be related more closely to the strain on families reaching unbearable proportions than to the deterioration of the elderly person (Lowenthal, Berkman & Associates, 1976; Zarit, Todd, & Zarit, 1986).

Mediating Variables of Caregiver Strain

The fact that caregiving can be arduous and debilitating has led to questions of what might aid informal caregivers to better carry out their responsibilities. While all caregiving families experience some level of strain, some families are able to function better than others. The mechanisms operating in these better-functioning families may be examined in the light of possible mediating variables of caregiver strain. Research evidence suggests that participation in support groups (Zarit et al., 1985), social support (Zarit, Reever, & Bach-Peterson, 1980), self-efficacy (Lovett, Gallagher, & Kwong, 1986), and problem-solving skills (Zarit et al., 1985) may mediate caregiver strain. There is also evidence that the life satisfaction of the caregiver (George & Gwyther, 1986), his or her health status (George & Gwyther, 1986), the number and type of activities of daily living that the care-receiver is able to accomplish (e.g., toileting, feeding, dressing or bathing) (Deimling, Bass, Townsend, &

Noelker, 1989), and demographic differences (e.g., age of caregiver, marital status, living arrangements of care-receiver) (Cantor, 1983) are closely related to caregiver strain. These mediating variables are discussed below.

Participation in support groups. Participation in support groups tailored specifically to the needs of caregivers and the relatives of impaired elderly has shown to be beneficial (Levy, Derogatis, Gallagher & Gatz, 1980; Zarit, 1980). Caregiver support groups have been found to mediate strain by offering a format in which experiences shared among participants promote a sense of emotional security (Levy, Derogatis, Gallagher & Gatz, 1980). In a recent study, Zarit, Anthony, and Boutselis (1987) looked at burden and strain in caregivers who attended time-limited caregiver support group sessions and found that group participation resulted in lower reports of burden. Another benefit of caregiver support groups is the focus on the imparting of helpful information to caregivers that enables them to learn new skills and to link up with supportive services to assist them with their caregiving tasks (Lazarus, Stafford, Cooper, Cohler, & Dysken, 1984).

Caregivers participating in caregiver support groups tend to become a source of emotional support for one another (Hausman, 1979).

Meeting with other caregivers caught in similar situations has been found to be an effective method of enabling caregivers to handle their conflicting feelings (Cohen, 1983; Zarit et al., 1987; Zarit et al., 1985).

The realization that others suffer the same burden and harbor similar feelings is very helpful to caregivers. As a result, a common theme heard

by caregiver support group participants is "I no longer feel so alone" (Silverstone, & Hyman, 1988). Lazarus et al. (1984) found in their study which focused on the benefits of caregiver support groups that group participation facilitated a sharing of common feelings and experiences that helped to relieve a sense of isolation and loneliness.

Studies of caregiver support groups that have focused on teaching caregivers problem-solving skills have shown that caregivers who are able to effectively apply problem-solving strategies generally report less stress or burden than those caregivers who use ineffective problem-solving methods (Zarit et al., 1985). Supportive evidence for this was found by Lovett et al. (1986) in a study of participants in a ten-week caregiver support group where instruction in problem-solving resulted in caregivers' indicating that they felt less overwhelmed by difficult problem situations.

Caregivers must often face difficult decisions regarding the type of care to provide for their care-receiver. In a support group for caregivers of mentally impaired relatives, for example, the focus was on sharing and support among group members (Schmidt & Keyes, 1985). The group met weekly for 90-minute sessions for a six-month period. It was found that participation in the group helped caregivers by increasing their knowledge of in-home supportive services and respite care. Caregivers also made decisions on whether it was appropriate to place their care-receiver in an institution. In a previously mentioned study, Zarit and Zarit (1983) found when looking at the correlation between caregivers' feelings of burden and their decision to institutionalize their care-

receiver, the decision to institutionalize was associated primarily with the social support available to them. These findings suggest that an intervention program, such as a group that increases informal social support, may be effective in assisting caregivers with their difficult task.

Being a caregiver also involves learning to set limits, the need for good communication skills, and knowledge of the aging process. In a study of 48 caregivers of frail elderly parents, adult child caregivers met in five separate eight-week support groups to make decisions about the extent of responsibility they could comfortably assume for their parents (Hausman, 1979). At the close of the eight-week sessions, participants indicated the following benefits of participating in their support groups: 1) caregivers had learned to set limits both for their own benefit and for the benefit of their aged relative; 2) caregivers had learned new communication skills; and 3) they had learned about successful aging (i.e., caregivers learned about the importance of managing stress, the importance of good nutrition and of exercising on a regular basis in order maintain their physicall and mental well-being as they age).

In Summary, research evidence shows that caregivers who participate in support groups have been found to: 1) experience decreased levels of perceived strain; 2) receive helpful information that will enable them to obtain assistance with caregiving tasks; 3) obtain mutual support from other support-group participants; 4) learn problemsolving skills; 5) have an opportunity to objectively evaluate the decision to institutionalize their care-receiver; 6) learn to set limits; and 7) learn about the aging process.

Social support. One outstanding mediating variable of caregiver strain appears to be social support. In other words, the ability of caregivers to cope with their caregiving situation may depend on the social support available to them. Social support is typically defined as help that is available to an individual in difficult or stress-arousing situations (Sarason & Sarason, 1982). This "help" may be in the form of family, friends, self-help groups, or religious organizations. Social support acts as a buffer against the stresses and shocks of daily life and has been said to provide individuals with assistance, emotional support, guidance, and "positive" interaction (Barerra, & Ainlay, 1983).

It has been found that the extent of strain reported by primary caregivers of persons with senile dementia is not related to the behavior problems caused by the illness, but is associated with the social support available to the caregiver (Zarit, Reever, & Bach-Peterson, 1980). Zarit et al. (1985) found caregivers to experience increased levels of stress when they felt isolated and unsupported, and concluded that the amount and quality of support the caregiver receives from other family members is an important factor in a caregiver's ability to cope with the demands of caregiving. In fact, the availability of a supportive social network seems to significantly enhance the ability of an individual to cope with both physical and psychological stressors (McCubbin, Sussman, & Patterson, 1983).

As it relates to stress and the caregiver, social support has two components: physical support and emotional support. The first component concerns the care-receiver and is physical or instrumental in

nature. It includes activities such as assistance with bathing, cleaning, cooking, and the tasks involved with day-to-day care. The second component, which concerns the caregiver, is emotional in nature and involves the feeling of support gained from knowing that there is someone who understands the caregiver's experience and offers encouragement in times of difficulty. This emotional component may include the caregiver's having someone who will call upon the caregiver periodically, having someone to talk to when troubled or upset, having someone to call on at any time, and having someone who will give needed encouragement (Zarit, Orr & Zarit, 1985).

Decreased social contact due to the demands of caregiving duties may be the single most stressful element in caregiving because it cuts off the caregiver from stabilizing interactions with other people (Zarit et al., 1985). Zarit et al. (1980) found that caregivers who received calls and visits from friends or family members felt less burdened than those who did not. It appears that social support for caregivers is a complex issue which is dependent upon some of the following variables: knowledge of and availability of community resources and the willingness and ability of caregivers to request assistance with caregiving duties from relatives, family and friends, and from other formal supportive services (e.g., respite care, home-delivered meals, and homemaker service). It has also been suggested that an intervention program that increases informal social supports may be an effective mediator with a caregiver who reports excessive feelings of strain (Cohen, 1983; Pinkston & Linsk, 1984; Zarit et al., 1980).

Self-efficacy. Self-efficacy is the personal judgment that one is capable of performing a specific behavior because one has the requisite skills, talents, and physical capacity (Bandura, 1982). Self-efficacy is not the same as self-esteem or self-confidence, but rather it is a judgment about specific self-expectations as to the ability to perform capably in specific situations. The level and strength of self-efficacy influences expectations of personal efficacy and determines whether coping behavior will be initiated, how much effort will be expended, and how long it will be sustained in the face of obstacles and adverse experiences (Bandura, 1982). This hypothesis has been supported in a wide variety of contexts including overcoming phobias, medical compliance in chronic illness, maintaining weight loss, and avoiding relapse after being able to quit smoking (Bandura, 1986).

