

The Role of Social Support  
in the  
Adjustment of Elderly Caregivers

by

Barbara LeBow

A thesis submitted to the faculty of Graduate Studies  
the University of Manitoba  
in partial fulfillment of the requirements for the degree of  
Master of Social Work  
School of Social Work  
University of Manitoba

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## ABSTRACT

Fifty-five randomly selected elderly primary caregivers were given the following tests - Perceived Support Network Inventory, Rosenberg Self-Esteem Scale, Beck Depression Inventory, Family Crises Oriented Personal Evaluation Scales, Zarit Burden Inventory and the Instrumental Activities of Daily Living Scale. It was found that social support plays a role in the adjustment of elderly caregivers to the caretaking role. Caregiver adjustment is enhanced by an increase in network size, by reciprocity of support and by receiving material aid from network members.

Respite is the greatest need voiced by this sample, while the most stressful part of providing care for this group is not having time for themselves, for their interests, and for other family responsibilities.

It was concluded that more research is needed which clarifies and specifies the impact of caretaking on the elderly. As well, the ways in which these individuals are able to utilize both formal and informal sources of support in order to deal with this particular stressor need further examination.

## INTRODUCTION

In 1949 Hill formulated the ABCX family crisis model. In his classic research on war-induced separation and reunion (1949, 1958), he outlined a set of major variables and their relationships which have remained virtually unchanged for over 35 years. There are two parts in his framework. First, a set of theoretical statements regarding crisis:

A (the event and related hardships)-interacting  
with B (the family's crisis meeting resources)-  
interacting with C (the definition the family  
makes of the event)-produce X (the crisis).

The second part consists of statements relating to:

the course of family adjustment which is said to  
involve (1) a period of disorganization, (2) an  
angle of recovery, and (3) a new level of organ-  
ization.

Since 1970, family stress research (Burr, 1973; Lipman-Blumen, 1975; Hansen & Johnson, 1979; Boss, McCubbin & Lester, 1979) has rendered empirical support to Hill's original conceptualizations.

The Double ABCX Model, which emerged from studies of war-induced family crises (McCubbin & Olsen, 1980; McCubbin & Patterson, 1982, 1983),



expands upon Hill's original ABCX Model and adds post-crisis variables in an effort to describe: (a) the additional life stressors and changes which may influence the family's ability to achieve adaptation; (b) the critical psychological and social factors families call upon and use in managing crisis situations; (c) the processes families engage in to achieve satisfactory resolution; and (d) the outcome of these family efforts (McCubbin & Patterson, 1983).

These ABCX Models serve as the theoretical framework for this exploratory study. The A phase is the caretaking role with B being personal psychological and support network variables interacting with the definition the caregiver makes of the event (C). The outcome (X) is how the caregiver is adjusting.

Research conducted to date reveals a concerted effort to identify which families, under what conditions, and with what resources are better able to cope with the hardships of family life. The major domains of research are family response to non-normative events, such as wars (McCubbin, Hunter & Dahl, 1975; McCubbin, Dahl, Lester, Benson & Robertson, 1976), natural disasters (Drabeck, Key, Erickson & Crowe, 1975), or chronic illness in children (McCubbin & Patterson, 1982) and family response to normative transitions over the life span, including parenthood (Russell, 1974; Hobbs & Cole, 1976), child launching (Aldous, 1978), post-parenthood (Burr, 1970; Rollins & Feldman, 1970; Harkins, 1978), retirement (Fengler, 1975; George, 1980) and widowhood (Lopata, 1973; Glick, Weiss & Parkes, 1974). Another domain of research is the

nature and importance of psychological resources and of social support in the management of stress. These will be briefly examined in the next section.

### Social Support

The role of the social network and the perceived support it offers to alleviate or mediate the effects of stress have emerged as major areas of family stress research in the last two decades. Studies have focused upon three major lines of inquiry. First, what is social support? Second, what kinds of social networks offer support to the family or individuals within the family in times of stress? Third, in what ways and for which types of stressor events is social support a mediator of family stress?

#### What is Social Support?

The concepts social support, social network, and personal network have been variously defined. Cobb (1976) views social support as information exchanged at the interpersonal level which provides (1) emotional support, leading the individual to believe that (s)he is cared for and loved; (2) esteem support, leading the individual to believe (s)he is esteemed and valued; and (3) network support, leading an individual to believe (s)he belongs to a network of communication involving mutual obligation and understanding.

Moss (1973) defined social support as the subjective feeling of belonging, of being accepted, of being loved, of being needed all for one's self. Gelein's (1980) definition is an enduring pattern of continuous or intermittent ties that play a significant part in maintaining the psychological and physical integrity of an individual over time.

A classical definition of a social network is a specific set of persons with the property that the characteristics of these linkages as a whole may be used to interpret the social behavior of the persons involved (Mitchell, 1969). Another conceptualization of social network is similar to Henderson's (1978) primary group - all kin, nominated friends, work associates, and neighbors.

The personal network has been defined as a support system involving the giving and receiving of objects, services, social and emotional supports defined by the receiver and the giver as necessary or at least helpful in maintaining a style of life (Lopata, 1975).

#### What Social Networks Offer Support?

Social support networks are classified as either formal or informal. The formal network provides the basic underpinning of services (income, medical care, housing) while the informal network provides assistance to further meet needs related to the activities of daily living.

During the 1970's, three categories of informal social networks came to be identified as primary: kin, friends, and neighbors. Research indicates that these networks perform specific tasks and that one network cannot readily be substituted for another in the performance of tasks (Rosow, 1967; Litwak & Szelenyi, 1969; Blau, 1973; Gordon, 1977; Dono, Falbe, Kail, Litwak, Sherman & Siegel, 1979).

Informal networks of social support potentially contribute to the well-being of older persons in many ways, including tangible assistance, fulfillment of social needs, bolstering of personal coping efforts, and provision of linkages to formal service networks (Ward, 1985).

According to Litwak (1978), the forging of linkages which maximize the service potential of both systems is crucial. He proposes that family and friends are best able to handle unpredictable and nontechnical tasks of living whereas organizations are best able to handle predictable and technical ones.

With regard to the elderly, Kulys & Tobin (1980) report that the aging are likely to look to friends for emotional closeness and to family members for instrumental help. Litwak & Szelenyi (1969) suggest that the social support system for the elderly can be divided as follows:

- . reliance on family for financial and long-term help,
- . reliance on neighbors for emergency or short-term help,
- . reliance on friends for emotional support.

Friend and Neighbor Networks. Arling (1976) discovered that morale is related to the number of friends and neighbors in the network, but not to contact with family members. Robertson (1976) found a positive relationship between interaction with friends and life satisfaction and happiness. Generally, interaction with friends is found to exert a positive influence on the morale of older persons (Adams, 1968; Larson, 1978). Involvement with a confidant is found to be more strongly and consistently related to personal adjustment than interaction with more casual friends (Lowenthal & Haven, 1968; Brown, 1974).

Neighbors of older people, especially in congregate living environments, appear to be a valuable source of social support (Rosow, 1967; Hochschild, 1973; Arling, 1976; Ferraro & Barresi, 1982). Researchers have noted the importance of neighbors' aid in the process of adjusting to widowhood, especially among those widows with higher education (Lopata, 1973, 1978).

Dono et al. (1979) found that unique support tasks can be performed by friends and neighbors, thereby enhancing the ability of older persons to remain independent for a longer period of time within the community. These supports are related to the structural features of the neighborhood such as proximity and regular face-to-face contacts. Proximity permits speed of reaction while face-to-face contact allows observation of changes in health and behavior (Cantor, 1979; O'Bryant, 1985).

The family network. Some researchers (Parsons, 1954; Gibson, 1972) challenged the idea that there exists a family network in contemporary industrialized societies. However, data from numerous studies testify to the extensiveness of family resource helping patterns (Sussman, 1965; Shanas, Townsend, Wedderburn, Friis, Mihoj & Stehouwer, 1968; Jackson, 1972; Cantor, 1979; Seelbach, 1979; Shanas, 1979; Morris & Sherwood, 1984). The elderly use the family as the first resource for social support, crisis intervention, and economic assistance (Miller, 1981).

Results demonstrate that families do not abandon their elderly, but perform support tasks responsibly (Shanas et al., 1968; Cantor, 1975; Morris & Sherwood, 1984). The majority of older people are not physically and socially isolated from their families (Litwak, 1960; Babchuk, 1978). Sussman (1965) stated:

The extended kin network is the basic social system in...urban society within which parent-adult child relationships are identified, described and analyzed ... The evidence also refutes the notion that nuclear family units are isolated and dependent upon the activities of other institutions and social systems (pg. 91).

The importance of family members in the support networks of the elderly has been documented in recent research as well (Streib & Beck, 1980; Stoller, 1982; Stoller & Earl, 1983). Troll & Smith (1976) state that

family bonds are strong over great distances and are characterized by obligation rather than shared interest, making them more durable than friendships. Modern technology provides the tools (telephones and airplanes) that help bridge geographic distances (Wellman, 1979).

### The Elderly in Good Health

Involvement with kin varies with stage in the life cycle (Schulman, 1975), but for the elderly in good health, frequent visits, letters or phone calls from adult children are the rule rather than the exception. Shanas (1973) demonstrated that over 80 percent of the elderly had one or more children with whom they visited frequently and who provided significant social and psychological support. Cantor (1975) also demonstrated that the elderly do maintain close ties with children, characterized by mutual affection and assistance.

Research establishes that older people typically live near, but rarely with, at least one child, interact frequently with their children, and are often involved in exchanges of mutual aid with their children as both providers and receivers (Shanas et al., 1968; Bultena, 1969; Hill, 1970; Shanas, 1973; Arling, 1976; Petrowsky, 1976; Powers & Bultena, 1976; Atchley, Pignatiello & Shaw, 1979).

Sibling relationships are significant especially for individuals who have never married or are childless. Often when people have no children, no surviving children, or have never married, their siblings

provide them with the kinds of support that others get from spouses and children (Lopata, 1973; Shanas & Maddox, 1976; Shanas, 1979). Troll, Miller & Atchley (1979) reported that married elderly without children tended to form closer relationships with their siblings upon the death of their spouses.

Roughly one unmarried old person out of ten lives with a relative. These relatives usually are brothers and sisters, who most often are themselves single or widowed. Cantor (1979) proposes that siblings, friends, and neighbors give support to elderly persons when spouses or children are not available.

#### The Impaired Elderly

The immediate family of the well older person is their major social support (Seelbach, 1979; Shanas, 1979). For the impaired elderly, caregiving by family members also is the norm (Shanas, 1962; Shanas et al., 1968; Sussman, 1976; Maddox & Dellinger, 1978; Silverstone, 1978; Shanas, 1979, 1979).

The amount of involvement and the role the family plays in the care of its ill elderly relative may vary depending on economic resources, family structure, quality of relationships, and other competing demands on family time and energy; however, most families, particularly the female members, provide substantial physical, emotional, social, and economic support (Shanas, 1960; Sussman, 1965; Brody, 1967; Shanas et



al., 1968; Weaver & Blenker, 1975; York & Calsyn, 1977, Treas, 1977; Morris & Sherwood, 1984). Families often look after their elderly without help from community service providers (Schmidt, 1980).

Older persons who live with their spouses in separate households rely primarily upon each other for assistance (Cantor, 1981; Johnson & Catalano, 1981). Older couples maintain their own intact household as long as possible and maintain considerable independence in the face of infirmities by nursing one another or reallocating household chores (Treas, 1977). The presence of the spouse is a major factor preventing institutionalization (Palmore, 1976). Among noninstitutionalized elderly who are bedfast or housebound, the spouse is the most frequent provider of care (Shanas, 1979). In a study of 158 couples, Stoller & Earl (1983) found that the networks of these elders increase in size and scope only when the functional capacity of either or both declines significantly.

