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University of Alberta

Effects on Spouses of Caring for a Partner With Dementia

David Lawrence Purcell ©

A thesis submitted to the faculty of graduate studies and research in partial
fulfillment of the requirements for the degree of
Doctor of Philosophy in Counselling Psychology

Department of Educational Psychology

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Creator of our universe, God of all goodness, share your healing grace with those who are afflicted with dementia. Share with all caregivers a portion of your strength and the depth of your wisdom. Grant enlightenment and compassion to all professionals who support these caregivers. Let your knowledge bless all researchers who delve into the mystery of dementia and its effects on our lives and cultures. For all families and communities who devote themselves to meeting the needs of those with dementia, I pray that you will anoint them with the gifts of unity and perseverence...

Abstract

A list of 76 statements was gathered in response to the prompt, Please list the effects that caring for someone with memory problems has had on you. Twenty-two spouse caregivers of individuals with dementia responded to this prompt. Concept Mapping was then used to identify seven underlying themes from these statements. These themes were labelled Managing our Surroundings, Disengaging, Shifting Responsibilities, Reacting to Spouse's Confusion, Feeling Helpless, Burning Out. This manner of conceptualizing perceptions about caring for a spouse was unique when compared with previous research.

Sixty-eight spouse caregivers were asked to rate how much these 76 perception statements applied to their lives as well as to complete a Caregiver Burden Inventory. Perceptions labelled Burning Out and Feeling Helpless had the lowest incidence in this sample. Perceptions labelled Learning to Cope, Shifting Responsibilities, and Reacting to a Spouse's Confusion had a higher incidence among these caregivers. Caregivers were most highly affected by their reactions to their spouse's confusion and shifting of responsibilities within their marital relationship. They found coping strategies that helped in their lives. A majority did not use formal support services.

A high overall endorsement of perception statements within the themes labelled Managing our Surroundings, Disengaging, Shifting Responsibilities, Reacting to Spouse's Confusion, Feeling Helpless, Burning Out was associated

with high levels of burden. These results suggested that Concept Mapping may be useful for developing scales based on self report items. The Concept Map offered a valuable pictorial tool for interventions with caregivers. Further research to describe perceptions and related themes about coping with caring for a spouse with dementia would be useful.

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Chapter 1: Introduction

From the Survey on Ageing and Independence (Seniors Secretariat, 1993) it has been estimated that by the year 2011 about 14% of all Canadians will be 65 years old or older. The numbers of people within this age category are increasing rapidly and this group of people is having a significant impact on political, economic, and social environments. As federal and provincial governments across Canada cut back allocation of financial resources to health care, our aging population has a significant impact on the way we manage health care and on the people who provide that care.

Dementia is a disease which rises in prevalence within higher age groups and its impact on health care management and health care providers is a concern. The effects on spouses of caring for their partners who suffer from dementia is the focus for this study.

Caring for People With Dementia

The prevalence of dementia rises significantly after 65 years of age. In Canada it is estimated that 28.5% of those who are 85 years of age or older currently suffer from some form of dementia (Ebly, Parhad, Hogan, & Fung, 1994). Dementia is a mysterious medical problem. Most types of dementia, including Alzheimer disease, have an unknown aetiology (Walsh, 1991). Although some forms of dementia can be treated, most are incurable and the resulting behaviours can only be managed (Walsh, 1991). Dementia patients are often institutionalized as the disease progresses and they eventually require care by many formal caregivers. Caring for dementia sufferers is a significant problem due to the rising prevalence of dementia, difficulty in treating and managing its effects, as well as escalating medical costs.

Many families prefer to provide in home care for family members who suffer from dementia. In response to this preference and the rising costs of institutionalization, some Canadian health care agencies are experimenting with ways of extending the length of time that dementia sufferers can be cared for in their homes.

Providing in-home care for someone with dementia can lead to high levels of psychological distress in the caregivers (George, 1984; George & Gwyther, 1986; Lieberman & Fisher, 1995; Motenko, 1989; Zarit, Reever, & Bach-Peterson, 1980). Caring for someone with dementia may be more difficult than for people with physical difficulties (Birkel & Jones, 1987) or for people with cancer (Clipp & George, 1993). Spouse caregivers may be affected more adversely than other family members (Draper, Poulos, Poulos, & Ehrlich, 1995; George & Gwyther, 1986). Understanding the experiences of spouse caregivers of people who suffer with dementia is important when assessing ways to help them with the stress of caring for their partners. Broadening our knowledge about the perceptions of spouse caregivers constituted the major focus of this study.

Researchers have made a concerted effort to study individuals and families who have cared for someone with dementia. One branch of research has been predominantly quantitative in nature. Within this branch of research, scales have been developed to produce total scores which represent a caregiver's perception of their overall burden (Poulshock & Deimling, 1984; Zarit, Reever, & Bach-Peterson, 1980). These types of scales have also been used to evaluate whether counselling interventions help to alleviate the burden of caregiving. (Knight, Lutzky, & Macofsky-Urban, 1993). Another branch of research has been predominantly qualitative in nature. Qualitative researchers have offered various descriptions about caring for someone with dementia (Lindgren, 1993; Lynch-Sauer, 1990; Wright, 1991). By using both qualitative and quantitative methods, these researchers discovered that caregiver perceptions about their caregiving experiences have influenced the stress that was experienced by these caregivers.

Importance of caregiver perceptions

Caregivers' perceptions of their experiences have a profound effect on their ability to cope and on their reported burden levels (George & Gwyther, 1986, p. 259; Gottlieb, 1989, p. 603; Neufeld & Harrison, 1995, p. 362; Pushkar Gold, Cohen, Shulman, Zucchero, & Andres, 1995; Walker, Shin, & Bird, 1990, p.151). For example, if caregivers with adequate social support have negative perceptions about that support, they have been found to exhibit poorer mental health than those who have neutral or positive perceptions (Brodaty & Hadzi-Pavlovic, 1990; Fiore, Coppel, Becker, & Cox, 1986). Evidence from this kind of research supports the notion that caregiver perceptions could be conceived as a mediating variable contributing to the impact experienced by people.

The notion that peoples' perceptions influence their experiences of stress also guides the work of counsellors who try to support caregivers. This has therefore spawned research about these kind of counselling interventions. Some researchers have tried to shift caregivers' perceptions about their experiences and then measure the effects of these changing perceptions on the experience of burden or stress. (Knight, et al., 1993; Toseland, Rossiter, Peak, & Smith, 1990; Zarit, Boutselis, Anthony, & Cheri, 1987).

Describing caregiver perceptions

Since researchers have discovered the influence of perceptions on stress experienced by caregivers, they have tried various ways to describe and to catalogue these perceptions. To date, descriptions of caregiver perceptions have come from both quantitative and qualitative research. Scales that measure burden or stress in caregivers' lives have been analyzed for factors that emerged from items on these scales. Novak and Guest (1989) developed such a burden scale. Their burden inventory clearly identified five underlying factors which contributed to a Total Burden score. This burden scale will be further explained in the literature review.

Other researchers used qualitative methods to describe caregiver perceptions and the resulting influence of those perceptions. Montenko (1989) showed that caregiver spouses who perceived continuing marital closeness also described a sense of greater well being. Neufeld and Harrison (1995), described how perceptions of reciprocity between the caregiver and the person experiencing dementia can have an impact on the feelings of the caregiver. Boss (1990) explained how perceptions of ambiguous boundaries within families added to their stress.

Wright (1993) suggested that "only through the combination of qualitative and quantitative data was the mind-set of caregivers brought into focus... " (p.127). Integrating qualitative and quantitative methods can offer a different synthesis of the data about caregiver perceptions than has been available in previous studies which relied on only one method. Concept Mapping (Trochim, 1989a) uses an integration of both qualitative and quantitative methods. It is a tool which allows a researcher to analyze qualitative data with the statistical techniques of multidimensional scaling and cluster analysis. This tool was used to assist the researcher in describing the perceptions of spouses who were caring at home for their partner who suffered from dementia.

Concept Mapping also offers other advantages over previous methods. When describing the perceptions of spouse caregivers, most quantitative researchers limited their focus to a few themes. Concept Mapping allows for a description of a larger number of themes. In her analysis of caregivers' perceptions, Wright (1993) did not limit her descriptions to a few themes, but she used researcher-defined categories in which to group the data. Concept Mapping avoids imposing researcher defined categories.

Concept Mapping Method

Concept Mapping is a structured conceptualization process which can lead to a greater understanding of perceptual themes underlying a common experience (Kunkel, 1991). Concept Mapping has an advantage over techniques such as factor analysis because it is able to handle a wider variety of data (Fitzgerald & Hubert, 1987) and presents results in ways that are more easily interpreted. This can also help to communicate results in a clear and effective manner. Participants can also collaborate in a meaningful way by labelling themes that emerge in the data (Daughtry & Kunkel, 1993). Concept Mapping can therefore be used to present the participants' categorization of the data. Some studies, as noted above, have used researcher defined constructs by which to categorize data. Concept Mapping was used in this present study to describe caregiver perceptions without the constraints of theoretically or diagnostically based formulations (Daughtry & Kunkel, 1993).

Objectives of the Study

This research follows within the tradition of other researchers, already noted above, who have improved our understanding of caregiver perceptions. Results from this study helped to describe the perceptions of spouses who provided at home care for their partner who suffered from dementia. The research questions answered in this study were, How do spouses perceive the effects of caring for a partner with dementia? and, What themes or clusters emerge from these perception statements?

Statements which emerged from the first question were then rated by a different and larger sample of spouses. This rating of statements was used to answer the third question, What is the incidence of these perception statements in a sample of spouse caregivers? This larger sample of spouses were also asked to complete a Caregiver Burden Inventory (Novak & Guest, 1989). Responses to this inventory helped answer the fourth question, How do caregivers' ratings of perception statements, compare with their scores on the Caregiver Burden Inventory?

Assumptions and Limitations

Eileen MaloneBeach and Steven Zarit (1991), stated that research strategies should ensure a broad range of the caregiving continuum is represented. In order to attain that goal the researcher recruited caregivers from a variety of sources and with various caregiving experiences. The sample of caregivers in this study consisted of volunteers from various health care and home care programs, the Alzheimer Society, and local physicians. This kind of sampling also facilitated ease of access to subjects and reduced expenditures.

Those included in the sample of caregivers had to meet two criteria. Participants identified themselves as caring for a person with dementia (Blieszner & Shifflet ,1990; Russo, 1995; Sainty, 1993). Participants were chosen on the basis of sharing a residence with the person suffering from dementia. This latter criterion was used by Draper et al. (1992). These two inclusion criteria ensured that there was "some minimum involvement appropriate to the research question" (Malonebeach & Zarit, 1991, p 104).

Whyte (1991), and Turnbull and Turnbull III (1993), have described the concept of participatory research and its importance for research with families. Participatory research promotes research as a means for making positive differences in the overall quality of family life. Concept Mapping is a tool which encouraged participation by subjects at various levels of the research project.

Self-report from the participants was the predominant manner for data collection. This manner of retrieving information about caregivers' perceptions has been used by many other researchers (Blieszner & Shifflett, 1990; Kinney & Stephens, 1989; Montenko, 1989; Pruchno & Resch, 1989; Reed, Stone, and Neale, 1990; Sainty, 1993; Shifren & Hooker, 1995; Zarit et al., 1980).

The approach used in this research enabled caregivers to describe their experiences using their own language rather than having their experiences constrained by researcher defined categories. One example of this approach included the kind of language used by the researcher. Participants were asked about the effects of caregiving on their lives. They were not asked to describe their burdens, or uplifts, or benefits that they experienced through giving care to their spouses who suffered from dementia.

Conclusion

A research method that integrated qualitative and quantitative methods was used in this study. This integrative approach was used to offer a unique description of spouse perceptions about caring for a partner with dementia. The frequency with which these perceptions occurred among a sample of spouse caregivers was also obtained. Such a comprehensive frequency distribution has not been previously published.

In this study, caregiver ratings about their perceptions were compared with their obtained scores on a burden inventory. Those who develop scales to measure caregiver perceptions and caregiver burden may be helped by this type of information.

Results from this research could help to advance the development of theory about caregiver perceptions and how those perceptions relate to the notion of burden. Planning of interventions and supportive efforts for spouses of people with dementia may also be improved by the results of this study.

In Chapter Two there will be a review of research literature concerning perceptions of spouses who care for someone with dementia. There will also be a review of themes emerging from this type of research and a more detailed description of the Concept Mapping method. Chapter Three will include a detailed description of the method used to address the four research questions. In Chapter Four the Concept Map and the prevalence of statements made by caregivers will be presented. The ratings of caregiver perceptions and how they compared with participants' burden inventory scores will also be presented in Chapter Four. These results and how they related to the current literature about caregiver perceptions will be discussed in the last half of chapter four. Chapter

Five will provide a summary of the research and the conclusions that were based upon this research. Implications for future research and for psychological practice are also included in this final chapter.

Chapter 2: Literature Review

Introduction

In 1991 between 10 and 12 percent of Canadians were 65 years and older (Desjardins, 1992; Seniors Secretariat, 1993). This segment of the Canadian population is growing very quickly and is expected to form almost 21% of the Canadian population by the year 2011 (Desjardins, 1992, p.13). This aging evolution is expected to reach a plateau in the year 2036 when "almost one Canadian in four will be 65 years or over, and more than one in ten will be at least 75" (Desjardins, 1992, p. 14). Dementia increases in prevalence after the age of 65. The impact on systems and people who care for persons with dementia will grow significantly into the next century. People find it especially difficult to provide care at home for their spouses who suffer from dementia. The purpose of this study is to gain more knowledge about how spouses perceive their experiences of caring for a partner with dementia.

Types of Dementia

Dementia is a broad term used to describe a variety of brain disorders with known and unknown aetiology. These disorders have in common a progressive deterioration of intellect, emotional control, and will, which occur in the presence of unimpaired consciousness (Walsh, 1991). The most common type of dementia is usually referred to as Alzheimer disease (AD). Age of onset for this disease is usually after 40 years of age. This disease produces pronounced brain atrophy mostly in the cortex of the frontal and temporal lobes (Walsh, 1991). A diagnosis of probable AD is given on the basis of a six month history of progressive cognitive decline. Initial declines include short-term memory deficits, two or more deficits in cognitive functioning, and slight personality changes. In the final stages someone who suffers from AD may become bedridden in a fixed fetal position and lose awareness of his or her environment (Harrell, 1991). While living with someone who suffers from dementia, one would see this person develop difficulty with their reading and/or writing. One would notice that the person with dementia becomes lost in new environments, has difficulty recognizing familiar faces and locations, becomes less able to look after personal hygiene (Harrell, 1991), and exhibits a blunting of emotional sensibility and impairment of social adjustment (Walsh, 1991).

Vascular dementia is the second most common type of dementia. The term "multi-infarct" dementia has also been used to describe this kind of dementia. Hachinski, Lassen, and Marshall (1975) used this term to describe extremely small holes which accumulate in various areas of brain tissue. It is also known that these holes are associated with the build up of fatty tissues in blood vessels which lead to the brain. Hachinski et al. (1974) also drew up a list of thirteen characteristic features for vascular dementia that they claimed would clinically differentiate vascular dementia from AD. These features include abrupt episodes of weakness, abrupt changes in gait, and changes in reflexes, along with pathological laughing and crying. After surveying a number of studies, Walsh (1991) suggested it is very difficult to differentiate between AD and multi-infarct dementia even with the help of angiography and computerized tomography scans.

There is also a large subgroup of symptoms that can be designated as "dementia of the frontal type" (Walsh, 1991, p. 83). The reported first signs of this type of dementia include a loss of interest in personal appearance and hygiene, uncharacteristic rudeness in social situations, and lack of insight. Dementia of the frontal type is different from AD because it leaves memory functioning relatively intact (Walsh, 1991).

Finally, there are a number of dementias related to other disorders such as Huntington's chorea, Parkinson's disease, drug and alcohol toxicity. There are some rare and also some unclassified dementias.

The symptoms and varieties of dementia are daunting to consider but we also know that the numbers of people suffering from these symptoms will increase in the next century.

Prevalence of Dementia

Between February, 1991 and May, 1992, a representative sample of people 65 years old and over were interviewed from every region in Canada as a part of a major project called the Canadian Study of Health and Aging. This project was initiated and supported by the Department of National Health and Welfare. One of the four major goals of this study was to estimate the prevalence of dementia among elderly Canadians. The authors of this study concluded that "imperfect sensitivity of the community screening test may have led to an underestimate of the true prevalence of dementia" (Canadian Study of Health and Aging Working Group, 1994, p. 906). Rockwood and Stadnyk (1994) concluded, however, that the Canadian Study of Health and Aging provided fairly reliable estimates when compared with other studies.

The Canadian Study of Health and Aging Working Group, estimated that in 1991, over a quarter of a million (252,600) Canadians, sixty-five years old and over could be diagnosed with dementia (Canadian Study of Health and Aging Working Group, 1994). They also estimated that by the year 2001 this figure will increase to about 364,000 and could eventually triple to about 778,000 by the year 2031. They noted by comparison, that the total population is likely to increase by the year 2031, only by a factor of 1.4.

This Working Group also estimated that of the 252,600 Canadians over 65, who suffered from dementia in 1991, 64% of these people had symptoms of the Alzheimer type. They estimated vascular type dementia to constitute 19% of the total cases. They also estimated dementia of the frontal type and other rare and unclassified dementias afflicted 17% of people over 65 with dementia. AD was more common in women and vascular dementia was more common in men.

Results from the Canadian Study of Health and Aging confirmed that dementia, and especially AD, is age related. The Canadian Study of Health and Aging Working Group estimated that 2.4 % of people aged 65-74 years could be diagnosed with dementia and 34.5% of people aged 85 years and over have some form of dementia. Ebly et al. (1994) further elaborated on the prevalence rates of dementia in very old Canadians. They estimated that the prevalence of dementia from 85 to 89 years of age was 23%; 40% from 90 to 95 years of age; and 58% in people older than 95 years. Ebly et al. (1994) also illustrated how the prevalence of AD continues to increase after 85 years of age while other dementias seem to reach a plateau or begin to diminish.

An increasingly older population in Canada combined with the higher morbidity rates for dementia in the elderly, plus the very disruptive behavioural, physical, and emotional effects of dementia, all combine to produce a major impact on the systems and people that care for persons with dementia.

The Impact of Caring for People With Dementia

During 1991, the total cost of caring for people in Canada with dementia was estimated at over 3.9 billion dollars (Ostbye & Crosse, 1994). Ostbye and Crosse also estimated that paid services for community care for people who suffer from dementia cost $615 million. Care for institutionalized people was about $2.18 billion. Even when unpaid costs ($636 million) for care in the community were added, the total cost of community care was $1.25 billion. This latter cost is nearly half of the cost for institutional care. These estimates about the cost of care are spawning new initiatives to care for people who suffer from dementia in their homes for as long a period as possible.

In Edmonton, Alberta, between 1983 and 1986, "considerably more than half of the mild and severe cases of cognitive deficits would be found in institutions" (Bland, Newman, & Orn, 1988, p. 2). This past trend has been changing. In March of 1994, the Capital Health Authority, Home Care Program staff began a new research initiative. They offered Home Care services to an experimental group of participants with AD, at an earlier stage of AD than had been previously available. They wanted to determine whether persons with AD who received the earlier Home Care Programs would stay more days in the community than those who did not receive such early intervention (Chu, 1994). In April of 1995 the Good Samaritan Society and the Capital Health Authority inaugurated a pilot project in which people who suffered from dementia were cared for in their homes. This care was supervised by physicians and nurses who specialized in care for the elderly and also drew on much informal care given by family and community members.

