

**The Differential Impact of
Caregiving on Spouse and
Adult Child Caregivers
of Family Members with
Irreversible Dementia**

A thesis submitted to the faculty of Graduate Studies
in partial fulfilment of the requirements for the degree of
Master of Social Work

School of Social Work
University of Manitoba

by

Rose Mary Schallmann

July 1990



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BY

ROSE MARY SCHALLMAN

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Abstract

The objective of this research was to determine whether there were differences in burden, depression and life satisfaction between adult child and spouse caregivers of family members with irreversible dementia. Sixty caregivers whose family members were on the waiting list for personal care home placement, were interviewed as to the impact of caregiving on their lives using three subjective measures.

Levels of burden were high and depression and life satisfaction in this sample were in ranges outside of those found to be normal for the average older population. Child caregivers living with their carereceiver were most affected by caregiving, followed by spouses living with their partner. The least affected were children not living with their carereceiver.

The results from this research suggest that social work interventions need to be addressed according to caregiver type as well as caregiver context.

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CHAPTER 1

Introduction

Demographic trends suggest that as the proportion of aged in our society continues to grow, the incidence of persons with irreversible dementia will increase. Estimates are that there are anywhere from 100,000 to 300,000 victims of Alzheimer's disease alone in Canada. There are at least 10,000 deaths per year from this disease (Health & Welfare Canada, 1984). This, together with the emphasis on community as opposed to institutional care as a moral philosophy as well as an economic necessity, will mean that there will be increasing numbers of people in the role of caregiver. Understanding the varying effects of caregiving on different categories of caregivers will be important in order for social workers to respond to caregiver needs.

The purpose of this study is to investigate the impact caregiving has on those caring for family members with an irreversible dementia. Greatest stress and unique problems have been found in those caring for individuals with mental deficits (dementia) rather than those with physical disabilities (Deimling & Bass, 1986; Isaacs & Achter, 1972;

Zarit, Reeve & Bach-Peterson, 1980). It is not dementia per se that creates the stress but the behavioral manifestations of the disease (Horowitz, 1985; Deimling & Bass, 1986). Researchers have found that caregiving places social, physical and financial burdens on the caregiver (Cohen & Eisdorfer, 1986; Grad & Sainsbury, 1963; Zarit, Orr & Zarit, 1985). Many studies do not examine whether there are differences in the burden felt by the various caregiver types. The studies that have analyzed differences in caregiver categories have shown varying results. These studies will be discussed in later sections of this research. Few studies, however, consider living arrangement (context) and caregiver category. All research reviewed in this thesis are from United States studies unless otherwise stated.

In the writer's experience in working with caregivers over the past eight years in the Continuing Care Program in Manitoba, many caregivers appear to be burdened, but the burden seems to be different for different types of caregivers. These differences appear to be related, in part, to the varying roles people must fulfil and the additional strains created as a consequence of their caregiving role. This may be also related to the context in which caregiving is provided.

The intent of this research was to determine whether caregiving does impact differently on spouse and adult child

caregivers, the two main caregiver groups in our society. Role strain theory was used to demonstrate role strain as a possible factor in the differences that may be found in caregiver consequences (ie. burden) with child and spouse caregivers. Role strain theory will be discussed in a later chapter. If there are differences in burden between child and spouse caregivers it would appear that the focus of social work intervention would need to vary with each group.

Dementia

Family caregiving for frail mentally impaired elderly members results in burdens and strains for those involved (Zarit, Orr & Zarit, 1985). Dementia is a term used to describe a loss or impairment of mental functioning (Mace & Rabins, 1981; U.S. Congress, 1987; Zarit, Orr & Zarit, 1985). The U.S. Congressional report (1987) states the symptoms of dementia can include the loss of language skills, the inability to think abstractly, the inability to care for oneself, personality changes, emotional instability and disorientation to time and place. Researchers frequently divide the deterioration of the individual with dementia into three stages; the forgetfulness stage, the confusional stage, and the demented stage (Burnside, 1979; Tanner & Shaw, 1985). Each stage presents different problems and concerns for

caregivers. Dementia can be caused by many different diseases, some of which are reversible and some of which are not (Mace & Rabins, 1981; U.S. Congress, 1987; Zarit, Orr & Zarit, 1985). Carereceivers in this study would be in the latter two stages of the disease in order to qualify for personal care home placement.

Reisberg (1981) found, at autopsy of dementia patients, Alzheimer's Disease (S.D.A.T.) made up more than 50% of the cases. Multi-infarct dementia (M.I.D.) made up 15% of cases, mixed (a combination of S.D.A.T. and M.I.D.) made up 25% of cases and other causes of dementia made up 15% of cases. No matter what the cause of the irreversible dementia, these diseases are ultimately progressive and fatal. For the caregiver, whether the patient has Alzheimer's disease or another type of irreversible dementia the caregiving experience, is similarly traumatic.

Caregiving for family members with dementia is felt to create more stress for caregivers and present unique problems for them due to the ill person's intellectual incapacities. This research was therefore focused on caregivers providing care to individuals with a diagnosis of irreversible dementia.

The Caregivers

Caregiver Categories

For the majority of their illness, most individuals with dementia are cared for by their families (U.S. Congress, 1987). The major responsibility for care in the community, regardless of family size, is often left to one caregiver (Marples, 1986). The spouse is usually the primary caregiver, but if there is no spouse, then this responsibility will fall on a child, usually a daughter or a daughter-in-law (Horowitz, 1985; U.S. Congress, 1987). If there is no child the caregiver will be another relative, a neighbour or a friend.

One common factor in all caregiver selection appears to be that women are more likely to become caregivers than men. Cantor (1983) found this to be true in her study in all classifications except that of spouse. In her study 48.6% of spouses, 75% of the children, 85.7% of other relatives and 92.3% of friends/neighbours were female. Other studies also show females assume caregiving more often than men (Horowitz, 1985; Robinson, 1983). Whether the ill elderly person is married or not greatly influences the scope and significance of the role of intergenerational family members (ie sons,

daughters, grandchildren). That is if he/she no longer has a spouse, other family members will be required to become more involved in providing care. A major realignment of the parent-child relationship occurs with the loss of a spouse (of the ill elderly person) particularly if the remaining elderly person is ill (Adams, 1968; Lopata, 1979). Carter and McGoldick (1980) also found the family's current developmental stage influences patterns of family response to stressful situations. For example a family with young children will react and cope differently to caregiving to an ill family member than will a retired spouse. Cantor's (1983) study found 22.5% of adult child caregivers were in the 20-39 age group, 57.5% were age 40-59, 10% were age 60-74. For the spousal caregivers group; 10.8% were age 40-59, 32.4% were age 60-74 and 48.6% were age 75+. Spousal caregivers are, therefore, more likely to be older than child caregivers. These two caregiver groups are also likely to vary in how they cope with their situations due in part to their different age and stage of life.

Spouses frequently are the primary caregiver, as more than one-half of elderly persons live with a spouse (Hess & Soldo, 1985). Older couples tend to rely primarily on one another for support and care (Johnson, 1980). Spouses also provide more comprehensive support and give it indefinitely (Johnson, 1980). The U.S. Congressional report (1987) states

that one-third to one-half of all caregivers are spouses and that one-quarter to one-third are adult children. As spouses and adult children provide the majority of care, the focus of this research was on these two main caregiver types.

In comparing the burden of spouses with adult child caregivers, Zarit, Reever and Bach-Peterson (1980) and Robinson (1983) found no differences in mental health and social participation. Cantor (1983) found spouses had the greatest degree of physical, financial and emotional strain than any other caregiving groups. In George and Gwyther's (1986) study spouses had lower levels of well being in all dimensions compared to adult children. They had significantly more visits to their doctors, poorer self-rated health, more signs of stress, were more likely to use psychotropic drugs and had lower levels of affect balance and life satisfaction. Filial caregivers (mostly daughters) had higher levels of stress and unhappiness. In a Canadian study by Novak and Guest (1987) children showed greater social burden including role strain than spouses, particularly children who lived with their parent. In areas of emotional and developmental burden spouses showed higher levels of psychological and emotional burden than adult children.

The research indicates that spousal caregivers may be especially at risk in providing care. Hess and Soldo (1985) found that spousal caregivers are older and are more likely

to have their own health problems. Cantor (1983) and Zarit, Todd and Zarit (1986) also found that the closer the relationship to the ill elderly person, the greater the strain. George and Gwyther (1984), however, found adult child caregivers often have more ambivalent feelings about caregiving, while spouses apparently saw their responsibilities as an inherent part of the marital relationship. Spousal caregivers are more likely to be involved in personal care tasks than adult child caregivers (Novak & Guest, 1987a). Performance of personal care tasks that involve bodily contact have been found to be strongly correlated with burden (Hooyman, Gonyea, & Montgomery, 1985). In contrast to child caregivers, spouses rely much less on outside support. They are more willing to accept burden and endure strain without resentment. Child caregivers have been found to undertake caregiving with greater reluctance (Johnson, 1983). The researcher felt further research of this area was required as the literature on the differences of the impact of caregiving on spousal and adult children caregivers is sparse and at times unclear.

Caregiving Contexts

Caregiving takes place in a variety of household contexts or living arrangements (Cantor, 1983; Noelker & Wallace, 1985;

Soldo & Myllyluoma, 1983). Caregivers include both elderly husbands and wives who usually share households, married and unmarried daughters and sons in two and three generation households and to a lesser extent other relatives and friends. The type of living arrangements (contexts) adult child caregivers and their ill parent occupy can differentially affect their family life. Families living in three generation households (ill elderly person, their son/daughter and grandchildren) as will be discussed in more detail later, can greatly affect family relationships. On the other hand, providing care to a mentally impaired parent living on their own, poses other concerns and strains for the adult child caregiver. The carereceiver may neglect their nutrition, hygiene and medications which may lead to further health problems. They may leave the stove on, this creates a fire hazard for themselves and others living near them. They may wander and become lost and/or hurt.

Depending upon the particular stage of the disease and the idiosyncratic needs of the patient, the care provided by the caregiver will vary (U.S. Congress, 1987). The type of care provided may range from making decisions for the individual on financial and legal issues to assuming complete responsibility for providing personal care (U.S. Congress, 1987). As demented patients are often unaware of their need for help, the care provided is often unappreciated and

resisted. This further complicates the caregiving role often leading to frustration and increased strain.

Consequences of Providing Care

Caregiving impacts on almost every area of the caregiver's life. It can affect their emotional and physical health, their social life, and their employment and financial status (Cohen & Eisdorfer, 1986; Grad & Sainsbury, 1963; U.S. Congress, 1987; Zarit, Orr & Zarit, 1985). In their study, Sainsbury and Grad (1970) found 75% of their families indicated caregiving created problems in their lives; caregivers' mental health showed a decline in 63% of cases; physical health declined in 58% ; and leisure activity declined in 50% of cases. In Cantor's (1983) study she found greatest deprivations for caregivers in the areas of personal desires, individuality and socialization. Rabins, Mace and Lucas (1982) found 87% of caregivers showed chronic fatigue, feelings of anger and depression; 56% had family conflict; 55% had a loss of friends, personal time, hobbies etc; 31% were concerned with their own health; 25% had guilt feelings. Sluss-Radbaugh et al. (1983) found 20% of caregivers showed a decline in health. Zarit, Reever and Bach-Peterson (1980) found changes in family activity, home arrangement and frequency of contact with friends. George and Gwyther (1986)

found caregivers showed lower affect balance, life satisfaction, less participation in social activities and greater use of psychotropic drugs than the general population.

As the effects of caregiving are all encompassing, all areas of a caregiver's life are affected by this role as are the lives of the caregiver's entire family network. It therefore follows that the particular caregiver type will determine others in the family who will be affected and further add to the pressures on the caregiver.

An adult child caregiver for instance, may have a spouse, children and even grandchildren in their lives who are competing for their time and energy. A spousal caregiver on the other hand may have adult children and grandchildren, but the pressure and need for daily active involvement with them may not be as vital as with young families. This is where the varying roles different types of caregivers must perform may affect the strains they experience. In some areas the caregiver's ways of coping and requirements for professional intervention may also be different. Many of the studies to date have been based on relatively small samples and often failed to consider stage of the illness or gender or generation of the caregiver. In a study by Noelker and Wallace (1985) it was found that intervention strategies need to be targeted appropriately in relation to the type of primary caregiver and to the household context in which

caregiving occurs.

In this research caregivers were questioned regarding their subjective feelings as related to caregiving and their lives at that point in time. Subjective feelings have been found to be most strongly correlated with impact of caregiving (Novak & Guest, 1986; Dry et al., 1985; Zarit, Todd & Zarit, 1986). Subjective measures of burden, depression, and life satisfaction were used to measure the impact on caregivers, as these are areas the literature often indicates are affected by providing care.

Burden

Researchers have focused much attention on defining caregiver burden. Burden has been broadly defined and has been measured differently in various studies. For the purposes of this research study, burden was defined " as the extent to which caregivers perceived their emotional or physical health, social life, and financial status as suffering as a result of caring for their relative." (Zarit et al., 1986, p. 261). In role theory, stress is considered an external event and strain is considered cognitive, affective and physiological change induced by stress. Degree of strain is affected by the individual's perception of the stressor (Morycz, 1985). It is therefore how the caregiver perceives their role of providing care to the elderly family

member and how they perceive its place within their total role set that creates the burden they experience.

There is great variability in the degree of burden felt by families. Burden has been found not to be predicted by the severity of impairment, inability to perform activities of daily living or the numbers of years of caregiving (Colerick & George, 1986; Gilhooly, 1984; Machin, 1980; Novak & Guest, 1986; Zarit, Reever & Bach-Peterson, 1980). Researchers have found that caregiver burden is strongly correlated with the caregivers subjective feelings toward providing care (Novak & Guest, 1986; Dry et al., 1985; Zarit, Todd & Zarit, 1986).

Depression

Depression, according to Beck is cognitively based on a negative view of self, a negative view of the world and a negative view of the future (Beck, Rush, Shaw & Emery, 1979). The caregiver of an individual with dementia, according to Beck's theory, would see themselves as failures, the world and future as bleak and hopeless.

Zarit and Zarit (1983) found that caregiving leads to depression, anxiety and psychological distress. Fiore, Becker and Coppel (1983) found 28 of his 68 subjects to be currently depressed. Kleban, Brody, Schoonover and Hoffman (1984) and

Rabins, Mace and Lucas (1982) also found caregivers had feelings of depression. Lezak (1978) pointed out that all caregivers experience some level of depression.

Life Satisfaction

According to Neugarten, Havinghurst and Tobin (1961), life satisfaction is the extent to which an individual takes pleasure from everyday activities, finds his/her life meaningful, has achieved his/her major goals in life, has a positive self image, and has an optimistic attitude and mood. The research indicates that caregiving may affect life satisfaction (Cantor, 1983; George & Gwyther, 1986; Rabins, Mace & Lucas, 1982; Sainsbury & Grad, 1970; Zarit & Reever, 1983).

Summary

It is apparent from the research that caregiving affects the lives of those providing care. It has also been found that the consequences of providing care may be even greater for those caring for family members with irreversible dementia as opposed to caring for family members with physical disabilities.

Some research has explored effects of caregiving on

different caregiver categories. These studies have varied in their results. Few studies have considered caregiving context (living arrangements) in addition to caregiver category. This research has taken both variables into consideration when exploring caregiver burden, depression and life satisfaction levels of caregivers.

CHAPTER 2

Role Strain Theory

Most of the literature to date discusses caregiving and the burdens caregivers experience as a consequence of providing care. Burden has not been conceptualized in a systematic manner. There are many disparities in the definitions and measurements of burden and this limits comparison of research results across studies. The concepts of role strain theory are useful in understanding and in discussing the difficulties encountered by caregivers (Wallace & Noelker, 1984).