Applying self-efficacy to caregivers, Lovett, Gallagher, and Kwong (1986) have suggested that increased self-efficacy in caregivers may result from interventions designed to help them increase their feelings of choice and predictability over daily events. They also suggest that self-efficacy is a major factor in the ability of caregivers to cope with their situation and may be a major predictor of persistence in the caregiving role as tasks become more difficult and stress-provoking. The strategy suggested by self-efficacy theory is to enhance personal judgments of capacity to cope with the demands of one's specific caregiving situation (Bandura, 1986). Feelings of self-efficacy are also central to initiating and maintaining behaviors that enable the caregiver to obtain a sufficient level of social support. In a study that looked at the relationship of self-

efficacy and social support in adjustment in aging, Holahan and Holahan (1987) found that self-efficacy was related to the amount of social support caregivers received. Self-efficacy relating to social support was conceived of as an individual's belief that he or she could manage effectively a number of social concerns relating to obtaining social support from the environment. Results of the study showed that initial self-efficacy was related to social support one year later. Therefore, because feelings of self-efficacy are central to initiating and maintaining behaviors that enable caregivers to obtain sufficient levels of support, it is probable that feelings of self-efficacy serve as mediators of caregiver strain.

Judgments of self-efficacy are based on sources of information which have strong implications for caregiver support groups. In their work with caregivers, Zarit et al. (1985) found that modeling or imitative behavior is an important source of new learning, especially in areas where caregivers previously had difficulty making a change. Within the context of caregiver support groups, self-efficacy may be enhanced by the following: 1) caregivers having opportunities to observe the performance of others; 2) caregivers learning new behavioral management and problem-solving skills; and 3) caregivers obtaining helpful information to link them with community resources to assist them with their caregiving tasks. Ultimately participation in a caregiver support group may facilitate an increased level of self-efficacy which may serve to mediate the level of strain.

Problem-solving skills. Caregivers are confronted with continual problem situations brought about by providing care. If caregivers learn to manage current problems better, they can develop skills that may help them with subsequent problems. There is considerable variation in how caregivers react to specific problems. For example, some report great distress by the demands placed on them to take over more responsibility in the supervising and care of their aged relative while others may not experience the same degree of distress under similar circumstances (Zarit et al., 1985). Caregivers who are able to apply effective problem solving strategies in response to altered behavior generally report less stress or burden than those who use ineffective methods (Zarit et al., 1985). Problem-solving in the context of a caregiver support group can be described as a process which provides strategies for the development of optimal means to manage stressors. Successful problem-solving may include identifying situations which trigger problem behavior, developing new responses to situations, and seeking assistance when caregiving tasks become excessive (Zarit et al., 1985).

The problem-solving method recommended by Zarit et al. (1985) in their work with families of patients with senile dementia is as follows: first, caregivers were instructed to identify what problems were most pressing. An effective method of obtaining this information was found to be requiring caregivers to keep a daily record of the occurrence of problem behavior. Second, caregivers generated alternative solutions (i.e., to think of as many solutions as possible). Third, they were instructed to choose a solution, carefully weighing the pros and cons--to list

alternatives and explore advantages or disadvantages that each might provide. Fourth, caregivers were taught cognitive rehearsal (i.e., when the caregiver selected a possible solution to deal with a problem, he or she then carried out the steps mentally). And finally, they carried out the plan and evaluated the outcome. Ideally the outcome will be that the problem behavior occurs less frequently, and then the caregiver may assume the plan is having a positive effect. Zarit et al. (1985) emphasize that problem solving is a process of trial and error, that there are no simple solutions, and that caregivers who are able to apply effective problem-solving strategies generally report less stress and strain than those who use ineffective methods to deal with problem situations.

A similar plan for helping caregivers learn problem solving skills was outlined by Napier and Gershenfeld (1985). Their problem-solving technique included the following: 1) general orientation, 2) problem definition and formulation, 3) generation of alternatives, 4) decision making, and 5) verification. They state that the general goal of problem solving is not to provide individuals with specific solutions to specific problem situations, but rather to provide a general coping strategy so that they may be in a position to deal more effectively with a wide variety of situational problems.

A study of participants in a 10-week intervention program incorporating instruction in problem solving demonstrated that caregivers with good problem-solving skills may feel less overwhelmed by difficult behaviors and problem situations related to caregiving, and that they may be more successful in developing and implementing a plan of action

(Lovett et al., 1986). In the study, 30 individuals caring for older impaired relatives were administered an index of caregiver stress and a measure of problem-solving skills. Instruments were administered before and immediately after attending 10 weeks of caregiver support group sessions based on education and mutual support. It was found in this study that the intervention program was successful in reducing caregivers' stress, burden, and depression although it did not affect their problem solving scores. Furthermore, Lovett et al. (1986) concluded that caregivers who receive training in problem-solving are able to manage their caregiving situations with less reported stress and may also experience an increase in self-efficacy as of result of this increased ability to cope.

<u>Life satisfaction</u>. A caregiver's level of life-satisfaction may mediate caregiver strain. Life satisfaction is essentially a cognitive assessment of one's progress toward desired goals (George, 1979). It has been found that life satisfaction is positively associated with the opportunity to satisfy a specific need and negatively associated with difficulty in satisfying that need (Emmons, 1986).

Caregivers who feel a loss of control over their lives because of the extreme demands of caregiving often experience distress and impaired social well-being (George & Gwyther, 1986). As a result, caregivers' levels of life satisfaction have been found to be lower than those reported by comparable age peers who have no caregiving responsibilities (George & Gwyther, 1986). The reason for this is that the constant demand for attention to caregiving duties, as well as the caregiver's loss

of familiar roles and social contacts, tends to produce feelings of helplessness and hopelessness (Cantor, 1983). Further, caregivers of mentally impaired older relatives often report that they suffer from problems with sleeping, eating, and maintaining an adequate energy level (Gallagher, Wrabetz, Lovett, Del Maestro, & Rose, 1988). In addition, Gallagher et al. (1988) state that caring for an impaired family member places an enormous emotional burden on the caregiver. This emotional burden may lead the caregiver to experience denial, anger, guilt, self-pity and depression. Co-residence with the care-receiver has been associated with decreased caregiver well-being (Cantor, 1983; George & Gwyther, 1986) because the closer proximity with the one requiring care results in increased physical and emotional demands on the caregiver.

It has also been found that the level of life satisfaction of the carereceiving relative and the caregiver are associated. Fengler and
Goodrich (1979) administered Life Satisfaction Scales A and B
(Neugarten, Havighurst, & Tobin, 1961) to a group of 34 couples between
the ages of 59 and 81 in which the wives were acting as spousal
caregivers. Results of the study showed that life satisfaction scores of
care-receiver husbands and caregiver wives were closely associated. It
was concluded from the results of this study that by helping the wife to
increase her feelings of life-satisfaction, the care-receiving husband will
also benefit. It appears, therefore, that life satisfaction is impacted by the
heavy demands of the caregiving experience.

Research suggests that life satisfaction may be increased by assisting caregivers to determine realistic goals for their caregiving situation (e.g., time they have available to devote to the needs of the care-receiver and evaluation of their own and their care-receiver's physical and emotional needs and capabilities) and also by offering increased support to the caregiver (Cantor, 1983; George & Gwyther, 1986). Thus progress may be made toward the desired goal of helping give care to the frail elderly which may increase the level of life satisfaction and therefore be a factor in mediating caregiver strain.

Health. The health of the caregiver is also an important variable to consider in understanding caregiver strain. It is not uncommon to hear of caregivers suffering from physical exhaustion or being physically injured as a result of their caregiving duties (Zarit et al., 1985). Research has shown that most caregivers had a larger number of doctor visits over a six-month period than peers unencumbered by caregiving responsibilities (George & Gwyther,1986). This study also found a relationship between the number of doctor visits and the caregiver's self-perceived health rating. The self-perceived health rating has been found to be a good assessment of health when compared to a physician's rating (Shanas, Townsend, Wedderburn, Friis, Milhoj, & Stehouwer, 1968) and is useful for measuring health in a survey format.

Caregiving makes many physical demands upon the caregiver.

These include lifting or assisting the care-receiver in transfer, dressing and bathing, and the caregiver's loss of sleep because of the need to provide 24-hour care. Since many caregivers are themselves advanced

in age, the physical demands of caregiving may result in physical injury to the caregivers themselves. The caregiver's health may be an important factor in determining the type of care that he or she is able to provide. Fengler and Goodrich (1979) found that a caregiver's health status was associated with their life satisfaction and ability to cope with the rigorous task of caregiving. Other studies have also suggested that caregivers' perceived health is a major predictor of life satisfaction (Pearlin & Schooler, 1978) which suggests that health status may act as a mediating variable of caregiver strain.