Such projects as these have already been initiated in the United States (Hall et al., 1995; Knight, 1991) and seemed to reduce the economic costs of institutionalization. There are many mental and physical health problems, however, for the family members who are providing community-based caring (Clipp & George, 1990; Cohen, Luchins, & Eisdorfer, 1990; George & Gwyther, 1986; Kinney & Stephens, 1989; Lindgren, 1993; Motenko, 1989), as well as family difficulties, social, and economic costs (Blieszner & Shifflett, 1990; Neufeld & Harrison, 1995; Scott, Roberto, Hutton, & Slack,1985). Caring at home for someone with dementia is associated with clinical depression and anxiety as well as immunologic dysfunction (Kiecolt-Glaser et al. 1991). An increased use of psychotropic drugs has also been documented among family caregivers (Clipp & George, 1990).

Research about the effects of caregiving on spouse caregivers has revealed some of their unique concerns. The mental health of spouses can be seriously affected by their caregiving role especially if they share a residence with their care receivers (Cohen et al., 1990; Pruchno & Resch, 1989). Even after their care receivers have been placed in institutions, detrimental effects on mental and physical health of caregivers continue (Clipp & George, 1990; Cohen et al., 1990). Draper, Poulos, C.J., Cole, Poulos, R.G., and Ehrlich (1992) compared elderly co-resident caregivers of stroke an dementia sufferers.

Spouses of the care receivers made up 90% of their sample. They concluded that although there were no differences in the levels of psychological morbidity between the two groups, social life disruption was more severe for dementia caregivers. These caregivers also received less help from family and friends. In a comparison of spouses caring for dementia and cancer sufferers, Clipp and George (1993) concluded that dementia caregivers suffer the greater impact. In a comparison between adult children and spouses caring for dementia sufferers, George (1984) discovered that spouses had poorer health, were more likely to take psychotropic drugs, had more financial problems, and spent less time in leisure activities. Kiecolt-Glaser, Dura, Speicher, Trask, and Glaser (1991) discovered that, relative to controls, spouse caregivers showed significant decrements on measures of functional immunity, experienced more days of illness from infectious disease and visited physicians more often. They also noted that in caregivers, "especially those who are older, chronic stress could have long term, potentially irreversible consequences" (p. 3).

Spouses who care at home for someone with dementia experience many shifts in their roles. Often, men are retiring and changing their focus from work to home and thus become responsible for the home environment. For many men this means learning new skills such as bathing, feeding, and clothing another person (Mathew, Mattocks, & Slatt, 1990). Women who have finished caring for their young children often find themselves resuming an old role but they also experience a reduction in coping resources (Fitting, Rabins, Lucas, & Eastham, 1986).

As governments and health care providers shift their emphasis to community-based programs, this has a great impact on the community, family, and individual environments. Providing care in the home for people with dementia has a great impact, especially on spouse caregivers. There are major shifts that take place in the lives of spouses who care for people with dementia. There are often detrimental effects on their mental health, social relationships, and on martial closeness. Researchers have tried to determine how family caregivers can better cope with these adverse effects. Some of these findings are described in the following sections.

Perceptions of Caregivers

People's perceptions about a situation influence the impact they experience in a particular situation. It has also been discovered that the perceptions of spouses who care for a partner with dementia will affect the impact that these spouses experience. Certain helping professionals have therefore designed cognitive counselling techniques to shift caregivers' perceptions in attempts to help them better cope with their stressors. There is a growing body of literature about studies that are designed to improve our understanding of caregiver perceptions. Within this body of literature one can find attempts to describe caregiver perceptions.

Caregiver Interventions

Some studies have endeavoured to measure the efficacy of counselling interventions with caregivers (Knight et al., 1993; Toseland et al., 1990; Zarit et al.,1987). Most interventions reported in these studies used either cognitive, psycho-educational, cognitive-behavioural approaches, or a combination of these approaches. These interventions used a variety of cognitive techniques to help alleviate stressful aspects of caregiving.

Counselling interventions which use cognitive techniques can shift people's behaviours and help them cope with stress. Aaron Beck (1976) published a theory which formed the basis for these techniques. Aaron Beck stated, "the 'intellectual' approach consists of identifying the misconceptions, testing their validity, and substituting more appropriate concepts" (p.214). His theory has been subsequently popularized by many psychologists and psychotherapists who have developed a variety of cognitive counselling techniques.

The use of cognitive counselling techniques such as shifting perceptions, challenging beliefs, problem solving, and reframing are beneficial for a caregiver's well-being. For example, cognitive therapy has been found effective when treating depression.

Empirical evidence to support the effectiveness of cognitive interventions can be found in the literature on caregiver interventions. Toseland et al. (1990) suggested that caregivers could alleviate their stress by identifying and solving problems, reassessing their roles as caregivers, and mentally anticipating and preparing for caregiving tasks. Scharlach (1987) concluded that interventions which focussed on daughters' perceptions of their situations could improve relations between themselves and their care receiving mothers.

The view that people's perceptions affect their experiences of stress also applies to people who are caring for someone with dementia. Caregivers of people who suffered with dementia, suffered from less depression and other psychopathology as their perceived satisfaction with support increased (Brodaty & Hadzi-Pavlovic, 1990; Fiore, Becker, & Copel, 1983; George & Gwyther,1986). Pratt, Schmall, Wright, and Cleland (1985) found that problem solving and reframing strategies were correlated with lower levels of burden among a group of caregivers. In Zarit et al.'s (1986) study of people caring for dementia sufferers, the findings "...are consistent with general models of stress, which propose that the impact of harmful events is mediated by whether subjects actually perceive them as harmful... " (p.265).

Describing Caregiver Perceptions

As noted previously, changing their perceptions about caregiving can elicit changes in caregivers' moods, mental health, and behaviours. To improve our understanding of caregiver perceptions, researchers have offered descriptions of perceptions about the impact of caring for someone with dementia. Some researchers have used quantitative methods and some have used qualitative methods. Most of these researchers have focussed on the issue of describing burdens or stressors. Others, however, have demonstrated a need to widen our descriptions of caregiver perceptions by including the spectrum of so-called positive, neutral, as well as negative perceptions about the impact of caring for a partner with dementia.

Burden scales and factor analysis.

A number of studies (eg. Kahn, Kemp, Staples, & Brummel-Smith, 1985; Quayhagen, & Quayhagen, 1989; Scharlach, 1987) have used Zarit's Burden Inventory (Zarit, Reever, & Bach-Peterson, 1980), to evaluate the efficacy of interventions aimed at relieving caregiver burden. Other burden measurement instruments have also been used (Kinney & Stephens, 1989) as have less directly applicable instruments such as the Beck Depression Inventory or the Brief Symptom Inventory (Toseland et al., 1990). These studies presupposed that caregiver burden has linear and additive characteristics. Participants are asked to look at a certain statement and to rate on a scale from zero to some higher integer how much that statement applied to their own life situation. Their responses were summed across all items and a total score was given for that particular inventory. In the case of Zarit's Burden Inventory (1980), respondents were asked to read a statement which portrayed a certain feeling about caring for their spouse. They were asked to indicate how often they had felt that way by using a scale where zero indicated never and four indicated nearly always. Some statements on the inventory included, "I feel resentful of other relatives who could but who do not do thing for my spouse. Because of my involvement with my spouse, I don't have enough time for myself. I feel my spouse is dependent" (p. 651).

Knight, Litzky, and Macofsky-Urban's review (1993) of studies between 1980 and 1990 suggested several difficulties with these previous studies. These difficulties pertained primarily to experimental design and included lack of adequate control of comparison groups. Knight, et al., however, indicated that caregiver burden studies can also attribute some of their difficulties to a lack of acknowledgement that caregiver burden is a multidimensional construct that is confounded by important variables, such as gender, length of caregiving, and presence of depression.

Poulshock and Deimling (1984) observed that many studies measured or operationally defined caregiver burden in a myriad of ways. They proposed that burden should refer to the "subjective perceptions of caregivers related to the degree of problems experienced in relation to elders specific impairments" (p. 238). In their study, burden was measured by asking caregivers to rate whether a specific aspect of caregiving was difficult, tiring or upsetting. Moreover, Poulshock and Deimling emphasized that burden is a multidimensional construct with "both a mediating and independent influence on the impact that caregiving has on a caregiver's life" (p. 238). Using factor analysis, they were able to distinguish two dimensions of burden from their burden inventory. These two dimensions were labelled as "negative changes in elder-caregiver/caregiver-family relationships and restrictions in caregivers' activities resulting from caregiving" (p. 233).

Novak and Guest (1989) noted that the small number of subscales on Poulshock and Deimling's inventory was a real weakness for the measurement of caregiver burden. They took up the challenge to refine the measurement of burden and create a more complex and reality-oriented measure (Poulshock & Deimling, 1984, p.238). Novak and Guest used factor analysis to develop a Caregiver Burden Inventory based on previous scales and on a sampling of caregivers of confused or disoriented older people. They devised a 24 item scale. Each item was rated by caregivers on a range from 0 (not at all descriptive) to 4 (very descriptive). These ratings could be summed over all items to give a total burden score.

Novak and Guest added to the previous development of burden scales by creating a five subscale inventory with four or five items on each subscale (p.800). Factor number one, labelled as "time-dependence burden" included statements such as, "My care receiver needs my help to perform many daily tasks"; and "My care receiver is dependent on me." Factor number two, labelled as "developmental burden" included statements such as, "I feel that I am missing out on life"; and "My social life has suffered." Factor number three, labelled as "physical burden"; included statements such as "I'm not getting enough sleep"; and "Caregiving has made me physically sick." Factor number four, labelled as "social burden" included statements such as, "I don't get along with other family members as well as I used to"; "I've had problems with my marriage." Factor number five, labelled as "emotional burden" included statements such as, "I feel embarrassed over my care receiver's behaviour"; and "I resent my care receiver" (p. 800).

Qualitative descriptions.

Instead of asking caregivers to rate statements about their experiences and then develop scales and themes from these ratings, some researchers have concentrated on describing perceptions about caregiving through qualitative methods. The effects of caregiving are perceived by caregivers to be most detrimental in the areas of mental health, spousal relationships, and social participation (George & Gwyther, 1986). More specifically, Kvale and Bolen reported that declining intimacy, redefinition of relationships, and shifts in marital role patterns during the progression of dementia have an impact on caregivers' lives (as cited in Blieszner & Shifflett, 1990, p. 58). There is a growing indication that "the characteristics of the caregiving situation and the resources available to the caregiver, rather than the condition of the patient, most directly affect caregiver well-being" (George & Gwyther, 1986, p.259; see also Zarit et al.,1980; Reeves, & Bach-Peterson, 1980). For example, a daughter's quality of relationship with her mother previous to that parent's need for more intensive care, affects the daughter's satisfaction with her role as caregiver (Walker et al.,1990, p. 151).

Other researchers have tried to provide conceptual frameworks for the effects of caregiving on the family as a system (Gottlieb, 1989; Matthews & Rosner, 1988). Pauline Boss (1988) used the phrase "ambiguous loss" to describe how family boundaries become ambiguous in families of men who were declared missing-in-action in Vietnam. She subsequently described in detail how people are affected by the ambiguous loss of a person in the family who cares for someone with dementia. Ambiguous loss is defined as the family's not knowing who is in and who is out of their family system. Members of families caring for someone with AD experience a physical presence with psychological absence. They perceive that setting boundaries, reassigning roles, and taking charge of family interactions in new ways has an impact on their lives (p.308).

Sauer-Lynch (1990) described eight themes that emerged from previously published research about caring for a family member with AD. The core themes included: 1) unending attempts to put patients in touch with their surroundings; 2) trying to predict when the next disconnection would occur; 3) experiences of asynchrony with the care receiver; 4) experience of loss of mutuality; 5) progressive diminishment of diversity in the relationship to the patient and others, and the environment by the caregivers; 6) attempts to attribute meaning to the patient's illness; 7) an ever-present search for personal connectedness; 8) gradual decline of reciprocal relationship.

Themes #5 and #8 were studied in greater detail by Motenko (1989), who concluded that caregivers who perceived continuity in marital closeness and perceived continuity in social supports experienced greater well-being. Neufeld and Harrison (1995) researched theme #8 in more detail. They divided the notion of reciprocity into four different kinds of perceptions. From the results of their study they concluded that women caring for someone with cognitive impairment who perceived their relationship to be reciprocal expressed more satisfaction with their ability to care, displayed higher self esteem, and showed enhanced ability to ask for support. The feelings of satisfaction and self esteem that these caregivers experienced may have contributed to their well-being and helped prevent depression (p.362).

Harris (1993) interviewed 15 males caring for a spouse who suffered from dementia. She reported six themes that emerged from data taken through semi-structured interviews. Harris found that 1) these men were committed to their spouses; 2) they experienced more social isolation; 3) there were a number of different coping strategies used by these men; 4) they experienced a sense of accomplishment through caring for their wives; 5) these men also expressed a need for support groups which consisted of only men; and 6) they expressed few expectations that other family members would help them with giving care.

Spouses will also experience many shifts in their marital relationships. Lore K. Wright (1991) has published a comprehensive description of the impact of AD on the marital relationship. In this study she used five theoretical dimensions of a marital relationship to analyze the impact of AD. In the Consensus/Instrumental dimension, Wright found that for AD couples (in which one partner was afflicted with AD) there was no true sharing of household responsibilities as there was for well couples. This had a mixed effect on people. For example, on the issue of money management, caregiver spouses who had never managed household finances previous to the onset of AD were more likely to experience problems. On the other hand, some of these caregivers reportedly enjoyed the control over resources to which access had been denied in the past (p.230); thus they did not report money management as a problem. Within the Tension dimension of their relationship, only 13% of caregiver spouses stated that they openly expressed feelings of tension with their spouses, in contrast to an ability to deal openly with tension that was reported by 53% of the well couples. In the Companionship/Confidant dimension, many caregiver spouses reported an exhaustion from their caregiver's clinging behaviours such as repeated questioning and constant requests for help. This prompted the caregivers to seek other companionship or escape into reading. Within the Affectional dimension, it was reported that more touching occurred from caregiver to care receiver than between spouses in the well couples. The touching, however, was more often instrumental in nature rather than affectionate touching. Within the Sexual dimension, responses varied greatly. "High sexual activity together with a clinging, demanding type of affection, occurred only with male afflicted spouses" (Wright, 1991, p.233). This often created resentment and discordance within the marital relationships. For some caregiver spouses and some well-group spouses, sexual activity decreased and did not produce resentment but was reported as congruent with their expectations for the aging process. Wright concluded that as afflicted spouses lost perceptual ability, their human development ended while their caregivers' development continued. This uneven human development between partners produces discordance within the marital relationship that is not as keenly felt in the well group who showed more evidence of shared meanings in their interactions and concordant developmental outcomes.

Perceptions about beneficial aspects of caregiving.

There are also descriptions emerging that focus on the perceptions of beneficial aspects of caregiving rather than the so-called negative aspects. (Abel, 1986; Archbold, 1983; Bliesner & Shifflett, 1990; Walker et al., 1990;) For example, Walker and Pratt (1991) outlined how caregiving can deepen expressions of affection within mother-daughter relationships.

Only three studies could be identified which dealt with how perceptions about beneficial aspects of caregiving had an impact on caregivers of people with dementia. Motenko (1989) and Kinney and Stephens (1989) hypothesized that greater gratification from caregiving would be associated with a higher level of well-being in caregivers. Both studies showed that the relationships between gratification or uplifts and caregiver well-being are somewhat complicated. Motenko (1989, p. 169) found a positive correlation between levels of gratification and caregiver well-being. However, Kinney and Stephens (1989, p. 404) noticed that total Uplift scores were not significantly associated with any index of well-being. They also reported that caregivers who spent greater amounts of time in caregiving activities reported more Activities of Daily Living uplifts. Contrary to expectations, those who reported more Activities of Daily Living and behaviour uplifts experienced more depressive symptoms. Only when the net effects of hassles and uplifts were analyzed and found to be in a positive direction, did caregivers also register fewer problems in their interpersonal relations. They also discovered no significant relationship between uplifts and depression when female caregivers were examined separately from males (p. 405).

Researchers have also been able to list some aspects of caregiving that are perceived to be beneficial. From their scales used to measure uplifts, Kinney and Stephens (1989) offered lists of uplifts most frequently reported by caregivers which included: a) seeing the care recipient calm, b) pleasant interactions between caregiver and care receiver, c) seeing the care recipient responsive, and, d) seeing the care recipient showing affection (p.404). Motenko (1989) asked general questions about whether participants experienced any moments of warmth, comfort or pleasure, or whether they experienced any satisfying changes in relationships (p. 168). Mathew et al. (1990) briefly referred to amusing experiences about caring for someone at home. He also mentioned that caring for someone at home, helped caregivers find satisfaction in knowing exactly how their care recipient was being treated.

These studies about perceptions of beneficial aspects of caregiving demonstrate that caregivers' perceptions about their experiences are very complex.

Analysis of Literature

This review has shown that attempts to describe caregiver perceptions about the impact of caring for someone with dementia has been a focus of past researchers. It has also been demonstrated that studying spouses' perceptions about caregiving is important because of the amount of distress experienced by spouses and because of the unique issues they face in giving care to their partners. There appear to be four aspects of spouses' perceptions about the impact of caregiving that warrant more research attention.

Lists of Caregiver Perceptions

Some studies have listed statements that described aspects of caregiving which have an impact on caregivers. Zarit (1980), Poulshock and Deimling (1984), Kinney and Stephens (1989), and Novak and Guest (1989) obtained reports from a mixture of spouses and other family members who were caring for someone with dementia to derive their lists of statements. Motenko (1989) relied on lists of statements from previous studies which had also sampled from a mixture of family members. Of the studies that used only spouses in their sample (Harris, 1993; Motenko, 1989; Wright, 1991; Zarit et al.,1986), only Wright reported lists of perceptions about caregiving that were obtained from these spouses. It may be helpful, therefore, to generate a list of perceptions about giving care to someone with dementia based on a sample of exclusively spouse caregivers.

Some researchers, already mentioned, have collected statements from caregivers by constructing their questions with terms such as "uplifts," "hassles," or "burdens." It is also clear that so-called uplifts for one caregiver may be classified as a burden by another caregiver. It would, therefore, also be helpful if a list of perceptions was collected without using terms that classify these perceptions as so-called positive or negative effects.

Incidence of Caregiver Perceptions

Motenko (1989) elicited responses from women who were caring for their husbands about how much certain aspects of caregiving bothered these wives. He then compiled some incidence rates to reveal how often certain items on the list of frustrations were endorsed. The statements used for this list of frustrations was derived from literature that sampled a mixture of family members. The statements on the lists were general in nature. For example, participants were asked about "the demands of caregiving," "changes in household responsibilities," "any aspect of your marriage relationship" (p. 168). Zarit et al. (1986), Fitting et al. (1986), and Novak and Guest (1989) also used lists of statements about the effects of caregiving. They reported their findings, however, as total burden scores or as subscale scores and not as incidence rates of specific items.

Barusch and Spaid (1989) gave incidence rates for aspects of caregiving that were perceived as problems for spouse caregivers. They did not describe how their list of statements was generated. Their list consisted of 34 items covering six areas of concern for caregivers. Approximately half of their sample who responded to this list of statements were caring for spouses who suffered from strokes, lung disease, and general frailty.

Reed et al. (1990) also reported incidence rates for statements endorsed by caregivers of people suffering from dementia. The list of statements focussed on aspects of caregiving that had an impact on caregivers' lives. These researchers reported incidence rates for specific content areas such as health, marriage, recreation, friends, financial and others (p. 203). The sample of people endorsing statements on their questionnaire included a mixture of spouses and adult children of a person suffering from dementia.