It has been the writer's experience that the burdens of caregivers are, to a large extent, more specifically related to the roles caregivers are called upon to perform. The more roles one is called upon to perform, the more role obligations one has to fulfil with more role partners. Multiple roles increase the likelihood of the caregiver being unable to cope as they may become overloaded. The likelihood of conflict increases with more role partners involved in a caregiver's life. The more one is overloaded and the more conflict one is subjected to, the greater the likelihood one will feel burdened.

The ability of caregivers to perform adequately in these roles will vary depending on the caregiver category, spouse or adult child and caregiving context, whether the ill elderly person is living alone or whether they are living with their family caregiver. This research focused on the two main categories of primary caregivers who provide care, adult child caregivers and spouse caregivers. Possible differences in the areas of role strain each group may encounter, as a consequence of their relationship to the patient, as well as a result of the varying contexts in which they provide care will be discussed. If different categories of caregivers vary in the reasons they experience role strain, alternate social work interventions may be needed to assist them in alleviating or dealing with their difficulties.

Role Theory

Role strain theory is just one of the many concepts included under the broader area of role theory. Prior to discussing role strain and its relationship to caregiving to elderly family members, a brief overview of role theory will be outlined.

"Role Theory is a science concerned with the study of behaviours that are characteristic of persons within contexts and with various processes that presumably produce, explain,

or are affected by those behaviours." (Biddle, 1979, p. 4).

The concept of role has been used in disparate ways in both the sociological and psychological literature. Role will be used to refer to normative expectations as well as the dynamic nature of a social position (ie role performance or behaviour). Both of these aspects are referred to in the works of Gross, Mason and McEachern (1958) and Bates and Harvey (1975).

Gross et al. (1958) view role as having three different facets: as a byproduct of a social position or location (eg. a mother would be considered as a social position and the roles of protector, provider etc. associated with it); the normative expectations that are associated with it; and the actual role behaviour as performed by a particular individual. Situational factors (ie setting where the role is performed and other interacting individuals present) will influence the normative expectations associated with a role and role behaviour in addition to the above three elements (Biddle, 1979).

The social positions of spouse and that of adult child will be referred to in this research. The role of caregiver is the byproduct of these positions when an ill elderly family member is present. The actual care provided (role behaviour) by each caregiver type is governed by the normative expectation of that individual's social position (ie. son,

daughter or spouse) and is also determined by situational factors, such as whether the ill elderly person lives alone or with other family members (context) and other interacting individuals present (ie.grandchildren, spouse of caregiver etc.).

Role Strain

Caregiver burden is a term used frequently in the literature when discussing caregiving consequences. Much of what is included under this concept (burden) actually refers to various types of role strain (Wallace & Noelker, 1984). Goode (1960, p. 483) refers to role strain as "the felt difficulty in fulfilling role obligations". Caregiver strains and burdens will be conceptualized using role strain theory (Wallace & Noelker, 1984).

Most of the literature on role strain relates to expected every day roles not unexpected events such as providing care to an ill elderly family member. Role strains are generally normal and encountered by all in day to day living. The role strain that will be discussed is strain experienced as a result of unanticipated and unpredictable circumstances created by caregiving. When a family member becomes ill and requires care, a one time balanced role relationship between spouses or parent and adult child becomes in a state of

change, and adjustments are required to cope (Wallace & Noelker, 1984). Several types of role strain will be discussed and applied to the caregiving situation.

There are at least six distinguishable and different problems when analyzing various role factors that may dispose individuals to strain: role conflict, role ambiguity, role demand overload, role discontinuity, role incongruence and role frustration (Bates & Harvey, 1985; Biddle, 1979; Komarovsky, 1976; Thomas, 1968). Different caregiver types may be affected more by some of these problems than others and reactions of individuals to these problems are diverse.

The three main problems of role strain more commonly encountered by caregivers will be discussed: role conflict, role ambiguity and role demand overload. Areas where role strains differ for spousal and adult child caregivers will be highlighted.

Types of Role Strain

Role conflict

The first type of role strain to be discussed is role conflict. This refers to incompatibilities in normative expectations placed on the individual, rather than an absence of norms or standards (Merton, 1976; Thomas, 1968), making

it impossible for the individual to conform to both sets of expectations at the same time. Role conflict is the most common and widespread of all role difficulties. It is frequently experienced and inevitably stressful. Studies have found it to cause low morale and productivity (Kahn, Wolfe, Quinn, Snoek & Rosenthal, 1964).

There are three types of incompatibilities:

- 1) Normative expectations of role partners that are consensual (sympathetic) but incongruent (out of place) with ego's own expectations (Komarovsky, 1976). For example a family member may agree that their ill elderly relative requires assistance but may not feel that he/she is in the position to provide care or to provide it to the extent that is being requested due to distance, employment, health etc. The impaired elder relative's expectations for assistance from the primary caregiver may exceed that which the caregiver anticipates providing, which may lead to complaints about excessive demands and dependency in the elderly person (Johnson & Catalano, 1983). When this occurs with an adult child caregiver other kin relationships (spouse, children etc.) may feel the effects of the incompatible expectations in the caregiver-elder relationship. All family members feel the repercussions of role and responsibility changes and shifts experienced by the primary caregiver creating disruption in the family.

- 2) Incompatible expectations that are maintained by ego (Komarovsky, 1976). The caregiver (particularly adult child caregivers) may be caught in the middle between two sets of people who the caregiver feels need different things from them. The caregiver may feel they must fulfil all role obligations even though this may be impossible. An adult child caregiver may be caught between their own child and/or a spouse who they feel obligated to give their time and attention and their frail elderly parent who needs care.

A spouse, on the other hand, may expect that he/she should provide care to their partner but due to ill health may not be able to cope with the caregiving requirements.

- 3) Incompatible expectations held by different role partners (Komarovsky, 1976). Other siblings may have different expectations regarding the care being provided or the way care is being provided by the primary caregiver than the caregiver has for himself. This can lead to family conflict, disagreements and resentment particularly when it is often one sibling that provides the majority of care.

Involvement of the caregiver (spouse or adult child) in the labour force can also create incompatible expectations by different partners (ie the employer).

Employment could inhibit provision of adequate care or limit the commitment of the family member to the home care option (Soldo & Myllyluoma, 1983). Caregiving may also affect job performance and create conflict between the caregiving role and the employee role.

Role conflict can be costly for the person in emotional and interpersonal terms. Few studies have dealt with the emotional reactions and social costs of such conflicts.

Role ambiguity

All roles contain some ambiguity and all meanings and boundaries of a role are open to some negotiation (Turner & Shosid, 1976). Due to increased longevity of the elderly population along with the absence of well-established role models for caregivers, intergenerational roles are especially problematic (ambiguous) for adult child caregivers and their ill elderly parents (Mutran & Reitzes, 1984). This can lead to an uncertainty about responsibilities and obligations associated with both of their roles.

Role ambiguity is one of the most basic types of role strain. Like role conflict, role ambiguity may generate stress for the individual. It is the incompleteness or lack of specificity of prescriptions for behaviour (absence of

norms) that can result in personal confusion for the individual (Thomas, 1968). That is, insufficient information is given to guide behaviour - what is desired or how to do it. Thomas (1968) describes role ambiguity as the difficulty felt in having inadequate or incomplete normative behaviour expectations. Role ambiguity has been found to be a source of unhappiness for those involved (Kahn, Wolfe, Quinn, Snoek & Rosenthal, 1964).

Absence of a normative structure is noted by Hagestad (1981) and Mutran and Reitzes (1984) as further complicating caring for older family members who are ill. They indicate reasons for this as being the necessity of more role negotiation required as a consequence of caregiving occurring in a family context and caregiving as we know it today being a relatively recent event for which appropriate norms have yet to be fully developed (Schorr, 1980).

Roles are more loosely constructed and less clearly defined with adult child caregivers than with spousal caregivers. There is no generally accepted standard for the interaction between generations, degree of involvement or amount of support. Studies have found that children feel more obligated to provide care and assistance than parents expect (Davidson, 1979; Hagstead, 1986; Knipscheer, 1987). There are also few formal or institutional expectations defining obligations for either adult child - elderly parent

relationships and this leaves it open for negotiation and ambiguity.

Kinship networks have been proven to be strong today, despite earlier claims to the contrary (Brody, 1981; U.S. Congress, 1987). It also has been found however that help from family may be neutral or may even decrease morale (Arling, 1976; Blau, 1973; Lee, 1979; Wood & Robertson, 1978) and wellbeing (Kerkhoff, 1966; Seelback & Sauer, 1977) of elderly people as this may be a threat to their feelings of independence and their need for reciprocity. The balance of mutual aid shifts between generations as parents become older and dependent (Aldores & Hill, 1985; Blau, 1973). In a study by Adams (1968), maintenance of satisfactory relations between widowed mothers and middle class adult children was found to be positively related to the level of reciprocity present between the two groups. Patterns of giving and receiving are influenced by constraints and opportunities of related social positions and competition among roles for time and energy of the individual (Mutran & Reitzes, 1984).

Children may perhaps want to provide care but their elderly parent may refuse assistance from them. Rewards and costs for providing care can also affect the support given. Rewards such as the satisfaction in fulfilling one's obligation to one's parent/spouse; costs such as decline in health, decrease in leisure time etc. Noelker and Wallace,

1985, found no notable differences in stress effects of caregiving between husband and wife caregivers, but significant differences among adult child caregivers in whether they were single or married. Married child caregivers report significantly greater disruptions in family relationships and more elder - caregiver conflict.

Additional sources of role ambiguity are due to the varied settings (contexts) caregiving takes place and the diverse types of caregivers. Caregiving occurs across households, within households and in a variety of household configurations. Caregivers can be spouses, children, other relatives and/or friends (Noelker & Wallace, 1985; Soldo & Myllylouma, 1983). Specific norms have not evolved to guide families in allocating a primary caregiver or for designating the appropriate context for caregiving (Ikels, 1983). Ambiguity therefore results, regarding who will fill the role, in what context and how the role should be performed. This in all likelihood can create more burden for the caregiver and increased family conflict.

Meaning and distinctiveness of roles are acquired in relation to the roles played by the person to counter-roles present in the situation (Lindsmith & Straus, 1956; Merton, 1957; Turner & Shosid, 1976). The interactional nature of roles suggests that changes or realignments of a person's hierarchy of roles alter intergenerational roles and the well-

being among elderly persons (Mutran & Reitzes, 1984).

Role ambiguity appears to be a role strain that would be encountered largely if not solely by adult child caregivers or caregivers other than a spouse. If a healthy spouse is present there is usually little ambiguity about who should provide the caregiving role. The writer has found this to be true even of spouses in poor marriages. They assume the role without question.

There are no rules however regarding how much assistance children should provide particularly when both parents are alive. With adult child caregivers, role ambiguity can often lead to family conflict and greater feelings of burden in the family caregiver. One child may be providing care (which is usually the case), while others do not participate equally or at all, creating resentment. Both child and spouse caregivers may encounter difficulties in how to provide care (role behaviour). There is no training readily available that prepares caregivers to provide physical care or to teach behaviour management skills necessary to cope with patients with dementia. Effects of role ambiguity have been found by Kahn et al. (1964) to be similar to those for role conflict. In their study it led to tension and futility and was negatively related to job satisfaction and self confidence.

Role demand overload

When role demands are in excess of the individual's capacity to meet such demands role overload occurs. Overload may occur independently of conflict although role conflict may create role overload. Multiple roles may increase the burden of overload and conflict. The more roles accumulated the greater the likelihood of running out of time (overload) and the greater the likelihood of confronting role partners' expectations that are contradictory or conflicting (Sieber, 1974). Goode's (1960) theory of role strain states that excessive demand is one of the determinants of role strain. Adverse effects and emotional disturbance can be precipitated by role overload under extreme environmental conditions. There is not adequate research that indicates the effects of role overload nor of the personality factors or the emotional reactions of individuals that may mediate these effects.

Role demand overload is excessive demands created by the caregiving individual's total role set obligations. One may lack sufficient personal time, energy, resources and /or commitment to enact all role obligations adequately. This would be particularly applicable to a married daughter in a three generation household who may be employed outside of the home, have obligations to spouse, as a parent, as well as a caregiver to an elderly parent (Noelker & Poulshock, 1982).

Caregiving is not her main activity and the amount of time available is limited. The lives of all family members may be acutely affected by caregiving. Adult child caregivers may be putting their marital relationship at some risk, parenting roles may be diminished, normal domestic activities may be neglected, family meals and sleep may be disrupted by behaviour problems and leisure activities may be sacrificed.

Unlike the spousal caregiver, the adult child caregiver may either be caring for their parent in the parent's home or in the child's home. If the parent lives alone, the child caregiver may experience role overload, as they attempt to maintain two households and/or have the constant worry that the parent will do something unhealthy or unsafe to herself and/or to others. For example, they may be concerned that their demented parent will burn something on the stove, smoke carelessly, neglect their nutrition, or wander and get lost.

Child caregivers may also have multiple caregiving responsibilities e.g. in-laws, aunts, uncles. These multiple responsibilities may lead to role overload and role conflict.

These caregivers often have difficulty in reconciling competing demands (Brody, 1981). Some would view the adult-child caregivers as being burdened with problems in role management (Komarovksy, 1976; Marks, 1977). That is, having difficulties allocating and organizing their time and resources sufficiently for enactment of all the roles.

Spousal caregivers, on the other hand, do not generally have as many competing demands on their time but they too must give up many leisure activities and assume various roles their partner previously performed. Wives, for example, may never have been involved with finances or household repairs while husbands may have never shopped, cooked or cleaned house. The consequence of this is that the caregiver is faced with learning new skills at a time in their lives when they least need these added pressures. They are already losing their spouse as they once knew them and their networks are thinning as their cohorts are frail, ill or no longer living. Therefore their avenues for support and assistance are limited.

In the writer's practice it has been evident that spousal caregivers see the caregiving role as an extension of their spousal role. The majority of the present generation of elderly persons are in first marriages of long duration and they entered into these marriages with the expectation of a life long commitment. This expectation to provide care to one's spouse is not only held by the caregiver but by their ill partner, their children and society. Spousal caregivers, as a result, may often feel it is mainly their responsibility to provide care.

The writer has found many spouses do not request help from formal or informal systems until later in the disease

process and may in turn increase their risk of becoming overburdened. Spouses also often delay placement and prolong the strain by continuing in the caregiving role longer, thus caring for a spouse with greater deficits and needs. This together with spousal caregivers having a greater likelihood of having several chronic health problems of their own can lead to overload.

Summary

In reviewing the literature on role strain and relating it to spousal and adult child caregivers, there appear to be some differences in the sources of strain for adult children and spouses. In some cases different modes of intervention may be in order to assist these two groups to cope.

Adult child caregivers seem most affected by role overload, role conflict and role ambiguity. They have multiple roles to fulfil; as parent, spouse, employee and caregiver. This can create overload and also conflict. As mentioned earlier the more roles one is called upon to perform, the more role partners one encounters and greater is the likelihood of conflict. Married caregivers with young children show greater evidence of decline in health, more family disruption and elder conflict particularly when the elderly family member is living with their adult child.

It has been found one person is usually the primary caregiver. In the case of an adult child being the caregiver, there are often other siblings available to provide care. This can lead to resentment and conflict as the primary caregiver may perceive other siblings as not doing their part.

Role ambiguity is also evident with adult child caregivers. There are no set norms in society regarding responsibility for care of a parent (one's loyalties are often felt to be with one's own spouse and children first) or how to provide the care effectively. Whether one should have their parent live alone or live with them is also unclear - there are no set expectations.

A reversal of roles and reduced opportunities for reciprocity is created when a child cares for his parent. This can create dissatisfaction and conflict for both child and parent. Family roles are established over many years and change is difficult.

Spouses, on the other hand, do not have the multiple roles to perform as do child caregivers. They do have to take on roles previously performed by their spouse as well as provide for their twenty-four hour care. They may have to acquire new skills to perform these new tasks which may be an added stress at a time when they are already experiencing considerable emotional and physical stress. Spouses are often at a time in their lives when their roles are decreasing (ie

no longer employed, children have moved away from home etc.). Role conflict is less likely for spouses as there are fewer role partners present in their lives.