Children, within and outside the household, are the next main source of assistance. Men, who are more likely than women to be married, are taken care of by their wives. Women, who are more likely to be widowed, are taken care of by their children, the most likely caregiver being an adult daughter.

Older persons who are only slightly or even moderately handicapped are likely to stay in their own homes, often alone, and receive help with transportation, meal preparation, shopping, and cleaning from nearby

children. It is middle-aged, female offspring who often provide the majority of support to their parents when both parents become frail or when one is widowed (Lopata, 1978; Shanas, 1979; Johnson, 1983; Stoller & Earl, 1983).

The prevalence of three-generation and even four generation families has increased (Troll, 1971). Members of different generations in families not only live near each other but interact significantly (Hagestad, 1980). Members of multigeneration families assist each other economically, visit frequently, and write and phone each other often (Bengtson, 1971; Wake & Sporakowski, 1972; Bengtson & Cutler, 1976; Sussman, 1976; Troll et al., 1979). Women more often than men, maintain kin contact and there are class differences in the types and frequency of contact. For example, visiting is more sex-segregated in working-class families than in middle-class families (Streib, 1968).

The cited research helps reconcile the paradox of the continuing importance of intergenerational kinship with the widespread notion of its historic decline. Parsons' (1965) later research led him to conclude:

The family can thus be seen to have two primary functions, not one. On the one hand it is the primary agent of socialization for the child, while on the other it is the primary basis of security for the normal adult. ...extended kin, especially members of the family of orientation but not only they, serve as a reserve of expectations of solidarity, and willingness to implement them, which can be mobilized in case of need (pgs. 35-36).

It is postulated that relatives provide assistance because of familial obligations (Cicirelli, 1981; Dunkle, 1983) or because the adult child views help to the parent as an opportunity to reciprocate for support provided in the past (Simmel, 1950; Cicirelli, 1981) or because parental caregiving provided a model of filial responsibility to the children (Dono et al., 1979; Cicirelli, 1981). Whatever the case, these supportive family networks, as well as friend and neighbor networks, are important resources for older people which protect them against the harmful effects of stress.

#### Social Support as a Mediator of Stress

Although some have argued that isolation has functional value for the elderly and is a result of voluntary disengagement (Cumming & Henry, 1961), it is increasingly believed that role loss is involuntary and results in loss of social identity, which might lead to pathology.

Evidence indicates that isolation and role loss are factors in the increased risk for morbidity and ultimate mortality among the elderly (Fischer, 1982). Indeed, a recent study found that decreased social interaction, impaired roles and attachments, and low perceived support were significant predictors of early mortality among the aged (Blazer, 1982).

Isolated elderly community dwellers tend to have poorer physical and psychosocial functioning than elderly individuals with support systems (Stein, Linn & Stein, 1982). Researchers have discovered that marriage, kin networks, and organizational affiliation generally operate to prevent suicide among the elderly (Maris, 1969; Bock, 1972).

Companionship and emotional support have been found to be important determinants of older adults well-being (Larson, 1978) and psychological adjustment to such age-related stressful events as widowhood and retirement (Lowenthal & Haven, 1968; Lopata, 1978; Matron & Reitzes, 1981; Krause, 1986; Wister & Strain, 1986). Research indicates that friends act as effective buffers against personal pains produced by major role losses such as widowhood, retirement, divorce, or decreased social participation (Rosow, 1967; Lowenthal & Haven, 1968; Blau, 1973; Wood & Robertson, 1976; Choler & Lieberman, 1980). Findings suggest that these age-linked stresses need not result in a decline in morale or in increased susceptibility to psychological and physical disorders, provided the older person maintains a link with an intimate social

acquaintance or confidant (Hochschild, 1973; Strain & Chappell, 1982; Chappell, 1983, Wister & Strain, 1986).

Research has suggested that supports buffer (Mitchell, 1969; Cassel, 1976; Cobb, 1976; Berkman & Syme, 1979; LaRocco, House & French, 1980) or have a direct effect (Dean & Lin, 1977; Gore, 1978; Lin, Simeone, Ensel & Kuo, 1979; Williams, Ware & Donald, 1981; Greenblatt, Becerra & Serafetinides, 1982; Cohen, Teresi & Holmes, 1985, 1985; Cohen, Teresi & Holmes, 1986) on the physical and mental stressors that increase susceptibility to disease.

Within the mental health field, several investigators have found a correlation between network structure and the speed of receiving attention (Hammer, 1963, 1964) and rehospitalization (Brown, Birley & Wing, 1972). Reduced social interaction has been linked to the development of psychological disorders in the elderly (Lowenthal, 1964; Clark & Anderson, 1967).

Susceptibility to physical illness likewise has been associated with the lack of social support (Cassel, 1976; Berkman & Syme, 1979). Studies have documented that informal supports have a positive association with recovery from illness and appropriate health behavior (Langlie, 1977; Quinn, 1982). To a moderate degree, the larger the network, the better the health status according to recent research (Gallo, 1983). Ehrlich (1985) found that people in rural, outlying areas who are highly functional remain in the community regardless of the size and level of

support of their network. Those who are less functional remain if they have a large, supporting network. Several studies have shown an association between social networks and mortality (Parkes, Benjamin & Fitzgerald, 1969; Berkman & Syme, 1979; House, Robbins & Metzner, 1982). These studies found an excess of coronary deaths among men who had recently lost their wives. Thus, research supports the role of social networks in both counteracting and coping with illness.

In the next section, the research on caregiver stress will be discussed. The following issues related to caregiving will be explored: characteristics of the caregivers, their perceptions of the impacts of caregiving, and their perceptions of needed assistance.

#### Caregiver Characteristics

Shanas (1979) conceptualizes a "principle of substitution" which implies that family members are available in serial order, so that if one individual is not available to help, another will step in. Research indicates that the role of primary caregiver to an older person will be assumed by a spouse, if there is one; a child, if there is not; and, in the absence of both spouse and children, other relatives such as siblings, nieces, and nephews emerge to provide extensive support (Shanas et al., 1968; Treas, 1977; Brody, Poulshock & Maschiocci, 1978; Shanas, 1979, 1979, 1981; Johnson, 1983; Kivett, 1985).

Cantor's (1975, 1980) research describes the hierarchical, compensatory nature of supports, where friends and neighbors assist only when family members are not available. Neighbor and friend networks provide support for elderly persons, but for short-term, less intimate needs and usually as a substitute for family support (Rosow, 1967; Cantor, 1975; Lopata, 1975, Cantor, 1979; Johnson, 1983; Meyers, Master, Kirk, Jorgensen & Mucatel, 1983; Cohen et al., 1985, 1985).

It appears that one person, usually a spouse or daughter, becomes the principal source of care during chronic or acute periods of disability, with little help from other family members (Danis, 1978; Mellor & Getzel, 1980). As a result, feelings of being overburdened can become common (Horowitz, 1978; Zarit, Reeve & Bach-Peterson, 1980) and may lead to institutionalization that could have been avoided if others helped (Kooperman-Boyden, 1979; Smith & Bengtson, 1979).

Johnson (1983) found that when the spouse is the primary caregiver, in comparison to an adult child, the patient is less likely to be institutionalized, more comprehensive care is provided, and less conflict, stress, or ambivalence appeared on the part of the caregiver. Females predominated as caregivers in this study, comprising two-thirds of the spouse caregivers and 59% of the offspring caregivers. The literature indicates that women carry out the bulk of caring and tending tasks for the elderly (Townsend, 1965; Shanas et al., 1968; Horowitz, 1985; Townsend & Poulshock, 1986).

Pearlin & Schooler (1978) have identified three personal psychological resources which can reduce the stressful consequences of strain for caregivers: (1) self-esteem - the positiveness of one's attitude toward oneself, (2) absence of self-denigration - the extent to which one does not hold negative attitudes towards one's self, and (3) mastery - the extent to which one perceives control over one's life in contrast to perceiving it as being fatalistically ruled.

### Impacts of Caregiving

Family caregiving and caregiving burden have become central topics in the aging literature (Johnson & Catalano, 1983). The capability of families to handle difficult caregiver tasks has been documented (Streib, 1972; Brody et al., 1978; Culfond, Olsen & Block, 1979). Yet, there is wide variation in both the behavior and experience of relatives who are confronted with an aged, ill family member. Caregiving involvement may range from a once-a-week visit to round-the-clock care for the bedridden (Gross-Andrews & Zimmer, 1977; Archbold, 1978; Danis, 1978; Weiler, 1978; Cantor, 1980; Tobin & Kulys, 1980) and the caregiving relative may experience minimal to extensive stress as a result of caregiving responsibilities (Archbold, 1978; Kulys & Tobin, 1978; Adams, Caston & Davis, 1979; Cantor, 1980; Mace, Rabins, & Lucas, 1980; Zarit et al., 1980; Goldstein, Regnery & Willins, 1981; Archbold, 1982; Brody, Kleban, Johnson, Hoffman & Schoonover, 1987).



Research which has touched upon intergenerational affective relations has concluded that the majority of both generations do report feeling close and/or being satisfied with the caregiving relationship (Adams, 1968; Jackson, 1971, 1972; Brody, 1974; Brown, 1974; Cantor, 1975; Johnson & Bursk, 1977). However, involvement in caregiving activities has not been found to be dependent upon strong affective bonds (Horowitz, 1978; Kulys & Tobin, 1978; Jarrett, 1985). There is some evidence to suggest that the impact of caregiving is perceived as relatively less stressful where a strong bond of affection exists within the caregiving dyad (Horowitz, 1978; Kulys & Tobin, 1978; Wood & Robertson, 1978; Bengston & Treas, 1980; Cicirelli, 1981).

Horowitz & Shindelman (1983) report warm, affective feelings toward older relatives but the dependency of the aged relative appears to modify the affective relationship, bringing the dyad closer emotionally but making daily interaction less enjoyable for the caregiver. Spouses especially were at risk in this regard. Further, research indicates that the worse the health of the carereceiver, the more stress and dissatisfaction with the caretaking role (Goldstein, 1979; Stoller, 1985).

Deimling and Bass (1986) in a study of 614 family caregivers found that disruptive behavior and impaired social functioning were more stressful for caregivers than the elders' cognitive incapacity. They suggest three possible reasons for this finding. First, cognitive symptoms are the initial signs of mental deterioration. As cognitive capacity

declines further, the other symptoms of disruptive behavior and impaired social functioning may occur. As a result, these late symptoms may be more directly linked to caregiver stress because of the severity of the problems they represent.

Second, the caregivers may feel that disruptive behavior and impaired social functioning increase the elders' need for supervision or care. Level or nature of care provision rather than the behavioral symptoms may cause caregiver stress.

Third, cognitive incapacity may be less stressful as it is defined as the outcome of the disease or aging process and beyond the individual's control. Disruptive behavior and impaired social functioning may be defined as unrelated to the disease/aging process. Elders displaying these characteristics may be evaluated negatively by family members. Negative evaluation may translate into higher levels of stress.

Recent research on the effectiveness of hospice homecare indicates that task difficulties rather than emotional stress may be the primary burden for caregivers (Bass, 1985).

The level of caregiving stress is related not only to the extent of the person's disabilities and amount of care needed, but also to whether the caregiver receives help and support from others. The burdens of caregiving can be intensified by the lack of effective support for family members who feel alone and who do not know how to utilize or

develop their networks (Zarit, Gatz, & Zarit, 1981; Zarit, 1982). Vulnerable caregivers appear to be those who do not mobilize or do not have a support network (Zimmer, Gross-Andrew & Frankfather, 1977; Cantor, 1980; Horowitz & Shindelman, 1983).

The research on family caregiving (Horowitz, 1978; Zarit et al., 1980) clearly points to the importance of strengthening the resources and social supports available to families as a means to improve the quality of care. An appropriate intervention appears to be the strengthening of family support systems, or, where none exist, the development of alternative support networks (Hooyman, 1983).