Harris (1993) reported common themes that emerged from males caring for wives with AD. He did not report any incidence rates for these themes nor did he report any frequencies of specific caregiver perceptions.

Several researchers have reported incidence rates of caregiver ratings on aspects of giving care that had an impact on their lives. None of these lists, however, have been based solely on the perceptions of spouse caregivers. Many of these incidence rates have been based on the perceptions of a mixture of caregivers. Therefore, exploring the incidence rates of how specific aspects of caregiving have an impact on spouses caring for someone with dementia would be helpful. This kind of information would add to the previous descriptions of spouses' perceptions about the effects of caring for someone with dementia.

Themes Emerging From Caregiver Perceptions

Some researchers have derived themes about the impact of caregiving from statements that caregivers have made about their experiences. Poulshock and Deimling (1984), Kinney and Stephens (1989b), Novak and Guest (1989) all used factor analysis to derive from two to five themes from statements made by caregivers. Sauer-Lynch (1990) used qualitative meta-analysis to derive several themes about the impact of caregiving from statements made by caregivers. Harris (1993) used phenomenological analysis to derive six themes about the experiences of males caring for their partners who suffered from dementia.

Wright (1993) demonstrated how the "triangulation" (p.127) of qualitative and quantitative data could bring about a meaningful interpretation of the perceptions of caregivers whereas the quantitative measurements alone were sometimes difficult to interpret. In order to effect this triangulation, Wright obtained scores from spouse participants for each marital relationship subscale on the Dyadic Adjustment Rating Scale. This rating scale was obtained by previous researchers using factor analysis (Spanier, 1976, Spanier &

Thompson, 1982). Wright (1993) also asked a series of open ended questions during a semi-structured interview and then derived themes from the resulting statements using grounded theory techniques. Wright then used the qualitative statements and themes to supplement the reporting of scores and comparisons of scores on the Dyadic Adjustment Rating scale. Wright was also able to report some frequency counts for various aspects of the marital relationship as described by this rating scale (p.127).

Although Wright has demonstrated the strength of using qualitative and quantitative approaches to supplement one another, none of these previous researchers have derived themes from caregiver perceptions by using a technique that integrates qualitative and quantitative methods. Concept Mapping provides an integrated use of qualitative and quantitative means to derive themes from participants' statements. The use of such an integration could offer a unique perspective about caregiver perceptions.

Burden Scores

Novak and Guest (1989) created profiles of caregivers by using Total Burden scores and scores based on subscales from their questionnaire. They clearly illustrated how two people with the same Total Burden score, "can have markedly different patterns of burden" (p. 802) revealed by variation in their subscale scores. Kinney and Stephens (1989b) found that almost 85% of items on a list about caregiving events were perceived by some caregivers as hassles and by other caregivers as uplifts. They alerted us to the "importance of assessing individual's appraisals of events, because many of the same events were interpreted differently by different respondents" (p. 403).

Both of these studies demonstrated that caregivers rate their perceptions about the impact of caregiving in a variety of ways. Although Wright (1993) reported frequencies of a number of perceptions of spouse caregivers, she did not compare these results with a burden inventory. No study was found in the literature which compared the way people rated their perceptions about caregiving with their obtained scores on a burden scale. This kind of information would also enhance our ability to describe caregiver perceptions and might also be helpful information for those who develop burden scales.

Summary

This review of literature cited the need for describing perceptions of people who care for spouses suffering from dementia. It also indicated a need for a study method that elicits perceptions from spouse caregivers in an open ended manner. This review of literature also suggested a need to obtain frequency counts based on spouses' ratings of their perceptions about the impact of caring for a partner with dementia. Only one previous study had offered such frequency counts about dynamics of the marital relationship. A comparison between these latter ratings and spouses' burden scores is also needed.

A method that yields a comprehensive catalogue of caregiver perspectives and yet still gives some descriptive definition to the data would be helpful. An integration of qualitative and quantitative methodology could offer a unique perspective of spouses' perceptions about caring for a partner suffering from dementia.

Such a method is available through Concept Mapping. No previous Concept Maps of caregiver perceptions about the impact of caring for a spouse with dementia have been published. The following sections provide a review of literature which describes the Concept Mapping method, previous applications of this method, and how Concept Mapping compares with other methods.

Concept Mapping

Introduction

Trochim (1989a) introduced a method that can be used to systematically collect ideas or statements generated by participants. This "structured conceptualization" process begins by collecting brain stormed statements from a group of people. These statements are grouped into piles in a way that makes sense to these participants. Matrix algebra is then used to represent how many participants placed a pair of statements in the same pile regardless of what a particular pile may have meant to the sorter. A two-dimensional nonmetric multidimensional scaling of this matrix is performed. This latter step produces a map. On this map, each statement is represented as a point and distances between each point represent how "closely," in other words, how often these statements were associated by the people who were sorting these statements into piles. Individual statements on this map are then grouped into clusters. Achieving a cluster solution takes place through a trial and error approach where different maps are configured using between twenty and three clusters. By naming each cluster, a clear conceptual framework is then graphically represented. This graphical representation expresses the framework of concepts in the language of the participants, and helps to show the major concepts and their interrelationships. The manner in which Concept Mapping will be applied to research concerning caregiver impact is described in the following sections.

Stages

Concept Mapping requires a number of steps to complete. The initial stages of defining the issue to be studied are as important as the later stages of generating statements, structuring statements, and the deriving themes from these statements.

Preparation.

Two preparatory steps are necessary before starting the Concept Mapping process. Trochim described these as selection of participants and developing the focus (Trochim, 1989a). First, people must be chosen who will participate in the process. Trochim has chosen a wide variety of relevant people, small homogenous groups, and used some random sampling schemes. He has used no set limit for the numbers of people involved but has found that between ten and twenty people was a workable number. Second, it is important to clearly define the domain of the study. This is achieved by wording the research question clearly and simply. Trochim (1989a) also described the importance of choosing one focus for the question that is asked (p.4).

Generation of statements.

A question derived from the preparatory steps normally provided a prompt for beginning the Concept Mapping process. In response to this prompt, participants would generate, in sentence form, all their ideas regarding the question or prompt. In an ideal situation statements could be generated with no predetermined limit. There are practical limits in the analysis phase, therefore, Trochim (1989a) reduced sets of statements to one hundred or less. The important goal was to represent the entire conceptual domain for the topic of interest. Redundant statements were removed. If the number of statements remained over one hundred, then other means were used to choose statements which ensured a representative sampling of the domain of the research question (p.5).

Structuring of statements.

Describing interrelationships between statements normally began with an unstructured card sorting procedure. Each statement generated was then printed on a separate index card and arranged in random order. A complete set of cards was then given to a number of participants with instructions to sort the statements into groups that were based on a common theme or idea. Trochim (1989a) noted that there were some restrictions placed on this procedure. Each statement could only be placed in one pile. The statements could not be put together in one pile. There could not be as many piles as the number of statements to be sorted. With these latter directions explained, participants were asked to simply sort the cards into piles in any way that made sense to them (p. 5).

Development of themes.

The next step involved analyzing the resulting sets of grouped statements using multidimensional scaling and cluster analysis. This two step process helped to identify the underlying or common categories which emerged when groupings of statements by individual sorters are considered in combination with groupings from other sorters (Trochim, 1989a). Fitzgerald and Hubert (1987) illustrated how multidimensional scaling depicted interrelationships in a spatial representation. Borgen and Barnett (1987) have clearly explained how cluster analysis can detect patterns in a data matrix.

The last stage in this two step process is to begin looking for "cluster solutions." This means that the researcher must choose the number of clusters into which the statements should be grouped. Trochim (1989a) noted that "essentially, the analyst must use discretion in examining different cluster solutions to decide on which makes sense for the case at hand" (p. 8). There is a numerical method that helps the researcher with this process. A "bridging value" (Trochim, 1991, p.58) numerically describes whether an item on a Concept Map has been sorted more often, or less often, with other statements that are close to it on the map. The bridging value is a number between zero and one. A bridging value that is closer to zero means that a certain statement was sorted primarily with other statements that are close to it on the map. A value that is closer to one means that a statement was sorted with other statements from various locations on the map. Once a number of clusters has been decided upon, a point and cluster map can be printed out.

Development and interpretation of maps.

Results from these previous steps were then visually inspected. Each group of statements was given a name which seemed to describe the set of statements as a cluster just as one would arrive at a name for various factors in factor analysis. Normally, this process would begin by giving the point and cluster maps to a number of participants. They were also given a list of statements included in each cluster and asked to describe in a short phrase or word the set of statements in that cluster. The group of participants would then arrive at a consensus label for each cluster (Trochim, 1989a, p.9; 1994, p.769). Daughty and Kunkel (1993, p.319) have described a process whereby the researchers themselves chose descriptive and justifiable names for each cluster.

The final result of this process was a visual representation or map. This map clearly depicted concepts which emerged from the analysis as well as interrelationships of statements which formed the basis for these concepts. Trochim (1989a) described how this map can provide an easy to understand and easily presentable summary of the conceptualization process.

Application of maps.

Concept Mapping has been used to plan or evaluate educational, psycho-educational, and community support and treatment programs (Trochim, 1989a; 1989b; 1994). Concept Mapping has been used by researchers investigating various areas in the field of psychology. It has been used for example, to describe the underlying themes reported in experiences of depressed college students (Daughtry & Kunkel, 1993), in the perceptions of students about what it is like to be gifted (Kunkel, Chapa, Patterson, & Walling, 1995), in the experiences of families in difficulty (Phillips, 1993), and in the dysfunctional beliefs of battered women (Chorney, 1994). Borgen and Barnett (1987) and Fitzgerald and Hubert (1987) gave examples of how MDS and cluster analysis produced clearer and more parsimonious representations than factor analytic solutions for some research in counselling and vocational psychology.

Each cluster which emerges from this mapping process can be considered a measurement construct and then used to provide direction for future research (Trochim, 1989b). The clear pictorial format of a Concept Map can also help people understand the concepts that are being mapped and how these concepts relate with one another. Thus, it is an excellent tool for communication and educational purposes (Trochim, 1989a).

Statistical Method

Multidimensional scaling and cluster analysis are the two statistical methods which are foundational to Concept Mapping. In this section these two methods are compared with factor analysis. The numerical principles for multidimensional scaling and cluster analysis are then reviewed.

Comparison of factor analysis, multidimensional scaling and cluster analysis.

Factor analysis, multidimensional scaling, and cluster analysis are a few of the different multivariate statistical techniques available to organize data into groups or categories. This literature review has identified several studies of caregiver perceptions that used factor analysis as the basis for their statistical analysis. Not only is factor analysis a commonly used and accepted technique; it also has a strong theoretical base (Aldenderfer & Blashfield, 1984).

Both cluster analysis and factor analysis are methods which help to identify underlying structures or schemata within a certain population's experience. The difference between the two methods was concisely described by Borgen and Weiss (1971):

> The central difference is in the treatment of the variance of the variable. Factor analysis usually partitions the variance among several sources or factors, while cluster analysis assigns the total variance to the underlying

> 'source.' Thus, cluster analysis yields results where variables are grouped into discrete sets or 'clusters,' while the results of factor analysis are typically less clear, with parts of the variance of each variable attributed to each of several 'subsets' of factors. (p.583)

Multidimensional scaling also bears a conceptual similarity to factor analysis. Fitzgerald and Hubert (1987) concluded, however, that multidimensional scaling has the "advantage of being generally more applicable to a wider variety of data, explicitly directed toward the task of spatial representation, and, in many cases, capable of providing lower dimensional solutions that are substantively interpretable" (p. 469).

Multidimensional scaling.

Fitzgerald and Hubert (1987) described multidimensional scaling as a class of methods that seeks to represent spatially, a set of numerical interrelations among a set of objects. This spatial representation is a point map of various items which can then be used for conceptual purposes.

In the Concept Mapping system described by Trochim (1989a), multidimensional scaling was the first statistical procedure carried out on the sort data. The multidimensional scaling process used a nonmetric two dimensional solution, and placed the set of points into a bivariate distribution which was then plotted on the X-Y axis. Nonmetric multidimensional scaling, when applied to a similarity matrix, can use distances to represent numerical relationships between the original items in the matrix (Kruskal & Wish, 1978). A map of points emerged which represented the set of statements' interrelationships based on a similarity matrix that had resulted from the sorting task. Points that appeared closer to each other on this map represented statements that were more likely to have been sorted together more frequently. Points that appeared farther apart, indicated statements that were more likely to have been sorted less frequently together.

Multidimensional scaling can represent any number of dimensions and therefore, the researcher must set the number of dimensions for the final representation. Kruskal and Wish (1978) suggested that two dimensional illustrations are generally easier to work with. For example, higher dimensional solutions require the use of statistical techniques to guide one to conclude whether a one, three, or four dimension solution will provide the best fit. The follow-up analytic processes will also guide the decision about how many dimensions to use. "For example, when a multidimensional scaling configuration is desired primarily as the foundation on which to display clustering results, then a two dimensional configuration is far more useful than one involving three or more dimensions" (p. 58). Trochim (1989a) confirmed that "in studies where we have examined other than two-dimensional solutions, we have almost universally found the two-dimensional solution to be acceptable, especially when coupled with cluster analysis" (p. 8).

In summary, multidimensional scaling is a mathematical method which can take values from a matrix that describes similarities in relationships and then plot these values in two-dimensional space. This is a quantitative method which does not categorize the items into groups. It is therefore used in combination with some other clustering method (Trochim 1989a). Trochim has often used two-dimensional multidimensional scaling in conjunction with a cluster analysis technique in order to produce a Concept Map (Trochim, Cook, & Setze, 1994).

Cluster analysis.

Trochim (Trochim, Cook, & Setze, 1994) most frequently used a hierarchical cluster analysis (Everitt, 1980) to categorize data from the multidimensional scaling analysis. He applied cluster analysis to the two dimensional scaling coordinates for each point generated from the multidimensional scaling analysis. The purpose of this clustering was to group individual statements on the map into clusters of statements which presumably reflect similar concepts.

There are a variety of computational methods that can be used in the clustering process. Ward's minimum variance technique (1963), however, has been rated as one of the more effective clustering analysis techniques (Milligan, 1981, Aldenderfer & Blashfield, 1984; Blashfield, 1984). Borgen and Barnett (1987) also concluded that Ward's algorithm is one of the more effective methods for recovering underlying structure and has been widely used in the behavioural sciences (p. 464).

Ward's technique is designed to minimize the variance within clusters at each stage of grouping. This approach merges single items or groups of items that result in the least increase in the within-groups sums of squares (or error sums of squares) (Borgen & Barnett, 1987, p. 465). In other words, the technique will first join proximity ratings for individual items such as statements, then merge these groupings or clusters in a step-by-step process so as to minimize increases of error sums of squares within a particular group. This algorithm can be repeated over and over from a stage where statements in close proximity are combined, to a stage where statements farther apart are combined until eventually all statements are combined into one cluster. This approach therefore, tends to ensure optimum within-cluster homogeneity. It does not ensure, however, optimum homogeneity of final cluster solutions because once joined to a cluster, separate items or statements are not separated at later stages of grouping. Borgen and Barnett (1987, p. 465) claimed that this is not a major practical difficulty with Ward's method. Trochim (1989a) also claimed that Ward's method generally gave more sensible and interpretable solutions than other approaches (p. 8).

Summary of concept mapping statistical analysis.

A number of statements about a particular experience are generated through interviews or brainstorming techniques. Participants in a study are then asked to sort these statements into piles. The results of this card sort are recorded in a similarity matrix which denotes which statements were sorted together by each individual. These individual matrices are then added together to form a "combined group similarity matrix". The group matrix is considered a relational structure of the conceptual domain as it numerically describes how the participants grouped the statements (Trochim 1989a, p. 6). Multidimensional scaling is then applied to the similarity matrix. Using a two-dimensional solution, multidimensional scaling identifies each statement as a separate point on a map. Points on this map represent statements which have been sorted together more frequently. Hierarchical cluster analysis then groups these points into a cluster map. Finally each of these clusters is given a name which best describes the statements contained in that particular cluster.

Conclusion

Researchers have published various lists of statements that describe caregiver perceptions about the impact of caring for someone with dementia. None of these lists have been elicited in an open ended manner from a sample of solely spouses caring, at home, for their partners who suffer from dementia. One of the research questions for this study will be, How do spouses perceive the effects of caring for a partner with dementia? Researchers have also identified the multi-dimensional nature of caregiver perceptions about caring for someone with dementia. They have generally used factor analysis or grounded theory methods to derive themes from statements collected from caregivers. It appears that Concept Mapping has never been used to derive underlying themes from a list of perceptions about giving care to a spouse suffering from dementia. Concept Mapping will therefore be used to answer the second research question, What themes or clusters emerge from these perception statements?

Researchers have also published incidence rates. These reports were created by asking caregivers to rate how much these perceptions applied to their lives. It appears that there is only one study that has published incidence rates based on a sample of spouses caring for a partner with dementia. A large group of exclusively spouse caregivers will therefore be asked to rate a list of statements generated in response to the first research question. Results from these ratings will address the third research question, What is the incidence of these perception statements in a sample of spouse caregivers?

A review of the literature also revealed that there are no published comparisons between peoples' ratings of their perceptions about caregiving and their obtained scores on a burden inventory. The lack of such comparisons will be addressed by the fourth research question, How do caregivers' ratings of perception statements, compare with their scores on the Caregiver Burden Inventory?

The method that was used to answer these four research questions will be described in Chapter Three.

Chapter 3: Method

Introduction

A review of the literature revealed a need for describing the perceptions of spouses who are caring for someone with dementia using an integration of qualitative and quantitative methods. In order to describe caregiver perceptions using such an integrated manner, this study proceeded in four phases.

Phase One involved answering the first research question, How do spouses perceive the effects of caring for a partner with dementia? Spouses who lived with someone suffering from dementia were asked to write short phrases or sentences which described their caregiving experiences. Their perception statements were then recorded and analysed.

Phase Two involved answering the second research question, What themes or clusters emerge from these perception statements? Statements from phase one were sorted into themes and these themes were illustrated by a Concept Map (Trochim, 1989).

Phase Three answered the third research question, What is the incidence of these perception statements in a sample of spouse caregivers? A survey of caregivers revealed to what extent the perceptions listed in phase one were rated as significant in the lives of a group of caregivers.

Phase Four answered the research question, How do caregivers' ratings of perception statements, compare with their scores on the Caregiver Burden Inventory? The caregivers described in phase three were asked to complete a Caregiver Burden Inventory (CBI). Scores on this burden inventory were compared with the ratings that these participants gave in phase three.

Ethical approval to conduct this research was obtained from the Department of Educational Psychology Research and Ethics Committee, the Capital Health Authority - Home Care Director, the Research Ethics Committee - Glenrose Rehabilitation Hospital Site, and the Board of the Alzheimer Society - Edmonton. A letter of endorsement from the Alberta College of Physicians and

Surgeons was also obtained.

Phase One: Generating Statements

Spouses of people who suffer from dementia were interviewed and their statements were collected and recorded. This answered the first research question: how do spouses perceive the effects of caring for a partner with dementia? The following is a description of how those statements were generated.

Questionnaires and Forms

Consent forms (Appendix A) were signed by each participant. These forms contained information about the purpose, procedures, benefits, and risks of this research. They also contained phone numbers of the research supervisor and of an independent office from the researcher where participants could direct enquiries, concerns, or complaints. Similar consent forms were used for each phase of this research.