Ambiguity regarding the role of caregiver is also not likely to be present with spouses. The caregiver role is a natural extension of the marital relationship and society has the expectation that a spouse will care for their ill partner as long as possible.

Time, energy and commitment are three factors that researchers have found play an important part in the degree of role strain experienced by caregivers (Marks, 1977). Time is more limited for adult child caregivers as a result of the multiple roles they play. Having a parent living alone in their own home can further reduce availability of time (travelling to and from their parent's home, another household to maintain etc.). Energy may be a significant factor with spousal caregivers due to their more advanced age, greater likelihood of chronic health problems of their own. They also generally provide more assistance to more impaired family for longer periods of time than adult child caregivers (Soldo & Myllyluoma, 1983). Adult child caregivers may deplete their energy from the numbers of roles they are performing. Durkheim (1953) states that commitment is the decisive factor in determining whether strain is experienced. He also states abundant energy is found for anything to which one is highly

committed.

Spouses have been found to be more committed to caregiving than any other family member (Gilleard, 1986; Levin et al., 1983; Shulman & Arie, 1978). They have been found to be much less likely to give up caregiving. Gilleard (1986) found the length of time spent living together and sense of having a close relationship is strongly related to the reluctance to consider institutionalization. Two studies by Levin, Sinclair and Gorbach (1983) and Gundy (1981) found that relationship factors have a great influence in determining family members feelings toward caregiving.

Adult child caregivers' commitment has been found to be more related to the level of current strain felt and existing competing roles rather than to any historical factors (relationships). With spouses the pre-morbid relationship significantly affects the spouses attitude towards caregiving. Present problems and emotional upset seemed to play no role in their willingness to provide care (Gilleard, 1986).

Hypotheses

Many research studies have indicated that the added role of providing care to a family member with irreversible dementia can create burden (Cohen & Eisdorfer, 1986; Grad & Sainsbury, 1963; Novak & Guest, 1987a; Zarit, Orr & Zarit,

1985), depression (Blazer & Williams; Coppel, Burton, Becker and Fiore, 1985; Haley, Levine, Brow, Berry & Hughes, 1987; Kahan, Kemp, Staples & Brummel-Smith, 1985; Myers et al., 1984; Robins et al., 1984) and decreased life satisfaction (Fengler, 1979; George & Gwyther, 1986; Haley et al., 1987) for caregivers. It has been illustrated in the previous section, with role strain theory, how child and spouse caregivers may be affected differently by the caregiving role in the areas of role conflict, role ambiguity and role overload. In this theory, role strain has been related to the numerous roles caregiver groups are called upon to perform. The literature has been unclear whether there are differences in the impact caregiving has on the lives of spouse and child caregivers.

Many studies do not separate caregivers according to relationship. Instead, they group caregivers together. Some reports that do consider relationship have found burden to be similar for child and spouse caregivers (Zarit, Reever, Bach-Peterson, 1980). Others report child caregivers have higher strain (Rankin & Pinkston, 1985) and still others report spouses with higher strain (George & Gwyther, 1986). The problem with many of these studies was that living arrangement (caregiving context) was not used as a variable. That is, child caregivers, regardless of whether they lived with their carereceiver or not, were considered as one group, when

compared to spouses in areas such as burden, depression and life satisfaction.

The researcher felt it was important to address the question of differences in the impact of caregiving with these child and spouse caregivers, as they have significant relationship and commitment differences in relation to their carereceiver. Due to the different stages of life each group is encountering, while in the role of caregiver, they have varying role obligations and varying numbers of role partners. This affects the degree of role strain (role conflict, ambiguity and overload) each group are likely to encounter. The more role strain one encounters in one's life the greater the likelihood one may feel burdened.

The problem in this study was to determine whether there were significant differences in spousal and adult child caregivers in their subjective feelings of burden, as well dimensions of burden (time dependence, social, emotional, developmental and physical burden), depression and life satisfaction.

The researcher expected to find differences in the consequences of caregiving for child and spouse caregivers from her eight years of experience dealing with caregivers as well as her review of the literature on role strain theory and caregiver burden.

The hypotheses were:

- 1) Caregivers, in general, with high burden scores would have high depression scores and low life satisfaction scores.
- 2) Child caregivers would feel more burdened than spouse caregivers.
- 3) Child caregivers would be more likely to have higher levels of depression and lower levels of life satisfaction than spouse caregivers.

Role strain theory is useful in understanding and discussing difficulties encountered by caregivers. It also suggests why child and spouse caregivers may perceive burden differently. Three types of role strain; role overload, role conflict and role ambiguity, were discussed in detail in the previous section. It has been illustrated how different caregiver categories in varying contexts can be differentially affected by role strain. If the caregiver role creates role strains in a caregiver's life they will feel more burdened in this role.

Child caregivers are more likely than spouse caregivers to experience role strain. They often have multiple roles to fulfil. Many are married (spouse role), have children in the

home (parent role), are employed (employee role), and at times are providing care to more than one ill relative (caregiver role/s). All of these roles have their obligations to be fulfilled and require the time, commitment and energy of the caregiver. The more numerous the roles a caregiver has, the more role partners he must interact with to fulfil role obligations. The more partners involved the greater the likelihood of conflict. If the caregiver does not have sufficient personal resources (time, energy etc.) to fulfil these primary roles in their life they may encounter role conflict and/or role overload. The caregiver may have a spouse, child, employer and carereceiver all making demands on them. They may chose to try to fulfil or feel they should fulfil all role obligations. This may put them at risk of overload. They may chose, instead, to provide care to their parent and devote less time to their other role responsibilities. This may put them at risk of conflict in their other roles.

When the care is provided in the caregiver's own home this can further exacerbate the situation. The caregiver then is "on call" 24 hours a day and the whole family unit can be further affected by this as well, by the lack of privacy etc. It is clear that the addition of the caregiver role to an already busy life can create role strain and lead to a person feeling burdened in the caregiving role.

Spouse caregivers are also married, but their spouse/carereceiver already occupies the central role in their life. Most spouse caregivers are no longer child rearing, so do not have an active parenting role. They are also more than likely retired and do not have this role to fulfil. As spouse caregivers have fewer roles and fewer role partners in their life, the researcher felt that they would be less likely to encounter role conflict and overload. If they experience less role strain, they are also less likely to feel as burdened in the caregiver role.

The third type of role strain discussed was role ambiguity. It also is more likely to be encountered by child caregivers. There are no set norms for children regarding the roles and responsibilities for providing care to an ill parent. It is not clear who should provide care to an ill parent and where care should be provided. There is no standard regarding the degree of involvement or amount of support expected from an adult child in these circumstances. Often there are several siblings in a family who could provide care or assist in the caregiving. Caregiving, however, most often falls on one child. This often creates resentments, anger and conflict within families. The caregiver would then feel more burdened in the caregiver role.

For spouse caregivers there is no ambiguity regarding who should provide care if one partner becomes ill and the

other partner is well. Spouses see providing care to their spouse as part of their marital role and are committed to this role. As a result of this commitment and a clear standard for role enactment, a spouse caregiver would be less likely to become burdened.

The researcher expected that child caregivers would likely have higher burden levels than spouse caregivers. With higher burden it was expected that caregivers would experience higher levels of depression and lower levels of life satisfaction. This would be as a consequence of being more burdened from the multiple roles that child caregivers fulfil in addition to caregiving (leading to role conflict and overload), and also from the ambiguity this role presents for them.

CHAPTER 3

Methodology

A sample of sixty caregivers (thirty spouses and thirty children) were selected from clients on the Manitoba Continuing Care Program. The clients meeting the research criteria were referred to the researcher by the Case Coordinators. Permission for conducting the research was obtained from the Office of Continuing Care.

Criteria for Selection

1. Subjects were the primary caregivers of family members with a medical diagnosis of some type of irreversible dementia.
2. Subjects were alert and orientated.
3. The carereceiver was on the waiting list for personal care home placement in Winnipeg.

The purpose of choosing the criteria that the carereceiver be on the waiting list for personal care home was that caregivers request placement at the time when they feel they no longer can cope. By selecting the sample from the

waiting list the researcher ensured that all of the caregivers are at a similar point of distress (have decided they cannot continue providing care at home).

Referral Process

Individuals were identified by:

1. A review of the existing personal care home waiting list for appropriate subjects. This was completed by Continuing Care supervisors.
2. Cases approved at weekly panels (process of new applicants for placement becoming eligible for the waiting list) were reviewed by the Continuing Care Supervisors for inclusion in this study.

Case Coordinators of clients identified by supervisors were requested to contact the caregivers to discuss the study and obtain their agreement to participate. The names of potential subjects were then forwarded to the researcher who sent out a letter of introduction. This was followed by a phone call by the researcher to the subject to arrange for an interview. A consent form, was signed at the beginning of the interview (See Appendix A). Interviews averaged from 1 1/2 to 2 hours in length and in most cases they were carried out

in the home of the caregiver. The questionnaire was read with each subject during the interview and they were asked to indicate their response to each question.

Instruments

The Zarit Burden Interview (BI)

Permission to use The Zarit Burden Interview was received by S. Zarit and J. Zarit (see Appendix B).

The Burden Interview has been used as the standard measurement for burden in many studies (see Appendix B). It is a 22 item unidimensional questionnaire designed to reflect the stresses experienced by caregivers of dementia patients. Answers range from (0) to (4) and the total score ranges from 0-88.

While there are no computed norms for this scale, Zarit and Zarit do provide some estimates of the degree of burden from preliminary findings. These are:

Score of 0-20 = little or no burden

Score of 21-40 = mild to moderate burden

Score of 41-60 = moderate to severe burden

Score of 61-88 = severe burden

Internal reliability for the Burden Interview has been estimated using Chronbach's Alpha at .88 (Hassinger, 1985)

and .91 (Gallagher et al, 1985). Test retest reliability is reported at .71 (Gallagher et al, 1985). Validity has been estimated by correlating the total score with a single global rating of burden ($r=.71$) and by correlating the total score with the Brief Symptom Inventory (Derogatis, Lipman, Covi, Richeis & Uhlenhuth, 1970; $r=.41$).

Caregiver Burden Inventory (CBI)

Permission to use The Caregiver Burden Inventory was obtained from M. Novak (see Appendix C).

The Caregiver Burden Inventory is multidimensional 24 item questionnaire (see Appendix C). The five factors measured are, time dependence, developmental burden, physical burden, social burden and emotional burden. Scoring ranges from 0 to 4 . Scoring on each dimension ranges from 0-20 except for factor 3 and 4 which score 0-16. The total burden score ranges from 0-92. There are no established norms for this instrument. The researcher omitted one question from the original inventory. The question was in the social dimension relating to marriage. As it did not apply to spouse caregivers it therefore was not included for child caregivers.

Reliability estimates for the total instrument using Chronbach's Alpha is .8935. For each factor Chronbach's Alpha is: .8969; .8497; .8654; .7453; .7766 (Novak and Guest, 1987a).

As there are similar questions on The Burden Inventory and The Caregiver Burden Inventory, and they are both designed to measure subjective burden, for interviewing purposes similar questions (see Appendix C & D for four similar questions*) were combined in the two instruments (see Appendix D). After implementation the data was separated out and used for the purposes of analysis. There were slight differences in the phrasing of the similar questions and the response choices, but the differences were not felt to make any differences in the results. CBI questions and responses were used in this study for the four similar questions. It was felt that the researcher could be more certain of the score on the CBI (a very new instrument) if the CBI was found to be strongly correlated with scores on the BI.

For the purposes of evaluating the impact of burden in different dimensions the CBI is a more useful instrument than the BI. The BI provides only a total burden score while the CBI provides both a total burden score as well as five sub scores (that make up the total score) which indicate different areas of burden. In this way the researcher could analyze whether the different groups (or individuals) vary in the areas they experience burden even though they may have similar total burden scores. This could then indicate an entirely different area of intervention required to help alleviate the burden.

The Beck Depression Inventory (BDI):

Permission to use The Beck Depression Inventory was obtained from A. Beck (see Appendix E).

The Beck Depression Inventory (short) is a multidimensional 13 item questionnaire (see Appendix E). The subject rates themselves on a scale of 0-3 on each of the dimensions. The dimensions are: sadness, pessimism, sense of failure, dissatisfaction, guilt, self dislike, self harm, social withdrawal, indecisiveness, self image, work difficulty, fatigability and anorexia. Total score ranges from 0-39.

The estimated degree of depression according to the Beck Depression Inventory is:

Scores of 0-4 = none or minimal depression

Scores of 5-7 = mild depression

Scores of 8-15 = moderate depression

Scores of 16+ = severe depression

The split-half reliability of the original Beck Depression Inventory was .93. The shortened Beck Depression Inventory correlated better than .90 with the long form. Beck (1972) reports the short form reliability is .96. Its concurrent validity ranged from .61 to .82.

Life Satisfaction Index (LSI-Z)

The Life Satisfaction Index-Z (Wood, Wylie & Sheafor, 1969) is a short form of the Life Satisfaction Inventory A (Neugarten, Havinghurst & Tobin, 1966). It consists of a series of 13 statements. The scoring of the statements are score two points for each "right" answer - marked with an X, one point for ? or no response (see Appendix F). Total score ranges from 0-26. Norms for this instrument are:

Scores of 0-9 = low life satisfaction

Scores of 10-18 = medium life satisfaction

Scores of 19-26 = high life satisfaction

Reliability of the Life Satisfaction Inventory-Z is .79.

Summary

Four subjective measures were used in this study to measure burden, depression and life satisfaction of the caregiver sample. Several research studies have found subjective feelings to be strongly correlated with the impact of caregiving (Novak & Guest, 1986; Dry et al., 1985; Zarit, Todd & Zarit, 1986).

The BI and CBI measure the caregiver's subjective feelings about providing care and how they feel this role affects them. Specific questions relate to various areas of

the caregiver role. They explore their perceived emotional and physical health, social and financial status in relation to being a caregiver. Levels of burden are determined from these measures. An individual's perception of the stresses of caregiving can create additional strains in their lives. Depending on the number of other stressors in other roles and the individual's ability to cope (time, energy, resources and commitment), caregivers will vary in their level of burden.

It was predicted that child caregivers will score higher on these burden inventories due to the multiple role responsibilities they have, which can lead to role strain. Due to these many other responsibilities, they may have less time and energy than a spouse caregiver. As well, due to their relationship to the caregiver and the ambiguity of the caregiver role for adult children (lack of standard norms), they may not be as committed to this role as spouse caregivers.

The BDI is a self report measure of the psychological well-being of an individual. It is a widely used measure of depression for both younger and older populations. Several studies have found depression prevalent in caregivers of dementia patients (Fiore, Becker & Coppel, 1983; Rabins, Mace & Lucas, 1982; Zarit & Zarit, 1983). If a caregiver experiences high burden levels, depression levels were expected to be high as well.

The LSI-Z has been commonly used with elderly populations and assesses the individual's perceived life satisfaction. Questions relate to self image, mood, attainment of life goals etc. Several studies have found caregiving may affect life satisfaction (Cantor, 1983; Fengler & Goodrich, 1979; George & Gwyther, 1986; Haley, Levine, Brow, Berry & Hughes, 1987; Harris, 1975; Rabins, Mace & Lucas; Sainsbury & Grad, 1970; Zarit & Reever, 1987). Some of these studies also use this measure, some use the longer form of the index. Caregivers with high burden were expected to have high depression levels and low life satisfaction levels.

CHAPTER 4

Results

DemographicsAgeAge of caregivers

Of the total sample, the average age of caregivers (those providing care) was 62.8 years (SD=12.2).

As would be expected spousal caregivers were older than child caregivers. The mean age of the child caregivers was 53.067 years (SD=7.45) with a range in age from 37-70 years and for spousal caregivers 72.6 years (SD=7.3) with ages ranging from 55-86 years. The difference in the mean age of the two groups, child and spousal caregivers, was statistically significant (t=10.077; p=.000).