#### Perceived Needs

In a 1983 study, Reece, Walz & Hageboeck assessed the care provided to 41 noninstitutionalized frail older persons by their children or grandchildren. In answer to an open-ended question, careproviders stated that respite in the form of daycare and meal preparation were the most needed outside help. Archbold (1980) found that the familial support which was most valued by caregivers was "parent-sitting" and siblings taking the parent to their home for several days. Caserta, Lund, Wright & Redburn (1987) discovered that respite oriented services were perceived as most needed and utilized the most by 597 family caregivers to noninsitutionalized dementia patients.

Strong family bonds and a sense of responsibility cease to offset the pressures of caregiving when the older person's health deteriorates to the point where they are unable to reciprocate in an emotional relationship and the careprovider is not allowed respite from responsibilities (Eggert, Granger, Morris & Pendleton, 1977; Cantor, 1983; Reece et al., 1983; Marcus & Jaeger, 1984; Hooyman, Gonyea & Montgomery, 1985; Miller, Gulle & McCue, 1986; Scott, Roberto & Hutton, 1986).

#### Summary

The literature suggests that the most comprehensive and unstressful support of the elderly will be provided by a spouse, with the principle of substitution operating. That is, family members will be available to provide care in serial order rather than acting as a shared-functioning unit. When a spouse or a child are not available siblings, friends, or neighbors will provide support to an elderly person.

In addition, the research indicates that for primary caregivers, the level of caregiving stress is related to the extent of the person's disabilities and amount of care needed and to whether the caregiver receives help and support from others. The burdens of caregiving may be intensified by a lack of effective support for family members who feel alone and who do not know how to utilize or develop their networks. Studies imply that social support mediates physical and mental stress for the elderly.

## METHOD

### Purpose

The purpose of this study was to investigate the role social support plays in the adjustment of elderly (those men and women 60 years of age and older) primary caregivers to the tasks of caretaking.

The extent of each person's social network and his/her perception of its intactness and support was assessed. A goal was to determine if these variables were able to discriminate among adjustment styles of the sample.

### Participants

A total of 55 people were individually interviewed. A sample of elderly caregivers was selected from the clients of the Manitoba Home Care Program, Winnipeg South Region.

Social workers at the Manitoba Home Care Program, Winnipeg South Region gave their supervisor the names of all clients who had caregivers over the age of 60. A total of 88 names were submitted to the supervisor. Each of the caregivers was asked if they would participate in the study - 59 agreed to participate (2 were disqualified because of language incapacabilities), 21 chose not to participate for various reasons including illness and not wanting to be bothered at a busy time of year,

3 died, 4 were unable to be reached, and 1 did not meet the criteria. This left a list of 57 careproviders of which 55 were interviewed. One person was unable to participate due to hospitalization and one decided he did not want to answer the questions.

### Hypotheses

Hypotheses were as follows:

1) Spouses functioning as primary caregivers will show a better level of adjustment, as measured by lower scores on the Beck Depression Inventory (Beck, 1972) and the Zarit Burden Inventory (Zarit et al., 1980) and higher scores on the Rosenberg Self-Esteem Scale (Robinson & Shaver, 1973), than will nonspousal primary caregivers, such as a child or sibling.

2) Primary caregivers with high scores on the Perceived Support Network Inventory (Oritt, Paul & Behrman, 1985) will show a better level of adjustment, as assessed by scores on the Beck Depression Inventory (Beck, 1972), the Rosenberg Self Esteem Scale (Robinson & Shaver, 1973), and the Zarit Burden Inventory (Zarit et al., 1980), than will those with low scores on the Perceived Support Network Inventory.

3) A variety of relationships between fostering social support and adjustment will be examined. Specifically, the use of acquiring social

support, reframing, family mobilization, spiritual support and passive appraisal were examined in relation to depression, self-esteem and perception of burden.

It is predicted that those individuals with a high degree of social support, family mobilization, reframing, and spiritual support will have a better level of adjustment.

### Instruments

#### Demographic Information

Demographic information was gathered on the elderly primary caregivers. Background data included age, sex, income, marital status, education, religion, retirement/employment, health status (Appendix A).

#### Network Assessment

Network variables and individual satisfaction with perceived support were measured through the use of the Perceived Support Network Inventory (Oritt et al., 1985), which specifically records support types and permits calculation of network dimensionality (Appendix B). This inventory has established psychometric properties. A test-retest study design (Oritt et al., 1985) collected reliability, internal consistency, and construct, convergent and discriminant validity data on the scale.

Test-retest reliability of the PSNI ranged from .72 to .88; internal consistency was .77; construct validity estimates ranged from .21 to .57; convergent validity estimates varied from -.25 to .20; discriminant validity estimates varied from -.11 to .19.

#### Personal Resource Assessment

To obtain information on the personal psychological resources of the elderly primary caregivers, the Rosenberg Self-Esteem Scale (Robinson & Shaver, 1973) and the Beck Depression Inventory (Beck, 1972) were utilized.

The ten-item scale by Rosenberg (Appendix C) is a self-report measure of the self-acceptance aspect of self-esteem. Test-retest reliability over a two-week period is reported as .85, and mean concurrent validity with other self-esteem measures approximates .60. The measure is scored such that high scores reflect a positive self-concept.

The short form of the Beck Depression Inventory (Appendix D), developed by Aaron Beck (1972), consists of categories describing behavioral manifestations of depression (e.g., sadness, social withdrawal). A graded series of four to five self-evaluative statements are ranked in order of severity of expression for each symptom. Each person is asked to choose the statement which is closest to their present state.



The split-half reliability of the 21-item, original BDI was .93. Its concurrent validity ranged from .61 to .82. Beck (1972) reports the 13-item short form reliability to be .96. Pehm (1976) describes the BDI as the best of presently available self-report measures of general depression severity. Standard scoring is used in computing depression scores, with the range of the scale going from 0 to 39.

The criteria for depression give rise to difficulty in this group of elderly people, as weight loss, insomnia, fatigue and poor concentration may be common features of aging or chronic illness. Using the short form of the Beck Depression Inventory should help overcome this measurement difficulty as the short form includes only one variable on anorexia which asks about appetite loss.

#### Coping Assessment

Each participant's ability to foster support was assessed by utilizing the Family Crises Oriented Personal Evaluation Scales (F-COPES). F-Copes (Olsen, et al., 1983) was developed to determine people's ability to accept help from others and to engage neighbors and relatives for support, and to determine their use of spiritual resources to understand and withstand crisis events.

Research utilizing the F-Copes Scale indicates the importance of social support in coping and adjusting (McCubbin & Patterson, 1982; Olsen, Russell & Sprenkly, 1983; Kessler, Price & Wortman, 1985; Trute, 1987).

Individuals and families who adapt well to problematic events appear to have a positive or neutral perception of the impact of a crisis, view themselves as directly able to meet their problems, and have a wide range of social resources which they readily utilize (McCubbin & Patterson, 1982; Olson, et al, 1985; Pratt, Schmall, Wright & Cleland, 1985).

This 29-item instrument (Appendix E) measures coping strategies of reframing and passive appraisal, and strategies of acquiring social support, mobilizing to accept help, and seeking spiritual support (Olsen et al., 1985). Olsen et al. (1985) reported moderate to high levels of internal consistency for each subscale (Cronbach's alpha ranged from .63 to .83), and test-retest reliability over four weeks ranging from .61 to .95. Participants are asked to choose how well each of the 29 statements describes their attitudes and behavior in response to problems or difficulties. Choices range from one to five, with one being strongly disagree and five being strongly agree. The instrument provides a descriptive analysis of the coping styles of the interviewees. Descriptive statistics, including means and standard deviations were used to portray the data.

In addition, primary caregivers' perception of burden was assessed by the Zarit Burden Inventory (Zarit et al., 1980). This 22-item questionnaire (Appendix F) is designed to measure stress, anger, frustration, and the burden of providing care for a family member who is physically and/or mentally impaired. Respondents agree or disagree with

each of the 22 statements. A total burden score is calculated such that high scores reflect a high level of burden. A reliability coefficient of .79 is reported by Zarit & Zarit (1982). Burdz (1986) reported a test-retest reliability of .89.

The literature suggests that caregiver's burden increases as functional abilities of the older person decrease. To assess the degree of incapacitation in the chronically ill individual as perceived by the caregiver, the Instrumental Activities of Daily Living Scale (Lawton, 1971) was administered (Appendix G). The IADL contains ratings of self-care ability in the areas of telephoning, shopping, food preparation, housekeeping, laundering, use of transportation, use of medicine, and financial behavior. The IADL items form an eight-point scale for women and a five-point scale for men. Lawton (1971) states that three items - cooking, housecleaning, and laundry - are "relatively specific to the female role and are therefore not included in scoring for males (p. 470)." The test-retest reliability correlation is .85, and mean concurrent validity with other functional measures approximates .60 (Lawton, Moss, Fulcomer & Kleban, 1982).

#### Checklist and Open-Ended Questions

The primary caregivers' perceptions of supplementary assistance needed and desired from their networks and from outside agencies in carrying out their caregiving role was tapped by the use of a checklist including the following categories - respite, transportation, meal preparation,

financial assistance, counseling, home repair, other (Appendix H). They also were asked to check the supplementary services currently being received.

Participants were asked to answer two open-ended questions. First, What is the most stressful part of this situation for you? Second, What advice would you give others in your situation?

## RESULTS

### DEMOGRAPHICS

#### AGE

The mean age of this sample was 69.9 years (SD=7.7).<sup>1</sup> Twenty-four careproviders were between 60-69 years of age, 22 were between 70-79 years of age, and six were between 80-88 years of age.

The mean age of the carereceivers was 78.3 years (SD=15). Carereceivers' ages ranged from 57 years to 99 years. Two were 57 and 59, six were between 60-69 years of age, 16 were between 70-79 years of age, 12 were between 80-89 years of age, 11 were between 90-99 years of age, and eight ages were unknown.

#### SEX

The ratio of female to male careproviders was 2:1. Females comprised 67.3% (37 women) of the sample with males totalling 32.7% (18 men).

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<sup>1</sup>Three individuals were younger than 60 years of age - one was 43, one 54, another 57. Analyses indicated that there were no major differences in their responses to questions.

RELATIONSHIP

There were 20 wives (36.4% of the sample) providing care to their husbands, 14 husbands (25.5%) caring for their wives, ten daughters (18.2%) supporting their mothers, two sons (3.6%) helping their mothers, two brothers (3.6%) and four sisters (5.5%) providing care to a sibling, and three women (5.5%) caring for an in-law.

MARITAL STATUS

Forty-seven individuals were married (85.5%), five were widowed (9.1%), one was divorced (1.8%), one never married (1.8%), and one other was living with a companion (1.8%).

RELIGION

Table 1 describes the religious preferences of this sample.

TABLE 1

Religious Background of Sample

Religion	Percent of Sample
Protestant	69.1%
Catholic	21.8%
Jewish	7.3%
Other	1.8%

Thirty individuals (52.7%) attended church services while 25 (47.3%) did not attend church. Of the 30 people who attended church, five (9.1%) did so more than once a week, 11 (20.0%) did so once a week, five (9.1%) did so 2-3 times a month, three (5.5%) did so once a month, and six (10.9%) did so less than once a month.

EDUCATION

The formal education of careproviders ranged from grade school to graduate school. Table 2 provides educational data.

TABLE 2

Educational Level of Sample

Educational Level	Percent of Sample
Grade School	9.1%
Some High School	32.7%
High School Graduate	27.3%
Technical Training	7.3%
Some University	12.7%
University Degree	3.6%
Graduate Degree	7.3%

INCOME

The gross income level of participants ranged from less than \$5,000 to over \$35,000. Table 3 depicts these data.