Activities of daily living. The Index of Independence in Activities of Daily Living (ADL) measure (Katz, Moskowitz, Jackson, Jaffe, & Cleveland, 1963) was developed to study over-all performance in bathing, dressing, going to the toilet, transferring, continence, and feeding in the aged. Research evidence shows that much of the strain that is associated with caregiving may be understood by examining the impairment of the aged relative (Deimling, Bass, Townsend, & Noelker, 1989). For example, studies show the most problematic ADL's for the caregiver are physical health problems that cause urinary or bowel incontinence or those that require heavy lifting (e.g., help with toileting) (Deimling et al., 1989; Stone, Cafferata, & Sangl, 1989). In a recent study, Deimling et al. (1989) found that care-receiver ADL limitations were important in determining the caregiver's health decline and restrictions on activity by both the caregiver and the care-receiver. The impairment-strain relationship, however, is not universally supported (Cantor, 1983; George & Gwyther, 1986; Zarit et al., 1980) since several

studies have found that formal or informal support with caregiving, rather than the degree of physical or mental impairment of the aged relative or friend, explain the differences in the level of strain experienced by caregivers. However, the level of impairment of the care-receiver is central to the caregiving situation, regardless of the relationship between level of impairment and the strain the caregiver experiences (Zarit et al., 1980). It is a major determinant of the nature and extent of care required and, as a result, it may be a major determinant of the level of the caregiver's physical and emotional involvement.

<u>Demographic differences</u>. The following demographic variables may also impact the level of perceived strain: 1) the socio-economic status, 2) the number of years in school, 3) the age of the caregiver, 4) the living arrangements of the care-receiver, 5) and the family dynamics.

For the first demographic variable, the socio-economic status, adequate financial resources have been linked with more years of education which leads to a sense of control, mastery, and increased ability to cope (Pearlin & Schooler, 1978). The increased financial burden in caring for an older relative is often a concern of caregivers (Clark & Rakowski, 1983; Pearlin & Schooler, 1978; Zarit et al., 1985). Brody and Schoonover (1986) found that female caregivers who work were of higher economic status than non-working female caregivers and that those working caregivers tended to pay for services to assist them with caregiving tasks (e.g., meal preparation and personal care). Non-working female caregivers were of lower socio-economic status and were shown to provide more services themselves. They also found that the

kinds of responses and resources caregivers are able to rely on in coping with strain make a difference to their emotional well-being and may be important in shielding them from emotional stress.

For the second demographic variable, education, the number of years of education may influence a caregiver's ability to obtain needed information and support services to assist with caregiving tasks (Shanas, 1980). Brody, Kleban, Johnson, Hoffman, and Schoonover (1987) found that non-working daughters had the lowest educational status.

Daughters who had given up their jobs for caregiving also had the lowest occupational status. Caregiving daughters with more years of education had the highest occupational status and had higher family incomes than non-workers. As a result, the care-receiving relatives of these more highly educated caregivers received more help from wider sources than those with fewer years of education. Research evidence supports the notion that there is an association between more years of education, higher employment status, and the ability to obtain support services (Brody et al., 1987; Deimling et al., 1989).

Regarding the third demographic variable, age, it has been shown that age is related to vulnerability to disease and increased health problems (Deimling et al., 1989). Earlier, Shanas (1979) found that the average age of most caregivers was between 55 and 64 years, and that the more advanced the age of the caregiver, the more likely age-related health problems will occur. Spousal caregivers tend to be even older. Studies by Brody et al. (1987), Cantor (1983), and Shanas (1980) have found that most spousal caregivers are at least 60 years of age and most

are 75 years or older, while the average age of adult child caregivers is between 59 and 62 years. The advanced age of most caregivers suggests that factors such as widowhood, retirement, limited income, and loss of supportive relationships may also impact the level of perceived strain (Brody et al., 1987).

The living arrangements of the care-receiver, have also been looked at in relation to caregiver strain. For example, Deimling et al. (1989) found that approximately 35% of caregiving adult children coreside with their impaired relative. Caregiving children who share a residence with an aged relative compared to adult children living in separate households may experience greater restrictions in their personal and social activities. Deimling et al. (1989) also looked at adult child caregivers who assisted parents living alone in the community. This arrangement comprises 11% of households nationally. The logistics of caregiving may be stress-provoking due to the distance some caregivers must travel in order to help their parent. Stone et al. (1989) found shared living accomodations to be a function of a high level of impairment of the care-recipient.

Another demographic variable influencing caregiver strain is family dynamics (i.e., the number of people living in the caregiver's household). Although family dynamics is a "given" with spousal caregivers, adult child caregivers may be either married, widowed or single. Research shows that the presence of a second, unimpaired adult may reduce the direct responsibilities of the primary caregiver or offset the additional competing demands of child-rearing, employment, or care of other

household members (Soldo & Myllyluoma, 1983). It was also found that in such households with other family members present, the caregivers were buffered against competing demands on their time and energy. However, in households with children under 18 years, or with an additional person requiring care, the competing demands for the caregiver's time and energy resulted in decreased morale of the caregiver as well as in increased physical strain

Caregivers' ability to cope with their perceived strain tends to be influenced by their own socio-economic status, their income level, their level of education, their age, the living arrangements of the care-receiver, and the family dynamics.

Summary. In general, the literature suggests positive effects of both formal and informal services that assist caregivers with the difficult task of providing care for an older family member or close friend. Although there is considerable public and academic interest in how to relieve the strain that caregivers face, development of interventions and research on the effectiveness of these interventions are only in the introductory stages. A widely available intervention to assist caregivers are support groups, which may help caregivers by reducing isolation, learning from others in similar situations, and receiving information about formalized supportive services. Most published reports on caregiver support groups have emphasized the positive benefits of the sharing of information and the emotional release that participating caregivers experience in the group setting (Clark & Rowkowski, 1983). Surprisingly little attention has been focused on a related approach to solving the problems of caregivers--that

is, to train them in problem-solving procedures that could potentially alleviate major sources of their stress. Previous studies looking at factors that appear to mediate caregiver strain indicate that this strategy may be useful (e.g., Lovett, Gallagher, & Kwong, 1986; Zarit et al, 1980; Zarit et al., 1986). Previous studies also indicate that there may be the additional positive benefit of an increase in self-efficacy when caregivers learn problem-solving skills (Lovett et al., 1986; Zarit et al., 1985) although there is no controlled research available to support this notion. Based on the indications of the positive benefits of instruction in problem-solving, an intervention has been developed as part of this study that includes not only the supportive features generally provided by support groups but also the training of caregivers in problem-solving techniques.

Previous reseach has looked at caregiver morale and well-being in relation to the demands of their caregiving situation (Fengler & Goodrich, 1979; George & Gwyther, 1986). This research shows that the isolation, lonelinesss, and role overload experienced by caregivers were most frequently associated with low morale and decreased well-being. However, research has not looked specifically at any correlation that may exist between a caregiver's life satisfaction and the perceived level of strain. Therefore, the current study has been designed to examine the possible correlation between caregivers' life satisfaction and their perceived level of strain.

Other important variables to consider when looking at caregiver strain are the caregiver's perceived health status, the activities of daily living that the care-receiver is able to accomplish for himself or herself, the number of people that the caregiver can call upon for assistance with caregiving tasks, and demographic differences.

In conclusion, the purpose of the current study is an attempt to examine the relationship between the level of strain experienced by informal caregivers of the frail elderly and their participation in a caregiver support group. Specifically, it is expected that: 1) participation in a caregiver support group will facilitate a decrease in the perceived level of strain; 2) training in problem-solving will facilitate an increase in perceived self-efficacy; and 3) a decrease in perceived level of strain, which is expected to result from participation in the caregiver support group, will be significantly correlated with an increase in self-efficacy and life satisfaction.

METHOD

<u>Subjects</u>

Subjects were 18 adult caregivers for physically or mentally impaired older relatives or close friends living in the San Bernardino area. Subjects consisted of 16 females and 2 males, all of whom were recruited through advertising in the local newspaper and through referral from a senior center. (See copy of newspaper recruitment article in Appendix A.) The average age of subjects was 57.8 years and the average age of their care-receiver was 75.4 years. Ten of the caregivers co-resided with their care-receiver; eight lived independently from the care-receiver. Eight of the care-receivers were mentally impaired, four had suffered from stroke, and six were frail. More than half of the caregivers were married, five were single, and two were widowed. Half of the subjects had completed nine to twelve years of high school, and nine had completed some college or were college graduates. Ten subjects were employed outside of the home. The mean number of family members or friends available to offer assistance with caregiving tasks was 1.22 for both groups combined. Support group participants had a mean number of .77 family or friends to call upon for assistance while the caregivers in the control condition had a mean of 1.33. (Demographic information appears in Table 1.)