Age of carereceivers

Of the total sample of carereceivers (those receiving care) the average age was 79.25 years (SD=7.895). Carereceivers' ages ranged from 55-96 years.

The mean age of carereceivers being cared for by children was 82.33 ($SD=8.34$), ranging from 55–96 years. The mean age of carereceivers being cared for by their spouses was 76.17 years ($SD=6.13$), ranging from 64–89 years. The difference in the mean age of the two groups was statistically significant ($t=3.263$; $p=.001$).

More child caregivers cared for older family members (carereceivers) than spousal caregivers. Family members cared for by child caregivers were widowed, thus more likely older than the spousal group where both partners were still living.

Age of the caregiver and the age of the carereceiver are correlated. The older the caregiver, the older the carereceiver for both spouse and child groups (see Table 1).

Table 1

Age of Caregiver by Age of Carereceiver by Relationship

	Age of Caregiver	Age of Carereceiver	n	r
Child	53.07	82.33*	30	.573
Spouse	72.60	76.17*	30	.680

* $p < .001$

GenderGender of caregivers

In the total sample female caregivers outnumbered male caregivers 2:1.

Females caregivers also outnumbered male caregivers when the spouse and child groups were analyzed separately. In the child caregivers group female (daughters) outnumbered male (sons) caregivers 3:1. In the spousal group the ratio of male to female (husband/wife) caregivers was 3:2 (see Table 2).

Female caregivers outnumbered male caregivers in both child and spouse caregiver groups.

Table 2

Gender of Caregivers

	Total	Children	Spouses
	%(n)	%(n)	%(n)
Male	31.7%(19)	23.3%(7)	40%(12)
Female	68.3%(41)	76.7%(23)	60%(18)
Total	100%(60)	100%(30)	100%(30)

Gender of carereceivers

In the total sample, females ($n=36$) requiring care outnumbered males ($n=24$). This was not the case when the two caregiving groups were analyzed separately.

In the child caregiving group care was being provided to females in 25 cases and to males in 5 cases. In the spousal group there were 11 females and 19 males requiring care (see Table 3). Child caregivers were more likely to be caring for female family members and spousal caregivers were more likely to be looking after male family members.

Cantor (1983) found women more likely to be the carereceiver except in the case of spouses. In her study child caregivers cared for female family members in 75% of cases and spouses cared for female family members in 48.6% of cases. As stated previously child caregivers were generally caring for parents who were widowed. As females outlive males, the parent left to be cared for would most often be a female. With spousal group it is not unusual for the carereceiver to be male as females live longer than males. In most cases, with marriage partners, the male spouse is the older partner.

Table 3

Gender of Carereceiver

	Total	Children	Spouses
	%(n)	%(n)	%(n)
Male	40%(24)	16.7%(5)	63.3%(19)
Female	60%(36)	83.3%(25)	36.7%(11)
Total	100%(60)	100%(30)	100%(30)

Marital Status

In this study 26 (86.7%) of the 30 child caregivers were married. All spousal caregivers were married.

Of the total sample 93% were married.

Employment Status

In the child caregiver group 19 (63.3%) of the sample were employed. In the spousal group 3 (10%) were employed.

Child caregivers were more likely to be working outside of the home than spousal caregivers. This is not an unusual finding. Generally, spouse caregivers are older than child caregivers and most are at or well above retirement age.

Diagnosis

All carereceivers in the sample had been diagnosed by their physician with some form of irreversible dementia as their primary diagnosis (see Table 4). The forms of dementia in the other category included Parkinson's dementia (3), Korsokoff's dementia (2), progressive supranuclear palsy (1) and one unspecified.

Table 4

Diagnosis of Carereceiver

	%(n)
Senile Dementia Alzheimer's Type	53.3% (32)
Senile Dementia	21.7% (13)
Multi Infarct Dementia	11.3% (8)
Other	11.7% (7)
Total	100% (60)

In Reisberg's (1981) study of dementia patients, at autopsy 50% were Senile Dementia Alzheimer's Type (SDAT), 25% a combination of SDAT and multi infarct dementia (MID) which would correspond to senile dementia diagnosis in this study, 15% MID and 15% other causes.

Level of Care

Level of care is determined in the assessment process for personal care home placement in Manitoba. The purpose of the assessment is to determine the degree of dependency on nursing time (professional and nonprofessional) that the care of an applicant requires. Six categories are assessed in determining the level; bathing and dressing, feeding, nursing intervention, ambulation, elimination, support and/or supervision. Each of these six categories of care are assessed as to degree of dependency from independent to maximum dependency. As all care receivers in this study were on the waiting list for personal care home a level of care was available. Levels of care range from level 1 to level 4; level 1 being the lightest care level.

The average level of care for the total sample was 2.573 (SD=0.562). The mean level of care for those being cared for by the child caregiver group was 2.27 (SD=0.45). The mean level of care for those being cared for by the spousal group was 2.8 (SD=0.55). The difference in the mean level of care between the two groups was statistically significant ($t=4.108$; $p=0.000$). Spousal caregivers looked after family members requiring higher levels of care than did child caregivers (see Table 5).

Johnson (1980) found spouses give more comprehensive

support and give it indefinitely, while child caregivers are often more ambivalent in their feelings regarding caregiving (Johnson 1980, 1983). It would then follow that spouses continue caregiving longer and therefore their carereceiver would likely have a higher level of disability.

Grad and Sainsbury (1968) and Kraus et al. (1976) showed spouses go to great lengths to prevent institutionalization. They do so at times at great costs to themselves, in the belief that they can better care for their ill spouse. Carereceivers in their studies were found to be well beyond levels of care that would justify institutionalization.

Table 5

Level of Care of Carereceiver by Relationship of Caregiver

	Total	Children	Spouses
Level	%(n)	%(n)	%(n)
2	50%(30)	73.3%(22)	26.7%(8)
3,4	50%(30)	26.7%(8) a	73.3%(22) b
Total	100%(60)	100%(30)	100%(30)

a None at level 4 for child caregivers

b Two at level 4 for spouse caregivers

Level of care and gender

The only other variable that showed a relationship with level of care was gender of the caregiver. Overall, female caregivers provided care to family members requiring higher levels of care than did male caregivers ($t=2.081$, $p=.021$). Wives provided higher levels of care than husbands, daughters and sons. Daughters provided similar levels of care to sons and husbands. Husbands, provided care to family members requiring higher levels of care than son caregivers (Table 6). Due to the small number of subjects in the son caregiver group, cautious interpretation of the data is required.

Table 6

Mean Level of Care by Relationship (ANOVA)

	Groups			
	1. Husband	2. Wife	3. Son	4. Daughter
	<u>n</u> =12	<u>n</u> =18	<u>n</u> =7	<u>n</u> =23
<u>M</u>	2.50	3.00	2.00	2.39
<u>SD</u>	.52	.49	.00	.49
<u>F</u>	10.26***			

Note. Group 1,2 $t=2.87^{**}$

Group 1,3 $t=2.25^{*}$

Group 2,3 $t=4.806^{***}$

Group 2,4 $t=4.437^{***}$

* $p<.05$. ** $p<.01$. *** $p<.001$

Spouse caregivers provided higher levels of care to their family care receivers than did the child caregivers. Female caregivers provided higher levels of care than did male caregivers overall, largely due to the fact female caregivers in the spousal group cared for only level 3 and 4 family members (see Table 7). Husbands provided similar levels of care to daughters and higher levels of care to sons.

Table 7

Level of Care by Relationship

Level	Relationship			
	Child		Spouse	
	son	daughter	husband	wife
2	7(100%)	15(65%)	6(50%)	2(11%)
3	-	8(35%)	6(50%)	14(78%)
4	-	-	-	2(11%)
Total	7(100%)	23(100%)	12(100%)	18(100%)

Level of care and living arrangement

Spouses care for family members requiring higher levels of care than both children living with their carereceiver and children not living with their carereceiver. Regardless of living arrangement child caregivers cared for family members requiring similar levels of care (see Table 8). Of those carereceivers cared for by children, four of the eight level 3 and thirteen of the twenty-two level 2 carereceivers lived alone.

No relationship was found between level of care of the carereceiver and their living arrangement. That is, the amount of care required by the carereceiver was not related to whether they lived with their caregiver or not. All spouse caregivers in the sample lived with their carereceiver.

Table 8

Mean Level of Care by Living Arrangement and Relationship

	Groups		
	1. Live with child n=13	2. Not live with child n=17	3. Live with spouse n=30
<u>M</u>	2.31	2.24	2.80
<u>SD</u>	.48	.44	.55
<u>F</u>			8.39**

Note. Living arrangements refers to caregivers living with or not living with the carereceiver.

Group 1,3 $t=2.93^{**}$

Group 2,3 $t=3.67^{***}$

** $p < .01$. *** $p < .001$.

Level of care was not correlated with life satisfaction, burden or depression.

Length Of Caregiving

The average length of time care was provided in the total sample was 58.4 months.

Children had provided care an average of 73.3 months (range=2-348 months; SD=99.35). Spouses provided care for an average of 43.3 months (range=6-240 months; SD=44.78). There was a trend toward child caregivers providing care longer but this was not statistically significant (t=1.501; p=.069).

The average length of time that care was provided was similar for child and spouse caregivers.

Living Arrangements

In the total sample 71.7% (43) of caregivers lived with the carereceiver and 28.3% (17) did not live with their carereceiver.

In the spousal group (n=30) all caregivers lived with their carereceiver. In the child caregiver group 43.3% (13) lived with their family member and 56.7% (17) lived in a separate residence. Of the 13 carereceivers who lived with their child caregiver, 12 were living with a daughter and one was living with a son caregiver.

The majority of the sample of caregivers lived with their carereceiver. If the caregiver was a spouse they would be

living with their carereceiver. If the caregiver was a child they were more likely to live separate from their carereceiver. If the caregiver was living with their carereceiver the caregiver was more likely to be a daughter.

Brody, 1985 estimates, in the United States, 4% of people 65 years and older live in three generation households at any given time. According to the 1982 Long Term Survey (Myers et al., 1984; Robins et al., 1984), 36% of extremely disabled carereceivers live with adult children, mostly daughters. Sixty percent of caregiving daughters had their parent living with them and 20% of those had children under 18 in the home as well (Stone, Cafferata & Sangl, 1987).

Instruments

The Zarit Burden Interview (BI)

The mean score for the total sample with the BI was 39.27, in the mild to moderate burden range. The maximum possible range in score is 0-88.

For the child caregivers group, the mean score was 42.57, moderate to severe burden and 35.86 for the spousal group, mild to moderate burden. The difference in the scores between the two groups was statistically significant ($t=1.925$, $p=.030$). The child caregiver group had a higher burden level

than the spousal group with the BI.

The Caregiver Burden Inventory (CBI)

The mean score for the total sample with the CBI was 40.85. The maximum possible range in score is 0-92.

The mean burden score for child caregivers was 40.33. The mean burden score for spouse caregivers was 41.37. The difference in the scores was not statistically significant ($t=.770$, $p=.385$). Child and spousal groups showed similar burden levels with the CBI.

Child caregivers had higher burden scores than spouse caregivers with the BI. Approximately 43% of child caregivers and 45% of spouse caregivers scored in the moderate to severe burden range. With the CBI child and spouse caregivers had similar burden scores. No norms have been established for this instrument.

Zarit, Reever and Bach-Peterson (1980) report few differences between child and spouse caregivers. They report for each group increased burden with increased caregiving responsibilities. Rankin and Pinkston (1985), on the other hand, report child caregivers have higher strain than spouses. George and Gwyther (1986) reported that spouses had twice the stress than child caregivers. The literature is unclear regarding which caregiver group is most burdened but all agree

caregivers are burdened.

The BI and CBI were highly correlated (Total sample: $r=.831$, $n=60$, $p=.000$; child sample: $r=.878$, $n=30$, $p=.000$; spouse sample: $r=.867$, $n=30$, $p=.000$).

Burden and living arrangement

With the BI children living with their carereceiver had higher burden levels than children not living with their carereceiver. They also had higher burden levels than spouses. Children not living with their carereceiver and spouses had similar burden levels (see Table 9).

Table 9

Mean Scores on the Zarit Burden Interview (BI) by Living Arrangement and Relationship (ANOVA)

	Groups		
	1. Live with child n=13	2. Not live with child n=17	3. Live with spouse n=30
<u>M</u>	48.54	38.00	35.86
<u>SD</u>	13.11	12.71	12.99
<u>F</u>			4.42*

Note. Living arrangements refers to the caregiver to living with or not living with the carereceiver.

Group 1,2 $t=2.211^*$

Group 1,3 $t=2.935^{**}$

* $p < .05$. ** $p < .01$.

With the CBI children living with their carereceiver had higher burden levels than children not living with their carereceiver and similar levels of burden to spouses. Children not living with their carereceiver also had similar levels of burden to spouses (see Table 10).

Table 10

Mean Scores on the Caregiver Burden Inventory (CBI) by Living Arrangement and Relationship (ANOVA)

	Groups		
	1. Live with child n=13	2. Not live with child n=17	3. Live with spouse n=30
<u>M</u>	48.62	34.00	41.37
<u>SD</u>	14.36	12.06	12.36
<u>F</u>			4.91**

Note. Living arrangements refers to the caregiver living with or not living with the carereceiver.

Group 1,2 $t=-3.118^{**}$

** $p < .01$.

Both the BI and CBI indicated child caregivers living with their carereceiver were more burdened than children not living with their carereceiver. Both inventories also indicate similar burden level for children not living with their carereceiver and spouses. The difference in results with these inventories were between children living with their carereceiver and spouses. The BI showed higher burden for

the child group while the CBI showed similar burden for both groups. With the CBI children living with their carereceiver did have a higher mean score than spouses but this did not reach statistical significance.

Burden and gender

In the total sample male caregivers (n=19) had lower mean burden scores than females (n=40) with both the BI and the CBI (BI, $t=2.031$, $p=.023$; CBI, $t=1.992$, $p=.029$). With the BI husbands had the lowest burden levels of all groups. Sons, wives and daughters had similar levels of burden (see Table 11).

Table 11

Mean Scores on the Zarit Burden Interview (BI) by Relationship
(ANOVA)

	Groups			
	1. Husband	2. Wife	3. Son	4. Daughter
	$n=12$	$n=17$	$n=7$	$n=23$
<u>M</u>	29.33	40.47	42.43	42.61
<u>SD</u>	11.68	12.13	18.76	12.35
<u>F</u>				3.02*

Note. Group 1,2 $t=2.269^*$

Group 1,3 $t=2.115^*$

Group 1,4 $t=2.864^{**}$

* $p < .05$. ** $p < .01$

With the CBI all four groups had similar levels of burden. Husbands did have the lowest mean burden score but the variance with the other groups was not statistically significant (see Table 12).

Caution should be taken in interpretation due to small sample number for sons.

Table 12

Mean Scores on the Caregiver Burden Inventory (CBI) by Relationship (ANOVA)

	1. Husband	2. Wife	3. Son	4. Daughter
	<u>n</u> =12	<u>n</u> =18	<u>n</u> =7	<u>n</u> =23
<u>M</u>	34.92	45.67	37.86	41.09
<u>SD</u>	10.50	11.84	22.20	41.09
<u>F</u>				1.70

Noelker and Wallace (1985) reported women caregivers were more adversely affected in the mental health area than men. Women reported more strain and found the caregiving experience more restricting and confining though equal time and effort caregiving was taken. Women are also more likely to appreciate the ill person's distress.