TABLE 3

Gross Annual Income Level of Sample

<u>Income</u>	<u>Percent of Sample</u>
Less than \$5000	1.8%
\$5 - 10,000	14.5%
\$10 - 15,000	10.9%
\$15 - 20,000	27.3%
\$20 - 25,000	20.0%
\$25 - 30,000	9.1%
\$30 - 35,000	7.3%
Over \$35,000	7.3%
Don't Know	1.8%



#### EMPLOYMENT/RETIREMENT

Only three careproviders worked outside of the home part-time while one worked full-time. Forty-eight (87.3%) of the 55 careproviders were retired. Three homemakers did not consider themselves retired.

#### RESIDENTS PER HOUSEHOLD

Forty-six (83.7%) careproviders had one other person residing with them. Thirty-five of these 46 people were husbands or wives providing care to their spouses, nine were husband and wife providing care to mothers (7) who lived in their own homes or sisters (2) who lived in their own homes, one was a widow caring for her sister-in-law, and one was a woman caring for her male companion.

Six individuals (10.9%) had two other people living with them. One careprovider lived with her husband and mother-in-law, who was the person receiving care; two lived with their husbands and mothers, who were the people receiving care; one lived with her granddaughter and sister, who was the person receiving care; one lived with his wife and brother, who was the one receiving care; and one lived with her husband and son while the carereceiver, being the woman's mother, lived in her own apartment.

Two participants (3.6%) shared a home with four other people. One careprovider was a sister living with her widowed brothers and sister and one was a wife living with her husband and children.

Only one person (1.8%) lived alone. The carereceiver and caregiver lived in their own apartments.

#### CAREPROVIDER'S HEALTH

Almost every careprovider (98.1%) perceived their health to be good - 19 (34.5%) rated their health as excellent and 35 (63.6%) felt their health was good. Only one (1.8%) respondent viewed their health as poor.

Those rating their health as excellent usually stated that they had no health problems. One had sleep apnea.

Those perceiving their health to be good had a range of health problems, sometimes experiencing multiple conditions. Fourteen individuals had arthritic conditions, including gout, osteoarthritis, rheumatoid arthritis, and artificial hips. Thirteen individuals had heart problems, including high blood pressure, stroke, heart attack, heart surgery, angina and arteriosclerosis. Five people had cancer, including lung cancer and mastectomy. One had experienced petit mal seizures most of her life, one had severe hearing loss, one had Paget's Disease and severe hearing loss, one had arthritis and was blind, one had polio and

osteoarthritis, one had ulcers, one had diabetes and ulcers, and one had back pain.

The individual who rated his health as poor had cancer.

#### CARERECEIVER'S HEALTH

Careproviders rated the health of the person they provided care to as excellent in three cases (5.5%), good in 17 cases (30.9%), and poor in 35 cases (63.6%).

Of the three carereceivers whose health was perceived to be excellent by careproviders, one was in the beginning stages of Alzheimer's, one had brain damage due to a stroke but had a "perfect" physical recovery, and one had had a stroke.

Of the 17 carereceivers whose health was seen as good, eight had had strokes with one individual currently having multiple sclerosis as well; three had heart conditions with one being diabetic also and another had glaucoma in addition to heart problems; two experienced effects of the aging process, both were 91 years of age; one had Parkinson's Disease; one had cancer and eye implants; and one had had a broken hip.

Those whose health was ranked as poor by their careproviders were more likely to be suffering from multiple health problems than were those

whose health was rated as good. Of the 35 whose health was rated as poor, nine had heart problems including strokes, angina, bypasses, and congestive heart failure. In addition, five of the nine had other conditions including osteoperosis, osteoarthritis, low blood pressure, and kidney failure. Eight individuals had Alzheimer's (three males and five females); five had Parkinson's Disease (four males and one female), two of whom had heart problems in addition; three had emphyzema, with one suffering from osteoperosis and liver damage due to alcohol abuse as well; three were experiencing the effects of aging, two of these individuals were 94 and one was 91. Three people had diabetes and each was suffering from other complications. One was an amputee, one had rheumatoid arthritis and one had arthritis, a heart condition and cancer of the esophagus. Two rated as having poor health had arthritis with one having cerebral palsy also. One person had cancer and one had a damaged inner ear that destroyed his balance.

#### Instrumental Activities of Daily Living Scale

Careproviders rated those they cared for on activities of daily living, including the ability to use the telephone, shopping, food preparation, housekeeping, laundry, mode of transportation, ability to handle finances, and responsibility for medications. Scores (see Table 4) ranged from an inability to do any of the activities to an ability to do six out of the seven listed.

TABLE 4

Care Recipient Scores on Instrumental Activities of Daily Living Scale

Number of Activities Performed	Percent of Sample
0	30.9%
1	20.0%
2	16.4%
3	12.7%
4	3.6%
5	10.9%
6	5.5%

LENGTH OF CARE

Most individuals had been providing care for over two years with 45 people (81.8%) providing it for that length of time or more. Two individuals (3.6%) had been providing care for 6 months or less, five (9.1%) for 7 - 12 months, two (3.6%) for 13 - 18 months, and one (1.8%) for 19 - 24 months.

## PERSONAL RESOURCE ASSESSMENT

### Rosenberg Self-Esteem Scale

There was a consistent, high level of positive self-esteem among the 55 caregivers as measured by the Rosenberg Self-Esteem Scale. The mean score was 25.1 (SD=2.5).

### Beck Depression Inventory

Careprovider's mean score on the short form of the Beck Depression Inventory was 3.2 (SD=2.4). Forty caregivers (73%) scored between 0-4, which indicates no depression on the Beck norms; eleven (20%) scored between 5-7, which indicates mild depression; and four (7%) scored between 8-10, with a score of 8-15 indicating moderate depression on the Beck norms. None of the social demographic characteristics correlated with depression.

## PERSONAL COPING ASSESSMENT

### Zarit Burden Inventory

The mean score on the Zarit Burden Inventory was 30.5 (SD=12.5). Caregivers perceived their level of burden as follows: 15 rarely felt burdened, 32 felt burdened sometimes, and 8 were frequently burdened.

Careproviders with high scores on the Zarit Burden Inventory were likely to be high scorers on the Beck Depression Inventory ( $r=.42$ ,  $n=55$ ,  $p=.001$ ). Therefore, level of burden appears to be related to degree of depression.

Caregiver's perception of the carereceiver's health appeared to be associated with caregiver's burden level. Those perceiving the carereceiver's health to be poor had higher scores on the Zarit Burden Inventory than did those perceiving carereceiver's health to be good ( $r=.27$ ,  $n=55$ ,  $p=.04$ ).

Education level also correlated with feelings of burden. Caregivers with higher levels of education had higher scores on the Zarit Burden Inventory than did those with less education ( $r=.29$ ,  $n=55$ ,  $p=.03$ ). Yet those with higher education levels were caring for someone who scored higher on the instrumental activities of daily living scale ( $r=.29$ ,  $n=55$ ,  $p=.03$ ). That is, while the more highly educated caregivers tended to be looking after less disabled people, they perceived their level of burden to be higher than other caregivers.

## NETWORK ASSESSMENT

### Size

The size of the elderly caregivers' networks was small (mean=2.7, SD=1.7). Size ranged from 0 to 9 individuals in a network.

The lower the reported health of the care recipient, the smaller the network of the careprovider ( $r=-.31$ ,  $n=55$ ,  $p=.02$ ).

### Relationship

Table 5 illustrates the relationship of network members to the caregiver.



TABLE 5

Relationship of Network Members to Caregiver

Relationship	Percent of Network Members*
husband	7.5%
wife	3.7%
daughter	29.1%
son	16.4%
sister	11.9%
brother	3.7%
mother	2.2%
inlaws	4.5%
niece	2.2%
nephew	.7%
friend	10.4%
neighbor	3.0%
professional	2.2%
granddaughter	.7%
no network members	1.5%

\*Network members named totalled to 134.

Six careproviders listed the carereceiver as a member of their networks; forty-nine did not list the carereceiver as a network member.

### Initiating Support

Of the 55 careproviders, 37 (67.2%) sought the help of their network members most of the time, 14 (25.5%) sometimes, and 4 (7.3%) never.

### Availability of Network Members

For 89% of the caregivers, network members provided help whenever they were asked to assist.

### Satisfaction With Support

There was a high degree of satisfaction with network support among this sample. Over 94% of the careproviders were satisfied with the support provided by their network members.

### Types of Support

Forty-five of the caregivers (81.8%) said they received emotional support from their network members. This type of support was received from family, friends or professionals who were listed as network members. Ten people (18.2%) said they did not receive this type of support.

Thirty-nine caregivers (70.9%) received advice from their network; sixteen (29.1%) did not.

Thirty-four caregivers (61.8%) participated in social activities with their network members whereas 21 (38.2%) did not. Higher levels of social participation with network members by caregivers is associated with lower health status of the care recipient ( $r=.36$ ,  $n=55$ ,  $p=.007$ ).

Thirty people (56.4%) had not received physical assistance from their network members; 24 (43.6%) had been assisted physically.

Thirty-eight caregivers (69.1%) neither needed nor expected material support from their network whereas 17 (30.9%) received material assistance in the form of goods - never money.

#### Reciprocity

Forty-eight careproviders (87.3%) stated that they provided support to their network members when these individuals experienced stress. Seven people (12.7%) did not provide such support to their network members.

#### Conflict

Fifty individuals (90.9%) reported few or no conflicts with their network members; 5 (9.1%) reported sometimes experiencing them.

## RELATIONSHIP BETWEEN PERCEIVED NETWORK INVENTORY AND ADJUSTMENT

It was hypothesized that caregivers with high scores on the Perceived Network Inventory would have a better level of adjustment as assessed by the Beck Depression Inventory, the Rosenberg Self Esteem Scale and the Zarit Burden Inventory. But only the network characteristics of size, reciprocity, emotional support and material aid were related to adjustment.

### Beck Depression Inventory

Lower Beck scores were associated with larger networks ( $r=-.29$ ,  $n=55$ ,  $p=.04$ ) and higher reciprocity ( $r=-.32$ ,  $n=55$ ,  $p=.02$ ).

### Rosenberg Self-Esteem Scale

Caregivers who perceived receiving emotional support from their network members had significantly lower scores on the self-esteem scale than those not receiving it ( $t=-2.78$ ,  $df=17.8$ ,  $p=0.01$ ).

Careproviders getting material aid had significantly higher scores on the self-esteem scale than did those not receiving it ( $t=2.63$ ,  $df=39.8$ ,  $p=0.01$ ).

## RELATIONSHIP'S IMPACT ON CAREPROVIDER'S ADJUSTMENT

Spousal careproviders did not show a significantly better level of adjustment than other family members on the Rosenberg Self-Esteem Scale ( $t=-1.59$ ,  $df=31.2$ ,  $p=ns$ ). The mean score on the Rosenberg Scale for spouses was 25.6 (SD=2.1) and for other family members it was 24.4 (SD=3.1).

On the Beck Depression Inventory scores for both groups were not significantly different ( $t=0.34$ ,  $df=41.1$ ,  $p=ns$ ). Spouses mean score on the Beck was 3.3 (SD=2.3) and the mean score of other family members was 3.1 (SD=2.4). Also, on the Zarit Burden Inventory the scores for both groups were not significantly different ( $t=1.77$ ,  $df=44.4$ ,  $p=ns$ ). Spouses mean score on the Zarit was 28.2 (SD=12.5) and the mean score of other family members was 34.1 (SD=11.8).

## COPING ASSESSMENT

Table 6 portrays the F-Copes data.

TABLE 6  
Scores on the F-Copes Scale

\*F-Copes was normalized on a younger sample - adolescents and parents.  
\*\*T-test for differences between means was done using the formula from the textbook, Statistical Concepts, C. McCollough and Loche Van Atta, 1963, pgs. 241-2.

### Internal Resources

When compared to norms established on F-Copes, these elderly careproviders were not different from other individuals as regards their use of passive appraisal and reframing as a coping strategy.