Subjects were not randomly assigned to the two groups. Eleven subjects elected to attend the nine weekly two-hour caregiver support group meetings held at a local senior center, however, two subjects

TABLE 1

Demographic Information:

	Total Group (n=18)	Experimental Group (n=9)	Control Group (n=9)
Marital Status (n=18	<u>3):</u>		
married	11	6	5
single	5	3	2
widowed	2	0	2
Mean Caregiver's Age in Years:	57.88	59.00	56.77
Mean Number Living in Caregiver's Home:	2.11	2.11	2.11
Number Years In School (n=18):			
1-8 years of school	9	5	. 4
9-12 years of school	4	2	2
some college	3	1	2
postgraduate	1 .	1 .	0
Employment (n=18):			
Employed full-time	5	2	3
· · · · · · · · ·	-	_	-

TABLE 1 continued

Employed			
part-time	5	4	1
Homemaker	4	1	3
Independent Income	1 .	0	1
low-income	0	0	0
Retirement	3	2	1
Mean Number of Family Members Who Assist With Caregiving Tasks:	1.22	.77	1.33
Occupation (n=18):	_	_	
Clerical/Sales	8	5	3
Manager	3	1	2
Professionals	5	2	3
Homemaker	2	1	1
Relationship to Care-Re	eceiver (n=18	<u>3):</u>	
Wife	5	3	3
Husband	1	1	0
Daughter	9,	5	5
Son	1	0	1
Friend	1	1	0
Mean Age of Care-receiver In Years:	75.47	76	77.77

TABLE 1 continued

Resident Status of Care-receiver (n=18):

Caregiver's home	10	5	5
Independent living	4	2	2
Convalescent home	2	1	1
With other relatives	2	1 .	1 -

dropped out following the first caregiver support group meeting. Nine subjects responded to the advertising but elected not to attend the caregiver support group sessions. These subjects agreed to participate in the control group by filling out pre-test and posttest questionnaires nine weeks apart. Their were eight females and one male in each group.

Measures

Caregiver strain. Strain was assessed by the Caregiver Strain Index (Robinson, 1983), a 13-item self-report inventory that measures perceived level of caregiver strain. This instrument was selected to examine level of strain because of its reliability and construct validity. Cronbach's alpha among the 13 items is reportedly .86 (Robinson, 1983). Questions are answered yes (=1) or no (=0), and focus on the following issues that caregivers face: inconvenience, confinement, family adjustments, changes in personal plans, competing demands on time, emotional adjustments, upsetting behavior, the parent seeming to be a different person, work adjustments, feelings of being completely overwhelmed, sleep disturbances, physical strain, and financial strain. Examples of questions on the Caregiver Strain Index are: "Sleep is disturbed (e.g., because____is in and out of bed or wanders around at night)"; "It is confining (e.g., helping restricts free time or cannot go visiting)"; "There have been work adjustments (e.g., because of having to take time off)". The 13-item scores were then summed. (The complete Caregiver Strain Index appears in Appendix B.)

<u>Self-efficacy</u>. The Daily Living Self-Efficacy Scale was used as a generalized measure of self-efficacy (Woodward & Wallston, 1987).

Woodward and Wallston's (1987) scale was selected since it had been used to assess self-efficacy in older adults and the scale also was found to have adequate internal consistency with an alpha level of .78. The scale consists of 13 items measuring preference for control (e.g., "If you had the chance, you would rather be a leader than a follower"; "In general day-to-day situations you want to make your own decisions"). Subjects responded to each item by indicating on a 10-point Likert scale their level of self-confidence of performance with respect to each situation or statement. The total scores were then summed with a possible range of 13-130. (The Daily Living Self-Efficacy Scale appears in Appendix C.)

Life satisfaction. Life satisfaction was assessed by the Life Satisfaction Index, Form A (Neugarten, Havighurst, & Tobin, 1961). Participants read each statement on the list of 20 items and indicated whether they agreed or disagreed with each statement. Examples of questions on the Life Satisfaction Index include, "As I grow older, things seem better than I thought they would be"; "This is the dreariest time of my life". Adams (1969) evaluated the reliability of the Life Satisfaction Index Form A using a discrimination (D) value and a bi-serial correlation between the mean of the affirmative response groups for each item and the Life Satisfaction Index mean score for the entire sample. The D values indicated that all items except item 11 fell within the acceptable range from 20% to 80% with the biserial correlation standard. This scale has also been found to be easy to administer to older populations (Neugarten et al., 1961). (The Life Satisfaction Index appears in Appendix D.)

Activities of daily living. The Index of Independence in Activities of Daily Living (ADL) (Katz, Ford, Moskowitz, Jackson, Jaffe, & Cleveland, 1963) was used to measure the level of independence with daily activities. The ADL Index was selected since it has been shown to be an effective survey instrument for studying the aging process (Katz et al., 1963). Caregiver subjects checked the description that best applied to their care-receivers' level of functioning in the following areas: independence or dependence of care-receiver in bathing, dressing, going to the toilet, transferring, continence, and feeding. The degree of inter-rater reliability (Katz et al., 1963) was made by assessed observations in 1,001 patients by trained observers and was assessed to be 95%. (The complete measure appears in Appendix E.)

Caregivers' health. Caregivers' health was assessed by the Self-Evaluation of Health (Shanas, Townsend, Wedderburn, Friis, Milhoj, & Stehouwer, 1968). Subjects were simply asked, "For someone your age, do you consider your health to be good, fair or poor?" Validity has been documented by other researchers who have tested this indicator for its convergent validity with physicians' assessments of health of the respondents (Shanas et al., 1968). This measure was incorporated within the questionnaire which subjects completed as a part of the pretest items. (See Appendix F.)

<u>Demographic information</u>. In addition to the above, subjects were also asked to report their marital status, their own age, number of people living in their home, number of years they had completed in school, employment status (i.e., employed full-time, part-time, homemaker,

independent income, low-income, retired), number of family members who assist them with caregiving tasks, their occupation or former occupation if retired, their relationship to the care-receiver, age of their care-receiver, and resident status of their care-receiver (i.e., resides with the caregiver, lives independently in own home, lives in convalescent home or lives with relatives other than the caregiver). (See Appendix F.)

Social support. Social support was assessed by caregiver subjects' responses when asked the number of family members and/or friends they can call on for help with caregiving responsibilities (e.g., taking the elderly care-receiver shopping or to the doctor, housekeeping, personal care of the patient, respite, meal preparation, etc.). (See Appendix F.) Procedure

This study used a pre-test/posttest design with a nonequivalent comparison group. At pre-test and posttest all subjects were given: 1) the Caregiver Strain Index (Robinson, 1983), 2) the Daily Living Self-Efficacy Measure (Woodward & Wallston, 1987), 3) the Life Satisfaction Index Form A (Neugarten et al., 1961) questionnaires, and 4) the demographic information survey. The following instruments were administered at pre-test only: 1) the Index of Independence in Activities of Daily Living survey (Katz et al., 1963), 2) the Self-Evaluation of Health (Shanas et al., 1968), 3) the Demographic Information survey, and 4) the Social Support questionnaire. Subjects in the experimental group attended nine two-hour caregiver support group sessions once a week for nine weeks (described below). The measures were administered to the experimental group during the first and ninth support group sessions. The control

group did not receive the treatment and therefore were mailed copies of the measures to complete and return by mail during the week of the first session and again at the end of the ninth session. All control group subjects completed the pre-test and posttest questionnaires.

The goal of the nine-week caregiver support group intervention was to alleviate strain by offering useful educational information and encouragement of mutual support among the caregivers. The objectives of the caregiver support group were these: 1) to educate caregivers about community resources, 2) to increase caregivers' awareness of their personal capabilities and limitations regarding their caregiving role, 3) to assist caregivers in enhancing their skills in problem-solving, assertiveness, behavioral management, stress-management, and methods of coping with physical and emotional demands, 4) to support caregivers in dealing with the isolation, grief, and stress involved in their caregiving role, and 5) to encourage group members to mutually support one another.

The caregiver support group sessions included nine two-hour sessions. The first hour of each session consisted of educational material presented by a psychologist, social worker, or resource person versed in the needs of the elderly. The second hour of each session was led by the facilitator and allowed participants to discuss caregiving issues and concerns. These two-hour support group sessions were held weekly in the early afternoon in a meeting room at a local senior center. These are discussed in detail below.

Caregiver support group sessions

Session 1. During session one, the pre-test materials were administered. An overview describing the content of the nine support groups sessions was presented by the group leader. All participants were then given a folder containing an outline of the nine sessions, resource materials, and blank paper to be used for optional note-taking throughout the nine weekly sessions. Each group member introduced himself/herself and told the group something about their caregiving situation.