On a questionnaire (Appendix B), participants were asked to supply relevant personal information. They were asked about their age, sex, education, language spoken at home, how long the person for whom they were caring had memory problems, years married, employment status, career before retirement, and services received to assist in caring for their partner. Similar questionnaires were administered to participants in each of the subsequent phases.

Participants were asked to write out short phrases or sentences in response to the stem, Please list the effects that caring for someone with memory problems has had on you (Appendix C).

Sample

Participants were recruited from a number of sources. Capital Health Authority Homecare nurses, Northern Alberta Regional Geriatric Program staff, Neuropsychology Unit staff, and local physicians gave prospective participants a letter of introduction (Appendix D). Some of these prospective participants gave permission for the referring agency or health care professional to forward their names and phone numbers to the researcher. This letter of introduction mentioned above was also published in an Alzheimer Society - Edmonton, newsletter and interested participants contacted the researcher directly.

Participants identified themselves as spouses who shared a non-institutional residence with a partner who suffered from dementia. There were a total of 22 participants in this phase of the study. Of these 22 participants, 15 (68%) were female and 7 (32 %) were male. Participants' ages ranged from 57 years to 81 years (mean for females = 68.5; mean for males = 72.7). The total years of education ranged from 4 to 18 years with the majority (75%) of participants having obtained 12 years of education. All participants reported that they were married and that they ranged from 8 years to 60 years of living together with their marriage partner. Over half of the participants (51%) had been married for 45 years or more. The reported duration of memory problems in the spouse who was diagnosed with dementia ranged from 12 months to 156 months (mean = 54.5). Almost half (45.5%) of the caregivers did not utilize any services to assist them in caring for their partner. A summary of demographic variables for this sample can be found in Table 3-1.

Procedure

The procedure for generating statements with a group of participants was described in Trochim(1989a). This procedure was adapted in order to gather data from one participant at a time.

Prospective participants were invited to take part in a personal interview. At the beginning of the interview, details about the purpose and procedures of this study were explained to the participant and any questions were answered.

Table 3-1
Demographic Summary Of Participants Who Generated Statements

Variable	Mean	S.D.	Category	n	% of sample *
Sex	N/A	N/A	Male	07	32
			Female	15	68
Age	69.8	8.01	55-59	03	14
			60-64	04	18
			65-69	03	14
			70-74	04	18
			75-79	05	23
			80-84	03	14
Years of Education	12.4	3.57	< 10	03	14
			10-12	05	23
			grade school + 1-2 yrs.	06	27
			grade 12 + 3 or more yrs.	06	27
			missing values	02	09
Paid Employment	N/A	N/A	full - time	00	00
			part - time	02	09
			none	20	91
Retired	N/A	N/A	yes	21	96
			no	01	05
Career (current or before retirement)	N/A	N/A	clerical	03	14
			managerial	02	09
			medical	04	18
			primary	01	05
			science	01	05
			service	03	14
			teaching	02	09
			other	04	18
			missing values	02	09
Marital Status	N/A	N/A	married	22	100
			common law	00	00
Years of Living Together	42.3	11.94	01 - 10	01	05
			20 - 39	05	23
			40 - 44	04	18
			45 - 49	06	27
			50 - 54	03	14
			55 - 59	01	05
			60 - 64	01	05
Months of Memory Problems	54.5	42.66	< 13	03	14
			13 - 24	06	27
			25 - 36	01	05
			> 36	12	55
Services Received to Help With Caregiving	N/A	N/A	day program	02	09
			homecare	05	23
			home care & others	05	23
			none	10	46
Referral source	N/A	N/A	Alzheimer Society Edmonton	01	05
			Home Care	11	50
			Neuropsychology Unit	09	41
			Physicians	01	05

* Figures rounded to the nearest whole percent

Issues concerning confidentiality were also addressed. Participants were asked to complete a consent form. Participants were also assured that they could withdraw from the study at any time without affecting any services provided by the various programs or physicians. They were then administered a questionnaire on which they were asked for relevant personal information. Participants were asked to respond to the following prompt in either short phrases or sentences, Please list the effects that caring for someone with memory problems has had on you. They were given the option of writing down their own responses or having the researcher record their responses. When participants asked for direction they were given open ended encouragement such as, are there any more ways that caring for this person has affected your life? The purpose of these prompts was not to influence any responses with preconceived notions, but to access the perspective of the person being interviewed (Glasser, 1992).

Editing Statements for Essential Meaning

Statements obtained from participants were copied to a master list. The researcher checked statements as they were added to the list, to determine whether they offered any new information not previously recorded.

Glaser (1978) introduced the name “saturation point” (p. 53) to label a point where no new information emerges from the data or when the same information continually emerges. When such a point has been reached, the domain being studied is considered to be adequately identified. Glaser and Strauss (1967, p.111) suggested that at this point a researcher should not continue to mark any of the data as it adds nothing to the emerging theory. Trochim (1989a) noted that “redundant statements” (p.5) need not be included in the final set of statements to be used in the Concept Map (see also Daughtry & Kunkel, 1993, p.318). The domain of caregiver perceptions in this study was considered complete or statements were considered redundant when no new substantive information was identified after three consecutive interviews.

As each statement was added to the master list it was marked with an "N" if it contained new information. It was marked with "N/A" if it did not answer the stimulus question. For example the statement, "Memory problems" was not clearly linked to an effect on the caregiver. This statement was then marked "N/A" and subsequently deleted from the master list. Some statements such as, "Eating for her in the morning is easy..." pertained to behaviours of the carereceiver and did not pertain to effects on the caregiver. These statements were also deleted from the master list. If a statement repeated information already gained from a previous statement, the number of this previous statement was recorded next to the newly added statement. Personal names and any identifying information were edited out of these statements. This process was continued until no new information was gathered from three consecutive participants. This point of redundancy was reached after data had been collected from 22 people. Collection of statements was therefore discontinued after 22 participants had generated 308 statements (Appendix E).

The resulting 308 statements were edited so that they contained only one idea. For example, the statement, "I have to make decisions on an hourly basis - at the end of the day I am really mentally exhausted" became two statements, "I have to make decisions on an hourly basis," and "at the end of the day I am really mentally exhausted." This process of editing expanded the master list into 362 unique statements.

The essential meaning (Trochim, 1989a, p.5; see also Daughtry & Kunkel, 1993, p.318) from statements on this master list was then extracted. This extraction included rewording statements for clarity and brevity. For example, a statement such as "at the end of the day I am really mentally exhausted" was further edited to become "I am exhausted." A statement such as, "I have to be careful how I express decisions I make for him because it provokes anger in him," was edited to become, "I have to be careful how I express decisions."

Statements that seemed similar with one another were placed together for the purposes of comparison. Once again, statements were marked with an "N" if they contained unique information or they were marked with a number of a statement with which they seemed redundant (Appendix F). When any judgements were made about the editing of statements by the primary researcher, they were checked by two others with many years of experience in Concept Mapping. These two others helped ensure that the essential meaning of the statements remained intact. It was discovered that once the statements had been *edited for essential meaning* this confirmed that no new essential information had been added to the list by the last three participants.

These latter statements were then edited for consistency of tense with a procedure used by Daughtry and Kunkel (1993). They determined that "equating the level of abstraction and providing parallel grammatical structure for each item" (p. 318), enhanced subsequent interpretation of the Concept Map. The statements were also edited in order to reflect inclusive language. Redundant statements were then eliminated by using only one number and one phrase to represent that group of statements (Trochim, 1989). A statement was designated as representative of the others if it subsumed the content of other similar statements. For example, He would start blaming me; He will argue about things; We disagree about things; and We argue were all subsumed by the statement We argue. Statements with phrases or verbs that occurred most often within a particular group were used to represent that group. For example, I focus on something positive; was used to represent the group of statements that included, Try to keep positive things in mind; Focus on things for which I am thankful; and Focus on something that is positive.

A list of 86 statements remained after this editing process. (Appendix G) Within this list of 86 statements, it was observed that some had essentially the same meaning even though they were expressed in a slightly different manner. For example, Not caring for my spouse leaves me feeling bad; had essentially the same meaning as, Caring for my spouse helps me feel good. Ten more statements were judged to be redundant using these criteria and they were dropped from the master list.

After this editing process there were 76 statements left on the master list. Trochim (1989) noted that there are serious practical reasons for constraining the number of statements to be used in the next steps. This number of 76 statements, however, seemed acceptable as it was well within the limit of 100 statements suggested by Trochim. This final list of 76 statements were also judged as meeting the criteria for reaching the point of redundancy.

Phase Two: Deriving Themes

The purpose of phase two was to answer the second research question, What themes or clusters emerge from these perception statements? After the 76 statements had been compiled in the manner described above, they were sorted into distinct themes. Three distinct steps led to the emergence of themes from these statements.

Pile Sort

The first step to derive themes from the 76 perception statements was called a Pile Sort. The following materials and procedure were used to conduct this Pile Sort.

Pile sort package.

Participants were given an envelope that contained a complete set of 76 perception statements. Each statement was placed on an individual slip of paper. The envelope also contained instructions for sorting the individual slips of paper into themes (Appendix H). Participants received these packages through personal contact at the referring agency or through the mail. The instructions asked participants to return these packages to the researcher through the mail.

Sample.

Twenty-seven caregivers of people suffering from dementia were recruited for this second part of the study. Volunteer participants were recruited from the same agencies listed in phase one. Eight of these participants did not adhere to the sorting instructions and their sorts were not used. A total of nineteen participants followed the instructions correctly. Of these nineteen participants 12 (63%) were female and 7 (37%) were male. Their ages ranged from 40 years to 85 years with a mean age of 56.6 (standard deviation; S.D.= 13.49). Their total years of education ranged from 10 years to 23 years. The mean of years of education for all participants was 14.9 years (S.D. = 3.31).

These sorters included 7 (37%) daughters; 6 (32%) wives; 3 (6%) husbands; and 2 (11%) sons of someone who had dementia. One person (5%) did not report their relationship with the care receiver. These people reported caring for the person with dementia from 5 to 72 months. The mean number of months of care reported by these caregivers was 30.0 months (S.D. = 23.64). A summary of the demographic variables for the people who sorted the statements is available in Table 3-2.

Procedure.

Each of the 76 perception statements was typed onto a slip of paper. Participants were asked to sort the slips of paper into piles in a way that made sense to the sorter (Trochim, 1994). Two restrictions applied: a) there could not be as many piles as there were statements, b) there could not be one pile of all statements. Participants were also asked to put a label on each pile which described the statements in a particular pile. The instructions reminded them not to sort the statements according to their importance for the sorter. Participants then returned their sorts by mail to the researcher. The researcher

Table 3-2
Demographic Summary For Participants Who Sorted Statements

Variable	Mean	S.D.	Category	n	% of sample *
Sex	N/A	N/A	Male	07	37
			Female	12	63
Age	56.6	14.02	35 - 44	04	21
			45 - 49	02	11
			50 - 54	03	16
			55 - 59	03	16
			60 - 64	03	16
			65 - 69	01	05
			75 - 79	01	05
			80 - 84	01	05
			85 - 89	01	05
Years of Education	14.9	3.31	10-12	03	16
			grade school + 1-2 yrs.	05	26
			grade 12 + 3 or more yrs.	11	58
Paid Employment	N/A	N/A	full - time	08	42
			part - time	01	05
			none	10	53
Retired	N/A	N/A	yes	08	42
			no	11	58
Career (current or before retirement)	N/A	N/A	clerical	01	05
			construction	02	11
			managerial	01	05
			medical	04	21
			sales	01	05
			science	01	05
			service	05	26
			other	04	21
Relationship to Care receiver	N/A	N/A	daughter	07	37
			son	02	11
			wife	06	32
			husband	03	16
			missing values	01	05
Months of Providing Care	30.0	23.64	< 13	06	32
			13 - 24	05	26
			25 - 36	01	05
			> 36	07	37
Months of Memory Problems	36.6	28.75	< 13	03	14
			13 - 24	06	27
			25 - 36	01	05
			> 36	12	55
Services Received to Help With Caregiving	N/A	N/A	day program	01	05
			homecare	01	05
			home care & others	01	05
			respite	01	05
			yard/house work	01	05
			none	13	68
			missing value	01	05
Referral source	N/A	N/A	Dementia Information Sessions	06	32
			Drug Study	07	37
			Neuropsychology Unit	01	05
			Outpatient Clinics	04	21
			Physicians	01	05

* Figures rounded to the nearest whole percent

then entered the data into The Concept System version 1.0 software (Trochim, 1989c).

Eight sorts were not used as participants had clearly contravened the sorting instructions. For example, some participants labelled their piles, "true," "false," "not applicable." These sorts were excluded because of the difficulties that can arise when including data from participants who create "larger more generic categories" (Weller & Romney, 1988, p. 22). As Trochim (1994) noted, "with a small overall sample size, the inclusion of sort data from extreme lumpers could easily lessen the interpretability of the maps" (p. 768).

Analysis: The Concept Map

The second step in deriving themes was to analyse the Pile Sort data using the Concept System software. This system uses matrix algebra to combine results of pile sorts across participants. The Concept System can then be utilized to indicate how many people placed a pair of statements together in a pile. The Concept System then uses multidimensional scaling to produce a point map where each point represents one of the statements. Each point on the map has an X-Y coordinate and the distance between points reflects the frequency with which items are sorted together. Statements which appear closer on the point map are items which were more frequently piled together. Statements more distant from each other were less frequently piled together. The 76 statements listed in phase one were entered into the Concept System according to how they were sorted by these 19 participants.

The Concept System can be used to draw boundaries around groups of statements which are likely to be conceptually similar. These groups of statements are called clusters. The Concept System uses an hierarchical cluster analysis to group items into internally consistent clusters (Borgen & Barnett, 1987). The minimum stability measure for Multidimensional Scaling stress score was set at 0.30 or less in order to accept the sorts. Trochim

(1989a) has judged 0.30 as being relatively stable.

Researcher discretion was used to decide on how many clusters would "make sense for the statements in the conceptualization" (Trochim, 1989, p. 8). Guided by the bridging values, and by boundaries which seemed to maintain internally consistent themes, the researcher chose the number of clusters that best offered conceptual clarity to the data at hand. The researcher also consulted with two others who have had many years experience with Concept Mapping during the process of choosing an appropriate number of clusters.

A statistical basis for judging the most appropriate number of clusters was provided by bridging values. The bridging value gave a numerical value between 1 and 0 to indicate if a statement was sorted often with other statements that were close to it on a multidimensional scaling point map. A value of 0 indicated it had been sorted often with statements that were close to it on the map. An average bridging index for each cluster also helped indicate whether a group of statements had been sorted together often. In other words, this average index gave a sense of the cohesiveness of the statements. This index helped to modify the "arbitrariness of decisions" which are inherent in some models of analysis (Glaser, 1978, p. 122).

Analysis: Concept Map Interpretation

The final step in creating a Concept Map was to produce labels for each of the clusters of perception statements.

Five caregivers from an Alzheimer Society support group assisted in this phase of the study. These caregivers ranged from 30 to 75 years of age. These participants included three wives and two daughters of someone who had been diagnosed with dementia. Their experiences of caring at home for their care receiver ranged from 8 months to 60 months.

Trochim, Cook, and Setze (1994) have outlined a process by which a group of people can interpret results of the Concept Mapping analysis. A portion of this process was utilized in order to label the clusters of statements.

Each participant was given a list of the 76 perception statements as they had been grouped into their respective clusters. Participants were asked to generate a short phrase or word to describe or label each cluster of statements. These labels were then recorded onto a list.

The researcher had also assigned a label to each cluster that seemed to reflect the nature of the statements in each cluster. These labels were then added to the list of labels that had been generated by the support group. The researcher then asked the participants to choose only one label for each cluster from the list of labels that had been generated. These labels were then used to name each cluster.

Phase Three: Rating Statements

The list of statements generated from phase one were incorporated into a survey. Responses to this survey answered the third research question, What is the incidence of these perceptions in a sample of spouse caregivers? The following is a detailed description of how this survey was administered and analyzed.

Questionnaire

The list of statements used for the Pile Sort in phase one was transformed into a questionnaire (Appendix I). Each item on this questionnaire consisted of one statement from the list linked to a five-point Likert type scale. This rating system ranged from "not at all" to "very much." Participants were asked, Please think about these effects on a person caring for a spouse, numbered 01 through 76. Decide if these statements apply to you. Please circle the letters below to show how much each statement applies to you."

Sample

The questionnaire was given to 90 volunteer participants. These participants were recruited using the same sources as those already mentioned in phase two. They were asked to return the questionnaire by mail or to the referring agency.

Of the 90 questionnaires distributed 71 were returned to the researcher. Of these questionnaires, 3 were not used because participants had incorrectly completed the questionnaires.

Of the remaining 68 participants, 40 (59%) were female and 28 (41%) were male. Their ages ranged from 50 years to 89 years with a mean age of 72.6 (S.D. = 7.94). Their total years of education ranged from 4 years to 21 years. The mean number of years of education for all participants was 12.3 years (S.D. = 3.13). Sixty-one of these spouse caregivers had lived with their partners from 5 years to 60 years (7 caregivers gave no response). Their mean number of years of residence with their partner was 45.2 years (S.D. = 11.87). Sixty-seven caregivers noted problems with their partners' memory on a range from 4 months to 168 months with a mean of 43.2 months (S.D. = 32.43). One participant did not respond to the question about duration of memory problems. Thirty-five of these participants (52%) did not receive any services to help care for their partners at home. A summary of the demographic variables for the people who responded to the survey is available in Table 3-3.

Procedure

Participants contacted through the Glenrose Rehabilitation Outpatient Clinics and the Alzheimer Drug Trials gave permission for hospital staff to introduce the researcher and participants. In a brief interview, the researcher reviewed the consent form with the participants and answered any questions about the purpose of the project and about confidentiality. The participants were given a questionnaire package to complete. They were invited to take the

Table 3-3
Demographic Summary Of Participants Who Rated 76 Statements and the CBI

Variable	Mean	S.D.	Category	n	% of sample *
Sex	N/A	N/A	Male	28	41
			Female	40	59
Age	72.6	7.94	50 - 54	01	02
			55 - 59	04	06
			60 - 64	05	07
			65 - 69	11	16
			70 - 74	16	24
			75 - 79	17	25
			80 - 84	11	16
			85 - 89	03	04
Years of Education	15.0	3.31	< 10	11	16
			10-12	20	29
			grade school + 1-2 yrs.	23	34
			grade 12 + 3 or more yrs.	14	27
			missing values	02	21
Paid Employment	N/A	N/A	full - time	01	02
			part - time	03	04
			none	64	94
Retired	N/A	N/A	yes	65	96
			no	03	04
Career (current or before retirement)	N/A	N/A	clerical	06	09
			construction	04	06
			managerial	05	07
			medical	06	09
			primary	02	03
			sales	06	08
			service	10	15
			teaching	05	07
			transportation	02	03
			other	22	32
Marital Status	N/A	N/A	married	68	100
			common law	00	00
Years of Living Together	45.2	11.87	01 - 19	03	04
			20 - 39	10	15
			40 - 44	04	06
			45 - 49	18	27
			50 - 54	14	21
			55 - 59	09	13
			60 - 64	02	03
Months of Memory Problems	43.2	32.43	< 13	11	16
			13 - 24	15	22
			25 - 36	12	18
			> 36	29	43
			missing value	01	02

* Figures rounded to the nearest whole percent

package home where they completed the consent form and the enclosed questionnaires. This package included return postage by which the participants could return these packages to the researcher. These participants were assured that they could decide at any time to quit participation in the study. Participants contacted through the other agencies gave permission for their names and phone numbers to be released to the researcher. The researcher reviewed the consent form with the prospective participants in a brief telephone interview. Prospective participants were then sent a questionnaire package through the mail. They were invited to complete the enclosed consent form and questionnaires. Participants then returned their packages to the researcher through the mail in pre-stamped envelopes.