Burden and age

Burden scores were negatively correlated with caregiver and carereceiver age for spousal caregivers. With the spousal caregiver sample, the younger the caregiver the higher their burden score (Zarit $r=-.490$, $n=30$, $p=.007$; CBI $r=-.549$, $n=30$,

$p=.002$). The younger the carereceiver the higher spousal caregiver burden score (Zarit $r=-.359$, $n=30$, $p=.055$; CBI $r=-.445$, $n=30$, $p=.014$). Correlations were also found between depression and age and life satisfaction and age of carereceiver for the spouse group. These statistics are reported on in the respective sections.

In the individual dimensions of burden (CBI) the younger the spousal caregiver the higher the social burden ($t=-.533$, $p=.002$), the higher the physical burden ($t=-.407$, $p=.026$), the higher the developmental burden ($t=-.478$, $p=.009$), and the higher the time burden ($t=-.490$, $p=.006$). No relationship was found with the emotional burden dimension.

The younger the caregiver and the younger the carereceiver the higher the burden score for the spousal caregiver. Age of caregiver and carereceiver was not related to the burden level of child caregivers.

No relationships were found in the child caregiver group between burden and age of the caregiver or age of the carereceiver.

The younger the spouse caregiver and his carereceiver the higher their burden scores. This finding may suggest that younger spouse caregivers are not as accepting of the disease for their younger spouse as older spouses with older carereceivers. They may feel that they should not be experiencing such tragedy at this stage in their lives. The

older caregiver with an older carereceiver may feel they have lived a long and good life and be more accepting of this disease at this stage.

As previously stated the age of the caregiver and the age of the carereceiver were correlated in this study. The younger the caregiver the younger the carereceiver for both child and spouse caregivers.

Burden and length of caregiving

The only correlation found between burden and length of caregiving was with spouses in the physical burden dimension. The longer care was provided the higher the physical burden ($t=.466$; $p=.009$). This may be related to decline in health and/or tolerance level in the spouse caregiver as caregiving is prolonged.

Burden was not correlated with length of caregiving for child or spouse caregivers with either burden inventory or individual CBI dimensions.

Burden, depression and life satisfaction

Caregivers with high scores on the Zarit Burden Interview were likely to be high scorers on the Beck Depression Inventory ($r=.646$, $n=60$, $p=.000$), the Caregiver Burden

Inventory ($r=0.831$, $n=60$, $p=.000$) and low scorers on the Life Satisfaction Index-Z ($r=.664$, $n=60$, $p=.000$). Similar results were found for the child and spouse groups individually. See the section on Depression, Burden and Life Satisfaction for statistics for the two groups individually.

Caregiver Burden Inventory Dimensions

The CBI instrument not only gives a total burden score but also scores in five individual dimensions that make up the total score. These dimensions indicate different burden areas and in turn may assist practitioners in assessing where they may need to focus their interventions with caregivers.

Time dimension

The time dimension includes time required for physical care, support and supervision on a daily basis to care for the carereceiver.

In the individual dimensions of burden the differences in the mean scores for the child and spouse caregiver groups were statistically significant in the time dimension ($t=2.827$, $p=.003$). This indicates spouses were more burdened in this dimension.

Children living with their carereceiver, however, had

equal time burden to spouses. They also did not differ significantly in this dimension with children not living with their carereceiver but the trend was to higher scores than children not living with their carereceiver. Children not living with their carereceiver had significantly lower time burden scores than spouses (see Table 13). Spouses were most burdened in the time dimension. Children not living with their carereceiver were least burdened.

Table 13

Mean Scores on the Time Dimension of The Caregiver Burden Inventory (CBI) by Living Arrangement and Relationship (ANOVA)

	Groups		
	1. Live with child n=13	2. Not live with child n=17	3. Live with spouse n=30
<u>M</u>	15.46	13.12	16.53
<u>SD</u>	3.15	3.74	2.90
<u>F</u>			6.17**

Note. Living arrangement refers to the caregiver living with or not living with the carereceiver.

Group 2,3 $t=3.508***$

** $p<.01$. *** $p<.001$.

Social dimension

The social dimension includes burden as a result of family relationships, effects on employment, resentment of family members, and lack of appreciation for one's effort etc.

In the social dimension child caregivers had significantly higher mean burden scores than spouses ($t=3.173$, $p=.001$). Children living with their carereceiver and children not living with their carereceiver both had higher mean burden scores in the social dimension than spouse caregivers (Table 14). Children were more burdened in the social dimension than spouses.

Children living with their parent had the same level of social burden as children living in a different residence than their carereceiver (Table 14).

Spouses were least burdened in the social dimension. Child caregivers, both living with and not living with their carereceiver were most burdened.

Table 14

Mean Scores on the Social Dimension of the Caregiver Burden Inventory (CBI) by Living Arrangement and Relationship (ANOVA)

	Groups		
	1. Live with child n=13	2. Not live with child n=17	3. Live with spouse n=30
<u>M</u>	3.62	2.89	1.23
<u>SD</u>	2.99	2.67	1.94
<u>F</u>			5.35**

Note. Living Arrangement refers to caregivers living with or not living with the carereceiver.

Group 1,3 $t=2.981^{**}$

Group 2,3 $t=2.439^{*}$

* $p<.05$. ** $p<.01$.

Emotional dimension

The emotional dimension includes negative emotions towards one's carereceiver such as embarrassment, shame and/or resentment, anger at interactions with them, and feeling unhappy and hopeless about the future. No statistically

significant difference was found in emotional burden for spouses and the total child caregiver group ($t=1.423$, $p=.080$).

Table 15

Mean Scores on the Emotional Dimension of the Caregiver Burden Inventory (CBI) by Living Arrangement and Relationship (ANOVA)

	Groups		
	1. Live with child $n=13$	2. Not live with child $n=17$	3. Live with spouse $n=30$
<u>M</u>	6.39	3.29	3.33
<u>SD</u>	3.45	3.48	3.32
<u>F</u>			4.16*

Note. Living arrangements refers to caregivers living with or not living with the carereceiver.

Group 1,2 $t=2.474^*$

Group 1,3 $t=2.710^{**}$

* $p<.05$. ** $p<.01$

In this dimension spouses had lower emotional burden than children living with their carereceiver and similar levels to children not living with their carereceiver (see Table 15).

Children living with their care receiver had higher mean burden scores in the emotional dimension than children not living with their care receiver (see Table 15).

Spouses and children not living with their care receiver had similar emotional burden. Children living with their care receiver had the highest emotional burden scores.

Developmental dimension

The developmental dimension is a feeling of being trapped or out of phase with the expectations one has about this time in their life.

There were no significant differences in this dimension for child or spouse caregivers ($t=.408$, $p=.408$). When living arrangement was analyzed there also were no differences (see Table 16).

Table 16

Mean Scores on the Developmental Dimension of the Caregiver Burden Inventory (CBI) by Living Arrangement and Relationship (ANOVA)

	Groups		
	1. Live with child n=13	2. Not live with child n=17	3. Live with spouse n=30
<u>M</u>	13.77	9.59	11.97
<u>SD</u>	5.22	3.64	5.82
<u>F</u>			2.52

Note. Living arrangements refer to caregivers living with or not with the carereceiver.

Physical dimension

The physical dimension are the physical effects on the caregiver, lack of sleep, decline in health etc.

There were no significant differences in the child or spouse groups in the physical dimension of burden ($t=1.267$, $p=.105$).

Children living with their carereceiver and spouses had

significantly higher physical burden scores than children not living with their carereceiver (see Table 17).

Table 17

Mean Scores on the Physical Dimension of the Caregiver Burden Inventory (CBI) by Living Arrangement and Relationship (ANOVA)

	Groups		
	1	2	3
<u>M</u>	9.39	5.12	8.40
<u>SD</u>	4.91	3.67	4.05
<u>F</u>			4.80*

Note. Living arrangements refers to the caregiver living with or not living with the carereceiver.

Group 1,2 $t=2.793^{**}$

Group 2,3 $t=2.608^{**}$

* $p<.05$. ** $p<.01$.

Children living with their carereceiver and children living in a separate residence had similar burden scores in time, social and developmental dimensions and higher scores in the physical dimension.. All three groups had similar burden scores in the developmental dimension. Spouses and children living with their carereceiver had similar burden

scores in time and physical dimensions. Spouses had higher time and physical burden than children not living with their carereceiver.

Spouses were also found to be more burdened in the physical dimension the longer they had been providing care ($t=.466$, $p=.006$).

Spouses are least burdened in the social dimensions. Along with children not living with their carereceiver, they are least burdened in the emotional dimension. Children not living with their carereceiver were least burdened in the physical dimension. All three groups had similar burden levels in the developmental dimension.

Children living with their carereceiver are either the most burdened or among the most burdened in all the individual burden dimensions. Spouses are least burdened in the social and emotional dimension.

Children not living with their carereceiver are the least burdened in all dimensions except the social dimension where they are the most burdened along with children living with their carereceiver. Their burden was similar to spouses and children living with their carereceiver in the developmental and similar to spouses in the emotional dimension. They also had similar burden levels to children living with their carereceiver in the time dimension.

The Beck Depression Inventory

On the short form of the Beck Depression Inventory the mean score for the total sample was 5.633.

The mean score for the child caregiver group was 6.267 and 5.00 for the spousal group. All scores are in the range indicating mild depression. The difference in the mean scores of the two groups was not statistically significant ($t=1.108$, $p=.136$).

Child and spouse caregivers had similar levels of depression.

In the general older population estimates are that from 1% to 10% are in mild to severely depressed range. Blazer and Williams (1980) report 3-5% of elderly persons (over 65) are felt to suffer from major depression. The most recent data from NIMH's Epidemiological Catchment Area (ECA) study reported that 1-2% of those over 65 suffered from a major depressive disorder and 1-3% suffer from chronic depression (Myers et al, 1984; Robins et al, 1984). Women have a higher prevalence than men in both types of diagnosis. This study did not find differences in depression between males and females.

Coppel et al. 1985 found 40% of the 68 Alzheimer caregivers he studied to be clinically depressed. Gallagher, Rose, Lovett and Silven (1986) found 25% of SDAT caregivers

with a current diagnosable major or minor depressive episode, with an additional 26% with depressive features present but not sufficient to diagnose. Kahan et al. (1985) found 45% of 40 SDAT caregivers were at least somewhat depressed.

All these studies report levels of depression in caregivers that are higher than expected in the general older population.

In this study 63% of children and 47% of spouses scored in the mild to severe range for depression. Average score for both groups were in the mild depression range. In the Haley et al. 1987 study with 44 dementia caregivers and 44 controls (non caregivers) using the BDI (21 item) found the caregivers to have average scores in the mild depression range much like this study. Non caregivers scored in the no depression range.

Depression and living arrangement

All spouses lived with their carereceiver. Spouse caregivers had depression scores in the mild depression range. Depression scores for children living with their carereceiver were in the moderate depression range. Children living with their carereceiver had higher depression scores than spouses and children not living with their carereceiver. Spouses and children not living with their carereceiver had similar depression scores (Table 18).

Table 18

Mean Scores on the Beck Depression Inventory (BDI) by Living Arrangement and Relationship (ANOVA)

	Groups		
	1. Live with child n=13	2. Not live with child n=17	3. Live with spouse n=30
<u>M</u>	8.31	4.71	5.00
<u>SD</u>	4.75	4.69	3.81
<u>F</u>			3.27*

Note. Living arrangements refers to caregivers living with or not living with their carereceiver.

Group 1,2 $t=2.286^*$

Group 1,3 $t=2.330^*$

* $p < .05$.

From these results child caregivers living with their carereceiver had lower levels of psychological well being than children caregivers not living with their carereceiver and spouse caregivers.

Depression and age

With the spousal group, age of the carereceiver correlated with depression. The younger the carereceiver the higher the depression score of the spousal caregiver ($r = -0.415$, $n = 30$, $p = .022$). Correlations were also found between burden and age and life satisfaction and age of carereceiver for this group of caregivers. These findings are reported on in their respective sections.

No correlation was found with depression and the age of the carereceiver for child caregivers.

There was no correlation between age of caregiver and depression for either child caregiver or spouse caregivers.

The younger the spousal carereceiver the higher the depression level of the caregiver. For child caregivers there was no relationship between depression and age of the carereceiver. This result may reflect spousal caregivers being less accepting of the disease when their spouse is younger as opposed to when they have lived to an old age and had a full life. Younger spouse caregivers may encounter financial problems if they or their carereceiver are not of pensionable age. They may also still have dependent children in the home.

Depression and length of caregiving

For the child caregiver group, depression was correlated with length of caregiving. The higher the depression level the greater the length of time care was provided ($r=.383$, $n=30$, $p=.037$).

There was no correlation between depression and length of caregiving for spouse caregivers.

The longer child caregivers provided care the higher their depression levels. For spouse caregivers there was no relationship between depression and length of caregiving. The differences between these two groups may be due to the difference in commitment to providing care. Spouses, as mentioned previously provide care indefinitely and without resentment while child caregivers are more reluctant and also often have divided loyalties due to the many other roles they are called upon to fulfil at this time in their lives. They then may, over time, become more depressed in continuing this additional caregiving role.

Depression and gender of caregiver

Level of depression did not vary with the gender of caregiver for either child or spouse caregivers.

Depression, burden and life satisfaction

Caregivers, as a whole, with high scores on the Beck Depression Inventory were likely to be high scorers on the Zarit Burden Interview ($r=.646$, $n=60$, $p=.000$) and the Caregiver Burden Inventory ($r=0.664$, $n=60$, $p=.000$) and low scorers on the Life Satisfaction Index-Z ($r=-0.562$, $n=60$, $p=.000$).

There were similar findings for the child caregiver (Zarit $r=.642$, $n=30$, $p=.000$; CBI, $r=.685$, $n=30$, $p=.000$; LSI, $r=-.549$, $n=30$, $p=.002$). Findings were also similar for the spouse caregiver group (Zarit, $r=.637$, $n=30$, $p=.000$; CBI, $r=.667$, $n=30$, $p=.000$; LSI, $r=-.472$, $n=30$, $p=.008$). That is, for the individual groups, child and spouse caregivers, high scorers on the Beck Depression Inventory were likely to be high scorers on the Zarit Burden Interview and the Caregiver Burden Inventory and low scorers on the Life Satisfaction Index-Z.

Life Satisfaction Index (LSI-Z)

The mean score for the total sample on the life satisfaction index was 15.03, indicating medium life satisfaction. Thirty-five per cent ($n=21$) of the sample scored high in life satisfaction with 18.5% ($n=11$) scoring

low.

For child caregivers the mean score was 15.63 and for spouse caregiver it was 14.43. Both scores indicate medium life satisfaction. The difference in mean scores was not statistically significant ($t=0.757$; $p=0.226$).

Child and spouse caregivers had similar levels of life satisfaction.

According to the national study carried out by Harris, 1975 the average life satisfaction score for males and females age 65 and older was in the high life satisfaction range (on the LSI-Z=18.8). Being in the medium life satisfaction range this caregiver sample was had lower life satisfaction scores than the national average. George and Gwyther (1986) reported on 510 caregivers of mentally impaired older people. They found that child and spouse caregivers reported markedly lower levels of life satisfaction than other relatives who provide care. In Fengler and Goodrich's (1979) study of wives caring for elderly disabled men, the wives scored in the medium life satisfaction range (comparable to LSI-Z of 13.7). In Haley et al. (1987) study using the LSI-Z the 44 in the control group scored an average of 21.00, high life satisfaction, while the 44 caregivers of senile dementia patients scored 15.88, in the medium life satisfaction range. Both studies show similar results to the findings in this research (medium life satisfaction).

Life satisfaction and age

With the spousal caregiver life satisfaction correlated (weak) with the age of the carereceiver. The younger the carereceiver the lower the life satisfaction score of the caregiver ($r=0.393$, $n=30$, $p=.032$). Correlations were also found between depression and age and burden and age of carereceiver with this group of caregivers. These findings are reported on in their respective sections.

The younger the carereceiver the lower the life satisfaction score of the spouse caregiver. For child caregivers life satisfaction was not affected by the age of the carereceiver. Spouses are perhaps less accepting of the disease/disability of their carereceiver when they are young than when their partner is at a more advanced age and not well. A similar finding was found with carereceiver age and depression of spouse caregivers (see Depression and Age).