### External Resources

The caregivers were found to be no different than the norm in their acquisition of social support and their mobilization of the family to acquire help.

They sought spiritual support as a coping strategy to a significantly lesser degree than the norm.

Caregiver's network characteristics were related to their coping strategies. The larger the caregiver's network, the higher their scores on the acquiring social support subscale ( $r=.35$ ,  $n=55$ ,  $p=.009$ ) and mobilization of family subscale ( $r=.30$ ,  $n=55$ ,  $p=.03$ ).

The greater the availability of network members, the higher the caregiver's score on the reframing subscale ( $r=.32$ ,  $n=55$ ,  $p=.02$ ).

More frequent initiation by careproviders of support from network members was positively associated with the amount of reframing ( $r=.33$ ,  $n=55$ ,  $p=.01$ ).

The greater the amount of reciprocity of support to network members by careproviders, the higher the scores on the reframing subscale ( $r=.30$ ,  $n=55$ ,  $p=.03$ ).

The worse the reported health of the care recipient, the lower the score of the careprovider on the acquiring social support subscale ( $r=.32$ ,  $n=55$ ,  $p=.02$ ).

The higher the score of the careprovider on the passive appraisal subscale, the higher the reported ADL Scale score of the carereceiver ( $r=.34$ ,  $n=55$ ,  $p=.01$ ).

#### RELATIONSHIP BETWEEN COPING STRATEGIES EMPLOYED AND ADJUSTMENT

It was hypothesized that caregivers with a high degree of social support, family mobilization, reframing and spiritual support would have a better level of adjustment, as measured by the Beck Depression Inventory, Rosenberg Self-Esteem Scale and Zarit Burden Inventory. But only reframing and spiritual support had an impact on adjustment.

The higher the careproviders' scores on the reframing subscale, the lower their scores on the Zarit ( $r=-.39$ ,  $n=55$ ,  $p=.003$ ) and the Beck depression scale ( $r=-.27$ ,  $n=55$ ,  $p=.05$ ).

Those with higher levels of spiritual support had lower scores on the Beck ( $r=-.35$ ,  $n=55$ ,  $p=.009$ ).

It seemed that both network and caregiver characteristics could have had an impact on the correlations between reframing and adjustment and between spiritual support and adjustment. The magnitude of the correlations remained unchanged when controlling for network, as well as caregiver, characteristics.



## PERCEIVED NEEDS

In this sample, 43.6% of the caregivers were satisfied with the services they were receiving.

A number of careproviders expressed a need for respite. Thirteen careproviders (23.7%) expressed dissatisfaction that they were not receiving respite or were not receiving adequate amounts of it.

Most individuals were satisfied with the Homecare services they were receiving. Those who expressed dissatisfaction were consistent in their comments. These seven caregivers (12.7%) stated that Homecare workers needed more training before being placed and they needed more supervision once placed. A "quick", "general briefing" was not enough to prepare them for the "variety of situations they would face in the homes". These careproviders felt a need for homecare more often, whether it was orderly services or homemaking helps, or at night, especially during a time of crisis. Caregivers stated that this would require greater "flexibility" on the part of Homecare.

Four careproviders (7.3%) expressed a desire for improved transportation services, stating that what they had experienced was "slow", "late", or "unreliable" service.

Three people (5.5%) were not satisfied with the housing arrangements of the carereceivers. All wanted to place their relative in a nursing home

and had put the person's name on the personal care list. In one case a sister wanted her sister placed, in another a daughter wanted her mother placed, and in the last a wife wanted her husband cared for in a nursing home.

Two caregivers (3.6%) were not receiving help with home maintenance and yardwork when they expressed a need for such service.

Two individuals (3.6%) would like help with the task of meal preparation. They expressed a desire to receive this help intermittently, perhaps "once a week" or "once a month", to add variety to meals and to provide a break for them from their "own cooking".

#### OPEN-ENDED QUESTIONS

##### Advice

One open-ended question was - What advice would you give others in your situation?

Ten of the careproviders (18.2%) advised others to become aware of what helps and resources are available in the community and within the family then "accept" and "utilize" them. They made statements such as "Being a member of the Alzheimer's Society helps reduce my stress." "Don't do it all yourself. Get other family members to help." "Having others in the family help with care lessens the burden."

Nine people (16.4%) providing care recommended maintaining a positive outlook. "Do not focus on what you don't have but appreciate what you do have." "The 'why me' attitude only generates stress and resentment."

Five others (9.1%) said to "accept your situation" and "try your best to deal with it."

Six caregivers (10.9%) mentioned maintaining faith in God and praying regularly when they answered the open-ended question.

Six of them (10.9%) stated they could not presume to give advice as "every situation is different". And ten (18.2%) did not wish to share their advice.

Four careproviders (7.3%) advised others to "maintain (their) interests" and to "keep active".

One person (1.8%) recommended that caregivers "keep (their) sense of humor", another (1.8%) said "everyone should know how to drive", another (1.8%) advised "having your home arranged for the convenience" of the carereceiver, another (1.8%) recommended "learning about aging" throughout your life as preparation for "what might happen to you physically and mentally", and one (1.8%) admonished "do not put your loved one in a care home".

A wide range of advice was offered by the 55 caregivers.

### Stress

Another question was - What is the most stressful part of this situation for you?

Not having time for themselves and their interests was most stressful for eighteen careproviders (34.5%). Meeting the needs of the carereceivers disrupted their relationships with other family members, their personal schedules and the activities they had planned. Even though they realized it was "never convenient when someone needs help", they found the interruptions - the "unexpected calls for help" and "demands of immediate attention" - stressful.

The most stressful part of providing care mentioned by fifteen participants (27.3%) was seeing the deterioration in their loved one's condition and "realizing the situation is not going to get any better." Many of these individuals specifically mentioned the degeneration in communication as a major, stressful problem as well as the fact that they cannot "do things together anymore" - from talking to traveling.

Five individuals (9.1%) worried about "what will happen (to my relative) when I'm unable to provide care".

Four caregivers (7.3%) found the fact that providing care was "constant" - "24 hours a day" - stressful.

Four others (7.3%) found meal times to be the most stressful part of providing care. These individuals stated, "Preparing meals then having them refused" or "He wants to eat constantly".

Four careproviders (7.3%) found dealing with Homecare the most stressful part of providing care. In this case, they were referring to the "incompetent professionals" - the "social workers, doctors, or nurses".

Three people (5.5%) found the worry about their loved one's falling as most stressful.

Two caregivers (3.6%) found "running back and forth between my home and (the carereceiver's) home" as stressful.

All careproviders identified stress, but they found different aspects of the caregiving situation to be personally stressful. Over 60% of them found not having time for themselves and their interests or seeing the deterioration in their loved one's condition as the most stressful part of providing care.

## DISCUSSION

In most situations involving homecare for disabled elderly individuals, primary caregivers are spouses. In the absence of a spouse, the role shifts first to children and then to siblings. This finding is consistent with prior research (Rosow, 1967; Shanas et al., 1968; Cantor, 1975; Lopata, 1975; Treas, 1977; Brody et al., 1978; Cantor, 1979; Shanas, 1979, 1979, 1981; Johnson, 1983; Meyers et al., 1983; Cohen et al., 1985; Kivett, 1985). Caregivers usually are females providing substantial physical and emotional support. Other research supports this finding (Shanas, 1960; Sussman, 1965; Brody, 1967; Shanas et al., 1968; Weaver & Blenker, 1975; York & Calsyn, 1977; Treas, 1977; Johnson, 1983; Morris & Sherwood, 1984).

Caregivers use the family as the major resource for social support and crisis intervention. Size of the network is small, yet members visit frequently and provide satisfying social, material, and physical support. These three types of support are reciprocated. Almost all caregivers in this study have a confidant, who usually is a spouse, but in the absence of a spouse is a daughter or sibling. The presence of a confidant is related to caregiver adjustment. This is consistent with other research findings (Hochschild, 1973; Strain & Chappell, 1982; Chappell, 1983; Wister & Strain, 1986).

Regardless of their relationship to the carereceiver, the length of time they had been providing care, or the carereceiver's dependency and

cognitive capacities, caregivers demonstrate a consistent, high level of positive self-esteem and show little depression. As well, they report not being burdened by their caretaking tasks. Caregiver adjustment is associated with larger network size, reciprocity of support and receiving material support from network members.

## Demographic Characteristics and Adjustment

### Carereceiver's Health

Research indicates that the worse the health of the carereceiver, the greater the stress and dissatisfaction with the caretaking role, a finding supported by the current investigation ( Goldstein, 1979; Stoller, 1985). When carereceiver's health is perceived to be poor, burden increases. These caregivers also have smaller networks and are less likely to use acquiring social support as a way to cope with stress.

Those caring for family members in poor health participate in social activities with their network members more often than do those caring for people whose health is perceived to be good. Participating in social activities does not appear to mitigate feelings of burden. Over 27% of the caregivers stated that the most stressful part of providing care was seeing the deterioration in their loved ones condition. They specifically mentioned the fact that they cannot "do things together

anymore". This may be why those who are caring for someone in worse health turn to others for social participation.

Only six caregivers list carereceivers as network members. It appears that carereceiver status disqualifies an individual from being considered someone to turn to in times of stress or when in need of social support. The caregiver appears to be defining the carereceiver as unable to give service or social/emotional support, even when carereceivers are physically and emotionally able to do so. Studies are needed which examine the characteristics of the carereceiver and the characteristics of the caregiver/carereceiver relationship that produce this definition by the caregiver.

#### Does Relationship Have an Impact on Careprovider's Adjustment?

Research indicates that when a spouse is the primary caregiver, in comparison to other family members such as children, caregivers experience less conflict, stress, or ambivalence (Townsend, 1965; Shanas et al., 1968; Johnson, 1983; Horowitz, 1985; Townsend & Poulshock; 1986).

Spousal careproviders in this study do not display a better level of adjustment than other family members as measured on the Rosenberg Self-Esteem Scale, the Beck Depression Inventory, and the Zarit Burden Inventory. A possible explanation for this discontinuity is the small number of non-spousal caregivers. Another possible reason for this



discontinuity may be the age of the sample. Careproviders were over the age of 60. Most past research has been conducted with caregivers between the ages of 45 and 60.

#### Elderly Caregivers Compared to Norms Established on F-Copes

These elderly caregivers are not significantly different from other individuals in their use of passive appraisal, reframing, acquiring social support, and mobilizing their families as strategies to manage stress. They appear not to seek spiritual support to cope: they did so to a lesser degree than the norm.

Elderly caregivers respond negatively to questions about church activities (e.g, questions 14 and 22 on the F-Copes). Yet many stated outright and others noted beside these two questions that because of health reasons they do not go to church. In addition, when answering a demographic question about church attendance, over half of the non-attenders state they want to participate but currently are unable to do so because of health problems - either their own or, more likely, those of the person they are caring for. Almost all respondents report facing their difficulties by having faith in God.

Their strong use of spiritual support when attempting to deal with stress is inadequately reflected by the F-Copes Scale.

### Network Characteristics Relationship to Coping Strategies

The network characteristics of size, reciprocity, availability of members and initiation of their support are related to the coping strategies of acquiring social support, mobilizing family, and reframing.

Caregivers with larger networks utilize acquiring social support and mobilizing family members as strategies for managing stress more often than do those with smaller networks. This is a logical prerequisite to acquiring social support.

Reframing occurs when careproviders provide help to network members as well as receive it, initiate support from network members, and have network members who make themselves available to provide assistance.

### Coping Strategies and Adjustment

It was hypothesized that high levels of social support, family mobilization, reframing and spiritual support would enhance caregiver's adjustment. Only reframing and seeking spiritual support are related to caregivers' adjustment to the stresses surrounding the caretaking role.