Survey Analysis

A frequency distribution for responses to each statement in the questionnaire was constructed. Scores on each statement were summed within each cluster to produce a Cluster Score and then summed across all clusters to obtain a Total Cluster Score. Descriptive statistics including means, and standard deviations were also obtained for each perception statement, for the Cluster Scores, and for Total Cluster Scores.

The percentage of the population who endorsed statements with "moderately," "quite a bit," and "very much", were calculated for each statement. The percentage of the population who endorsed statements with "not at all," and "slightly," were also calculated.

Phase Four: Comparing Statement Ratings With Burden Inventory Scores

The survey described in phase three included a third questionnaire made up of a Caregiver Burden Inventory (Novak & Guest, 1989). Responses to the Caregiver Burden Inventory (CBI) and part two of this survey were used to answer the fourth research question, How do caregivers' ratings of perception statements about the effects of caring for their spouse, compare with their scores on the Caregiver Burden Inventory? The following is a description of how this comparison was conducted.

Questionnaire, Sample, and Procedure

The Caregiver Burden Inventory consists of 24 items about the experiences of caregiving. Respondents are asked to think about these experiences in the past month and to rate how well each statement describes their experience. Participants in this study were asked to rate their responses using a 5-point Likert-type scale which ranged from "Not at all descriptive" to "Very descriptive." This burden inventory "measures the impact of burden on caregivers" (Novak & Guest, 1989, p. 978). It has five subscale scores which are added together to yield a Total Burden score.

The same sample population that was described in phase three completed this questionnaire. The same procedures were used to collect this data as were outlined in phase three.

Analysis

The median value of the total score on the Caregiver Burden Inventory was used to divide the sample population into two groups. Total burden scores from the Caregiver Burden Inventory that were above this median value were designated as High scores. In a similar fashion, total burden scores from the Caregiver Burden Inventory that were below the median value were designated as Low scores. These High and Low scores were compared with the scores obtained on each of the seven Cluster Scores and the Total Cluster Scores by using an Hotellings T^2 test. A Pearson product-moment correlation analysis between the perception statements data and the burden data was also conducted.

Further Analyses

A multiple analysis of variance was conducted to determine if people differed in their Cluster Scores, according to sex, age group, education group, months of memory problems, length of residence with care receiver, and whether or not they used services to help care for the care receiver.

The High and Low scores from the CBI were also compared according to sex using a T-test.

Summary

Concept mapping was used in this study as an alternative approach which combined qualitative and quantitative research strategies. This approach also allowed for examination of caregiver perceptions from their perspective. It was hoped that conceptual clarity about spouses' perspectives on caring for someone with dementia would be gained by following the method described in this section. Ratings of these perceptions and concepts by a sample of caregivers were compared with their ratings on a Caregiver Burden Inventory. Results obtained from the analyses of data collected according to this method along with a discussion of these results are presented in the next chapter.

Chapter 4: Results and Discussion

The purpose of this study was to describe caregivers' perceptions of caring for a spouse who suffers from dementia. The four phases of this research project answered four separate research questions. The results of this research and a discussion of how they integrated with results from previous studies are presented in this chapter.

Phase One: Statements Generated

How do spouses perceive the effects of caring for a partner with dementia? was the first research question answered in phase one of this study. In order to answer this question, participants generated short phrases or sentences in response to the request; Please list the effects that caring for someone with memory problems has had on you. The results obtained from phase one are described in this section.

After collecting statements from the 22nd participant, it was observed that a saturation point had been reached. No new information had been added to the master list of statements from three consecutive participants. A total of 308 statements were collected from these 22 participants (Appendix E).

These statements represented a variety of feelings, thoughts, and behaviours as they related to the experiences of these caregivers. Some statements were very curt descriptions. Others were narrative statements which included many details about the caregivers' perceptions. Most of the statements were prefaced with the word "I" and then described some thought, feeling, or behaviour of the caregiver. Some of the statements, by way of contrast, tended to focus on the behaviours of the spouse with memory problems. As a consequence, the effect on the caregiver was implied rather than directly stated in some of the statements that were used for analysis. Some of the statements which illustrated this type of response include; My husband is slow at walking; The minute I am not around, he comes looking for me; He will argue about his blood sugar levels. Some of the participants reported their perceptions in the third person. For example some participants stated, You learn to plan ahead...; You are always wondering...; Gives a greater sense of being needed.

After the original 308 statements had been edited for essential meaning (Appendix F), and then compared for redundancy, this original list was reduced to 86 statements (Appendix G). Ten statements were further eliminated because they were well represented by other statements. This entire editing process yielded a final list of 76 statements (Table 4-1) about the perceptions of caregivers (hereafter labelled "perception statements").

Phase Two: Concept Map

The second research question asked; What themes or clusters emerge from these perceptions? Concept Mapping was used to derive the themes from the 76 statements that were collected in phase one. Results obtained through this Concept Mapping process are presented in this section.

Multidimensional Scaling

The Concept System software (Trochim, 1987c) was used to derive themes from sort data that had been collected from 19 participants. This Concept System first yielded a multidimensional scaling point map (Appendix K). This map used dots to represent each of the 76 statements that were sorted. Dots that appeared closer together represented statements that had been sorted more often in the same pile. This particular map resulted in a final stress value of 0.28 (0 = perfectly stable, 1 = perfectly unstable).

Fitzgerald and Hubert (1987) noted that solutions with stress values above 0.15 "might be considered problematic but even this weak guideline is open to challenge in the presence of a substantively interpretable representation" (p. 474). They noted that rules for appropriate stress values are difficult to establish as there are no step by step processes that yield optimal

Table 4-1
Final List of 76 Perception Statements

"Please list the effects that caring for someone with memory problems has had on you."

01 We are clearing out some possessions.
02 I focus on something positive.
03 We argue.
04 I help my spouse with things she or he cannot do alone.
05 Our family shows affection more often.
06 I take one day at a time.
07 I have to be patient.
08 We do not see our family members as often.
09 I have to buy special supplies.
10 I feel like I was stabbed.
11 My spouse is easier to get along with.
12 I have taken over things that my spouse used to do.
13 I have to take my spouse for medical help.
14 I am responsible for our personal affairs.
15 People do not believe me when I tell them of my spouse's memory problems.
16 I feel relaxed when my spouse is not around.
17 I am bothered by my spouse's mental confusion.
18 I tell people about my spouse's memory problems.
19 I have to stay alert.
20 I check up on my spouse.
21 We sleep separately.
22 I get angry at my spouse's actions.
23 I feel hopeless.
24 I have difficulty understanding changes in my spouse's personality.
25 I take special safety precautions.
26 I control what is said to my spouse.
27 I plan my spouse's activities.
28 I worry about my spouse.
29 I do things now that I have never done before.
30 I remind my spouse over and over.
31 I do some things that I like to do.
32 It is hard to get out on my own.
33 I get frustrated when my spouse cannot do what he or she used to do.
34 I don't know how my spouse will behave.
35 I never know where I will find things.
36 People will tell me about their problems caring for someone with memory problems.
37 I worry about our future.
38 I try not to take things personally.
39 I have less time to spend with others.
40 I get tired.
41 Our family disagrees about how to treat my spouse.
42 Caring for my spouse is like a horror.
43 I cannot leave my spouse alone.
44 We still get together with friends.
45 I do not sleep well.
46 The whole load of caring for my spouse falls on me.
47 I feel embarrassed by my spouse's actions.
48 My religious practice helps.
49 I feel sad.
50 I have trouble going anywhere with my spouse.
51 I am concerned about my spouse getting lost.
52 Caring for my spouse helps me feel good.
53 I have a hard time getting work done.
54 I feel helpless.
55 We are planning to move.
56 I am learning to cope with my spouse.
57 I question myself.
58 I have others to help me care for my spouse.
59 When my spouse gets something fixed in mind, it is frustrating.
60 I walk away from my spouse's anger.
61 I try not to show that I am upset.
62 Caring for my spouse is stressful for me.
63 I get like a robot.
64 I try to get us laughing.
65 My health suffers.
66 I find it hard to communicate with my spouse.
67 I cannot satisfy my spouse.
68 I feel sneaky.
69 I have to be more flexible.
70 I get upset.
71 I look for things that get misplaced.
72 Everyday life is like caring for a child.
73 I am responsible for my spouse's personal care.
74 I get strained by answering questions over and over.
75 I decided that I need a life of my own.
76 I am amazed at my strength.

solutions. They concluded that both a relatively stable stress value and the embedding of a reasonable cluster solution into the scaling map offer criteria for a "goodness of fit" (p. 474).

Daughtry and Kunkel (1993, p. 319) reported that 0.27 represented a reasonably stable solution. Trochim, Cook, and Setze (1994) conducted statistical tests on a multidimensional scaling map with a final stress value of 0.31. They reported that details within this map were "highly and significantly correlated" (p. 772). It was concluded, therefore, that the multidimensional scaling map from this study with a stress value of 0.28 provided an acceptably stable solution.

In the next section, it will be revealed that a cluster solution could be found that did not appear "worm-like" (Fitzgerald & Hubert, 1993, p. 474) in order to connect very distant points into a cluster of items. The clusters embedded in the two dimensional scaling map from this study were also conceptually clear and without any gross anomalies.

For these reasons, the researcher decided that the two dimensional solution as depicted in Appendix K was an acceptable model of the data. A more stable stress value and better fit between the model solution and the actual data would likely be obtained by a three dimensional model. Using higher dimensions or the actual distances of the MDS solution would however, make it difficult to present the results in two dimensional clusters. The desire to present the results in an easily interpretable manner that makes intuitive sense further supported the use of this two dimensional solution (Trochim, 1989a).

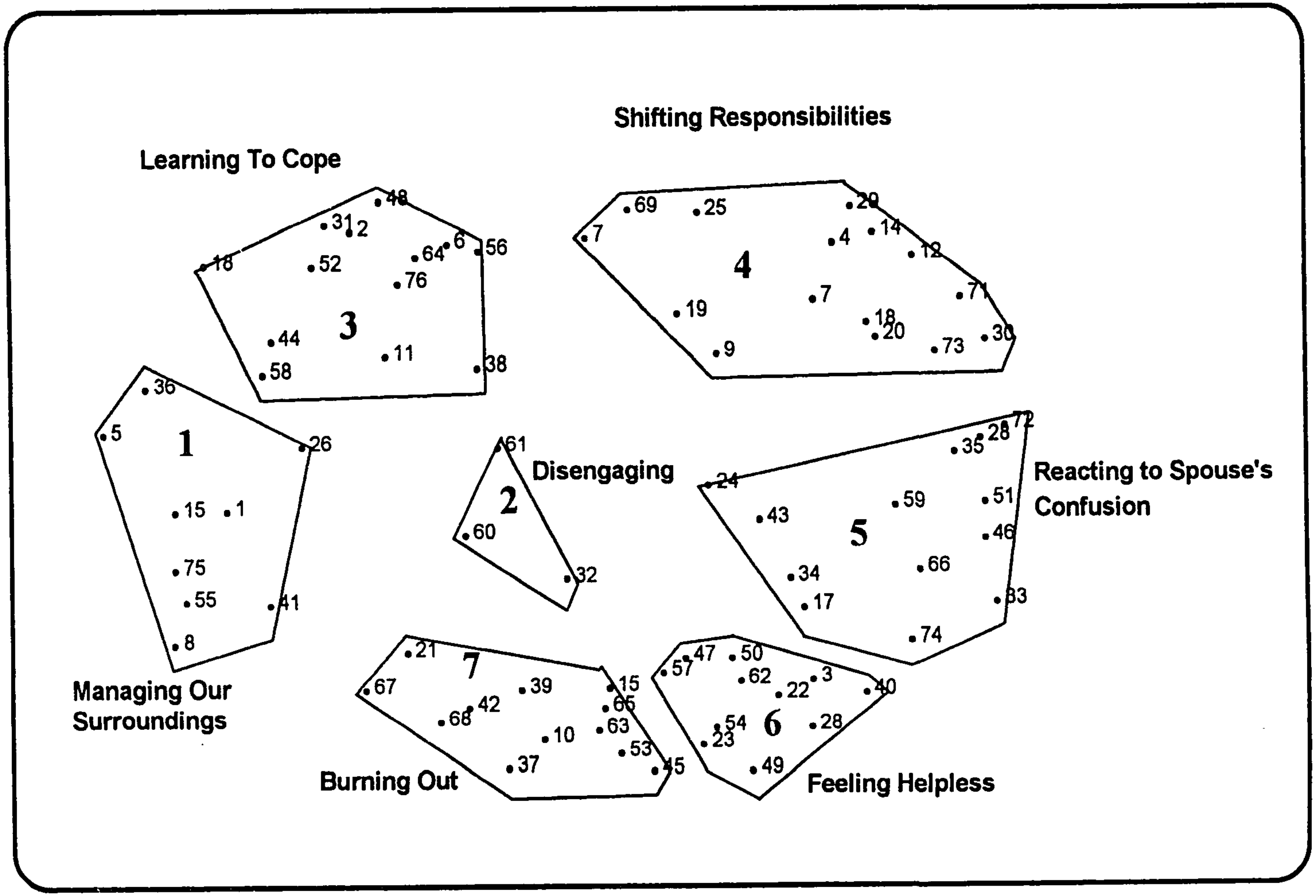
Cluster Solutions

The Concept System software was then used to generate cluster solutions for the multidimensional scaling map. These cluster solutions collected points on the map into groups or clusters. Clusters were examined and compared in the following order. The researcher started by examining a solution with nine clusters. Then the process of examination and comparison proceeded using five clusters, then eight clusters, then six clusters then seven clusters. The six, seven, and eight cluster solutions, along with bridging values for the statements and the clusters appear in Appendices L, M, and N. These comparisons revealed that a nine cluster solution separated some statements which had very similar content into separate clusters. The researcher judged that a nine cluster solution produced clusters which were too narrow in scope. An examination of the five cluster solution was then conducted. In this cluster solution there appeared to be too many statements grouped into Cluster #5. Some of these statements according to their content and bridging values, appeared to form subsets or separate groupings. By this process of elimination, cluster solutions with six (Appendix L), seven (Appendix N), and eight (Appendix M) clusters appeared to be the most conceptually clear, without being too narrow in their scope.

The seven cluster solution (Figure 4-1) was chosen as the final cluster solution. This cluster solution seemed to offer the most conceptual clarity when reviewed by the researcher and two others who had considerable experience with Concept Mapping. For example, the seven cluster solution created a separate cluster which included the statements, It is hard to get out on my own; I walk away from my spouse's anger; and I try not to show that I am upset. These statements seemed to reflect different content from other statements with which they were grouped in the six cluster solution. In the six cluster solution the bridging values of these statements identified them as a possible subset of that particular cluster.

Comparison of the eight and seven cluster solutions revealed that within the eight cluster solution some statements which were similar in content were placed into separate clusters. For example, I have to buy special supplies, seemed to relate closely with a statement from another cluster, I look after things that I have never done before. In the seven cluster solution, items such as these

Figure 4-1
Concept Map With Seven Clusters of Spouse's Perception Statements



were placed into the same cluster. The researcher therefore, judged the seven cluster solution to be more appropriate than the other solutions.

Themes Derived

The statements in each cluster were rank ordered according to their bridging index numbers. These index numbers indicated how likely it was, that a statement was sorted primarily with other statements that were close to it on the multidimensional scaling map. The statements with the lowest bridging values, and therefore sorted primarily with other statements close by, were used as a guide to label the theme for each cluster. In Table 4-2 each statement is listed in rank order within its cluster. Those statements sorted primarily with others close by, appear at the beginning of each list. Those statements sorted primarily with others that were farther away, appear toward the bottom of each list. The actual bridging values and their corresponding statements can be found in Appendix N.

Once a list of seven names was chosen by the researcher (Appendix O), these names were reviewed by two other researchers who had many years of experience with the concept mapping process. These seven labels were judged to be consistent with the data.

Theme Validation and Interpretation

These seven labels were then used in a discussion at an Alzheimer Society Edmonton, support group meeting. The group helped to brainstorm other possible labels for the seven clusters (Appendix O). These support group members then chose the final seven labels for each cluster (Figure 4-1). The 76 perception statements, as they were grouped into clusters, and listed with their respective cluster labels are contained in Table 4-2.

The cluster themes as chosen by the support group participants and the

Table 4-2
Seven Clusters of Perception Statements With Mean Ratings, Standard Deviations, and Frequency Distributions

Decide if these statements apply to you...Not at all ...Slightly ...Moderately ...Quite a Bit ... Very Much

			Frequency Distribution (nearest whole percent)					
Cluster Names and Statements	Mean	S.D.	1	2	3	4	5	n
Cluster 1: Managing Our Surroundings								
41. Our family disagrees about how to treat my spouse.	1.40	0.85	76	13	06	03	02	67
26. I control what is said to my spouse.	2.62	1.43	30	23	15	18	14	66
01. We are clearing out some possessions.	2.06	1.23	46	24	16	09	06	68
36. People tell me about their problems caring for someone with memory problems.	2.36	1.28	33	27	19	13	08	67
55. We are planning to move.	1.34	0.91	85	07	03	02	03	68
05. Our family shows affection more often.	3.23	1.31	14	12	32	20	22	65
08. We do not see our family members as often.	2.88	1.32	20	17	36	11	17	66
75. I decided that I need a life of my own.	1.53	1.04	72	15	06	03	04	68
15. People do not believe me when I tell them of my spouse' memory problems.	2.40	1.41	41	15	24	09	12	68
Cluster Mean and S.D.	2.20	0.54						
Cluster 2: Disengaging								
32. It is hard to get out on my own.	3.16	1.49	21	13	24	15	28	68
60. I walk away from my spouse's anger.	2.81	1.52	28	18	21	10	22	67
61. I try not to show that I am upset.	3.21	1.20	09	19	32	22	18	68
Cluster Mean and S.D.	3.05	0.12						
Cluster 3: Learning to Cope								
64. I try to get us laughing.	3.37	1.15	08	13	31	30	18	67
02. I focus on something positive.	3.74	1.30	11	08	13	33	34	66
48. My religious practice helps.	3.42	1.72	27	08	05	17	44	66
56. I am learning to cope with my spouse.	3.82	1.01	02	09	25	34	30	67
06. I take one day at a time.	4.39	0.85	00	03	15	22	60	67
52. Caring for my spouse helps me feel good.	3.14	1.32	17	14	26	27	17	66
76. I am amazed at my strength.	3.15	1.44	24	04	27	25	21	68
38. I try not to take things personally.	3.30	1.38	15	12	26	21	26	66
11. my spouse is easier to get along with.	2.32	1.37	43	10	29	07	10	68
58. I have others to help me care for my spouse.	2.29	1.25	31	35	16	09	09	68
31. I do some things that I like to do.	3.26	1.07	03	25	28	31	13	68
44. We still get together with friends.	2.88	1.36	16	31	19	16	18	68
18 I tell people about my spouse's memory problems.	2.94	1.27	13	28	25	19	15	68
Cluster Mean and S.D.	3.25	0.52						
Cluster 4: Shifting Responsibilities								
04. I help my spouse with things she or he cannot do alone.	3.99	1.09	02	10	19	25	43	67
12 I have taken over things that my spouse used to do.	4.12	1.26	04	13	07	16	59	68
13. I have to take my spouse for medical help.	3.96	1.39	09	12	09	16	54	68
20. I check up on my spouse.	3.85	1.28	05	15	18	16	46	67
09. I have to buy special supplies.	1.94	1.38	57	21	06	05	12	67
14. I am responsible for our personal affairs.	4.62	0.83	02	03	04	15	77	68
27. I plan my spouse's activities.	3.28	1.53	21	13	15	21	31	68
73 I am responsible for my spouse's personal care.	2.94	1.60	27	21	12	12	28	67
19. I have to stay alert.	4.03	1.18	04	09	15	24	49	68
29 I look after things that I have never done before.	3.85	1.42	07	18	10	12	53	68