Session 2. During session two, an attorney spoke for the first hour on legal concerns which included the following: separation of property, durable power of attorney, and wills and estate planning. Durable power of attorney forms were made available for use by the participants. The second hour consisted of a group discussion during which spouse caregivers spoke of their concerns regarding their future financial status should they have to institutionalize their spouse. Adult children attending the group expressed concern over power of attorney issues regarding their parents' estates.

Session 3. During session three, the following problemsolving method was presented as a group exercise:

- A. Participants were asked to examine what problems they were experiencing in their caregiving role and which problem they would like to handle more effectively.
- B. Participants then identified specific situations and behaviors that were unacceptable and stress-producing for them. (i.e.,

care-receiver refusing to eat or wandering behavior of care-receiver).

The group selected two problem situations to work on together during the day's session.

- C. Brainstorming techniques were presented (i.e., list as many solutions to the problem situation as possible without censoring ideas) after which participants engaged in brainstorming as a group to generate as many solutions as possible to specific problems.
- D. Proposed solutions were discussed and evaluated.

 Participants who had a specific problem in their own caregiving situation selected a solution to implement and agreed to report the results to the group the following week.
- E. The problem-solving process was summarized, and caregivers were encouraged to implement the problem-solving process in their everyday lives and particularly in the caregiving situations that were stress-producing for them.

Session 4. Session four was planned to focus on assertiveness for caregivers. However, the speaker was unable to attend so the facilitator led a group discussion. The focus of the discussion was on the frustration and anger that caregivers experience in dealing with the manipulative behavior of the one they care for. At the close of the session caregivers were asked to relate an experience using the problem-solving method (presented in session 3) in their caregiving situations.

Session 5. The fifth session featured a speaker who is an experienced caregiving daughter of a victim of Alzheimer's disease. The

topic of the presentation was "caregiver well-being". The discussion following the presentation focused on feelings of guilt that caregivers experience when they allow time for their personal concerns.

Caregivers were encouraged to look after their own physical and emotional needs (i.e., by going away for a weekend or by getting help with caregiving tasks).

Session 6. During the sixth session a clinical psychologist spoke on depression and guilt related to the burden of caregiving. The lecture included symptoms of depression that caregivers often experience (e.g., lack of appetite, loss of energy, feelings of helplessness and hopelessness). The discussion which followed focused on feelings of frustration and anger associated with caregiving that often lead to caregivers' feelings of guilt and remorse.

Session 7. Session seven focused on managing behavioral problems of the care-receiver and the negative feelings that these behaviors produce in the caregiver. The speaker was a licensed social worker from a local hospital who participated in the second hour of group discussion. The group facilitator emphasized the importance of using the problem-solving method presented in session three for caregivers trying to manage the behavioral problems of the one they care for.

Session 8. Session eight featured a speaker who was an activities director for an adult day health care center. The director explained the day-time respite program in which caregivers may obtain respite from caregiving by bringing their care-receiver to the day care center. This topic was of particular interest to several group members

who were considering placing their care-receivers in either a day care center or in board and care.

Session 9. At the ninth and final session the group of caregivers enjoyed a light lunch and then participated in a review of the problem-solving method. Caregivers reported on their experiences in applying the method to their own lives. Caregivers also gave an informal verbal evaluation of the caregiver support group sessions which they had just completed. The session closed with participants completing the written posttest.

RESULTS

Comparison of Experimental and Control Groups: Pre-test Scores

There were no significant differences between the caregivers who participated in the caregiver support group and those who participated in the control group in terms of marital status, caregivers' age, mean number of other people living in the caregivers' home, level of education, occupational status, caregiver's relationship to the care-receiver, mean age of care-receiver or resident status of the care-receiver. However, differences were found in the mean number of family members or friends who assist the caregiver with caregiving tasks, with the control group having twice as many (see Table 2.)

Scores on the Index of Independence in Activities of Daily Living (ADL) indicate the functional dependence of the care-receiver upon the caregiver. Caregivers in the two groups were fairly evenly divided on the number of functions they perform for their care-receiver. (ADL scores are summarized in Table 3.)

Caregivers in the control group received slightly more assistance with caregiving tasks than did caregivers participating in the caregiver support group. (Table 4 summarizes the type and amount of assistance that caregivers in both groups received.)

T-tests revealed no significant differences between the experimental group and the control group when comparing pre-test scores on perceived level of strain, self-efficacy, and life satisfaction. Caregivers in the control condition scored slightly lower at pre-test than support group

TABLE 2

Comparison of Mean Number of Family Members Who Assist With

Caregiving Tasks

	Exp.	Control	Т	2-Tail
	(n=9)	(n=9)	Value	Probability
Variable	x	Χ̄	(df=16)	
Assistance	.77	1.33	-2.95	.02

TABLE 3

Activities of Daily Living

Number of Activities*	Total	Experimental	Control	
	(n=18)	(n=9)	(n=9)	
	<u> </u>	<u> </u>	<u> </u>	
,				
1	4	2	2	
1-2	5	· 3	2	
3-4	4	1	3	
5-6	5	3	2	

^{*} Measure of level of care-receivers' functioning in the following areas: bathing, dressing, going to toilet, transferring, continence and feeding.

Table 4

Type of Assistance Caregivers Receive From Friends and Family

	Total		
	Group	Experimental	Control
	(n=18)	(n=9)	(n=9)
House/Maintanence:	9	6	3
Management of Financi	al		
Affairs:	2	0	2
Meal Preparation:	7	3	4
Personal Care:	5	3	2
Respite:	1.1	6	5
Shopping:	4	1	3
Social Activities			•
for Care-receiver:	11	5	6
Transportation:	5	1	4
Total:	54	 25	29

participants on perceived level of strain and somewhat higher on life satisfaction. (See Table 5.) In summary, then, the two groups were fairly comparable on demographics, the activities of daily living, perceived level of strain, self-efficacy and life satisfaction.

Comparison of Experimental and Control Groups: Posttest Scores

Contrary to expectation, posttest results were similar to pre-test results in that there were no significant differences between the two groups on perceived level of strain, self-efficacy, and life satisfaction. (These data are summarized in Table 6.) The specific hypotheses are addressed below.

The first hypothesis, that participation in a caregiver support group would facilitate a decrease in perceived level of strain, was not supported. As Table 7 shows, there was no significant decline in scores for strain for those who participated in the caregiver support group.

The second hypothesis was that training in problem-solving would facilitate an increase in perceived self-efficacy. As Table 7 shows, participation in the caregiver support group did not result in a significant increase in self-efficacy. However, posttest scores reflected a slight (but not significant) increase in both self-efficacy and life satisfaction at posttest. Although a specific hypothesis was not formulated regarding life satisfaction, results showed that there was a slight (but not significant) increase in life satisfaction as well.

The third hypothesis was that a decrease in perceived level of strain, which was expected to result from participation in the caregiver support group, would be significantly correlated with an increase in self-efficacy

TABLE 5

Comparison of Strain. Self-Efficacy and Life Satisfaction at Pre-test For Experimental and Control Group Subjects (n=18)

Group

Variable	Exp. (n=9) X	Control (n=9) X	T Value (df=1	2-Tail Probability 6)
Strain	20.000	18.556	1.26	.277
Self-Efficacy	92.778	92.777	0	1.000
Life Satisfaction	10.667	13.111	-1.22	.240

TABLE 6

Comparison of Strain, Self-Efficacy, and Life Satisfaction at Posttest

Variable	Exper.	Control	Т	2-Tail
	(n=9)	(n=9)	Value	Probability
	X	Σ̄	(df=16)	
Strain	20.5556	19.444	.80	.443
Self-Efficacy	95.000	102.222	-1.12	.278
Life Satisfaction	12.5556	12.778	10	.924

Table 7

Comparison of Strain, Self-Efficacy and Life Satisfaction from Pre-test to Posttest

Experimental Group (n=9)					
				2-Tail	
Variable	Pre-test	Posttest	T Value	Probability	
	, x	x	(df=8)		
Strain	20.000	20.555	-1.05	.325	
Self-Efficacy	92.778	95.000	72	.494	
Life Satisfaction	10.667	12.556	-1.29	.234	
Control Group (n	<u>1=9)</u>				
				2-Tail	
Variable	Pre-test	Posttest	T Value	Probability	
g and the second	x	×	(df=8)		
Strain	22.556	20.444	.59	.569	
Self Efficacy	92.777	102.222	2.37	.135	
Life Satisfaction	13.111	12.778	.52	.620	

and life satisfaction. Participation in the support group did not result in declines in perceived level of strain or in a significant inverse correlation between level of strain with self-efficacy and life satisfaction. (See Table 8.).