In the face of a crisis, the ability to reframe is related to lower depression as well as the perception of burden. Caregivers who are able to positively redefine stressful events to make them more manageable

appear not to be depressed nor to perceive themselves as burdened careproviders. Individuals who adapt well to the role of caregiver seem to view themselves as directly able to meet their problems.

Seeking spiritual support is also related to lower depression. Having and utilizing spiritual resources to understand and withstand stress and crisis events appears to accompany lower depression in elderly caregivers.

#### Network Characteristics' Relationship to Adjustment

It was hypothesized that high levels of all network characteristics would lead to a better level of caregiver adjustment. Only network size, reciprocity, material aid and emotional support are important determinants of elderly caregivers' adjustment to the stresses surrounding the tasks of caretaking.

Caregivers with larger networks, who reciprocate support, have little depression. Receiving emotional support from network members is related to lower self-esteem of elderly caregivers. The reverse is true with receiving material aid from network members, increased material aid is related to higher self-esteem of caregivers. This age group seems to have a strong desire to personally handle their emotional needs. If unable to do so, their feelings of self-esteem suffer.

## Perceived Needs

### Respite

Respite is the greatest service need voiced by this sample. This is consistent with other research findings (Eggert et al., 1977; Archbold, 1980; Cantor, 1983; Reece et al, 1983; Marcus et al., 1984; Hooyman et al., 1985; Miller et al., 1986; Scott et al., 1986; Caserta et al, 1987).

### Stress

The most stressful part of providing care for most of these caregivers is not having time for themselves, for their interests, and for other family responsibilities.

Providing the needed respite from caretaking tasks would help reduce the stress experienced when there isn't time for others or for their own interests and activities.

Elderly careproviders are likely to have small networks. Therefore, they are less likely to have members of their family to whom they can turn for respite. This may be one reason why those with larger networks are less burdened as caregivers. They have a larger number of family members who are willing and able to take on the caretaking role for

short periods of time. Homecare services need to more thoroughly meet the need of respite voiced by elderly caregivers.

Research indicates that over 75% of all long-term care to the elderly is provided by family members and that institutionalization of an older person appears to be associated with the collapse of family supports under the weight of the growing caregiver responsibilities. Findings supported by the current investigation.

The need for some form of respite from the continuous care demands is the most apparent type of outside assistance desired by elderly primary caregivers to help lift the weight of their responsibilities. What steps need to be taken by Homecare to assist these elderly caregivers in continuing to provide long-term care for their frail family member and avoid institutionalization? Homecare could work on the expansion of community day programs which afford careproviders respite and give care recipients needed social stimulation. The concept of short-term care could be broadened to include weekend programs and more short-term residential programs. Careproviders receiving respite from their caretaking responsibilities will be more apt to continue providing high levels of physical and emotional assistance.

This forging of linkages between the caregiver's formal and informal networks is crucial. The Homecare network is providing assistance to elderly caregivers which help them meet the needs of daily living in their own homes. Family networks of social support are contributing to

the adjustment of elderly caregivers, providing tangible assistance, fulfilling social needs and bolstering personal coping efforts.

## CONCLUSION

Vulnerable caregivers appear to be those who do not mobilize their support network and who do not reframe when facing difficulties (Zimmer et al., 1977; Cantor, 1980; Horowitz & Shindelman, 1980; Zarit et al., 1981; Zarit, 1982). Caregivers who adapt well to their role have a wide range of social resources which they readily utilize. They actively engage relatives, friends and neighbors for support. They also seek out community resources and accept help from others. In addition, caregivers who adjust well to their role are able to positively redefine the impact of a problem and view themselves as directly able to meet their problem.

Adjustment is enhanced and perception of burden is decreased when caregivers receive material support from their network members - when they feel network members care enough and take the time to provide material assistance. This material support may lead to higher levels of self-esteem - they feel valued - which in turn aides adjustment. Two psychological resources improve caregivers' adjustment: 1) mastery - the extent to which they perceive control over their life in contrast to perceiving it as being fatalistically ruled and 2) self-esteem - the positiveness of their attitude toward themselves which seems to increase when they receive material support from their network members (Pearlin & Schooler, 1978).

This exploratory research points to the importance of strengthening the resources and social supports available to elderly caregivers as a way of improving their ability to provide care. It helps orient health care workers to the network dimensions and strategies individuals employ when coping with the caretaking role, accounting for the better adjustment of some. By identifying the strengths of individuals and their social networks, the results offer health care providers targets and goals around which interventions and programs can be built. It is recommended that studies which manipulate social support variables be carried out in the clinical setting. Pre and post tests could be given to determine whether increased network size or improving caregiver ability to reframe and reciprocate support improves their adjustment to the tasks of caretaking.

This study offers guidance for prevention and therapeutic intervention. A central theme is the need to develop social support as a clinical tool to help individuals provide positive homecare to the elderly.



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LETTER



THE UNIVERSITY OF MANITOBA

SCHOOL OF SOCIAL WORK

Winnipeg, Manitoba  
Canada R3T 2N2

November 1987

Dear

My name is Barbara LeBow, and I am a graduate student in social work. I am doing a study as partial fulfillment of requirements for my university degree, and have drawn the names of 60 individuals registered with the Manitoba Home-care Program, Winnipeg South Region to interview. You are one of the individuals whose name was given to me by a case coordinator.

I would like to study the role of family members, as well as friends and neighbors, in the care of each other. I am interested in the help families are receiving and how you feel about it. This study has been approved by the University of Manitoba and the Manitoba Homecare Program, although I am not an employee of Homecare. The study will have no effect on the services you receive from Homecare.

Participants will be interviewed and asked to fill out several questionnaires. This should take approximately one to two hours of your time. People have found these questionnaires interesting and helpful. The information you provide will be used for scholarly research only and will be entirely confidential. Participation in this study is voluntary. Arrangements will be made to meet you in your home or any other convenient place.

Your help and cooperation would be greatly appreciated. In the next few days, I will call you to see if an interview time can be arranged. Feel free to call me at home (452-2898) if you have any questions regarding the study. Or you can call my research advisor, Dr. Barry Trute at the number listed below. A brief summary of results will be sent to all participants in the spring.

Sincerely,

*Barbara LeBow*

Barbara LeBow, B.S.  
452-2898

Barry Trute, Ph.D.  
Professor  
474-9798



CONSENT FORM

CONSENT FORM

I AGREE TO PARTICIPATE IN BARBARA LeBOW'S 1987  
STUDY OF THE ROLE FAMILY MEMBERS PLAY IN THE  
CARE OF EACH OTHER.

\_\_\_\_\_  
(NAME)

\_\_\_\_\_  
(CO-SIGNED)

\_\_\_\_\_  
(DATE)

APPENDIX A  
DEMOGRAPHIC INFORMATION

# \_\_\_\_\_

DATE OF INTERVIEW \_\_\_\_\_

AGE \_\_\_\_\_

SEX 1 MALE

2 FEMALE

MARITAL STATUS 1 MARRIED

2 DIVORCED

3 SEPARATED

4 WIDOWED

5 NEVER MARRIED

6 OTHER

RELIGION 1 PROTESTANT

2 ROMAN CATHOLIC

3 JEWISH

4 OTHER \_\_\_\_\_ (PLEASE SPECIFY)

DO YOU ATTEND CHURCH SERVICES?

1 YES

2 NO

IF YES, ABOUT HOW OFTEN DO YOU ATTEND?

1 MORE THAN ONCE A WEEK

2 ONCE A WEEK

3 TWO OR THREE TIMES A MONTH

4 ONCE A MONTH

5 LESS THAN ONCE A MONTH

6 NOT AT ALL

EDUCATION

- 1 GRADES 1-8
- 2 SOME HIGH SCHOOL
- 3 HIGH SCHOOL GRADUATE
- 4 TECHNICAL TRAINING (i.e., COMMUNITY COLLEGE)
- 5 SOME UNIVERSITY
- 6 UNIVERSITY DEGREE
- 7 GRADUATE SCHOOL

GROSS ANNUAL INCOME (BEFORE TAX DEDUCTIONS)

- 1 LESS THAN \$5,000
- 2 BETWEEN \$5,000 and \$10,000
- 3 BETWEEN \$10,000 and \$15,000
- 4 BETWEEN \$15,000 and \$20,000
- 5 BETWEEN \$20,000 and \$25,000
- 6 BETWEEN \$25,000 and \$30,000
- 7 BETWEEN \$30,000 and \$35,000
- 8 OVER \$35,000

ARE YOU CURRENTLY EMPLOYED OUTSIDE THE HOME?

- 1 YES FULL-TIME
- 2 YES PART-TIME
- 3 NO

HOW MANY PEOPLE THAT YOU ARE RELATED TO ARE LIVING IN YOUR HOME?

- 1 ONE
- 2 TWO
- 3 THREE
- 4 FOUR
- 5 FIVE OR MORE

ON A SCALE OF ONE TO FIVE, WITH ONE AS EXCELLENT AND FIVE AS POOR, HOW WOULD YOU RATE YOUR HEALTH?

EXCELLENT 1      2      3      4      5 POOR

LIST YOUR CURRENT MEDICAL PROBLEMS AND INDICATE THE LENGTH OF TIME EACH HAS BEEN PRESENT.

<u>CONDITION</u>	<u>YEARS</u>
1 _____	_____
2 _____	_____
3 _____	_____
4 _____	_____

ARE YOU RETIRED?

1 YES

2 NO

ON A SCALE OF ONE TO FIVE, WITH ONE AS EXCELLENT AND FIVE AS POOR, HOW WOULD YOU RATE THE HEALTH OF THE PERSON YOU PROVIDE CARE TO?

EXCELLENT 1      2      3      4      5 POOR

LIST THEIR CURRENT MEDICAL PROBLEMS AND INDICATE THE LENGTH OF TIME EACH HAS BEEN PRESENT.

<u>CONDITION</u>	<u>YEARS</u>
1 _____	_____
2 _____	_____
3 _____	_____
4 _____	_____

WHAT IS YOUR RELATIONSHIP TO THE PERSON YOU PROVIDE  
CARE TO?

1. HUSBAND
2. WIFE
3. MOTHER
4. FATHER
5. DAUGHTER
6. SON
7. BROTHER
8. SISTER
9. OTHER \_\_\_\_\_ (PLEASE SPECIFY)

HOW LONG HAVE YOU BEEN PROVIDING CARE?

1. 0-6 MONTHS
2. 7-12 MONTHS
3. 13-18 MONTHS
4. 19-24 MONTHS
5. MORE THAN 24 MONTHS

APPENDIX B  
PERCEIVED SUPPORT NETWORK INVENTORY



FIRST NAME, LAST INITIAL \_\_\_\_\_

RATE THE EXTENT TO WHICH YOU AGREE WITH THE FOLLOWING STATEMENTS BY CIRCLING THE APPROPRIATE NUMBERS.

DURING TIMES OF STRESS:

	ALMOST NEVER	1	2	3	4	5	USUALLY	6	7	ALMOST ALWAYS
--	--------------	---	---	---	---	---	---------	---	---	---------------

I SEEK THIS PERSON OUT FOR SUPPORT OR HELP

1 2 3 4 5 6 7

THIS PERSON PROVIDES ME WITH SUPPORT OR HELP WHEN I ASK

1 2 3 4 5 6 7

I AM SATISFIED WITH THIS PERSON'S SUPPORT OR HELP

1 2 3 4 5 6 7

PLACE A CHECK NEXT TO THE CATEGORIES OF SUPPORT YOU MIGHT EXPECT TO RECEIVE FROM THIS PERSON DURING TIMES OF STRESS:

\_\_\_\_\_ EMOTIONAL SUPPORT \_\_\_\_\_ MATERIAL AID SUPPORT

\_\_\_\_\_ ADVICE AND INFORMATION \_\_\_\_\_ PHYSICAL ASSISTANCE

\_\_\_\_\_ SOCIAL PARTICIPATION

THIS PERSON RECEIVES SUPPORT FROM ME DURING TIMES OF STRESS FOR HIM/HER.