07. I have to be patient.	4.49	0.72	00	02	09	29	60	68
25. I take special safety precautions.	3.25	1.42	13	21	21	16	28	67
69. I have to be more flexible.	3.21	1.2	14	11	28	39	09	65
71. I look for things that get misplaced.	3.36	1.39	13	18	13	30	25	67
30. I remind my spouse over and over.	3.55	1.42	10	18	15	19	37	67
Cluster Mean and S.D.	3.65	0.78						
Cluster 5: Reacting to Spouse's Confusion								
34. I don't know how my spouse will behave.	2.72	1.25	21	22	31	15	10	67
17. I am bothered by my spouse's mental confusion.	2.78	1.44	09	15	12	35	29	68
43. I cannot leave my spouse alone.	2.78	1.44	27	19	22	15	18	68
24. I have difficulty understanding changes in my spouse's personality.	2.51	1.39	32	24	15	19	10	68
74. I get strained by answering questions over and over.	3.30	1.46	17	15	18	21	29	66
66. I find it hard to communicate with my spouse.	3.28	1.40	13	21	15	25	25	67
59. When my spouse gets something fixed in mind, it is frustrating.	3.44	1.46	12	21	16	15	37	68
35. I never know where I will find things.	3.21	1.46	15	24	18	15	29	68
51. I am concerned about my spouse getting lost.	3.43	1.49	13	21	10	19	36	67
33 I get frustrated when my spouse cannot do what he or she used to do.	2.88	1.26	13	31	25	16	15	68
46. The whole load of caring for my spouse falls on me.	3.71	1.52	18	06	09	24	44	68
28. I worry about my spouse.	4.06	1.14	03	10	13	25	49	68
72. Everyday life is like caring for a child.	3.34	1.54	22	08	15	24	31	67
Cluster Mean and S.D.	3.26	0.88						
Cluster 6: Feeling Helpless								
47. I feel embarrassed by my spouse's actions.	1.90	1.07	46	30	16	03	05	67
50. I have trouble going anywhere with my spouse.	2.46	1.40	35	22	15	18	10	68
23. I feel hopeless.	2.40	1.25	32	25	16	24	03	68
54. I feel helpless.	2.09	1.19	44	21	22	09	04	68
62. Caring for my spouse is stressful for me.	3.15	1.35	15	19	24	22	21	68
22. I get angry at my spouse's actions.	2.37	1.13	24	40	18	15	04	68
57. I question myself.	2.53	1.33	31	21	22	18	09	68
70. I get upset.	2.88	1.01	09	26	39	23	03	66
03. We argue.	2.32	1.10	27	34	24	13	03	68
49. I feel sad.	2.91	1.30	15	27	27	15	16	67
40. I get tired.	3.46	1.33	09	21	15	28	28	68
Cluster Mean and S.D.	2.54	0.78						
Cluster 7: Burning Out								
65. My health suffers.	2.24	1.38	44	19	16	10	10	68
63. I get like a robot.	1.97	1.31	57	13	12	12	06	67
16. I feel relaxed when my spouse is not around.	3.10	1.48	21	16	21	18	25	68
45. I do not sleep well.	2.92	1.44	23	18	23	17	20	66
10. I feel like I was stabbed.	1.88	1.32	62	12	11	08	08	65
39. I have less time to spend with others.	3.32	1.48	18	15	15	24	29	68
53. I have a hard time getting work done.	2.61	1.39	27	27	19	12	15	68
42. Caring for my spouse is like a horror.	1.47	0.85	71	16	10	02	02	68
21. We sleep separately.	2.42	1.86	62	02	02	05	31	65
67. I cannot satisfy my spouse.	2.54	1.36	31	21	21	16	10	67
68. I feel sneaky.	1.88	1.14	55	17	18	08	03	66
37 I worry about our future.	3.26	1.31	10	21	25	21	24	68
Cluster Mean and S.D.	2.46	0.83						

concept map were compared in a manner suggested by Trochim (1994). When the map was looked at on a "regional" level the researcher noted two dimensions or regional boundaries for this particular map. Moving in a direct line or axis from Cluster Six toward Cluster Three one can notice a difference in content between these regions. The clusters and statements closer to Cluster Six tended to reflect caregivers' perspectives about a lack of efficacy within their situation. For example, Cluster Six is labelled Feeling Helpless. The statements near this region included, I feel hopeless; I do not sleep well; I feel sad. From a clinical perspective these statements reflected symptoms of depression. In the other direction, statements and themes near Cluster Three more often reflected caregivers' perceptions about a sense of efficacy over their caregiving. For example, Cluster One was labelled, Managing Our Surroundings, and Cluster Three was labelled, Learning to Cope. Some statements within this region defined by these latter clusters included, I focus on something positive; People tell me about their problems caring for someone with memory problems; I control what is said to my spouse.

A shift in statement content was also noticed when moving from the region defined by Cluster Four and Cluster Five toward another imaginary pole located between Cluster One and Cluster Seven. Cluster Four and Cluster Five tend to reflect content which pertained to intramarital aspects of the spouses' relationship. These statements for example included, I remind my spouse over and over; Everyday life is like caring for a child; I worry about my spouse. On the other pole, Cluster One and Cluster Seven included material which more often pertained to extramarital aspects of the spouses' relationships. For example, Cluster One was entitled Managing our Surroundings. The statements in this region included, Our family disagrees about how to treat my spouse; I have less time to spend with others; We are planning to move.

Phase Three: Statements Rated by Sample Population

The list of statements generated from phase one were incorporated into a survey. Responses to this survey answered the third research question; What is the incidence of these perceptions in a sample of spouse caregivers? Results obtained in response to this survey are presented in this section.

Sixty-eight spouses who were caring for their partners at home, rated the 76 perception statements from phase one on a five-point Likert-type scale. They were asked to decide if each of the 76 statements applied to them "not at all," "slightly," "moderately," "quite a bit," or "very much." A Cluster Score was calculated by summing the ratings of all statements for a particular cluster of statements. From the total rating for each statement and from the Total Cluster Scores, Cluster Means and standard deviations along with means and standard deviations for each statement could be calculated. A summary of these ratings and the means are presented in Table 4-2. The statements also appear in rank order within each cluster. Those statements that were more often sorted with statements nearest to them are listed at the top of each list.

Incidence Rates According to Individual Responses

The ratings of statements were examined according to how each individual participant responded. This type of examination gave an idea of the range of responses that were collected.

The lowest number of statements that were rated with "moderately," "quite a bit," or "very much" by any one individual was 9 statements. The highest number of statements that were rated as applying "moderately," "quite a bit," or "very much" by any one individual was 72 statements. The mean number of statements that were rated with the terms "moderately," "quite a bit," or "very much" was 43.9 (S.D. = 13.92), or 58% of the total statements. The perception statements data was analyzed according to statements that were rated with the phrase, "very much". The highest number of statements rated with this latter term by any one individual was 54. Only one individual did not rate any statements in this fashion. The mean number of statements rated in this way was 17.2 (S.D. = 11.23) or 23% of all statements.

Incidence Rates by Group and Cluster

Six statements were rated with the term “very much” by a majority of the sample population. These statements were, in descending rank order, I am responsible for our personal affairs (77%); I have to be patient (60%); I take one day at a time (60%); I do things that my spouse used to do (60%); I have to take my spouse for medical help (54%); I do things now that I have never done before (53%). Five of these statements were from the cluster entitled, Shifting Responsibilities. One of these statements came from the cluster named, Learning to Cope.

All of the 76 perception statements were rated with the terms “moderately,” “quite a bit,” or “very much” by at least some of the participants. Of these statements, 50 were rated in this latter manner by a majority of participants. Table 4-3 lists the 76 perception statements in rank order. They were placed in descending rank order by the percentage of participants who declared that these statements applied to them “moderately,” “quite a bit,” or “very much”. From this list, 24 statements were rated with these terms by 70% or more of the sample population. Of these 24 statements, 10 statements came from the cluster named Shifting Responsibilities; 7 came from the cluster labelled Learning to Cope; 4 came from the cluster Reacting to Spouse’s Confusion; 1 came from the cluster Managing Our Surroundings; 1 came from the cluster Feeling Helpless; and 1 came from the cluster named Disengaging. The three clusters with the highest number of statements rated in this manner were also the clusters with the highest Cluster Means. Shifting Responsibilities had a Cluster Mean of 3.65 (S.D.=0.78); while Reacting to Spouse’s Confusion had a Cluster Mean of 3.26 (S.D.=0.88); and Learning to Cope had a Cluster

Table 4-3
Percentage* of Participants Who Reported That the Statements Applied to Them Either Moderately, Quite a Bit, or Very Much.

I have to be patient.	98
I take one day at a time.	97
I am responsible for our personal affairs.	96
I am learning to cope with my spouse.	90
I help my spouse with things she or he cannot do alone.	88
I have to stay alert.	87
I worry about my spouse.	87
I have taken over things that my spouse used to do.	82
I focus on something positive.	82
I check up on my spouse.	81
I have to take my spouse for medical help.	79
I try to get us laughing.	79
I am bothered by my spouse's mental confusion.	77
The whole load of caring for my spouse falls on me.	77
I have to be more flexible.	76
I do things now that I have never done before.	75
Our family shows affection more often.	74
I try not to take things personally.	73
I do some things that I like to do.	72
I try not to show that I am upset.	72
I am amazed at my strength.	72
I remind my spouse over and over.	72
I get tired.	71
Everyday life is like caring for a child.	70
Caring for my spouse helps me feel good.	70
I worry about our future.	69
I look for things that get misplaced.	69
I get strained by answering questions over and over.	69
I have less time to spend with others.	68
When my spouse gets something fixed in mind, it is frustrating.	68
I plan my spouse's activities.	66
It is hard to get out on my own.	66
Caring for my spouse is stressful for me	66
I take special safety precautions.	66
I am concerned about my spouse getting lost.	66
I find it hard to communicate with my spouse.	66
I get upset.	66
My religious practice helps.	65
We do not see our family members as often.	64
I feel relaxed when my spouse is not around.	63
I never know where I will find things.	62
I do not sleep well.	59
I tell people about my spouse's memory problems.	59
I feel sad.	58
I don't know how my spouse will behave.	57
I get frustrated when my spouse cannot do what he or she used to do.	56
I cannot leave my spouse alone.	54
I walk away from my spouse's anger.	54
We still get together with friends.	53
I am responsible for my spouse's personal care.	52
I question myself.	49
I cannot satisfy my spouse.	48
My spouse is easier to get along with.	47
I control what is said to my spouse.	47
I have a hard time getting work done.	46
People do not believe me when I tell them of my spouse's memory problems.	46
I have difficulty understanding changes in my spouse's personality.	44
I feel hopeless.	43
I have trouble going anywhere with my spouse.	43
People will tell me about their problems caring for someone with memory problems.	40
We argue.	40
We sleep separately.	37
I get angry at my spouse's actions.	37
My health suffers.	37
I feel helpless.	35
I have others to help me care for my spouse.	34
We are clearing out some possessions.	31
I get like a robot.	30
I feel sneaky.	29
I feel like I was stabbed.	26
I feel embarrassed by my spouse's actions.	24
I have to buy special supplies.	22
Caring for my spouse is like a horror.	13
I decided that I need a life of my own.	13
Our family disagrees about how to treat my spouse.	11
We are planning to move.	09

* Figures rounded to nearest whole percent

Mean of 3.25 (S.D.=0.52).

It was also observed that nine statements applied "not at all" in the lives of a majority of participants. These statements are listed here in rank order from highest to lowest percentage of people for whom these statements did not apply: We are planning to move (85%); Our family disagrees about how to treat my spouse (76%); I decided that I needed a life of my own (72%); Caring for my spouse is like a horror (71%); I feel like I was stabbed (62%); We sleep separately (62%); I get like a robot (57%); I have to buy special supplies (57%); and I feel sneaky (55%). Of these latter statements, five came from the cluster entitled Burning Out, three came from the cluster entitled Managing our Surroundings, and one statement came from the cluster named, Shifting Responsibilities.

There were a total of 26 statements that applied "not at all" or "slightly" in the lives of the participants. Of these 26 statements, 8 (29%) were from the cluster named Burning Out; 7 (27%) statements were from the cluster labelled Feeling Helpless; and 7 (27%) were from the cluster labelled Managing our Surroundings. These clusters also had the three lowest Cluster Means. Managing our Surroundings had a Cluster Mean of 2.20 (S.D. = 0.54), while Burning Out had a Cluster Mean of 2.46 (S.D. = 0.83), and Feeling Helpless had a Cluster Mean of 2.54 (S.D. = 0.78).

Phase Four: Comparison of Cluster Scores With Caregiver Burden Inventory Scores

The Caregiver Burden Inventory is a 24 item inventory about caregiver experiences. These items are grouped into five subscales which reflect different facets of a Total Burden score. These five factors have been labelled, Time-Dependence, Developmental, Physical, Social, and Emotional Burden (Novak & Guest, 1989). The same caregivers sampled in phase three also completed a Caregiver Burden Inventory. Their Cluster Scores as described in the previous section were then compared with their ratings of the Caregiver Burden Inventory. These comparisons helped answer the fourth research question, How do caregivers' ratings of perception compare with their scores on the Caregiver Burden Inventory? Results from these comparisons are reported in this section.

Comparison of Low and High Burden Groups

The median score (46) from participant's Total Burden scores on the Caregiver Burden Inventory was used to divide the participants into two groups. The Low Burden group (n=24) was compared with the High Burden group (n=20) using an Hotellings T^2 Test. This statistical test was used to test the null hypothesis that the means of the High and Low Burden groups were equal on each of the seven Cluster Scores. The test was found to be significant, $F(7,36) = 1.80$ $\rho < 0.01$. The null hypothesis, therefore, that people in the High and Low Burden groups obtained the same scores on each of the seven clusters was rejected. In other words, there were statistically significant differences between the scores of those people in the High Burden group when compared with those scores in the Low Burden group.

Follow up analyses of variance were conducted. The Cluster Scores on the seven Clusters were designated as the dependent variables and the High and Low Burden designation was used to define the independent variable. A significance level $\rho < 0.05$ was used for these follow-up analyses. The test for Cluster 1, $F(1,42) = 6.89$, Cluster 2, $F(1,42) = 10.57$, Cluster 4, $F(1,42) = 14.67$, Cluster 5 $F(1,42) = 35.86$, Cluster 6 $F(1,42) = 33.86$, and Cluster 7 $F(1,42) = 64.48$ were all significant. The test on Cluster 3 $F(1,42) = 0.002$, $\rho \geq 0.968$ was not significant.

Correlational Analysis of Cluster Scores With Burden Inventory Scores

Pearson product-moment correlations were also computed. These correlations were computed to compare participants' Cluster Scores and their scores on the CBI (Table 4-4). Six of the seven Cluster Scores and the Total Cluster Scores were all significant at the 0.01 level (2-tailed). These correlations ranged from a relatively moderate correlation between the cluster Disengaging and Total Burden scores (r=0.48) to a very high correlation between Burning Out and Total Burden scores (r=0.85). Learning to Cope was the only cluster of statements that did not correlate significantly with the Total Burden scores (r=0.14). This cluster had a slight negative correlation with the CBI subscale named Emotional Burden (r= -0.14) and a very low correlation with the subscale Time-Dependence Burden (r=0.33). These minimal to negative correlations for the cluster labelled Learning to Cope was a very different pattern of correlations from the moderate to high correlations found between the other Cluster Scores and the CBI scores.

Summary of Results

The researcher collected 308 statements from 19 participants about their experiences of caring for a spouse who suffered from dementia. These statements were edited for essential meaning then compared for redundancy. This process resulted in a final list of 76 perception statements. These 76 statements that were collected in phase one covered a wide range of perceptions about caregivers' experiences.

Concept Mapping was used in phase two to derive seven clusters of statements from which seven themes emerged. These themes were entitled, Managing Our Surroundings, Disengaging, Learning to Cope, Shifting Responsibilities, Reacting to Spouse's Confusion, Feeling Helpless, and Burning Out.

These statements were then rated in phase three as to how much they applied to the lives of 68 spouses caring at home for a partner with dementia. The clusters of statements which applied most to the lives of these caregivers were entitled, Shifting Responsibilities, Reacting to Spouse's Confusion, and

Table 4-4
Pearson Product-Moment Correlation Coefficients Comparing Cluster Scores and CBI Scores

Clusters	Descriptors	Time-Dependence Burden	Developmental Burden	Physical Burden	Social Burden	Emotional Burden	Total Burden
Managing Our Surroundings	Pearson Correlation	.45**	.38**	.49**	.27*	.38**	.52**
	Sig. (2-tailed)	.00	.00	.00	.04	.00	.00
	N	62	61	61	58	62	58
Disengaging	Pearson Correlation	.47**	.52**	.32**	.27*	.16	.48**
	Sig. (2-tailed)	.00	.00	.01	.04	.20	.00
	N	66	66	66	62	67	62
Learning To Cope	Pearson Correlation	.33**	.05	.20	.06	-.14	.14
	Sig. (2-tailed)	.01	.71	.14	.68	.30	.29
	N	59	60	60	57	60	57
Shifting Responsibilities	Pearson Correlation	.81**	.52**	.46**	.30*	.24	.63**
	Sig. (2-tailed)	.00	.00	.00	.02	.07	.00
	N	58	59	59	56	59	56
Reacting To Spouse's Confusion	Pearson Correlation	.78**	.65**	.53**	.36**	.49**	.75**
	Sig. (2-tailed)	.00	.00	.00	.01	.00	.00
	N	61	62	61	58	62	58
Feeling Helpless	Pearson Correlation	.66**	.74**	.58**	.47**	.59**	.79**
	Sig. (2-tailed)	.00	.00	.00	.00	.00	.00
	N	63	64	63	60	64	60
Burning Out	Pearson Correlation	.67**	.70**	.71**	.50**	.65**	.85**
	Sig. (2-tailed)	.00	.00	.00	.00	.00	.00
	N	58	59	59	56	59	56
Cluster Total	Pearson Correlation	.80**	.65**	.59**	.38*	.49**	.77**
	Sig. (2-tailed)	.00	.00	.00	.01	.00	.00
	N	46	46	46	44	46	44

** Correlation is significant at the .01 level

* Correlation is significant at the .05 level

Learning to Cope. The incidence rates for each of the 76 perception statements were also reported. Statements which seemed to apply the least in this sample of caregivers came from the clusters entitled, Burning Out, Feeling Helpless, and Managing our Surroundings.

The ratings for each statement from phase three were summed across each cluster to produce seven Cluster Scores. These seven Cluster Scores were then summed to obtain Total Cluster Scores. A comparison between these Cluster Scores and these same spouses' scores on the Caregiver Burden Inventory (CBI) was made in phase four. A significant positive correlation was discovered between participants' Cluster Scores and their CBI Total Burden Score. Many significant and positive correlations were also discovered between each of the Cluster Scores and the subscales scores on the CBI. The one exception occurred when comparing scores on Cluster Three, entitled Learning to Cope, with the CBI subscale and total scores. Scores from Cluster Three showed no overall positive and significant correlations with the CBI scores.