Surprisingly, there was a significant correlation found at posttest between life satisfaction and perceived level of strain (r=-.67, p<.03) in caregivers who participated in the control condition (see Table 9). A similar but nonsignificant correlation was found at posttest between life satisfaction and perceived level of strain (r=-.54, p<.06) in caregivers who participated in the caregiver support group (see Table 8). In other words, these results suggest that caregivers' perceived level of strain may be associated with level of satisfaction.

Overall, results of this study show that strain did not decrease in the caregivers who participated in the support group--however, these caregivers did show a nonsignificant improvement on self-efficacy and life satisfaction. Also, a strong but nonsignifiant negative correlation approaching significance was found between perceived level of strain and life satisfaction in the caregivers who participated in the support group (although this trend was also apparent in the experimental group's pre-test scores and in the control group's pre-test scores).

Table 8

Correlations Between Caregivers' Perceived Level of Strain, Self-Efficacy. And Life Satisfaction (LSAT) in Experimental Group Subjects (n=9)

	Pre-test		
	Self-Efficacy	LSAT	
	, r	r	
Strain	.04	53	
•	p=.456	p=.070	
	Posttest		
	Self-Efficacy	LSAT	
	. r	r	
		·	······································
Strain	.15	54	
	p=.353	p=.066	

Correlations Between Caregivers' Perceived Level of Strain. Self-Efficacy, and Life Satisfaction (LSAT) in Control Group Subjects (n=9)

TABLE 9

	Pre-test		
	Self-Efficacy	LSAT	
	r	r	
			<u> </u>
Strain	.33	21	
	p=.195	p=.292	
	Posttest		,
	Self-Efficacy	LSAT	
	r	r .	
Strain	.49	67	
	p=.090	p=.025	

DISCUSSION

This study was undertaken to examine possible mediating effects of support group participation among informal caregivers of the frail elderly.

Based upon the results of this study, the hypothesis that participation in a caregiver support group would facilitate a decrease in the level of perceived strain cannot be supported. Rather, the results show that the perceived level of strain increased in the support group participants and decreased slightly in the caregivers in the control condition over the nineweek period. There are several possible explanations for the direction of these data. First, the strain that caregivers were experiencing at the onset may not have been evaluated effectively. The instrument used to measure strain (Robinson, 1983) focused primarily on situational and physical aspects of caregiving (i.e., the inconvenience and confinement of caregiving, physical strain, restrictions on caregiver's free time, and family adjustments) and not on the emotional strain and feelings that caregivers in the support group seemed to be experiencing (i.e., feelings of frustration, guilt, anger; and depression). And, although this current instrument offers valuable information about the caregiving situation, the results of this study may not be significant because it is unlikely that the physical demands upon a caregiver would change significantly within a nine-week period. Second, group participants may have begun to focus more attention on problems related to their caregiving situation because of participation in the caregiver support group which may have resulted in increased levels of perceived strain. Other factors to consider when looking at these results are that this study is based on a small sample

size. Furthermore, the results here differ from less controlled studies which have used only a post-evaluation instrument but nevertheless conclude there is a positive relationship between participation in a caregiver support group and decreased levels of perceived caregiver strain (Cohen, 1983; Levy et al., 1980; Zarit, 1980).

The hypothesis that training in problem solving will facilitate an increase in perceived self-efficacy was not supported by the results of the current study. This may in part be explained by the difficulty in utilizing the general self-efficacy instrument (Woodward & Wallston, 1987) to evaluate caregiver self-efficacy, since the measure was designed to be a general measure of desire for control in a cross-sectional comparison of adults aged 20 to 99 years. It is suggested that a specific measure developed to address situations familiar to caregivers would more accurately assess their level of self-efficacy.

The hypothesis that a decrease in the perceived level of strain is negatively correlated with an increase in self-efficacy was not suggested by these findings. It must be noted that past research has merely suggested the possible correlation between caregiver strain and self-efficacy (Lovett et al., 1986; and Zarit et al., 1985). For example, in these less-controlled studies in which caregivers received training in problem solving skills aimed at increasing their self-efficacy, results were not conclusive. As was suggested earlier, there is a need for a more precise instrument to evaluate caregiver self-efficacy and caregiver strain.

The results of this study do not support the hypothesis that a decrease in the perceived level of strain is significantly correlated with an

increase in life satisfaction. However, a significant negative correlation was found between caregivers' life satisfaction scores and scores measuring perceived level of strain in control group subjects. Although not significant, the results also suggest a correlation between perceived level of strain and life satisfaction in caregivers who attended the caregiver support group sessions. Previous research has demonstrated that caregivers' life satisfaction is influenced by the demands of their caregiving situation (Cantor, 1983; Slivinske & Fitch, 1987), however, past reseach has not looked at the direct relationship between caregiver strain and caregiver's life satisfaction. It was also found in the current study that while not significant, participating caregivers' life satisfaction scores increased slightly from pre-test to posttest, while there was a slight decrease in life satisfaction scores of caregivers in the control condition from pre-test to posttest. It is possible that caregivers who did not participate in the caregiver support groups were experiencing additional strain in their caregiving situations during the nine-week period or that possibly their lower health ratings influenced their lower life satisfaction scores at posttest. However, this difference between the life satisfaction scores of caregivers participating in the support group sessions and the scores of those in the control condition tends to reinforce the benefits of participation in a caregiver support group.

Although they are not significant, these results suggest a correlation between participating caregivers' life-satisfaction scores and scores on the activities of daily living measure. Caregivers in both the support group and those in the control condition who had high life satisfaction

scores also had correspondingly fewer activities of daily living to perform for their care-receiver. Previous research has shown that the constant demand for attention to caregiving duties produces feelings of helplessness and hopelessness in caregivers (Cantor, 1983; George & Gwyther, 1986) and that caregiving places an enormous emotional burden on the caregiver (Gallagher et al., 1988). However, recent research has focused primarily on caregiver well-being and has not looked at caregivers' life satisfaction. It is therefore suggested that future research look at interventions that will further assist the caregiver with caregiving tasks in order to increase the caregiver's life satisfaction. An increased level of life satisfaction should also enable the caregiver to relate in a more positive manner with the care-receiver. This has strong implications for the care-receiver who will benefit from a better quality of physical care as well as from improved social interaction with his or her caregiver.

Although the results of this study do not support the notion that participation in a caregiver support group facilitates a decrease in perceived level of caregiver strain, the results suggest that improvements in participating caregivers' life-satisfaction scores at the end of the nine-week support group sessions and the negative correlation with caregivers' perceived strain at posttest may be the result of positive changes in their caregiving situation. For example, caregivers may have been demonstrating benefits of participating in the caregiver support group sessions, such as: 1) they may have begun to use the problem-solving or behavioral-management techniques that were introduced

during the caregiver support group sessions, or 2) they may have obtained supportive services to assist them with caregiving duties (i.e., homemaker service or respite care), or 3) they may have benefitted from the increased social support resulting from interacting with other group members during the support group sessions. Common comments from group participants were that not only did they feel better to hear that someone else in the group was in a more difficult situation than they were, but also they were able to find humor in situations that had previously made them feel frustrated and angry.

The demographics for the caregivers were fairly similar in several areas: marital status, number of other people living in the household, number of years of education, occupational status, age of the one they care for, living-status with the care-receiver, and the type of impairment of the care-receiver (i.e., dementia, stroke, frail). The group of caregivers consisted of sixteen women and only two men. More than half of the caregivers co-resided with their care-receiver, and most caregivers had some education after high school. Half of the caregivers were employed in either clerical or professional positions, and the other half were retired. Slight differences were found in two other areas: participating caregivers reported slightly better health than those in the control condition, and the mean age of the support group participants was three years older than the mean age for caregivers in the control condition. However, an important significant difference was found in the number of persons caregivers in the support group could call upon for assistance with caregiving duties as opposed to the number which caregivers in the

control condition could call upon. The caregivers participating in the support group indicated they had half the number of family members or friends to call upon for assistance with caregiving duties as did the caregivers in the control condition.