ALMOST NEVER	2	SOMETIMES	4	USUALLY	6	ALMOST ALWAYS
1		3		5		7

GENERALLY SPEAKING, I HAVE SERIOUS CONFLICTS WITH THIS PERSON.

ALMOST NEVER	2	SOMETIMES	4	USUALLY	6	ALMOST ALWAYS
1		3		5		7

APPENDIX C

ROSENBERG SELF-ESTEEM SCALE

PLEASE INDICATE WHETHER YOU AGREE OR DISAGREE WITH THE FOLLOWING  
STATEMENTS:

	<u>STRONGLY AGREE</u>	<u>AGREE</u>	<u>DISAGREE</u>	<u>STRONGLY DISAGREE</u>
I FEEL THAT I'M A PERSON OF WORTH, AT LEAST ON AN EQUAL BASIS WITH OTHERS.	1	2	3	4
I FEEL THAT I HAVE A NUMBER OF GOOD QUALITIES.	1	2	3	4
ALL IN ALL, I AM INCLINED TO FEEL THAT I AM A FAILURE.	1	2	3	4
I AM ABLE TO DO THINGS AS WELL AS MOST OTHER PEOPLE.	1	2	3	4
I FEEL I DO NOT HAVE MUCH TO BE PROUD OF.	1	2	3	4
I TAKE A POSITIVE ATTITUDE TOWARD MYSELF.	1	2	3	4
ON THE WHOLE, I AM SATISFIED WITH MYSELF.	1	2	3	4
I WISH I COULD HAVE MORE RESPECT FOR MYSELF.	1	2	3	4
I CERTAINLY FEEL USELESS AT TIMES.	1	2	3	4
AT TIMES I THINK I AM NO GOOD AT ALL.	1	2	3	4

APPENDIX D

BECK DEPRESSION INVENTORY

*Instructions: This is a questionnaire. On the questionnaire are groups of statements. Please read the entire group of statements in each category. Then pick out the one statement in that group which best describes the way you feel today, that is, right now! Circle the number beside the statement you have chosen. If several statements in the group seem to apply equally well, circle each one.*

*Be sure to read all the statements in each group before making your choice.*

**A. (Sadness)**

- 3 I am so sad or unhappy that I can't stand it.
- 2 I am blue or sad all the time and I can't snap out of it.
- 1 I feel sad or blue.
- 0 I do not feel sad.

**B. (Pessimism)**

- 3 I feel that the future is hopeless and that things cannot improve.
- 2 I feel I have nothing to look forward to.
- 1 I feel discouraged about the future.
- 0 I am not particularly pessimistic or discouraged about the future.

**C. (Sense of failure)**

- 3 I feel I am a complete failure as a person (parent, husband, wife).
- 2 As I look back on my life, all I can see is a lot of failures.
- 1 I feel I have failed more than the average person.
- 0 I do not feel like a failure.

**D. (Dissatisfaction)**

- 3 I am dissatisfied with everything.
- 2 I don't get satisfaction out of anything anymore.
- 1 I don't enjoy things the way I used to.
- 0 I am not particularly dissatisfied.

**E. (Guilt)**

- 3 I feel as though I am very bad or worthless.
- 2 I feel quite guilty.
- 1 I feel bad or unworthy a good part of the time.
- 0 I don't feel particularly guilty.

**F. (Self-dislike)**

- 3 I hate myself.
- 2 I am disgusted with myself.
- 1 I am disappointed in myself.
- 0 I don't feel disappointed in myself.

**G. (Self-harm)**

- 3 I would kill myself if I had the chance.
- 2 I have definite plans about committing suicide.

- 1 I feel I would be better off dead.
- 0 I don't have any thoughts of harming myself.

**H. (Social withdrawal)**

- 3 I have lost all of my interest in other people and don't care about them at all.
- 2 I have lost most of my interest in other people and have little feeling for them.
- 1 I am less interested in other people than I used to be.
- 0 I have not lost interest in other people.

**I. (Indecisiveness)**

- 3 I can't make any decisions at all anymore.
- 2 I have great difficulty in making decisions.
- 1 I try to put off making decisions.
- 0 I make decisions about as well as ever.

**J. (Self-image change)**

- 3 I feel that I am ugly or repulsive-looking.
- 2 I feel that there are permanent changes in my appearance and they make me look unattractive.
- 1 I am worried that I am looking old or unattractive.
- 0 I don't feel that I look any worse than I used to.

**K. (Work difficulty)**

- 3 I can't do any work at all.
- 2 I have to push myself very hard to do anything.
- 1 It takes extra effort to get started at doing something.
- 0 I can work about as well as before.

**L. (Fatigability)**

- 3 I get too tired to do anything.
- 2 I get tired from doing anything.
- 1 I get tired more easily than I used to.
- 0 I don't get any more tired than usual.

**M. (Anorexia)**

- 3 I have no appetite at all anymore.
- 2 My appetite is much worse now.
- 1 My appetite is not as good as it used to be.
- 0 My appetite is no worse than usual.

APPENDIX E

FAMILY CRISES ORIENTED PERSONAL EVALUATION SCALES

DECIDE HOW WELL EACH STATEMENT DESCRIBES YOUR ATTITUDES AND BEHAVIOR IN RESPONSE TO PROBLEMS OR DIFFICULTIES. IF THE STATEMENT DESCRIBES YOUR RESPONSE VERY WELL, THEN CIRCLE THE NUMBER 5 INDICATING THAT YOU STRONGLY AGREE; IF THE STATEMENT DOES NOT DESCRIBE YOUR RESPONSE AT ALL, THEN CIRCLE THE NUMBER 1, INDICATING THAT YOU STRONGLY DISAGREE; IF THE STATEMENT DESCRIBES YOUR RESPONSE TO SOME DEGREE, THEN SELECT A NUMBER 2, 3, OR 4 TO INDICATE HOW MUCH YOU AGREE OR DISAGREE WITH THE STATEMENT ABOUT YOUR RESPONSE.

- 1 - STRONGLY DISAGREE
- 2 - MODERATELY DISAGREE
- 3 - NEITHER AGREE NOR DISAGREE
- 4 - MODERATELY AGREE
- 5 - STRONGLY AGREE

WHEN I FACE PROBLEMS OR DIFFICULTIES IN MY FAMILY, I RESPOND BY ...

ACCEPTING THAT WE HAVE THE STRENGTH WITHIN OUR OWN FAMILY TO SOLVE OUR PROBLEMS.

STRONGLY DISAGREE 1 2 3 4 5 STRONGLY AGREE

ACCEPTING GIFTS AND FAVOURS FROM NEIGHBORS (FOOD, TAKING IN MAIL, ETC.).

STRONGLY DISAGREE 1 2 3 4 5 STRONGLY AGREE

SEEKING INFORMATION AND ADVICE FROM THE FAMILY DOCTOR.

STRONGLY DISAGREE 1 2 3 4 5 STRONGLY AGREE

FACING PROBLEMS "HEAD-ON" AND TRYING TO GET SOLUTIONS RIGHT AWAY.

STRONGLY DISAGREE 1 2 3 4 5 STRONGLY AGREE

WATCHING TELEVISION.

STRONGLY DISAGREE 1 2 3 4 5 STRONGLY AGREE

SHOWING THAT I AM STRONG.

STRONGLY DISAGREE 1 2 3 4 5 STRONGLY AGREE

ATTENDING CHURCH SERVICES.

STRONGLY DISAGREE 1 2 3 4 5 STRONGLY AGREE



WHEN I FACE PROBLEMS OR DIFFICULTIES IN MY FAMILY, I RESPOND BY ...

ACCEPTING STRESSFUL EVENTS AS A FACT OF LIFE.

STRONGLY DISAGREE 1 2 3 4 5 STRONGLY AGREE

SHARING CONCERNS WITH CLOSE FRIENDS.

STRONGLY DISAGREE 1 2 3 4 5 STRONGLY AGREE

KNOWING LUCK PLAYS A BIG PART IN HOW WELL I AM ABLE TO SOLVE FAMILY PROBLEMS.

STRONGLY DISAGREE 1 2 3 4 5 STRONGLY AGREE

ACCEPTING THAT DIFFICULTIES OCCUR UNEXPECTEDLY.

STRONGLY DISAGREE 1 2 3 4 5 STRONGLY AGREE

DOING THINGS WITH RELATIVES (GET-TOGETHERS, DINNERS, ETC.).

STRONGLY DISAGREE 1 2 3 4 5 STRONGLY AGREE

SEEKING PROFESSIONAL COUNSELING AND HELP FOR FAMILY DIFFICULTIES.

STRONGLY DISAGREE 1 2 3 4 5 STRONGLY AGREE

BELIEVING I CAN HANDLE MY OWN PROBLEMS.

STRONGLY DISAGREE 1 2 3 4 5 STRONGLY AGREE

PARTICIPATING IN CHURCH ACTIVITIES.

STRONGLY DISAGREE 1 2 3 4 5 STRONGLY AGREE

WHEN I FACE PROBLEMS OR DIFFICULTIES IN MY FAMILY, I RESPOND BY ...

SHARING MY DIFFICULTIES WITH RELATIVES.

STRONGLY DISAGREE 1 2 3 4 5 STRONGLY AGREE

SEEKING ENCOURAGEMENT AND SUPPORT FROM FRIENDS.

STRONGLY DISAGREE 1 2 3 4 5 STRONGLY AGREE

KNOWING I HAVE THE POWER TO SOLVE MAJOR PROBLEMS.

STRONGLY DISAGREE 1 2 3 4 5 STRONGLY AGREE

SEEKING INFORMATION AND ADVICE FROM PERSONS IN OTHER FAMILIES WHO HAVE FACED THE SAME OR SIMILAR PROBLEMS.

STRONGLY DISAGREE 1 2 3 4 5 STRONGLY AGREE

SEEKING ADVICE FROM RELATIVES.

STRONGLY DISAGREE 1 2 3 4 5 STRONGLY AGREE

ASKING NEIGHBORS FOR FAVOURS AND ASSISTANCE.

STRONGLY DISAGREE 1 2 3 4 5 STRONGLY AGREE

SEEKING ASSISTANCE FROM COMMUNITY AGENCIES AND PROGRAMS DESIGNED TO HELP FAMILIES IN MY SITUATION.

STRONGLY DISAGREE 1 2 3 4 5 STRONGLY AGREE

WHEN I FACE PROBLEMS OR DIFFICULTIES IN MY FAMILY, I RESPOND BY ...

DEFINING THE FAMILY PROBLEM IN A MORE POSITIVE WAY SO THAT I DO NOT  
BECOME TOO DISCOURAGED.

STRONGLY DISAGREE 1 2 3 4 5 STRONGLY AGREE

ASKING RELATIVES HOW THEY FEEL ABOUT PROBLEMS I FACE.

STRONGLY DISAGREE 1 2 3 4 5 STRONGLY AGREE

FEELING THAT NO MATTER WHAT I DO TO PREPARE, I WILL HAVE DIFFICULTY  
HANDLING PROBLEMS.

STRONGLY DISAGREE 1 2 3 4 5 STRONGLY AGREE

SEEKING ADVICE FROM A MINISTER.

STRONGLY DISAGREE 1 2 3 4 5 STRONGLY AGREE

BELIEVING IF I WAIT LONG ENOUGH, THE PROBLEM WILL GO AWAY.

STRONGLY DISAGREE 1 2 3 4 5 STRONGLY AGREE

SHARING PROBLEMS WITH NEIGHBORS.

STRONGLY DISAGREE 1 2 3 4 5 STRONGLY AGREE

HAVING FAITH IN GOD.