Discussion and Further Analysis

Results from this study have confirmed information from previous research. The results from this study have also contributed new information to that which has been previously published. A discussion about how results from this study contributed to research about caregivers' perceptions is offered in the following sections.

Statements Generated

The final list of 76 perception statements (Table 4-1) collected in this study represented a wide range of issues related to caring for spouses with dementia. Results from this study contributed some new statements related to the notion of coping mechanisms that had not been mentioned in previous literature. Issues such as sexuality and grieving were not represented directly by any statements from this study. The method of data collection and cohort effects may have accounted for these issues not appearing on this final list of 76 perception statements.

The 76 perception statements generated in phase one of this study represented a wide range of caregiver perceptions about the effects of caring for a partner with dementia. They echoed caregivers' statements from other studies about feeling helpless or frustrated while providing care to one's spouse (Blieszner & Shifflett, 1990, p.60). Statements about difficulties with communication were parallel to those descriptions collected by Liken and Collins (1993, p.24). Many of the 76 perception statements from this study would fit within the eight categories described by Reed (1990, p. 203) as health, work, family, friends, recreation, chores, home, and financial. Some studies listed "uplifts" (Kinney & Stephens, 1989), "gratifications" (Motenko, 1989), "caregiver's esteem" (Given, Stommel, Collins, King, & Franklin, 1992), or "positive aspects of the new nonexistent relationship" (Blieszner & Shifflett, 1990). Perception statements derived in this study adequately represented the domain of perceptions listed in previous studies about caregivers of people with dementia.

Statements about sexuality and grief.

There were two important issues not addressed directly by any of the statements collected in this study. Direct statements about sexuality were not represented. There were a few statements from this study such as, We sleep separately; I decided that I need a life of my own; and I find it hard to communicate with my spouse; that indirectly referred to the dynamics of the couple's marital relationship. Other studies, however, offered more direct statements about how some spouses struggled with issues related to fidelity, or the meaning of their marriage relationship, and about their experiences of reduced sexual activity (Reed, 1990, p. 203; Wright, 1993, pp. 48-54).

Grief was another issue not directly addressed by statements from this study. Statements such as, We are clearing out some possessions; I feel sad; and I have taken over things that my spouse used to do; made oblique references to the grieving process. In other studies, however, more direct perceptions about this process have been collected. For example, statements such as, I miss him (Bleiszner & Shifflett, 1990, p. 60); and, I started to grieve many years before he died (Liken, 1993, p.24); are much more direct perceptions about grieving.

A husband caring for his wife, admitted in an interview, that speaking about sex was "difficult for our generation" (Harris 1993, p.553). Difficulty reporting on the issue of sexuality as well as the issue of grief could be partly explained by age cohort effects. For example, popular literature and other media which encourage discussion of these kinds of issues in the public forum and also offer people a common language about these issues are only recent developments within our culture. This kind of communication was not a part of this age cohort's earlier developmental years. This factor would account for a lack of spontaneity about these issues especially within the open ended format of data collection used in phase one of this study. Wright (1991) demonstrated that this cohort of people can speak about the issue of sexuality, but a semi-structured interview was used to elicit responses in this area of the caregivers' lives. This cohort of people therefore, can speak about the issues of grieving and sexuality but a semi-structured interview is necessary to elicit explicit responses.

Statements about learning to cope.

Participants in phase four of this study could be called very experienced spouse caregivers. They had many years of life experience as 49% were 75 years of age or older. They had many years of experience living with their partners as 64% had been living with their partners for 45 or more years. They also had much experience caring for a partner with dementia as 43% had 3 or more years of this kind of experience. This group of people experienced a lot of burden with their caring role as they reported equal or more burden than caregivers in previous research. The information they gave about learning to cope was made valuable by this depth of experience.

The information they gave was made even more valuable because it appeared to be unique to this study. Haley, Levine, Brown, and Bartolucci (1987), Knight (1991), and Wright (1991), used scales developed with other populations to measure coping styles of people caring for a spouse with dementia. Only Wright (1993) published statements from spouse caregivers about coping with tension within the marital relationship. Statements about coping that were collected in this study were then compared with those statements collected by Wright (1993, p. 37). The following information was found to be unique.

Spouse caregivers in this current study found that focussing on something positive had a great effect on their lives. They would focus on something positive through the use of humour, by using inspirational reading, or by finding support in religious beliefs and practice. Some of these caregivers maintained their positive focus because giving care to their spouse made them feel better or the effects of dementia had made their spouse easier to get along with. For these caregivers it was important to continue finding enjoyable activities for themselves. They also reported that it was important to connect with other people. These connections were made to procure help with caring for their spouse, to maintain some social activities in their lives, or in order to explain their spouses' dementia to others.

These statements about learning to cope could provide helpful information for professionals and other caregivers who are involved in support groups or information sessions about caring for someone with dementia. There is a need for further research to collect and publish a more in depth list of perceptions about learning to cope with the effects of caring for a spouse with dementia.

Themes Derived

Through the use of Concept Mapping, seven themes emerged from the perception statements data. When compared with themes that emerged from previous studies, these seven themes represented good coverage of the domain of caregiver perceptions. The use of Concept Mapping also offered a unique conceptualization of caregiver perceptions not offered by previous research Results from this study can readily be used for clinical application.

Comparison with previous research.

Novak and Guest (1989), Sauer-Lynch (1990), Wright (1991), and Harris (1993), derived themes from statements which described the effects on people who cared for family members with dementia. One can observe that there were no themes from this current study which directly related to a theme named Sexual Dimension (Wright, 1991) nor to the theme labelled Attributing Meaning (Sauer-Lynch, 1990). Other than these latter two themes, results from this study yielded a comprehensive list of themes about caregiver perceptions, when compared with this previous research.

Social Burden (Guest & Novak, 1989), Personal Connectedness (Sauer-Lynch, 1990), Companionship (Wright, 1991), and Social Isolation (Harris, 1993) all seemed directly related to the notion of interpersonal relationships and was consistently reported by these researchers. In this current study there was no overall theme that dealt solely with social relationships nor with personal connectedness. This issue, however, was addressed by some of the 76 perception statements collected in this study. Statements with this kind of content were most often placed in the cluster labelled Managing our Surroundings. This demonstrated how caregivers conceptualized this notion of social connectedness in a different manner than previous researchers. These caregivers conceptualized interpersonal connectedness as part of a larger issue. Management of their surroundings meant more than just personal relationships with family and friends but also included their interactions with, and influence over their whole environment.

This difference in conceptualization was also evident in other parts of the Concept Map. For example, the concepts of Burning Out, and Feeling Helpless occupied an important portion of the Concept Map and yet these kind of concepts are not reported in any lists of themes published by the researchers cited above.

Relationship of themes.

The pictorial representation of the Concept Map in Table 4-1 offered an opportunity to look at the organization of the clusters on a regional level defined by a set of axes. This pictorial representation had important theoretical and clinical implications.

Coppel, Burton, Becker, and Fiore (1985) demonstrated that depression in spouse caregivers was significantly related to their perception of lack of control within the context of upsetting behaviours by the spouse who suffered from Alzheimer disease. Examination of the Concept Map confirmed their findings. A clear difference in the content of perception statements along an axis that stretched from the clusters labelled Feeling Helpless or Burning Out toward the cluster labelled Learning to Cope was noticed. Statements within the area defined by Feeling Helpless and Burning Out described symptoms of depression and of a caregiver's lack of efficacy over the difficulties associated with giving care to their spouse. As one moved along an axis toward the cluster entitled Learning to Cope, the statements emphasized perceptions about having a sense of efficacy as a caregiver.

Coppel et al. (1985) also proposed that "...cognitions and their interactions with intrapersonal or interpersonal contexts may prove to be important aspects of adjustment or depression" (p. 265). A pictorial representation of this proposal can be seen in the Concept Map presented in Table 4-1. On the right hand side of the map, statement content referred to perceptions about intramarital issues between the couple. On the left side of the map the statement content changed to addressing perceptions about extramarital issues between the couple and their environment. In this map caregivers have reflected that intramarital and extramarital contexts are important and underlying variables that affected their adjustment to caring for someone with dementia.

Interpretation of themes from the Concept Map.

This Concept Map illustrated two predominant tensions in the lives of these caregivers. First, they experienced a tension between attaining a sense of efficacy and losing a sense of efficacy in their role as caregiver. Second, they experienced a tension between managing intramarital interactions within the couple relationship and managing interactions with their surroundings.

Coppel et al. (1985) offered no explanation about how these variables interacted. They did not explain why caregivers reported more depression when dealing with disturbing behaviours of their spouses and less depression when they were dealing with major life changes caused by their caregiving. The Concept Map produced in this current study could not offer any explanations, about how these variables interacted. Results from the Concept Map, however, confirmed the existence of these two variables and that they were important to the lives of spouse caregivers. More research about the interactions of these two variables would be warranted.

Furthermore, one can observe on the Concept Map that perceptions about burning out and feeling helpless occupied a larger portion of these caregivers' attention. One can also observe that these perceptions included descriptions of trauma and depression. These observations led to the following hypothesis. Caregivers might heighten their sense of efficacy by focussing more of their attention on how they are learning to cope and less attention on their perceptions about burning out.

One can also observe on the Concept Map that perceptions about interactions within their couple relationship occupy a much larger share of their attention than issues related to managing their surroundings. These caregivers may be helped by focussing more of their attention on managing their surroundings and on the broader picture of their caregiving role while focussing less of their attention on difficulties within their marital relationship.

Didactic use of themes from Concept Map.

This pictorial representation of a Concept Map also offered a useful didactic tool. Such a pictorial representation can be used for either group or individual interventions with caregivers. For example, a group of caregivers could be presented with the Concept Map and invited to take some time reflecting on the themes and the content of each theme. It would then be very easy to start a group discussion because this map is a fairly comprehensive representation of spouse caregivers' perceptions and each person in the group could find something with which to relate. Once the group has achieved some level of comfort in their discussion a facilitator could then move the group on to the next phase. The facilitator could ask the caregivers about what might be missing from this picture as a way of addressing more difficult issues such as sexuality and grieving. This Concept Map will, therefore, provide a valuable tool for group facilitators and for others working individually with caregivers.

Incidence Rates

Caregivers' perceptions about their situation are considered to be mediating variables in the prediction of burden, satisfaction, and depression among caregivers (Brashares & Catanzaro, 1994; Haley et al., 1987; Lawton et al., 1990; Morris, Morris, & Britton, 1988; Pushkar Gold et al., 1995; Walker, Shin, & Bird, 1990). There is only one study (Wright, 1990), however, which reported the incidence of these perceptions in a sample population of spouses caring for their partner with dementia.

Results from this current study added new information to these previous results. It was discovered that Shifting Responsibilities, Reacting to a Spouse's Confusion, and Learning to Cope were all themes that were endorsed more highly as applying in the lives of these caregivers. Some items were rated as applying not at all by a majority of caregivers. These incidence rates and their significance are discussed in the following sections.

Shifting responsibilities.

Spouses in this study endorsed more statements from the cluster Shifting Responsibilities as applying "moderately," "quite a bit," or "very much," than statements from any other cluster of statements. Taking on responsibilities for a spouse's personal care, for supervising activities, for all personal affairs, and for attempting new roles or work were all rated as the statements from Shifting Responsibilities, which applied the most highly to the live's of these spouse caregivers.

These results confirmed the results from other studies which reported changes in the reciprocity of relationships as a major concern for spouses and other caregivers. For example Wright (1991) discovered, "when the afflicted spouse had previously managed the family finances, the caregiver spouse was now more likely to experience problems." Wright also noted, however, that some spouse caregivers experienced enjoyment of their new found control over financial resources (p.230). Bliesner and Shifflett (1990) reported role changes and loss of reciprocity in interests and pursuits among some spouse caregivers. They too, reported both "costs" and "benefits" that were associated with these changes (p.60). Whether the effects on spouses were perceived as problems or benefits, diverged widely (Kinney & Stephens, 1989b).

This study did not try to discover which effects were perceived as burdens, as uplifts, or as neutral. This study however, offered data on how much certain perceptions applied in the lives of spouse caregivers. According to this sample of spouses, being patient; being responsible for personal affairs; taking over things that their spouse used to do; staying alert; helping their spouse with things that she or he cannot do alone; and taking their spouse for medical help, represented the perceptions that applied most highly to their lives when caregivers considered the shifting responsibilities within their marital relationships.

Reacting to spouse's confusion.

Reacting to a spouse's decline in cognitive functioning was rated as having a major effect on caregivers in this study. Only one previous study has reported incidence rates of perceptions about this area of impact on caregivers (Wright, 1991). This current study, however, obtained incidence rates on a variety of perceptions about caregivers' reactions to their spouse's confusion.

In her research, Wright (1991) noted that as high as 63% of 30 caregivers reported exhaustion from repeated questioning by their dementing spouse (p.231). As high as 40% of these same spouse caregivers reported clinging and demanding behaviours from their afflicted spouses (p.232).

This study confirmed these incidence rates reported by Wright. As high as 50% of 66 caregivers in this study reported that, I get strained by answering questions over and over, applied either "quite a bit" or "very much." As many as 33% of 68 caregivers reported that, I cannot leave my spouse alone, applied to them either "quite a bit" or "very much." Results from this study suggested that there are perceptions which apply even more in the lives of caregivers than those reported by Wright.

Within the theme of Reacting to Spouse's Confusion, these are the perceptions in descending rank order that were rated more highly than the perceptions about strain from answering questions over and over: I worry about my spouse; The whole load of caring for my spouse falls on me; When my spouse gets something fixed in mind, it is frustrating; I am concerned about my spouse getting lost; Everyday life is like caring for a child.

Learning to cope.

Results from this study confirmed that perceptions about one's coping have an important effect on caregivers (Coppel et al., 1985; Haley, Brown, & Bartolucci, 1987; Morris, Morris, & Britton, 1988). Harris (1993) and Wright (1993) listed statements that described these perceptions in samples of spouse caregivers. Only Wright reported some incidence rates of coping styles but did not report the incidence of the caregivers' perception statements. These results added new information about incidence rates for these perceptions.

The cluster of statements entitled Learning to Cope had the third highest Cluster Mean of all seven clusters. Within this cluster there were ten statements rated by 50% or more of participants as applying "moderately," "quite a bit", or "very much." The following items are listed in descending rank order as to how much they applied to caregivers' lives, I take one day at a time, I am learning to cope with my spouse, I focus on something positive, My religious practice helps, I try to get us laughing, I try not to take things personally, I am amazed at my strength, Caring for my spouse helps me feel good, I do some things I like to do, I tell people about my spouse's memory problems.

Items rated as applying "not at all".

Results from this study confirmed that a majority of caregivers do not perceive any major shifts or disruptions to their lives even as they report many burdens related to their caregiving role. For example, Pushkar Gold et al. (1995), revealed that measurements of health effects did not change for many people even as the severity of the dementia increased (p. 192). One husband reported, "It's not what we planned but it's not as awful as people think." Other spouses reported that giving care had enhanced their personal growth (Harris, 1993, p.553).

Caregivers in this study had about the same level of burden as participants in studies conducted by Brashares (1994), Pearson et al. (1993), as well those in the Canadian Study of Health and Aging as reported by O'Rourke et al. (1996). Caregivers in this present study reported relatively more burden than those in studies conducted by Motenko (1989) and Zarit (1980). Results from this study revealed that even as people reported similar levels of burden as in previous studies, a majority of people perceived no major disruption to their lives. For example, a majority of spouses rated the following statements as not applying at all in their lives, Our family disagrees about how to treat my spouse (76%); We are planning to move (85%); I decided that I need a life of my own (72%); We sleep separately (62%). They apparently also perceived no traumatic feelings as a part of their life. The majority of spouses rated the following as not applying to their lives, Feeling like I was stabbed (62%); Caring for my spouse is like a horror (71%); I get like a robot (57%). The cluster of statements entitled Feeling Helpless and Burning Out, had two of the three lowest Cluster Means.

It was also discovered in this study that the majority (52%) of caregivers did not use any formal services. Wright (1993) has cited a history of findings from the late 1980's that the majority of caregivers did not use formal services to help with their responsibilities. She reported that 50% of husbands and 58% of wives in her own sample did not use formal services (p. 63). This study confirmed what seems to be a longitudinal trend for the majority of spouse caregivers. Even though spouses experienced burden from their caregiving, the majority did not perceive any traumatic impact on their lives and did not seek formal support services.

It is hard to interpret the reluctance of caregivers to use formal services. Some caregivers interviewed in this study found it an intrusion to have helping professionals in their home and sometimes the person with dementia found a new face in their home hard to accept. Harris (1993) found that participants in his study did not consider their formal support to be adequate and therefore relied on friends and family for support. Wright (1993) reported that some spouse caregivers felt duty-bound to be the sole caregiver for their own spouse. Results from this study indicated that a majority of caregivers perceived themselves as learning to cope with stressors in their lives. Many spouses therefore do not seek formal help because they give a priority to finding ways of coping and then perceive themselves as coping very well without formal services.

Summary.

These caregivers had many years of life experience. They had been living with their partners for a long time and had much experience at caring for their partners. These long term and committed relationships meant that caregivers' personal identities and patterns of relating were closely tied to their couple relationship. Any disturbance or change to this relationship would have a major impact on the caregivers' lives. These factors helped explain why this sample of caregivers rated perception statements about shifting responsibilities and reacting to a spouse's confusion as greatly affecting their lives. Their length of caregiving and committed relationships helped these caregivers learn to cope with their difficulties and develop a sense of efficacy as a caregiver. This overall sense of efficacy helped explain why a majority of caregivers perceived no traumatic effects in their lives and did not make use of formal support services.

On the other hand, 29% and 38% of caregivers respectively described their experience as like a horror or like being stabbed. There is a need to quickly identify and intervene with caregivers who perceive their situation as traumatic.

Comparison of Incidence Rates With Caregiver Burden Inventory

Comparing Caregiver Burden Inventory (CBI) Scores in this study with their respective Cluster Scores led to the conclusion that most Cluster Scores were positively correlated with CBI scores. Concept Mapping therefore, may offer a way to develop scales based on self report with relatively smaller sample sizes than those scales developed through factor analysis.

Concept Mapping as a tool for scale development.

An Hotellings T^2 test between Cluster Scores in the High Burden group and Cluster Scores in the Low Burden group led to the conclusion that there were significant differences in the Cluster Scores between these two groups. A further univariate analysis of variance showed that all Cluster Scores in the High Burden group were significantly different from those in the Low Burden group, except for those from Cluster Three. Further analyses using Pearson product-moment correlation coefficients revealed moderate to highly positive correlations between Cluster Scores and the CBI Total Burden and Subscale scores, except for those scores from Cluster Three. These results suggested that in Clusters One, Two, Four, Five, Six, and Seven, people in the High Burden group tended to endorse statements from these clusters as applying more to their lives than people in the Low Burden group. These results also suggested that there may be a linear relationship between the Cluster Scores in Clusters One, Two, Four, Five, Six, and Seven and the Subscale and Total Burden scores on the CBI.

Concept Mapping, therefore, is a useful tool for scales developed from self report items. For example, the Physical Burden subscale on the CBI consisted of one less item than the other subscales. Novak and Guest (1989) had to use extra calculations to correct for this missing item when analysing their data. Cluster Seven, Burning Out, had the highest correlation of all clusters with the CBI Subscale, Physical Burden. Cluster Seven may therefore, provided items which could be added to the Physical Burden subscale of the CBI.

Concept Mapping displayed another strength. A relatively low number of participants (n=41) produced the list of 76 perception statements and seven clusters of statements in this study. Novak and Guest (1986) used 107 participants, Poulshock and Deimling (1984) used 614 participants, and Given et al. (1992) used 377 participants to develop their scales using factor analysis techniques. Concept Mapping offered a comprehensive domain of self report items and clusters of items by sampling markedly fewer participants than were needed for other methods.