A major problem with this study was the diversity among the caregiver participants both in the support group and in the control condition. The 18 caregivers who volunteered to participate in the study were a mix of caregivers for spouses, parents, and close friends. Often the needs and concerns of spousal caregivers are different from those of adult children and close friends. That is to say, spousal caregivers are often dealing with frustration regarding their sexual and personal needs; caregiving children are concerned about being caught in the middle between their parent's needs and those of their own children; and, finally, caregiving friends most often do not co-reside with their care-receiver and may experience less emotional turmoil than that experienced by family caregivers. These differences create a problem in group discussions where mutual concerns are the focus. It is recommended that future research allow for a more aggressive volunteer-subject recruitment program in order to obtain a larger number of participants who could be included in three separate caregiver support groups: a spousal group, an adult child group, and a group for close caregiving friends.

Another consideration when evaluating the outcome of this study is that since both men and women were included in each of the two groups, there may be differences within the groups of caregivers because of their sex. Research evidence has shown that adult caregiving daughters assume different tasks when performing the caregiving role than do caregiving sons (Brody et al., 1984). For example, caregiving daughters assist their care-receiver with personal needs such as toileting and dressing while sons frequently assist with transportation and financial management. It is therefore suggested that future research looking at caregiver strain allow for subjects to be divided into groups according to sex so that more accurate assessment of possible helpful interventions can be made.

Participating subjects in the caregiver support group assisted their care-receivers in the activites of daily living (e.g., bathing, dressing, toileting, transfer, and feeding) more often than caregivers in the control condition. However, there was no difference between the two groups of caregivers in regards to caregivers who were caring for an incontinent care-receiver. Results of the present study show that caregivers participating in the support group had limited assistance with caregiving tasks. This suggests that there may be an association between the high number of activities of daily living support group participants performed for their care-receiver and the caregivers' perceived level of strain.

A major consideration in evaluating the outcome of this research is that this intervention differed in several ways from typical caregiver support groups, and this may account for the modest results. Although support and participant sharing were included in the treatment plan, considerable time and emphasis were placed on the teaching of problem-solving skills. It could be concluded that this approach is not as

successful as one that focuses on support and the sharing of information by the caregivers themselves. With respect to the length of the treatment, nine weeks may have been too brief a period to demonstrate positive effects of participating in a caregiver support group. Other studies have shown positive results in groups in which caregivers participated in support groups for a longer period of time (Lovett et al., 1986; Schmidt & Keyes, 1985). Subjects in these studies often have ongoing contact with respite care programs for their care-receiver. This contact may facilitate lover levels of perceived strain among participating caregivers.

New behaviors and skills take time to assimilate, and caregivers may have only begun to use the problem-solving techniques they were exposed to in the caregiver support group sessions. In addition, many problem situations are not quickly resolved and may require that the caregiver try several solutions before finding the one that will solve the problem. In fact, it appeared that when the group sessions ended, several caregivers were only just beginning to make changes in behavioral patterns and to follow-up on community resources. Several participating caregivers indicated that they would like to continue attending caregiver support group sessions when new groups are offered. This suggests the need for a longer treatment period and a continuing need for the ongoing support of the group.

An overriding problem in this study was the difficulty in obtaining a sufficient number of volunteer caregiver participants. Volunteers were respondents to an article which appeared in the local newspaper and in the monthly newsletter of the senior center in which the group meetings

were held. Another problem was that group meetings were held in the afternoon which made it difficult for some caregivers who had no one to stay with their care-receiver while they attended the group. Also, the group sessions began in the hottest part of the summer which may have discouraged some potential participants.

A major difference between this study and several other research efforts is that research conducted at large Universities with gerontological research departments may include subjects who may have higher expectations for improvement following treatment (Zarit et al., 1985; Lovett et al., 1986) than subjects recruited for the present study.

A problem common to research designs using volunteer subjects is that the decision to volunteer may exemplify that participants are already more in control of their lives and are more self-efficacious than those who do not choose to volunteer. Volunteer subjects may also be more assertive by nature, and this may enable them to obtain assistance with their caregiving tasks. Another possibility is that volunteers might be seeking help because they are experiencing an extreme amount of strain. Subjects in the support group and in the control condition were all volunteers in the sense that they initially responded to advertising for the support group sessions, even though some decided not to join the group. These individuals, however, did agree to participate in the control condition.

The results of this study also raise questions about whether existing measures of strain are sensitive to the types of change occurring in interventions with caregivers. Previous studies have shown that

caregivers rate positively those strategies which deal with their situation and reportedly feel more supported even though overall ratings of stress do not change (Zarit et al., 1987; Zarit et al., 1980). A shortcoming of the current study is that participating caregivers were not given the opportunity to indicate how they rated strategies introduced in the support group setting for dealing with their caregiving situations. It is recommended that future research efforts offer an opportunity for a general written evaluation of the treatment program at its conclusion.

Conclusion

As people begin to live longer, the number of those who are assuming the role of informal caregiver is rapidly increasing. The intense physical and emotional strain that caregivers experience often brings the family to prematurely make the decision to institutionalize their loved one. Frequently the care-receiver's health declines rapidly after institutionalization, and as a result the caregiver experiences feelings of guilt and remorse about the decision. Caregiving involves not only the two-person dyad of caregiver and care-receiver, but it also impacts the entire family system. It is recommended that future interventions include as many family members as possible who are impacted by the caregiving situation. It is imperative that interventions be developed to assist caregivers with their difficult role, and that future research continue to look at methods that will increase supportive services for caregiving families. It is also important for the public sector and the private sector to become educated as to the needs and concerns of informal caregivers in order to generate necessary funding for supportive services to assist

caregivers (e.g., support groups, in-home services, respite care, legal services, individual and group counseling for family members, training in problem-solving, and behavioral management). These supportive services will serve to improve the quality of life for both caregiving families and also for the one for whom they care.

APPENDIX A RECRUITMENT ARTICLE

Workshops offered for

care givers

SAN BERNARDINO—
The Highland District Council on Aging Inc. and Senior Outreach Program will present a series of free workshops for people who are caring for a frail or mentally impaired older, relative, from 1:30 to 3:30 p.m. Wednesdays at the Highland Senior Center, 3102 E. Highland Ave.

Attorney Bob Holcomb will speak on "Legal Issues for Caregivers" at the meeting this Wednesday.

"Topics to be addressed at upcoming sessions include: "Depression and Guilt," "Managing Behavior Problems," "Assertiveness and Communication," "Caregiver Stress Management" and "Problemsolving."

For information, call the Highland Senior Center, (714) 862-8104, or Senior Outreach, (714) 874-9330.

APPENDIX B

CAREGIVER STRAIN INDEX

The following is a list of things which other people have found to be difficult in helping to care for a loved one. Would you please indicate whether any of these apply to you by placing an X in the "Yes" column when you agree and in the "No" column when you disagree.

	<u>Yes</u>	<u>No</u>
Sleep is disturbed (e.g., because		
is in and out of bed or wanders around at		
night).	·	<u></u>
It is inconvenient (e.g., because		
helping takes so much time or it's		
a long drive over to help).		
It is a physical strain (e.g., because		
of lifting in and out of a chair; effort		
or concentration is required.		
It is confining (e.g., helping restricts free		
time or cannot go visiting).		

APPENDIX B (continued)

There have been family adjustments	
(e.g., because helping has disrupted	
routine; there has been no privacy).	
There have been changes in personal plans	
(e.g., had to turn down a job; could	
not go on vacation).	
There have been other demands on my	
time (e.g., from other family members).	
There have been emotional adjustments	
(e.g., because of severe arguments)	
Some behavior is upsetting (e.g., because	
of incontinence;has trouble	
remembering things; oraccuses	
people of taking things).	
It is upsetting to findhas changed	•
so much from his/her former self (e.g., he/she	
used to be).	

APPENDIX B (continued)

There have been work adjustments (e.g.,	•
because of having to take time off).	
It is a financial strain.	
Feeling completely overwhelmed (e.g.,	
because of worry about;	
concerns about how you will manage)	

APPENDIX C

THE DAILY LIVING SELF-EFFICACY SCALE

Below are 13 situations that you might experience in daily living. For each situation that is true for you circle the number that best describes how confident you would feel in your ability to handle each specific situation. For each situation that is not true for you circle the number that best describes how confident you would feel in your ability to handle the situation if you had to.