STRONGLY DISAGREE 1 2 3 4 5 STRONGLY AGREE

APPENDIX F

ZARIT BURDEN INVENTORY

THE FOLLOWING IS A LIST OF STATEMENTS WHICH REFLECT HOW PEOPLE SOMETIMES FEEL WHEN TAKING CARE OF ANOTHER PERSON. AFTER EACH STATEMENT, INDICATE HOW OFTEN YOU FEEL THAT WAY; NEVER, RARELY, SOMETIMES, QUITE FREQUENTLY, OR NEARLY ALWAYS. THERE ARE NO RIGHT OR WRONG ANSWERS.

DO YOU FEEL THAT YOUR RELATIVE ASKS FOR MORE HELP THAN HE/SHE NEEDS?

0. NEVER 1. RARELY 2. SOMETIMES 3. QUITE FREQUENTLY 4. NEARLY ALWAYS

DO YOU FEEL THAT BECAUSE OF THE TIME YOU SPEND WITH YOUR RELATIVE THAT YOU DON'T HAVE ENOUGH TIME FOR YOURSELF?

0. NEVER 1. RARELY 2. SOMETIMES 3. QUITE FREQUENTLY 4. NEARLY ALWAYS

DO YOU FEEL STRESSED BETWEEN CARING FOR YOUR RELATIVE AND TRYING TO MEET OTHER RESPONSIBILITIES FOR YOUR FAMILY OR WORK?

0. NEVER 1. RARELY 2. SOMETIMES 3. QUITE FREQUENTLY 4. NEARLY ALWAYS

DO YOU FEEL EMBARRASSED OVER YOUR RELATIVE'S BEHAVIOR?

0. NEVER 1. RARELY 2. SOMETIMES 3. QUITE FREQUENTLY 4. NEARLY ALWAYS

DO YOU FEEL ANGRY WHEN YOU ARE AROUND YOUR RELATIVE?

0. NEVER 1. RARELY 2. SOMETIMES 3. QUITE FREQUENTLY 4. NEARLY ALWAYS

DO YOU FEEL THAT YOUR RELATIVE CURRENTLY AFFECTS YOUR RELATIONSHIP WITH OTHER FAMILY MEMBERS OR FRIENDS IN A NEGATIVE WAY?

0. NEVER 1. RARELY 2. SOMETIMES 3. QUITE FREQUENTLY 4. NEARLY ALWAYS

ARE YOU AFRAID WHAT THE FUTURE HOLDS FOR YOUR RELATIVE?

0. NEVER 1. RARELY 2. SOMETIMES 3. QUITE FREQUENTLY 4. NEARLY ALWAYS

DO YOU FEEL YOUR RELATIVE IS DEPENDENT ON YOU?

0. NEVER 1. RARELY 2. SOMETIMES 3. QUITE FREQUENTLY 4. NEARLY ALWAYS

DO YOU FEEL STRAINED WHEN YOU ARE AROUND YOUR RELATIVE?

0. NEVER 1. RARELY 2. SOMETIMES 3. QUITE FREQUENTLY 4. NEARLY ALWAYS

DO YOU FEEL YOUR HEALTH HAS SUFFERED BECAUSE OF YOUR INVOLVEMENT WITH YOUR RELATIVE?

0. NEVER 1. RARELY 2. SOMETIMES 3. QUITE FREQUENTLY 4. NEARLY ALWAYS

DO YOU FEEL THAT YOU DON'T HAVE AS MUCH PRIVACY AS YOU WOULD LIKE, BECAUSE OF YOUR RELATIVE?

0. NEVER 1. RARELY 2. SOMETIMES 3. QUITE FREQUENTLY 4. NEARLY ALWAYS

DO YOU FEEL THAT YOUR SOCIAL LIFE HAS SUFFERED BECAUSE YOU ARE CARING FOR YOUR RELATIVE?

0. NEVER 1. RARELY 2. SOMETIMES 3. QUITE FREQUENTLY 4. NEARLY ALWAYS

DO YOU FEEL UNCOMFORTABLE ABOUT HAVING FRIENDS OVER, BECAUSE OF YOUR RELATIVE?

0. NEVER 1. RARELY 2. SOMETIMES 3. QUITE FREQUENTLY 4. NEARLY ALWAYS

DO YOU FEEL THAT YOUR RELATIVE SEEMS TO EXPECT YOU TO TAKE CARE OF HIM/HER, AS IF YOU WERE THE ONLY ONE HE/SHE COULD DEPEND ON?

0. NEVER 1. RARELY 2. SOMETIMES 3. QUITE FREQUENTLY 4. NEARLY ALWAYS

DO YOU FEEL THAT YOU DON'T HAVE ENOUGH MONEY TO CARE FOR YOUR RELATIVE, IN ADDITION TO THE REST OF YOUR EXPENSES?

0. NEVER 1. RARELY 2. SOMETIMES 3. QUITE FREQUENTLY 4. NEARLY ALWAYS

DO YOU FEEL THAT YOU WILL BE UNABLE TO TAKE CARE OF YOUR RELATIVE MUCH LONGER?

0. NEVER 1. RARELY 2. SOMETIMES 3. QUITE FREQUENTLY 4. NEARLY ALWAYS

DO YOU FEEL YOU HAVE LOST CONTROL OF YOUR LIFE SINCE YOUR RELATIVE'S ILLNESS?

0. NEVER 1. RARELY 2. SOMETIMES 3. QUITE FREQUENTLY 4. NEARLY ALWAYS

DO YOU WISH YOU COULD JUST LEAVE THE CARE OF YOUR RELATIVE TO SOMEONE ELSE?

0. NEVER 1. RARELY 2. SOMETIMES 3. QUITE FREQUENTLY 4. NEARLY ALWAYS

DO YOU FEEL UNCERTAIN ABOUT WHAT TO DO ABOUT YOUR RELATIVE?

0. NEVER 1. RARELY 2. SOMETIMES 3. QUITE FREQUENTLY 4. NEARLY ALWAYS

DO YOU FEEL YOU SHOULD BE DOING MORE FOR YOUR RELATIVE?

0. NEVER 1. RARELY 2. SOMETIMES 3. QUITE FREQUENTLY 4. NEARLY ALWAYS

DO YOU FEEL YOU COULD DO A BETTER JOB IN CARING FOR YOUR RELATIVE?

0. NEVER 1. RARELY 2. SOMETIMES 3. QUITE FREQUENTLY 4. NEARLY ALWAYS

OVERALL, HOW OFTEN DO YOU FEEL BURDENED IN CARING FOR YOUR RELATIVE?

0. NEVER 1. RARELY 2. SOMETIMES 3. QUITE FREQUENTLY 4. NEARLY ALWAYS

APPENDIX G

INSTRUMENTAL ACTIVITIES OF DAILY LIVING SCALE



MALES

FEMALES

	A. ABILITY TO USE TELEPHONE	
1	1. OPERATES TELEPHONE ON OWN INITIATIVE; LOOKS UP AND DIALS NUMBERS, ETC.	1
1	2. DIALS A FEW WELL - KNOWN NUMBERS.	1
1	3. ANSWERS TELEPHONE BUT DOES NOT DIAL.	1
0	4. DOES NOT USE TELEPHONE AT ALL.	0
	B. SHOPPING	
1	1. TAKES CARE OF ALL SHOPPING NEEDS INDEPENDENTLY.	1
0	2. SHOPS INDEPENDENTLY FOR SMALL PURCHASES.	0
0	3. NEEDS TO BE ACCOMPANIED ON ANY SHOPPING TRIP.	0
0	4. COMPLETELY UNABLE TO SHOP.	0
	C. FOOD PREPARATION	
	1. PLANS, PREPARES AND SERVES ADEQUATE MEALS INDEPENDENTLY.	1
	2. PREPARES ADEQUATE MEALS IF SUPPLIED WITH INGREDIENTS.	0
	3. HEATS AND SERVES PREPARED MEALS, OR PREPARES MEALS BUT DOES NOT MAINTAIN ADEQUATE DIET.	0
	4. NEEDS TO HAVE MEALS PREPARED AND SERVED.	0

M

F

D. HOUSEKEEPING

- |   |   |
|---|---|
| 1. MAINTAINS HOUSE ALONE OR WITH OCCASIONAL ASSISTANCE (E.G., HEAVY-WORK, DOMESTIC HELP). | 1 |
| 2. PERFORMS LIGHT DAILY TASKS SUCH AS DISH-WASHING AND BED - MAKING.                      | 1 |
| 3. PERFORMS LIGHT DAILY TASKS BUT CANNOT MAINTAIN ACCEPTABLE LEVEL OF CLEANLINESS.        | 1 |
| 4. DOES NOT PARTICIPATE IN ANY HOUSEKEEPING TASKS.  | 0 |

E. LAUNDRY

- |  |   |
|--|---|
| 1. DOES PERSONAL LAUNDRY COMPLETELY.                   | 1 |
| 2. LAUNDERS SMALL ITEMS; RINSES SOCKS, STOCKINGS, ETC. | 1 |
| 3. ALL LAUNDRY MUST BE DONE BY OTHERS.                 | 0 |

F. MODE OF TRANSPORTATION

- |  |   |
|--|---|
| 1. TRAVELS INDEPENDENTLY ON PUBLIC TRANSPORTATION.                                 | 1 |
| 2. ARRANGES OWN TRAVEL VIA TAXI, BUT DOES NOT OTHERWISE USE PUBLIC TRANSPORTATION. | 1 |
| 3. TRAVELS ON PUBLIC TRANSPORTATION WHEN ASSISTED OR ACCOMPANIED BY ANOTHER.       | 1 |
| 4. TRAVEL LIMITED TO TAXI OR AUTOMOBILE, WITH ASSISTANCE OF ANOTHER.               | 0 |
| 5. DOES NOT TRAVEL AT ALL.   | 0 |

MALES

FEMALES

G. RESPONSIBILITY FOR OWN MEDICATION

- |   |   |   |
|---|---|---|
| 1 | 1. IS RESPONSIBLE FOR TAKING MEDICATION IN CORRECT DOSAGES AT CORRECT TIME.       | 1 |
| 0 | 2. TAKES RESPONSIBILITY IF MEDICATION IS PREPARED IN ADVANCE IN SEPARATE DOSAGES. | 0 |
| 0 | 3. IS NOT CAPABLE OF DISPENSING OWN MEDICATION.                                   | 0 |

H. ABILITY TO HANDLE FINANCES

- |   |   |   |
|---|---|---|
| 1 | 1. MANAGES FINANCIAL MATTERS INDEPENDENTLY (BUDGETS, WRITES CHECKS, PAYS RENT AND BILLS; GOES TO BANK); COLLECTS AND KEEPS TRACK OF INCOME. | 1 |
| 1 | 2. MANAGES DAY-TO-DAY PURCHASES, BUT NEEDS HELP WITH BANKING, MAJOR PURCHASES, ETC.   | 1 |
| 0 | 3. INCAPABLE OF HANDLING MONEY.   | 0 |

APPENDIX H

CHECKLIST

ARE YOU SATISFIED WITH THIS SITUATION AS IT EXISTS?

LIST OF HELP CURRENTLY RECEIVED

RESPIRE	1 YES	2 NO	1 YES	2 NO
TRANSPORTATION	1 YES	2 NO	1 YES	2 NO
MEAL PREPARATION	1 YES	2 NO	1 YES	2 NO
FINANCIAL ASSISTANCE	1 YES	2 NO	1 YES	2 NO
COUNSELING FOR THE CARE RECEIVER	1 YES	2 NO	1 YES	2 NO
COUNSELING FOR YOU	1 YES	2 NO	1 YES	2 NO
COUNSELING FOR THE FAMILY	1 YES	2 NO	1 YES	2 NO
HOME REPAIR	1 YES	2 NO	1 YES	2 NO
ALTERNATE HOUSING	1 YES	2 NO	1 YES	2 NO
OTHER _____ (PLEASE SPECIFY)				
_____			1 YES	2 NO
_____			1 YES	2 NO
_____			1 YES	2 NO
_____			1 YES	2 NO