Life satisfaction scores did not vary with gender or living arrangement of the child or spouse caregivers.

Life satisfaction and length of caregiving

Life satisfaction was negatively correlated with length of caregiving for the child caregiver group. The longer a child caregiver provided care the lower the life satisfaction

($r = -.357$, $n = 30$, $p = .053$). No correlation was found between life satisfaction and length of caregiving for spouses.

The greater the length of time care is given the lower the level of life satisfaction for child caregivers. For spouse caregivers there was no relationship between length of caregiving and life satisfaction. Child caregiver seem to have lower life satisfaction as the length of time of caregiving increases. As with depression and length of caregiving (ie.the higher depression the longer the caregiving) this may again be a reflection of the differences in commitment as a result of the different relationship and the multiple roles in which adult child caregivers are involved. This correlation is not found with spouse caregivers.

Life satisfaction, burden and depression

Caregivers with high scores on the Life Satisfaction Index-Z were likely to have low scores on the Zarit Burden Interview ($r = -0.427$, $n = 60$, $p = .001$), the Caregiver Burden Inventory ($r = -0.562$, $n = 60$, $p = .000$) and the Beck Depression Inventory ($r = -0.499$, $n = 60$, $p = .000$).

Similar results were found with the two individual caregiver groups (child and spouse). See previous section on Depression, Burden and Life Satisfaction for statistics for the two groups individually.

CHAPTER 5

Discussion

The research hypotheses were supported to a large degree according to the results of this study. The first hypothesis was found to be correct - the higher the burden scores, the higher the depression scores and the lower the life satisfaction scores. It appears from these results that there may be some relationship between these three variables for caregivers of family members with dementia. Practitioners should be alerted to the possibility that indications of distress in one of these areas could mean attention should be given to the other areas as well.

The second and third hypotheses predicting that child caregivers would have higher burden and depression scores and lower life satisfaction scores were partly supported. There were differences between the child and spouse caregiver groups. These differences were in the areas of burden and depression. Some of these differences only became apparent when living arrangement was considered.

Differences were not found with the two groups, child and spouses, in burden when using the CBI, in depression or in life satisfaction. Zarit et al. 1980 also found in their study, no differences in burden between these two groups. In

the present study, the only difference between the two groups was when the BI was used. Children were then found to be more burdened than spouses. This was similar to the findings of the Rankin and Pinkston, 1985 study. In other words burden (except with the BI), depression and life satisfaction were similar for both child and spouse caregiver groups.

Differences between child and spouse caregivers became apparent, however, when the groups were analyzed as three groups instead of as two groups. Living arrangement became more significant than the researcher had expected when examining group differences. The three groups analyzed were spouses, children living with their carereceiver and children not living with their carereceiver.

When living arrangement was introduced as an independent variable, life satisfaction scores for the three groups being analyzed still were not significantly different. Depression and burden (BI only) scores, however, were higher for children living with their carereceiver. This group had significantly higher scores for depression and burden (BI only) than for spouses and for children not living with their carereceiver. For burden measured with the CBI, children living with their carereceiver had significantly higher scores than children not living with their carereceiver. They had burden scores similar to that of the spouse group. The children living with their carereceiver had higher average burden scores (CBI) than

the spouse group but they did not reach statistical significance.

Role strain theory suggests that children living with their carereceiver would be more at risk of experiencing higher burden and depression scores than the other groups. With the carereceiver living with their child caregiver, probably a spouse and possibly teenage or young adult children, the risk of increased role strain would be greater in this living arrangement. This would be particularly so when dealing with a carereceiver with dementia. Greater disruptions are possible when a mentally impaired family member is present. Family routines can be disrupted due to behaviour problems. Sleep patterns may be altered due to wandering and/or agitation day or night etc. Tensions and frustrations are likely to increase in the family with the presence of this type of carereceiver. A carereceiver with a dementia is often not capable of cooperating with normal family routines. This can cause conflicts within the family. More role partners are interacting in a three generation household. Role theory states that the more role partners present, the greater the likelihood of conflicts occurring.

For the caregiver, having the carereceiver in the home, may alleviate some of the worry they would otherwise have if the carereceiver was on their own. On the other hand, living together quite often means more input into the day to day care

is provided by the caregiver. This perhaps leaves less time and energy to perform in other roles and may create overload and conflict with these roles.

It has been the researcher's experience that fewer resources are requested by this family type. They often feel that having someone in the home to provide care further disrupts the household routine and invades the privacy of the family. This type of caregiver would therefore be at greater risk of role overload and increase the potential for burden and depression.

Spouse caregivers, on the other hand, no longer have these multiple roles to fulfil. They are often alone in their own home caring for the primary person in their life - their spouse/carereceiver. This primary role they must fulfil is clear (no ambiguity). One would expect the commitment to this role would also be greater than for child caregivers.

The CBI allows further analysis of burden through the five burden dimensions. Highest burden scores for both groups were found in the time dimension, followed by developmental, physical, emotional, then the social dimension.

It was expected that child caregivers would have higher scores in the dimensions of burden than spouse caregivers for reasons stated above. With the burden dimensions significant differences in child and spouse groups were found in the time and the social dimension. In the time dimension spouses had

significantly higher burden scores than children. In the social dimension children had significantly higher score than spouses. Otherwise, all other dimensions (emotional, developmental and physical) scores were similar for child and spouse caregivers. Total burden scores for child and spouse groups were similar but when the dimensions were examined it could be seen that there were differences between these two groups in the areas the burden was felt. One group was high scoring in one dimension and low in the other, while the other group had reversed scores in each of the same dimensions. It can be seen how total burden scores can mask the differences of the two groups.

When the variable living arrangement was introduced in the analysis, all three caregiver groups had similar developmental burden levels. They are all then, similarly feeling out of phase with where they expected to be at this time in their lives. None of the groups expected to be caring for a family member with dementia.

Children living with their carereceiver had higher scores than spouses in two dimensions, the social and the emotional dimension. Novak and Guest (1987a) had similar findings in their study for the social dimension. They found spouses to have higher burden in the emotional dimension.

With the social dimension children not living with their carereceiver had similar scores to children living with their

carereceiver and both had significantly higher scores than spouse caregivers. The social dimension remained significantly higher for children than for spouses regardless of the child caregiver's living arrangement. The intensity of the social burden scores was however, the lowest in comparison to all other burden dimension. The social dimension includes burdens related to disruptions in family relationships and employment. It also measures caregiver's feelings of resentment toward other family members who do not assist and also their feelings of being unappreciated for the job they are doing. Several child caregivers who were living with their carereceiver indicated to the researcher that if they had to make the decision over again, about having their parent live with them, they would decide against this option. They found having a mentally impaired family member in the home too disruptive in their lives. They felt their own spouse and children suffered as a result. They felt any gains experienced by their parent were far outweighed by the negative effects on them and their family. Their presence created family tensions and disagreements. Due to the pressures of trying to fulfil all roles adequately, under less than ideal conditions, it is not surprising these child caregivers have difficulties with other family members, their work etc. (role conflicts).

The second dimension in which child caregivers living

with their carereceiver differ significantly with spouses was the emotional dimension (as well as the other child group). The emotional dimension includes negative feeling towards the carereceiver. This includes feeling of embarrassment, shame, and resentment toward their carereceiver. It includes anger about interactions with the carereceiver and feeling unhappy and hopeless about the future.

These children not only have higher burden in the social and emotion dimensions when compared to spouses, they also were equally burdened to spouses in all other dimensions (time, developmental and physical dimensions). Another difference was shown in the time dimension. When the child group was considered as a whole, spouses had higher time burden. When living arrangement was considered, their time burden was similar to spouses. As the carereceiver lives with the caregiver they were present when care was required and as a consequence experience the time and physical burdens similar to that of spouse caregivers.

When analyzing spouse caregivers and child caregivers not living with the carereceiver, the child group was significantly higher than spouse caregivers in the social dimension. This child group seemed to feel the negative impact of the caregiver role in relation to their other roles (work, family etc.) regardless of living arrangement. Spouses had significantly higher time and physical burden scores than

this group. Spouses have been found to provide more physical care to their partner than other caregivers provide (Novak & Guest, 1987a). Emotional and developmental burden levels were found to be similar.

When the two child caregiver groups were analyzed they were found to have similar time, developmental and social burden scores. Children living with their carereceiver had significantly higher emotional and physical burden scores than the other child group. Both of these child caregiver groups experienced similar social burden levels. This indicates that despite different living arrangements, children not living with their carereceiver still felt the impact of the caregiver role in relation to their other roles (family, work etc.). They also were found to have similar time burden to the children living with their carereceiver. This could be due to the time spent travelling back and forth making visits to their carereceiver, shopping for them, caring for a second household etc.

Children living with the carereceiver appear to be the most affected by caregiving. Their depression and burden (BI) levels were higher than spouse caregivers as well as child caregivers not living with their carereceiver. When compared to children not living with their carereceiver, children living with their carereceiver experienced higher burden in the emotional and physical dimensions. When compared to

spouses they had higher social and emotional burden. In all other dimensions they had similar burden to both other groups.

It should also be noted however that despite the fact that these three groups had differences in the effects they were experiencing from caregiving, they had all made the decision to institutionalize their family members. This indicates that these three groups had all reached the point at which they felt they could not continue caregiving. Spouse caregivers for instance were in the mild to moderate range of burden, while child caregivers were in the moderate to severe range (BI). From this one could speculate that factors other than caregiver burden may determine the decision to institutionalize their family member. From the literature it has been found spouses delay placement as long as possible. If burden was the only deciding factor in placement, one would expect spouses levels of burden to be higher than children. In this study spouse caregivers' burden and depression levels were lower than children not living with their carereceiver but both had made the decision to institutionalize their carereceiver. Spouse caregivers were caring for family members requiring higher levels of care than child caregivers but this has been found in many studies, as well as this study, not to be correlated with burden (Colerick & George, 1986; Gilhooly, 1984; Manchin, 1980; Novak & Guest, 1986; Dry et al., 1985; Zarit, Todd & Zarit, 1986).

Several variables used in this study will now be discussed in relation to the variables of burden, depression and life satisfaction for child and spouse caregivers. The findings will also be related to role strain theory.

Age

Younger spouse caregivers were found to be more burdened than older spouse caregivers. Spouse caregivers in general had higher burden, depression and lower life satisfaction when caring for a younger carereceiver. No correlations were found with burden, depression and life satisfaction and age of caregiver or carereceiver for child caregivers. This may be, in part, a reflection of the differences in relationship between the caregiver and carereceiver, one being a spousal relationship, the other being a child-parent relationship. Spousal caregivers are slowly losing the primary person in their lives as they once knew them. As well, it appears that the impact was greater on the younger the spouse caregiver (for burden) or the younger their carereceiver (for burden, depression and life satisfaction). Caregiving spouses in this situation may feel they and/or their spouse may be too young for this to be happening to them and may feel resentful and angry (emotional burden). Older caregiving spouses with older carereceivers may feel they have lived a good long life and may be more accepting of health problems. It may also be,

that younger spouses have more roles than older spouses. They may have more similarities to the child caregiver if they are closer to their age group.

Gender

Female caregivers were more burdened overall, than males in this study. Other studies have also had similar findings (George & Gwyther, 1984; Novak & Guest, 1989). Female spouses were most burdened, followed by wives, daughters and sons. Male spouses were the least burdened. Caution should be taken in interpretation due to the small numbers in son caregiver group. No gender differences were found for depression and life satisfaction.

As has been stated earlier, females may report distress more readily than men, discussing their feelings more openly. Family life may be more central for women and they may be more sensitive to relationship problems that occur as a result of caregiving and in turn be emotionally affected by this. As women are the primary kin-keepers in our society they may be more affected than men by disruptions due to family obligations (Firth, Hubert & Forge, 1970; Komarovsky 1950, 1956). Walum (1977) reports that men are more likely to repress or deny their emotions than women, so under reporting of stress in men may be the case. In Johnson's (1983)

findings men were more likely than women to ask for and receive help from other female relatives with their caregiving. Women relatives were more likely to respond to requests for help from a male caregiver who was presumed not to be able to deal with these tasks. Women caregivers are presumed to be able to be able to perform these tasks perhaps because women's caretaking role continues over a lifetime, starting at childhood when they are socialized into this role. They therefore also have the expectation of themselves that they should be able to handle this role.

Sons are often less immediately involved in caregiving often relying on their wives to fulfil this role (Horowitz, 1985). This may, perhaps, be one of the reasons sons report less strain than other caregivers. Johnson 1983 reports on what he calls the "pass through" effect. This is when men turn to sisters or wives to provide major caregiving. Work demands for the male caregiver are considered a legitimate justification for men not to have the time for caregiving. For women work is considered secondary and discretionary (Lopata & Norr, 1980) and not a legitimate justification for not having the time for other caregiving. Women therefore may feel more pressure to continue in all roles (leading to overload and role conflict). They otherwise may see themselves as inadequate and/or feel guilt-ridden. These feeling can lead to feeling burdened as a caregiver.

Level of Care

Spouse caregivers looked after family members requiring higher levels of care than child caregivers. As spouses are expected to care for their partner, if they are ill (societal norm), it is not unusual to find that a spouse will care for their partner to a later stage in the disease (thus a higher level of care) process before considering placement. Spouses are known to go to great lengths to prevent institutionalization (Grad & Sainsbury, 1968; Kraus et al., 1976).

Overall females caregivers provided care to family members requiring higher levels of care than males. This was largely due to the fact that female spouses cared for only level 3 and 4 care receivers, increasing the average for females. Female spouses provided the highest level of care, followed by male spouses and daughters. Sons provided the lowest level of care but this difference was not statistically significant when compared to daughters. Care should be taken in interpretation as the sample of son caregivers was small ($n=7$). As this role is more expected of spouse caregivers to fulfil, they may be more accepting and show less evidence of negative effects.

Level of care was not correlated with life satisfaction, burden and depression. Many other researchers have also found

burden not to be predicted by severity of impairment of the carereceiver (Colerick & George, 1986; Gilhooly, 1984; Manchin, 1980; Novak & Guest, 1986; Dry et al., 1985; Zarit, Todd & Zarit, 1986). They have found instead, that caregiver burden to be strongly correlated with the caregiver subjective feelings toward providing care.

Length of Caregiving

There were no statistically significant differences in length of time caregiving for child or spouse caregivers. For child caregivers depression levels increased and life satisfaction decreased the longer care was provided - there was no relationship between burden length of caregiving. This has been the finding in several other studies of caregiver burden (Colerick & George, 1986; Novak & Guest, 1985; Zarit, Reeve & Bach-Peterson, 1980). Child caregivers may develop increasing dissatisfaction over time in a role they are less committed to and/or less prepared for as compared to spouse caregivers. There was no correlation for spouse caregivers for length of caregiving and depression or life satisfaction. The only correlation with burden for spouse caregivers was in the physical dimension. The longer spouses provided care, the higher was their physical burden. This may indicate spouses, being older, with a greater likelihood of chronic health

problems than child caregivers, may have more physical problems.

Living Arrangements

All spouses lived with their carereceiver. In the child caregiver groups 43.3% lived with their family member (all but one lived with a daughter) and 56.7% lived alone. As females are usually the caregivers, it is not unusual to see that the carereceivers were more likely to be living with the daughter. It has been found that if a son is the primary caregiver, his wife often assumes much of the caregiving (Horowitz, 1985). It may therefore be more disruptive for a carereceiver to live with a son when a daughter-in-law would be the one providing care.

There was no correlation between living arrangement and level of care. This means the level of care of the carereceiver was not a factor in whether a child caregiver had their parent living with them or not.

CHAPTER 6

Implications

These findings show that both caregiver groups are affected by caregiving and that there are similarities and differences in the impact. Social workers need to address the problem areas each type of caregiver may encounter in order to assist them in providing care to their family member for as long and as well as is possible.