- 1. You want a job where you have a lot of control over what you do and when you do it. How confident are you that you could handle this?
 - 1 2 3 4 5 6 7 8 9 10
- 2. In general you avoid situations where someone tells you what to do. How confident are you in your ability to know what to do on your own?
 - 1 2 3 4 5 6 7 8 9 10
- 3. If you had the chance, you would want to have as much of a say in running the government as possible. How confident are you that your input is important?
 - 1 2 3 4 5 6 7 8 9 10

APPENDIX C (continued)

4.	4. If you had the chance, you would rather be a leader than a follower.									
Ho	w con	fident	t are yo	u in yoเ	ır abil	ity to be	a lead	er?		
					$\overline{}$					
	1.	2	3	4	5	6	7	8	9	10
5.	Wher	the o	chance	arises, <u>y</u>	you w	ant to b	e able t	o influ	ience t	he actions
of	others	. Ho	w confic	dent are	you t	hat you	could i	nfluen	ce oth	ers?
	1	2	3	4	5	6	7	8	9	10
										,
6.	In ge	neral	day-to-d	day situ	ations	you wa	ant to m	ake y	our ow	n decisions
Нс	w cor	ifident	t are yo	u in you	ır abil	ity to de	cide?			
	1	2	3	4	5	6	7	8	9	10
7.	In ge	neral,	you av	oid situa	ations	wfhere	someo	ne els	se tells	you what
yo	น shoเ	ıld be	doing.	How c	onfide	nt are y	ou in y	our at	oility to	know wha
yo	u shoi	uld be	doing	without	the h	elp of so	omeone	else'	?	
			•						,	
	1	2	3	4	5	6	7	8	9	10
										•

APPENDIX C (continued)

8.	In ger	neral (day-to-c	lay situa	ations	you wa	ınt to ha	ave cor	ntrol ov	er your
de	stiny.	How	confide	nt are y	ou tha	at you w	ill be a	ble to i	nfluenc	e your
de	stiny?									
	1	2	3	4	5	6	7	8	9	10
9.	In ge	neral	day-to-c	day situ	ations	you fee	el more	capab	le (of h	andling
the	em) tha	an oth	ers are	. How	confid	ent are	you in y	our ab	ility to	
ha	ndle s	ituatio	ns <u>bett</u>	<u>er</u> than	others	s?				
			,							
	1	2	3	4	5	6	7	8	9	10
10	. In ge	neral	day-to-	day situ	ations	s you pr	efer to	do son	nething	about a
pro	blem	rathe	r than s	it by an	d let it	continu	ue. Hov	v confi	dent ar	e you
tha	at you	could	solve t	he prob	lem?					
	1	2	3	4	5	6	7	8	9	10
					•			٠		
11	. In g	enera	l day-to	-day sit	uation	ıs you v	vould ra	ther gi	ve orde	ers than
rec	ceive t	hem.	How co	onfident	are y	ou in yo	our abili	ty to gi	ve effe	ctive
ord	ders?				·					
						•				
	1	2	3	4	5	6	7	8	9	10

APPENDIX C (continued)

12. You would rather run your own business than listen to someone else's orders. How confident are you in your ability to run your own business on your own?

1 2 3 4 5 6 7 8 9 10

13. In general day-to-day situations you would like to get a good idea of what a job is all about before you begin. How confident are you in your ability to find out what a job is all about?

1 2 3 4 5 6 7 8 9 10

APPENDIX D

LIFE SATISFACTION INDEX

Here are some statements about life in general that people feel differently about. Would you read each statement on the list, and if you agree with it, put a check mark in the space "Agree." If you do not agree with a statement, put a check mark in the space "Agree." If you do not agree with a statement, put a check mark in the space under "Disagree." If you are not sure one way or the other, put a check mark in the space "?." Please be sure to answer every question on the list.

		Agree	Disagree ?
1.	As I grow older, things seem		
	better than I thought they would be.		·
2.	I have gotten more of the breaks in		
	life than most of the people I know.		
3.	This is the dreariest time of my life.		
4.	I am just as happy as when I was		
	younger.		
5.	My life could be happier than it is	,	
	now.		

APPENDIX D (continued)

6.	These are the best years of my life.			
7.	Most of the things I do are boring			
	or monotonous.			
8.	I expect some interesting and			
	pleasant things to happen to me			
	in the future.		·	
9.	The things I do are as interesting			
	to me as they ever were		· · · · · · · · · · · · · · · · · · ·	
10	. I feel old and somewhat tired.			
11	. I feel my age, but it does not			
	bother me.			
12	. As I look back on my life I am			
	fairly well satisfied.			
12	. I would not change my past life			
13				
	even if I could.			

APPENDIX D (continued)

14. Compared to other people my age,I've made a lot of foolish decisions in my life.	 	
15. Compared to other people my age, I make a good appearance.		
16. I have made plans for things I'll be doing a month or a year from now.	 	
17. When I think back over my life, I didn't get most of the important things I wanted.	 	
18. Compared to other people, I get down in the dumps too often.		
19. I've gotten pretty much what I expected out of life.		
20. In spite of what people say, the lot of the average man is getting worse, not better.		

APPENDIX E

THE INDEX OF INDEPENDENCE IN ACTIVITIES OF DAILY LIVING

We are interested in the functioning independence or dependence of the person you are caring for. For each area of functioning listed below, check the description that applies. (The word "assistance" means supervision, direction of personal assistance.)

Bathing--either sponge bath, tub bath, or shower.

Receives assistance Receives no assistance Receives assistance (gets in and out of tub in bathing only one in bathing more by self if tub is usual part of the body than one part of (such as back or leg). the body. means of bathing).

<u>Dressing</u>--gets clothes from closets and drawers--including under-clothes, outer garments and using fasteners (including braces if worn).

Gets clothes and gets Receives assistance Gets clothes and gets completely dressed dressed without without assistance. assistance except for assistance in tying shoes.

in getting clothes or in getting dressed, or stays partly or completely dressed.

APPENDIX E (continued)

<u>Toileting</u>--going to the "toilet room" for bowel and urine elimination; cleaning self after elimination, and arranging clothes.

Goes to "toilet room" Receives assistance cleans self & arranges in going to "toilet clothes without room" or in cleansing assistance self or in arranging clothes after elimina-(may use object for tion or in use of night support such as cane, walker or wheelchair & bedpan or commode. may manage night bedpan or comode, emptying same in morning).

Doesn't go to room termed "toilet" for the elimination process.

Transfer

Moves in and Moves in or out of bed as well out of bedor chair as in and out ofchair with assistance. without assistance (may be using object for support such as cane or walker).

Doesn't get out of bed

APPENDIX E (continued)

Continence

Controls urination and bowel movement completely by self.

Has occasional "accidents" control; catheter is used, or is incontient.

Supervision helps keep urine or bowel

Feeding

Feeds self without assistance.

Feeds self except for getting assistance in cutting meat or butter- partly or completely ing bread. intravenous fluids.

Receives assistance in feeding or is fed by using tubes or

APPENDIX F

DEMOGRAPHIC INFORMATION

1.	 Please circle the one that applies to you: 								
	married	S	single	wide	wc	widow	er/		
2.	Your ag	je:	· · · · · · · · · · · · · · · · · · ·						
3.	3. For someone your age, do you consider <u>your</u> health:								
1	2	3	4	5	6	7	8	9	10
ve	ry								excellent
ро	or					·			
4.	4. Number of family members living in your home:								
5.	Number	r of ye	ears of	school	you h	ave co	mplete	d (circ	cle one):
	1-8								
	9-12								
	some co	ollege	!						
	college	gradu	uate						
	postgra	duate		*					•

APPENDIX F (continued)

6.	Please circle the one tha	t applies to you:	
	Employed full time	Employed part time	Homemaker
	Independent Income	Low Income	Retirement
·			
7.	Number of family member	ers you can call on for help	with caregiving
	responsibilities (e.g., stay	ying with one you care for s	so that you can
	go		
	out, or taking the one you	u care for to the doctor):	•
	r		
8.	If employed please indic	cate occupation:	•
	If retired please indicate	previous occupation:	
۵	What is your relationship	to the one you are caring	
	?	to the one you are caring	
101	*		
10	. The age of the person y	ou are caring for:	•
11	. Where does the one rec	ceiving care, live?	
	•		
	In my home	Convalescent hom	е
	Independently	Other, Specify	

APPENDIX F (continued)

12. What help, if any, are you	u currently receiv	ing for the caregiving	g fron
relatives and/or friends? If the	e answer for the	item is yes, place a	
check mark under "Yes" if the check mark under "No."	answer for the i	ems is no, place a	
13. Physical and emotional h	nealth of person	you are caring	
			°
Type of Assistance			
	<u>Yes</u>	<u>No</u>	
a. Housekeeping/			
Maintenance			
b. Management of			
Financial Affairs			
c. Meal Preparation			
d. Personal Care of			
patient.			

APPENDIX F (continued)

e. Respite (time		*
away from patient)		
f. Shopping (grocery)		
g. Social/Recreational		
activities for patient	 	
h. Transportation	 <u> </u>	
i. Other, please specify:		

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