This caregiver sample may be among the most stressed in that all participants in this study had already made the decision that they could not continue caregiving indefinitely. They all had their family member panelled for personal care home placement. The writer has found in practice, that this is a decision family members find very difficult to make (particularly spouses). Many put off this decision, often to their own detriment. All participants' family members were on the waiting list for placement. They may serve as an example of how depressed and burdened caregivers can become, before they decide they cannot continue caregiving. This can alert social workers to the potential problems caregivers may encounter and to then assist them at an earlier stage to prepare for or avoid some of the difficulties.

Levels of burden were high and depression and life satisfaction in this sample were in ranges outside of those found to be normal for the average older population. Forty-four per cent of the sample scored in the moderate to severe burden range with only 8 1/2% showing no burden. Twenty-three per cent of the sample were in the moderate to severe range of depression, only 27% showed no depression. Sixty-five per cent were in the low to medium life satisfaction range - the norms for the general population are in the high range. It may be suggested from these results that this caregiver group were experiencing negative effects on their lives, at least in part, as a result of caregiving and the role strains it created. Many caregivers, regardless of their category, could benefit from assistance in coping with their caregiving role and the conflict, ambiguity and overload they experience.

Children living with their carereceiver were the group that were most affected by the caregiver role. They had the highest depression and burden scores of all groups. Role strain theory suggests that these child caregivers can experience more role strain difficulties than other groups. They have divided loyalties, to their parent, to their own spouse, children, employment etc. (role conflict/role overload). Spouse caregiver were at a different stage in their lives (average age 72.6 years) and their spouse carereceiver would be the primary person in their life, unlike

child caregivers (average age 53 years). It was therefore not surprising to find children living with their carereceiver more burdened and depressed than spouses, with all these often conflicting roles to fulfil, as well as providing 24 hour care in their own home.

Children not living with their carereceiver were not as burdened as children living with their carereceiver but they had also made the decision to place their parent on a waiting list for personal care home. Even though the burden and depression levels were lower for this group, providing care to someone with a dementia, while they are living alone in the community, can go on for only so long. The risks to them and perhaps others around them soon become are too great. If child caregivers are not able to care for their parent in their own home, the writer has found placement must occur at an earlier stage.

As it was apparent from this study that caregivers living with their carereceiver seem to be most affected by caregiving, practitioners should be cautious when dealing with families that are asking for advice regarding considering taking their parent into their home - or be careful about suggesting this to families who may be reluctant to consider this option. It is important that the social worker meet with all family members involved in this decision and not just the primary caregiver. It can also be very useful to meet with

families who already are living together to reassess the situation and possibly assist the family in renegotiating some of the role allocations. This can possibly assist in reducing overload, conflict and ambiguity of roles. The spouse of the caregiver, the children in the home, as well as siblings of the primary caregiver should all be involved. It is important that all members are aware of the impact this may have on their lives so that they are better prepared for what may occur. They then may be more adequately equipped to deal with the situation. The caregiver may insist that they will be the one providing care, but particularly when dealing with a family member with dementia, behaviours etc. are not always under the control of the caregiver. The carereceiver can cause disruptions in the household that will affect all family members either directly or indirectly.

Family members should be as knowledgeable about the disease process as possible and know that the course is not entirely predictable. That is, they should be aware that the person they are now caring for can be different a week, a month or a year from now. Having all members present, facilitates their knowing of the care needs involved and the part each is prepared or able to play in providing the care required to avoid role strain. Family members should be aware of the formal support system and assistance that is available should their informal system be unable to cope adequately (to

help reduce role overload).

In the writer's experience many child caregivers find that they are on their own in providing care. The literature indicates that there is usually one caregiver, often a daughter. More work should be done with families so that they are all clear about the expectations on them. In turn, they will be able to verbalize their concerns and the limitations they feel about the caregiving. Families may then work together more effectively in providing care, rather than one caregiver becoming overloaded and in conflict with the others. Even if there still is one main caregiver, a family conference will assist others in the family to better understand the caregiver's role. They may then have greater tolerance for the adjustments they will have to make in their lives and not be so resentful or demanding of the caregiver..

Child caregivers living with their carereceiver were also usually female (daughters). Females were more burdened than males overall in this study. Practitioners must be aware that females may be more at risk of becoming burdened than males, particularly if they are a female spouse. As discussed earlier females may be more sensitive to their carereceiver's disability and may expect more of themselves as a caregiver than males. This has been a role that is expected of females throughout their lives. The literature also suggests that females may be more open regarding their feelings of strain

than men and thus appear more stressed. As the two factors, being female and living with the carereceiver, are related to burden, particularly for child caregivers, social workers should be sensitive to the fact that these child caregivers may be more at risk of becoming burdened. As stated previously, these caregivers should be encouraged to have all willing family members actively involved in the care plan for the carereceiver. The writer has found that one must work with many of these women to assist them in setting priorities and limitations among the numerous roles they are attempting to fulfil. They must be encouraged to ask for help from both the informal and formal system when necessary, in order to avoid or reduce the role overload. They often have to be assisted in realizing that it is not their own shortcomings that make it difficult or impossible to fulfil all role obligations, at all times, to the satisfaction of everyone.

The longer child caregivers provide care the higher the depression levels and the lower the life satisfaction scores. This was not the case with spouse caregivers. This finding may be related to the many roles child caregivers are called upon to perform and their inability to continue over time without adverse affects. This may be particularly so when dealing with a person with a dementia. The carereceiver is slowly deteriorating over time and more and more of the activities of daily living have to be taken on by the

caregiver. Spouses on the other hand, have been found in the literature, to have a greater commitment (stronger bond) to providing care and doing so indefinitely. They also are more likely have less ambiguity about caregiving being their role, have fewer outside role obligations to fulfil than child caregivers and therefore more time and less interference or obstacles (ie. role conflicts) to overcome to provide care effectively. This relates to the time, energy and commitment factors researchers have found play an important part in the degree of role strain experienced by caregivers (Marks, 1977). Child caregivers may therefore be in greater need of supportive counselling and increased services over time to assist them in coping.

The only dimension of burden correlated with length of caregiving for spouses was the physical dimension. This increase in physical burden the greater length of time caregiving was provided may be more related to the decline in health and/or energy level of an elderly spouse caregiver over time when providing care to their partner. Researchers have found spouse caregivers to be more physically burdened than other caregivers (Cantor, 1983; George & Gwyther, 1986; Novak & Guest, 1987a). Interventions that may assist, if this is the case, would be assistance with the actual physical care. As spouses are often resistant to accepting help, the writer has found, regular ongoing contact with them is

imperative. It is important to have regular monitoring of any changes in the health of the carereceiver, as well as the caregiver. Developing a trusting relationship with the caregiver and encouraging frequent contact with any questions and concerns is important. The writer has found in this way one can be more aware of when the caregiver is ready to accept help, whether it be individual counselling (cognitive therapy, relaxation training, behavioral interventions), home care service, plan for placement etc. Once accepted, gradual increases in input are more readily implemented. Spouses in particular seem to need time to make changes. They also need to be encouraged to try different approaches e.g. in behaviour management, coping strategies etc. They may find they do not work at one point in time, but when dealing with a person with a dementia, they must be encouraged to try the same intervention the next day or the next week, as they may then be successful.

Spouse caregivers caring for a younger carereceiver were found to have higher burden, higher depression and lower life satisfaction scores. There was no correlation for child caregivers and age of carereceiver. Burden also was correlated with the age of the spouse caregiver. Younger spouse caregivers had higher burden levels. Spouse caregivers were perhaps more accepting of their carereceiver's illness when they were older and perhaps this was more

expected when at a more advanced age than when their carereceiver was younger. Younger spouse caregivers may feel they are missing out on life having their young spouse ill (and also the caregiver themselves being younger in the case of burden) and unable to enjoy preretirement and early retirement years together. They may also still be involved in more roles due to their young age, similar to child caregivers. It may affect them financially if they have not reached pensionable age, or perhaps they may still have children in the home that are not yet independent. Child caregivers, on the other hand, are caring for their parent and this is often not their primary relationship, as is the case with spouses. In other words, the child and spouse relationships are unique and the losses this involves for spouses are very different and more significant than for adult child caregivers.

Individual counselling may be needed regarding the losses being experienced by the spouse caregiver ie loss of their confidant, often their sexual partner etc. They must be assisted in expressing and dealing with feelings they have regarding the anger, resentment and often guilt they have around their partner becoming ill particularly at a young age. They must be reassured that most people have such feelings and be given permission to have these feelings, that may otherwise seem unacceptable to them. Practical information regarding

finances such as spousal and disability pensions and tax benefits may also be explored with them.

In the burden dimensions child caregivers living with their carereceiver had significantly higher social and emotional burden scores than spouses. They otherwise scored just as high as spouses in physical, time and developmental burden. They scored higher in emotional and physical burden when compared to child caregivers not living with their carereceiver and had similar scores to spouses in developmental, social and time burden.

The social burden dimension seems to be the one that shows the greatest differences in negative affect on child caregivers in general, as opposed to spouse caregivers. Novak and Guest (1987a) found child caregivers to be more socially burdened than spouses in their research. Also child caregivers not living with their carereceiver were less burdened in all areas (except the social dimension) and yet they also have made the decision to institutionalize their parent. This further demonstrates the fact that child caregivers are able to provide care to a certain limit and that limit is much less than that which spouses are prepared and /or able to provide. These limits are probably due, in a large part, to the role strain this generation of caregivers experience.

Higher scores in the social dimension for both child

caregiver groups reflects negative family interactions, problems with employment, feelings of resentment toward others and not feeling appreciated for one's efforts. Both child groups were more affected in this dimension than spouses. This again relates to role conflict, overload and ambiguity for child caregivers as discussed previously.

Higher scores in the emotional dimension for children living with their carereceiver are related to the negative feelings, anger, embarrassment and resentment felt toward their carereceiver. As child caregivers are felt to be less committed to providing care than spouses, it would follow that they may be more resentful of their carereceiver when in this role. The writer has found this to be the case with many child caregivers. They in turn, feel guilty about feeling this way. This is intertwined with their feelings about other siblings who could be assisting them and will not (role conflicts). In counselling caregivers who are burdened in this way, much is often revealed about past family conflicts between siblings and/or their parents, that have never been resolved. Feelings attached to past relationships and experiences should be explored and discussed. Often if these problems are so far in the past and the players so resistant to change, caregivers must be worked with around leaving these problems behind them. Only then can they go on to function adequately in the present situation.

The similar scores in time and physical burden for child caregivers living with their carereceiver and spouses is a reflection of both caregivers living with their carereceiver. They are thus subject to providing physical care and the time needed to provide this care. These area had the highest burden scores. Interventions in this area could involve education regarding providing safe physical care as well having relief in the form of sitter, homemaking and/or provision of some physical care by the formal home care system.

All three groups had similar level of developmental burden. This dimension was the second highest burden dimension next to the time dimension. This is a measure of the degree to which caregivers had expected things would be different at this point in their lives. Little can be done to change what has happened ie the disease. Supportive and/or often grief counselling can assist caregivers through their difficult periods.

From this research social workers may have to direct more attention to female caregivers, particularly those caring for carereceivers living in the same residence. They should also consider in their assessment the length of time caregiving has taken place with child caregivers. In this study was shown that the length of time of caregiving was related to depression and life satisfaction for child caregivers.

Social work interventions with this group would have to be directed toward family counselling and/or marital counselling. Despite the fact only one person is generally the caregiver, all family members are affected by the caregiving situation. In turn, the families actions and reactions to the caregiver's role impact on the caregiver and carereceiver. This can increase the role strains due to the numbers of role partners involved. This can also increase the likelihood of conflicts. Family counselling sessions may help to facilitate more assistance from the family network and help to reduce the burden, depression and increase the life satisfaction of the caregiver. It may also assist them in recognizing their limits and the impact their caregiving role is having on other family members.

Practitioners also should be conscious of the fact that encouraging or recommending the caregiver take their family member into their home should be carefully considered. Several child caregivers in this study advised that they would not choose to have their parent move in with them if they had it to do over again. They found their lives and their children's lives put into turmoil. Families further advised they should have asked for home care help earlier and/or should have started personal care home placement plans sooner.

With spouse caregivers, females were more at risk of becoming burdened, as was the case with child caregivers.

They were also providing care to a carereceiver at a higher care level than any other group. Practitioners should be prepared to see the possibility of younger spouse caregivers more burdened than older spouse caregivers. Also seeing spouse caregivers being more depressed, being more burdened and having lower levels of life satisfaction when caring for a younger carereceiver. They may be more in need of intervention in these areas than the more elderly spouse caregiver. These spouses may need more individual counselling to assist them in working through their feelings of loss, resentment regarding becoming caregivers at this point of their lives and guilt regarding the resentment they may feel. Programs, such as caregiver support groups often do not reach this younger spousal group. Most groups are attended by older spouse caregivers, as dementias are more common in the older elderly population. This further intensifies this younger groups feeling of uniqueness and isolation from other caregivers.

Spouse caregivers, like child caregivers felt they should have asked for home care assistance earlier and/or planned for placement earlier. It has been the writer's experience, with spouse caregivers, that they delay placement as long as possible and often do not request or hesitate to accept home care assistance, for far too long. Baruch (1988) found spouse caregivers have a general preference for managing their

situation on their own. This may be in part due to the anticipated resistance they feel that their carereceiver will give to home care assistance (eg. respite service etc.). As well, as they often feel that they can provide the best care, and that it is their job to do so. They otherwise feel they are shirking their responsibility. In planning for personal care home placement Farcas (1980) found delaying may be a way of avoiding the finality this brings. The writer has found spouses must be encouraged to make realistic plans at the right time. They must also be counselled to accept help in order to assist in preserving their own health and in turn to be able to provide care longer. Often assurance and concrete assistance about the course of action in making and implementing plans is needed.

Further research should look at caregiving comparing spouse and child caregivers living in the same residence as the carereceiver. The research should be directed at looking more specifically at the role difficulties each encounter and how their formal and informal networks assist them in coping. It would be useful to have longitudinal research with caregivers of dementia patients as much is said in the literature about the caregiver role changing over time. The various stages of the disease bring accompanying shifts in care needs. Research on strength of past and present

relationships and how this impacts on commitments of both spouse and child caregivers may be important. Study of male caregivers and how they cope may reveal some of the reasons they seem to have lower burden than females. With son caregivers for example it may be that their wives or children are actually the primary caregiver. With male spouses it has been found that other females assist, while if the spouse caregiver is female this would not happen as readily. It may not be that females are more easily burdened but may be they take on more themselves than do male caregivers.

CHAPTER 7

Summary

This chapter provides a summary of the major findings of this research. Each issue has been discussed previously in more detail. It is important to remember that the sample was small, non random and is based only on cross-sectional data. Conclusions can only be related to this sample and care should be taken in not making generalizations to other caregiver population groups.

The primary research question in this study was to determine whether there were significant differences between child and spousal caregivers in areas of burden, depression and life satisfaction.

Levels of burden were high and depression and life satisfaction in this sample were in ranges outside of those found to be normal for the average older population. These variables were also highly correlate with one another. In general for both child and spouse caregivers in this study the higher the burden level of the caregiver, the higher their depression level and the lower their life satisfaction level.

Children living with their carereceiver had higher burden and depression levels than spouses and children not

living with their carereceiver. In the burden dimensions children living with their carereceiver were more burdened in the social and emotional dimensions than spouses and equally burdened in all other dimensions (physical, time and developmental). These child caregivers were higher in physical and emotional dimensions, and similar in the social, time and developmental dimensions, when compared to child caregivers not living with their carereceiver.

The longer child caregivers provide care the higher their depression and the lower their life satisfaction scores. There was no correlation found with burden and length of caregiving for child caregivers. There was no relationship between length of caregiving and depression or life satisfaction for spouses. With spouses the longer care was provided the higher was the physical burden. No other correlation was found with burden and length of caregiving for spouse caregivers.

Spouses caring for a younger carereceiver had higher burden and depression levels and lower life satisfaction levels than spouses caring for older carereceivers. Younger spouse caregivers also had higher burden scores than older spouse caregivers. Caregiver age was not related to depression or life satisfaction for spouse caregivers. No correlation was found for child caregivers with age of carereceiver or caregiver and burden, depression or life

satisfaction.

Female caregivers were more burdened than males in this study. Female spouses were most burdened, then daughters and sons. The least burdened were male spouses. There were no gender differences for depression or life satisfaction.

Often the social and psychological costs of caregiving become too high for family caregivers. Not all effects of caregiving, such as depression, burden and decreased life satisfaction, are preventable or remediable. There is no set answer or solution for any one situation. Social workers must assist some families in deciding when it is no longer wise to continue their caregiving or reduce the amount of care they provide. Some families go beyond the limits of human endurance as they feel they have no other choices. They must be assisted in judging when it is time to provide care to their family member from another setting (personal care home).

Interventions with adult child caregivers need to focus on counselling with family members. The caregiver, his or her spouse, children and/or siblings of the caregiver need to negotiate proper role allocations so that the responsibility for care can be shared and not rest on one person, creating role overload. In addition, they must be assisted in recognizing and accepting their limits and set priorities

without feeling guilty for having done so. A clear understanding of the situation by all family members can lead to a more balanced caregiving situation and assist them in continuing caring for the family member longer, by reducing role strains.

Spouse caregivers must be assisted in developing skills needed to assume roles previously held by their partner or to seek appropriate substitutions. Spouses need to be counselled to be conscious of tending to their own health needs, allow time for themselves and decrease their isolation so that they have a life beyond caregiving (ie resuming former activities, renewing old friendships etc). Many spouses, once their partner is placed in personal care home or dies, have great difficulty picking up their lives again. Little is available to assist these caregivers after placement of their partner. All caregivers must also be knowledgeable of the disease process and of available resources to assist in providing care. They must be encouraged to seek help from both formal and informal resources (respite, family and individual counselling, sitter services, support groups and family etc.) rather than to continue to struggle on their own indefinitely.

Due to the progressive degenerative course of dementias often over long unpredictable years, much of the focus of social work intervention must be on assisting all caregivers to better cope with their challenging task.

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APPENDIX A

I hereby consent to participate in Rose Mary Schallmann's study on the Differential Impact of Caregiving on Spouse and Adult Child Caregivers of Family Members. I understand my participation is voluntary. I understand that all information is confidential and will be used to identify general trends.

(signed)

(date)

(witness)

APPENDIX B



College of Health and Human
Development

Department of Individual and
Family Studies

S-110 Human Development Building
The Pennsylvania State University
University Park, PA 16802

April, 1988

Dear Colleague:

Thank you for your interest in The Memory and Behavior Problems Checklist and The Burden Interview. The enclosed booklet includes descriptions of the measures, psychometric information, and a brief bibliography. You are welcome to use these instruments or parts of them in your research and to make copies of them for that purpose, with appropriate citation of the source in any papers or reports you prepare.

If you do use these measures, we would appreciate learning of your results.

Sincerely,

Steven H. Zarit, Ph.D.

Judy M. Zarit, Ph.D.

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BURDEN INTERVIEW

INSTRUCTIONS: 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.

1. 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
2. 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
3. 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
4. Do you feel embarrassed over your relative's behavior?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
5. Do you feel angry when you are around your relative?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
- * 6. 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
7. Are you afraid what the future holds for your relative?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
- * 8. Do you feel your relative is dependent upon you?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
9. Do you feel strained when you are around your relative?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

- * 10. 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
11. 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
- * 12. 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
- ✓ 13. Do you feel uncomfortable about having friends over, because of your relative?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
14. 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
15. 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
16. 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
- ✓ 17. 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
18. 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

19. Do you feel uncertain about what to do about your relative?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
20. Do you feel you should be doing more for your relative?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
21. 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
22. Overall, how burdened do you feel in caring for your relative?
0. Not at all 1. A little 2. Moderately 3. Quite a bit 4. Extremely

APPENDIX C

Table 1

Caregiver Burden Inventory (CBI)
(Mean=22.14; s.d.=16.30)

<u>Factor</u>	<u>Factor Loading</u>
<u>Factor 1: Time Dependence (Mean=6.98; s.d.=5.89)</u>	
1. My carereceiver needs my help to perform many daily tasks.	.88
* 2. My carereceiver is dependent on me.	.77
3. I have to watch my carereceiver constantly.	.77
4. I have to help my carereceiver with many basic functions.	.71
5. I don't have a minute's break from my caregiving chores.	.66
<u>Factor 2: Developmental Burden (Mean=7.08; s.d.=5.89)</u>	
1. I feel that I am missing out on life.	.78
2. I wish I could escape from this situation.	.78
* 3. My social life has suffered.	.71
4. I feel emotionally drained due to caring for my carereceiver.	.65
5. I expected that things would be different at this point in my life.	.63
<u>Factor 3: Physical Burden (Mean=4.37; s.d.=4.72)</u>	
1. I'm not getting enough sleep.	.73
* 2. My health has suffered.	.73
3. Caregiving has made me physically sick.	.70
4. I'm physically tired.	.69
<u>Factor 4: Social Burden (Mean=2.54; s.d.=3.54)</u>	
* 1. I don't get along with other family members as well as I used to.	.81
2. My caregiving efforts aren't appreciated by others in my family.	.79
3. I've had problems with my marriage.	.73
4. I don't do as good a job at work as I used to.	.61
5. I feel resentful of other relatives who could but do not help.	.60
<u>Factor 5: Emotional Burden (Mean=2.02; s.d.=3.04)</u>	
1. I feel embarrassed over my carereceiver's behavior.	.81
2. I feel ashamed of my carereceiver.	.74
3. I resent my carereceiver.	.64
4. I feel uncomfortable when I have friends over.	.64
5. I feel angry about my interactions with my carereceiver.	.53



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Canada R3T 2N2

Tel: (204) 474-8009
FAX: (204) 275-5465

To: Rose Mary Schallman, Graduate Student
School of Social Work, 521 Tier Bldg.

From: Mark Novak, Ph.D. Associate Dean (Academic)
188 Continuing Education Division

Date: July 23, 1990

You have my permission to use the Caregiver Burden Inventory in your Master's degree study of Alzheimer's Caregivers.

Table 2. Caregiver Burden Inventory (CBI)
(Mean = 22.14; SD = 16.30)

Factor	Factor loading
<u>Factor 1: Time-Dependence Burden (Mean = 6.98; SD = 5.89)</u>	
1. My care receiver needs my help to perform many daily tasks.	.88
*2. My care receiver is dependent on me.	.77
3. I have to watch my care receiver constantly.	.77
4. I have to help my care receiver with many basic functions.	.71
5. I don't have a minute's break from my caregiving chores.	.66
<u>Factor 2: Developmental Burden (Mean = 7.08; SD = 5.89)</u>	
1. I feel that I am missing out on life.	.78
2. I wish I could escape from this situation.	.78
*3. My social life has suffered.	.71
4. I feel emotionally drained due to caring for my care receiver.	.65
5. I expected that things would be different at this point in my life.	.63
<u>Factor 3: Physical Burden (Mean = 5.47; SD = 5.9)</u>	
1. I'm not getting enough sleep.	.73
*2. My health has suffered.	.73
3. Caregiving has made me physically sick.	.70
4. I'm physically tired.	.69
<u>Factor 4: Social Burden (Mean = 2.54; SD = 3.54)</u>	
*1. I don't get along with other family members as well as I used to.	.81
2. My caregiving efforts aren't appreciated by others in my family.	.79
3. I've had problems with my marriage.	.73
4. I don't do as good a job at work as I used to.	.61
5. I feel resentful of other relatives who could but do not help.	.60
<u>Factor 5: Emotional Burden (Mean = 2.02; SD = 3.04)</u>	
1. I feel embarrassed over my care receiver's behavior.	.81
2. I feel ashamed of my care receiver.	.74
3. I resent my care receiver.	.64
4. I feel uncomfortable when I have friends over.	.64
5. I feel angry about my interactions with my care receiver.	.53

APPENDIX D

Burden Questionnaire

The following are a list of statements, which reflect how people sometimes feel when taking care of another person. After each question, circle the response that best reflects your present feelings. There are no right or wrong answers.

1. My carereceiver needs my help to perform many daily tasks.

0.	1.	2.	3.	4.
Not at all	Slightly	Moderately	Quite	Very
descriptive		descriptive		descriptive

2. Do you feel that your relative asks for more help than he/she needs?

0.	1.	2.	3.	4.
never	Rarely	Sometimes	Quite	Nearly
			Frequently	always

3. My carereceiver is dependent on me.

0.	1.	2.	3.	4.
Not at all	Slightly	Moderately	Quite	Very
descriptive		descriptive		descriptive

4. I have to watch my carereceiver constantly.

0.	1.	2.	3.	4.
Not at all	Slightly	Moderately	Quite	Very
descriptive		descriptive		descriptive

5. I have to help my carereceiver with many basic functions.

0.	1.	2.	3.	4.
Not at all	Slightly	Moderately	Quite	Very
descriptive		descriptive		descriptive

6. I don't have a minute's break from my caregiving chores.

0.	1.	2.	3.	4.
Not at all	Slightly	Moderately	Quite	Very
descriptive		descriptive		descriptive

7. I feel that I am missing out on life.

0.	1.	2.	3.	4.
Not at all descriptive	Slightly	Moderately descriptive	Quite	Very descriptive

8. Do you feel uncomfortable about having friends over because of your relative?

0.	1.	2.	3.	4.
Never	Rarely	Sometimes	Quite frequently	Nearly always

9. Do you feel you have lost control of your life since your relative's illness?

0.	1.	2.	3.	4.
Never	Rarely	Sometimes	Quite frequently	Nearly always

10. I wish I could escape from this situation.

0.	1.	2.	3.	4.
Not at all descriptive	Slightly	Moderately descriptive	Quite	Very descriptive

11. Do you feel that because of the time you spend with your relative you don't have enough time for yourself?

0.	1.	2.	3.	4.
Never	Rarely	Sometimes	Quite frequently	Nearly always

12. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?

0.	1.	2.	3.	4.
Never	Rarely	Sometimes	Quite frequently	Nearly always

13. Do you feel that you don't have as much privacy as you would like because of your relative?

0.	1.	2.	3.	4.
Never	Rarely	Sometimes	Quite frequently	Nearly always

14. My social life has suffered.

0.	1.	2.	3.	4.
Not at all descriptive	Slightly	Moderately descriptive	Quite	Very descriptive

15. I feel emotionally drained due to caring for my carereceiver.

0.	1.	2.	3.	4.
Not at all descriptive	Slightly	Moderately descriptive	Quite	Very descriptive

16. I expected that things would be different at this point in my life.

0.	1.	2.	3.	4.
Not at all descriptive	Slightly	Moderately descriptive	Quite	Very descriptive

17. Do you feel strained when you are around your relative?

0.	1.	2.	3.	4.
Never	Rarely	Sometimes	Quite frequently	Nearly always

18. Do you feel that you don't have enough money to care for your relative, in addition to the rest of your expenses?

0.	1.	2.	3.	4.
Never	Rarely	Sometimes	Quite frequently	Nearly always

19. I'm not getting enough sleep.

0.	1.	2.	3.	4.
Not at all descriptive	Slightly	Sometimes descriptive	Quite	Very descriptive

20. My health has suffered.

0.	1.	2.	3.	4.
Not at all descriptive	Slightly	Sometimes descriptive	Quite	Very descriptive

21. Caregiving has made me physically tired.

0.	1.	2.	3.	4.
Not at all descriptive	Slightly	Sometimes descriptive	Quite	Very descriptive

22. I'm physically tired.

0.	1.	2.	3.	4.
Not at all descriptive	Slightly	Sometimes descriptive	Quite	Very descriptive

23. I don't get along with other family members as well as I used to.

0.	1.	2.	3.	4.
Not at all descriptive	Slightly	Sometimes descriptive	Quite	Very descriptive

24. My caregiving efforts aren't appreciated by others in my family.

0.	1.	2.	3.	4.
Not at all descriptive	Slightly	Sometimes descriptive	Quite	Very descriptive

25. I've had problems with my marriage.

0.	1.	2.	3.	4.
Not at all descriptive	Slightly	Sometimes descriptive	Quite	Very descriptive

26. I don't do as good a job at work as I used to.

0.	1.	2.	3.	4.
Not at all descriptive	Slightly	Sometimes descriptive	Quite	Very descriptive

27. I feel resentful of other relatives who could but do not help.

0.	1.	2.	3.	4.
Not at all descriptive	Slightly	Sometimes descriptive	Quite	Very descriptive

35. Do you feel that you will be unable to take care of your relative much longer?

0.	1.	2.	3.	4.
Never	Rarely	Sometimes	Quite frequently	Nearly always

36. Do you wish you could just leave the care of your relative to someone else?

0.	1.	2.	3.	4.
Never	Rarely	Sometimes	Quite frequently	Nearly always

37. Do you feel uncertain about what to do about your relative?

0.	1.	2.	3.	4.
Never	Rarely	Sometimes	Quite frequently	Nearly always

38. Do you feel you should be doing more for your relative?

0.	1.	2.	3.	4.
Never	Rarely	Sometimes	Quite frequently	Nearly always

39. Do you feel you could do a better job in caring for your relative?

0.	1.	2.	3.	4.
Never	Rarely	Sometimes	Quite frequently	Nearly always

40. Overall, how burdened do you feel in caring for your relative?

0.	1.	2.	3.	4.
Never	Rarely	Sometimes	Quite frequently	Nearly always

APPENDIX E

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UNIVERSITY of PENNSYLVANIA

PHILADELPHIA 19104-3246

Center for Cognitive Therapy

Please reply to:
Room 602
133 South 36th Street
Philadelphia, PA 19104-3246
(215) 898-4100

Rose Mary Schallmann

Winnipeg, Manitoba, R

CANADA

April 21, 1989

Dear Ms. Schallmann :

On behalf of Aaron T. Beck, M.D., I am responding to your recent inquiry regarding our research scales.

For your convenience, I have enclosed a copy/copies of the most recent version of the Beck Depression Inventory

You have Dr. Beck's permission to use and reproduce the scale(s) for use in your master's research

There is no charge for this permission.

In reciprocation, we would like you to send us a complimentary copy of any reports, preprints, or publications you prepare in which our materials are used. These will be catalogued in our central library to serve as a resource for other researchers and clinicians.

If you have any further questions, feel free to contact me.

Sincerely,

Mark Patrick
Research Materials Coordinator
for Aaron T. Beck, M.D.
Director, Center for Cognitive Therapy

Enclosures

Beck Depression Inventory (short)

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 F

LIFE SATISFACTION INDEX Z

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

(Key: Score 2 points for each "right" answer—marked with X; 1 point for ? or no response).

- | | AGREE | DISAGREE | ? |
|---|-------|----------|---|
| 1. As I grow older, things seem better than I thought they would be. | X | | |
| 2. I have gotten more of the breaks in life than most of the people I know. | X | | |
| 3. This is the dreariest time of my life. | | X | |
| 4. I am just as happy as when I was younger. | X | | |
| 5. These are the best years of my life. | X | | |
| 6. Most of the things I do are boring or monotonous. | | X | |
| 7. The things I do are as interesting to me as they ever were. | X | | |
| 8. As I look back on my life, I am fairly well satisfied. | X | | |
| 9. I have made plans for things I'll be doing a month or a year from now. | X | | |
| 10. When I think back over my life, I didn't get most of the important things I wanted. | | X | |
| 11. Compared to other people, I get down in the dumps too often. | | X | |
| 12. I've gotten pretty much what I expected out of life. | X | | |
| 13. In spite of what people say, the lot of the average man is getting worse, not better. | | X | |