Cluster three, an underlying concept not correlated with burden.

Scores on the cluster labelled Learning to Cope, did not have any significant positive correlations with the CBI scores. This pattern of relationship with the CBI scores was very different from the patterns for scores from clusters such as Feeling Helpless and Burning Out. Scores on these latter clusters had high positive correlations with CBI Total Burden scores. This difference in pattern was consistent with the interpretation of themes from the Concept Map that was stated above. In that interpretation, Learning to Cope items were associated with an underlying dimension. This underlying dimension was labelled as a caregiver's perceived sense of efficacy within the caregiving role. This was conceived as opposite to the lack of efficacy described by items in the clusters labelled Feeling Helpless and Burning Out. All of these factors contributed to the conclusion that the cluster of items labelled Learning to Cope described an underlying theme that was different from burden.

These items that were clustered under the title of Learning to Cope could eventually provide a measurement scale that would complement scales used to measure burden. These items could provide a way to measure a spouse caregiver's perceptions about their growth and adaptation in the face of burden.

If a measure such as this could be developed it might help to investigate research questions such as, Do spouses who perceive a higher sense of efficacy about giving care also perceive themselves as less burdened, less depressed, or as experiencing less trauma than those who have a lower sense of efficacy?

Further Analysis

Previous researchers reported that males and females experienced significantly different levels of burden (Barusch & Spaid, 1989; Morris et al., 1991). Fitting et al. (1986) also reported different levels of depression between male and female caregivers. Zarit et al. (1986) demonstrated that different burden levels between males and females at the initial stages of giving care disappeared when burden levels were reported at later stages of the caregiving process. Other researchers have demonstrated that males and females may take on different caregiving roles and styles (Horowitz,1985) and that males and females reported burden differently (Lutzky & Knight, 1994). These variables could confound the comparison of differences in burden scores between males and females. Pruchno and Resch (1989), and Harper and Lund (1990) also noted that males and females may have similar scores on burden scales but can be burdened by different factors related to a total burden score. Kiecolt-Glaser (1991) concluded however, that there were no sex related differences in depressive symptoms, social supports, nor health related problems.

A further analysis of the data was done, therefore, to find out whether there were any differences in the Total Burden Scores between males and females in this study. A T-test was conducted to test the null hypothesis that males and females had no differences between their Total Burden scores on the CBI. The resulting value, $\underline{t}$ (52.23) = 1.747 was not significant at the 0.05 level. This result supported the hypothesis that reported levels of burden are affected by many aspects in a caregiver's life. There is likely a complex interaction of a number of variables that contribute to the experience of burden. Whether someone is male or female will not therefore, be a good predictor of levels of burden.

Researchers have also reported that demographic variables such as age, sex, and education as well as variables about the caregiver context such as relationship to care receiver and use of professional services, affected the perceptions of caregivers (Barusch & Spaid, 1989; Clipp & George, 1993; Fitting et al., 1986; George & Gwyther, 1986; Walker, Shin, & Bird, 1990). A multivariate analysis of variance was conducted on the perception statements data. This analysis was used to test the null hypothesis that the joint distribution of the seven Cluster Means were equal when compared by the six variables of age, sex, years of education, years of living with spouse, months of memory problems, and whether or not the caregiver accessed services to help with caregiving. This analysis was done using the SPSS for Windows release 8.0 software (SPSS Inc., 1997). The design for this MANOVA was a 2 (sex) by 2 (age: ≤73 years vs. ≥74 years) by 2 (education: ≤12 years vs. >12 years) by 2 (memory problems: ≤36 months vs. ≥37 months) by 2 (living together: ≤48 years vs. ≥49 years) by 2 (caregiver services vs. no services) analysis. This analysis was done in relation to the participants' Cluster Means in each of the seven clusters. An analysis was done on the main effects and on the two-way interaction effects. The 0.05 alpha level to achieve significance was used. No statistically significant results were obtained for any of the six demographic variables as main effects nor for any of their two-way interactions.

These analyses suggested that these demographic variables and caregivers' contexts, in themselves, are not good predictors of caregivers' perceptions about their lives. It is likely that other variables such as cognitive coping strategies or styles of management (Harvath,1994; Knight, 1991) also interact with demographic and situational variables. Perceptions of caregivers seem to be a mediating variable in their experiences of burden and other caregiving experiences. These perceptions themselves have complex interaction effects with environmental, demographic, and personality factors (Cohen, Luchins, & Eisdorfer, 1990; Hadjistavropoulous et al., 1994; Haley, Brown, & Bartolucci, 1987; Motenko, 1989; Novak & Guest, 1989).

Summary

A list of 76 perception statements was produced as a result of sampling 19 spouses who provided care at home to their partners who were suffering from dementia. These statements described the perceptions of how caring for a spouse with dementia affected one's life. These statements were consistent with those gathered through previous research and they adequately represented the domain of perception statements of spouses caring for a partner with dementia.

The perception statements which addressed the issue of learning to cope offered some information not previously published about spouse caregivers. These statements described how spouse caregivers focussed on positive thoughts, how they connected with other people for support, and how they needed to continue some pleasurable activities. These statements could provide helpful information for supportive interventions with caregivers. There is also a need to more fully catalogue and publish the perceptions about learning to cope with caring for a spouse who suffers from dementia.

Concept Mapping was used to derive seven clusters of statements from these 76 perception statements. These seven clusters were given appropriate labels by the researcher in consultation with an Alzheimer support group. These labels described themes that emerged from the seven clusters of statements. The Concept Map illustrated how caregivers conceptualized perception statements data in a different manner than those themes generated previously by researchers.

Caregivers conceptualized some of their major concerns as Feeling Helpless and Burning Out. Learning to Cope was conceptualized as an important way to prevent feeling helpless or burning out. This tension between learning to cope and feeling helpless revealed an underlying dimension of this Concept Map. This dimension pertained to a caregiver's sense of efficacy in providing care for their partner. Another underlying dimension to the Concept Map was the tension between managing intramarital aspects and managing extramarital aspects of the couple's relationship. Within the sphere of their intramarital relationship, these caregivers conceptualized Reacting to a Spouse's Confusion and Shifting Responsibilities as their major concerns. Managing our Surroundings was a concept that not only included interactions with family and friends but also included interactions with the couples' environment. These results demonstrated a need to involve caregivers and their feedback at all stages of research. This is especially true if one is interested in capturing the way caregivers conceptualize the effects of caregiving on their lives. The Concept Map of caregiver perceptions that emerged in this study can be readily used for supportive interventions with caregivers.

A sample of 68 spouse caregivers were asked to rate how much these 76 perception statements applied in their lives. The effects of caring for a spouse on a couple's intramarital relationship were most noticed in their shifting responsibilities and the caregiver's reactions to their spouse's confusion. These results could be partially explained by the habitual patterns that had developed in these couples' relationships. Changes in these patterns were very influential in their personal lives. Their long term commitments, many years of life, and many months of caregiving experiences also helped a majority of caregivers to develop perceptions that they had a sense of efficacy in their caregiving role. This was consistent with the fact that the majority of caregivers did not perceive their caregiving had a destructive nor horrifying impact on their lives. This also helped to explain why a majority of caregivers did not use formal support services.

There was, however, a minority of caregivers who described caregiving as having a traumatic influence on their lives. How to quickly identify and intervene with these caregivers is an important research and clinical issue. Results from this study suggested that helping a caregiver with effects on their couple relationship are of the most concern to spouse caregivers. These results suggested that help with the following intramarital difficulties are of primary importance to spouse caregivers: Learning to be patient; Taking over their spouse's personal affairs; Helping their spouse with things that they cannot do for themselves; Dealing with worry about their spouse; Responding to a spouse who gets something fixed in mind; Managing the load of caring for their spouse.

This sample of 68 caregivers was asked to complete a Caregiver Burden Inventory (CBI). Their ratings on the 76 perception statements were summed across the seven clusters to provide seven Cluster Scores. Scores on the CBI and Clusters Scores were compared. Except for Cluster Three, all other Cluster Scores had moderate to highly positive correlations with CBI scores. These correlations suggested that there was likely a positive linear equation which described the relationship between these six Cluster Scores and the CBI subscale scores. Concept Mapping could therefore be used to produce comprehensive lists of self report items and clusters of items about caregivers' perceived burden. Concept Mapping used a markedly smaller sample size to produce such items and clusters of items than the samples used by other methods. This gave Concept Mapping an advantage over these other methods.

Cluster Three scores were not related in a linear manner with the CBI scores. Cluster Three labelled, Learning to Cope, seemed related to an underlying theme different from Burden. This cluster of items could eventually be used as a scale to measure caregivers' perceptions about efficacy in their role as a caregiver. Such a scale might be used to research whether spouses who perceive a higher sense of efficacy in their caregiving role also perceive themselves as less burdened.

Cluster Scores were compared on various environmental and demographic variables. There were no differences found in these comparisons. Neither were there any differences found between men and women on their CBI scores. These results confirmed that the relationships between burden, perceptions of caregivers, and demographic variables is a complex relationship. In isolation, these variables do not predict participants' scores on behaviour based questionnaires.

Chapter 5: Conclusions and Implications of This Research

Concept Mapping was used to describe the perceptions of spouses who provided care at home for their partners who suffered from dementia. There were four research questions to be answered about these perceptions. Each of these four questions with their respective conclusions are described at the beginning of this chapter. Then the implications of results from this study for future research and psychological practice are presented at the end of this chapter.

Caregiver Perception Statements

Caregiver perceptions of their experiences have an effect on their ability to cope with stress and an effect on their mental and physical health. Counselling interventions to alleviate caregiver stress have been designed, therefore, to help shift caregivers' perceptions of their experiences. Spouses who are caring for a partner with dementia may experience more stress than others who are caring for partners with other chronic illnesses. Previous research that described spouses' perceptions about caring for a partner with dementia have been lacking in two ways. The number of studies has been minimal and most studies have used predominantly forced answer or structured interview techniques. The researcher therefore, used an open ended format in order to answer the first research question, How do spouses perceive the effects of caring for a partner with dementia?

Spouses living at home with a partner who suffered from dementia were prompted, Please list the effects that caring for someone with dementia has had on you. A final list of 76 perception statements was collected from 22 participants. There were no new topics addressed by these perception statements. These statements provided fairly comprehensive coverage of the domain of spouse caregiver perceptions when compared with other studies. Some previously unpublished perception statements about the theme, Learning to Cope were collected in this study. Spouse caregivers reported that they focussed on something positive when coping with caring for a partner with dementia. They used inspirational reading, positive thoughts, humour, and religious ideas and practices to maintain a positive focus. Continued participation in pleasurable activities was also an important way of coping. Giving care to their spouse helped some caregivers to feel good and in some cases caring for their spouse was made easier by the effects of dementia. Maintaining contact with people who could help with caregiving and who could help with social activities was also important. Telling others about their spouse's dementia was another coping mechanism reported by caregivers. There is a need to collect and publish a more in depth list of perceptions about coping from spouses who are experienced in providing care for their partners with dementia.

Themes

Phenomenological methods and also quantitative methods such as factor analysis, had been used to derive themes from caregiver perceptions about the effects of caring for someone with dementia. Wright (1991) had used pre-defined themes by which to gather and then report caregiver perceptions. She also demonstrated the utility of using both qualitative and quantitative methods within the same research project. Concept Mapping provided an integration of qualitative and quantitative methods in order to derive themes from caregiver perceptions.

Concept Mapping was therefore used to answer the second research question, What themes or clusters emerge from these perception statements? Nineteen people caring for a family member who suffered from dementia were asked to sort the 76 perception statements into piles that made sense to them. Concept Mapping was used to derive seven clusters of statements from these perception statements. The researcher, in consultation with an Alzheimer Society, Edmonton support group, then appointed labels to each of the clusters.

Seven themes that emerged from the perception statements were entitled, Managing our Surroundings, Disengaging, Learning to Cope, Shifting Responsibilities, Reacting to Spouse's Confusion, Feeling Helpless, Burning Out.

The Concept Map in Table 4-1 offered a unique conceptualization of perception statements data. Feeling Helpless and Burning Out were conceptualized as having a major impact on caregivers' lives. In order to alleviate that impact, most caregivers focussed on their perceptions about Learning to Cope. Within the sphere of their marital relationship these spouses conceptualized that Shifting Responsibilities and Reacting to Spouse's Confusion had a major effect on their lives. This Concept Map did not create a separate grouping for statements about social isolation or social interaction. Perceptions about social interaction were conceived as part of a wider issue of Managing our Surroundings. The conceptualization of this Concept Map was primarily caregiver generated. This Concept Map appeared very different when compared with previous researcher generated themes about the effects of providing care for a spouse with dementia. These results demonstrated a need to involve caregivers and their feedback at all stages of the conceptualization process.

This Concept Map also illustrated in pictorial form a proposal made by Coppel et al. (1985, p.264). There were two axes on this map which depicted two underlying variables. On the first axis, perceptions about efficacy or lack of efficacy as caregivers were evident. On the second axis perceptions about intramarital or extramarital contexts were depicted. A Concept Map cannot explain how these two variables might interact with one another. This map, however, confirmed that these variables are perceived by spouse caregivers as having an important effect on their lives. Observations of this map also suggested that spouse caregivers could alleviate distress by focussing more attention on intrapersonal interactions and on their experiences of efficacy as caregivers.

The Concept Map also offered a useful didactic tool. Its pictorial representation of topics and statements about caring for a spouse can be used readily in either group or individual interventions with caregivers.

Incidence Rates

Incidence rates for a broad list of perceptions about caring for a spouse who suffers from dementia have not been published. A third research question was therefore asked, What is the incidence of these perception statements in a sample of spouse caregivers? A sample of 68 spouse caregivers rated the 76 perception statements as to how much these statements applied in their lives. These ratings were also summed across each of seven clusters of statements in order to obtain Cluster Scores. These Cluster Scores were then summed across all seven clusters to obtain a Total Cluster Score.

Caregivers in this study perceived that the greatest effects of caregiving on their lives took place within the context of their intramarital relationship with their spouses. Most of these relationships were long term (mean = 45.2 years; S.D. = 11.87). Most of the caregivers had many years of life experience (mean = 72.6; S.D. = 7.94). Any disturbance to their habitual patterns of relating would be perceived as having a great influence on their lives.

The majority of caregivers perceived themselves as coping well. This helped to explain why a majority of caregivers perceived no traumatic effects nor major disruptions to their lives. In turn, it helped partially explain why a majority of these caregivers did not make use of formal support services.

In contrast, approximately one third of these spouse caregivers described the effects on their lives as at least slightly traumatic or disrupting. Quickly identifying and intervening with this group of caregivers would be important. Results from this study showed that a group of caregivers who are experiencing disruption in their lives will be most affected by worry about their spouse;

perceive that the whole load of caring for their spouse falls on themselves; get perplexed when their spouse gets something fixed in mind; find it difficult to take on responsibility for their spouse's affairs; find it a challenge being patient; and become frustrated when helping their spouse with things that the spouse cannot do alone. Targeting these areas for intervention would be helpful for those caregivers who find their role disrupting to their lives. These same caregivers would also be helped by more in depth collection and publication of perceptions about learning to cope.

Comparison of Cluster Scores With Caregiver Burden Inventory Scores

It has been observed in other research that caregivers' perceptions are related to their self reported burden. Therefore, a fourth research question was asked, How do caregivers' ratings of perception statements compare with their scores on the Caregiver Burden Inventory?

The same caregivers who rated the 76 perception statements were also asked to complete a Caregiver Burden Inventory (CBI). This 24 item inventory is grouped into five subscales. Each subscale reflects a different facet of a Total Burden score. Their median score on the CBI was used to divide the participants into a High Burden group and a Low Burden group. An Hotellings T^2 test was conducted to compare the means between the High and Low Burden groups. It was discovered that there was a difference in the mean scores between the two groups. Follow-up analyses of variance showed that for Clusters One, Two, Four, Five, Six, and Seven, people in the High and Low Burden groups had different Cluster Scores. The test on Cluster Three did not find any difference between the two groups. Pearson product-moment correlations were then computed on the Cluster Scores and the Burden Scores. Moderate to highly positive correlations were found between each of Clusters One, Two, Four, Five, Six, and Seven and the CBI Total Burden Scores. Many moderate to high correlations were also discovered between the Cluster Scores and the CBI Subscale Scores. Cluster Three showed no correlation to the Total Burden Score and from low positive to low negative correlations on the CBI Subscale scores.

It was confirmed by the results from this study that spouses' perceptions about their caregiving experiences are closely related to their self-reported levels of burden. When caregivers reported any one of the following clusters of perceptions as applying to themselves they also reported higher levels of burden on the CBI: Managing our Surroundings; Disengaging; Shifting Responsibilities; Reacting to Spouse's Confusion; Feeling Helpless; Burning Out.

Implications for Psychological Practice

Assessing effects on spouses caring for a partner who suffers from dementia, is a concern of psychologists. It was confirmed by results from this study that impact on caregivers is multidimensional. This makes assessment a very difficult task. Results from this study were also used to support the conclusion that there is a minority of caregivers at any given moment who experience their caregiving role as disruptive or traumatic. Even though assessment of the impact on caregivers may be difficult, quickly identifying this group of caregivers is important. Results from this study can be used to identify this group of caregivers. A helping professional could ask a caregiver about perceptions related to the clusters labelled Feeling Helpless and Burning Out. If these perceptions applied very much in the life of a caregiver it would indicate to the helping professional that the caregiver was perceiving a high rate of burden in their life.

The researcher also concluded that there is a need for the following cautions when making assessments using the self report of caregivers. Some caregivers within this age cohort may not spontaneously report any effects on their lives that are related to sexuality or grieving. Some caregivers will spontaneously focus on the care receivers' behaviours rather than reporting effects on themselves. These factors would limit the ability of a helping professional to make an accurate assessment based on spontaneous self report. If helping professionals are aware of these tendencies they can better plan their interviews with caregivers. The use of a semi-structured interview could elicit reports about issues which caregivers find difficult to discuss.

Interventions which help change the perceptions of spouses are also of concern to psychologists. Caregivers are reportedly most affected by their perceptions about learning to become patient; taking over their spouse's personal affairs; helping their spouse with things that they cannot do for themselves; dealing with worry; responding appropriately when a spouse gets something fixed in mind; and managing the whole load of caring for a spouse. These are the perceptions therefore that should be the initial focus for assessment and intervention. An helping professional could ask questions for clarification about these latter perceptions or ask how much each of these perceptions apply in the life of a particular caregiver. Once the most important concerns of the caregiver are identified then the helping professional should focus on shifting those perceptions.

Caregivers can benefit from shifting their perceptions in a particular manner. Spouse caregivers should be helped to shift the focus of their perceptions away from their intramarital concerns. They need to pay more attention to managing their surroundings, or in other words, to pay more attention to their extramarital concerns. They also need to shift their attention away from their perceptions about being helpless in the face of their caregiving. Caregivers will derive maximum benefit when these two shifts can occur together. Shifting their focus onto how they are learning to cope while at the same time helping them focus on their extramarital concerns will offer the most relief from their perceived burden.

The Concept Map which emerged from this research is a valuable tool for group and individual interventions. Caregivers should find that their own experiences relate easily to the Concept Map. This tool could provide a quick way to establish a good working rapport within group and individual interventions. The Concept Map clusters and statements within those clusters will provide ample topics and examples of caregiver experiences to facilitate discussion with caregivers about their own concerns and needs.

Implications for Future Research

A saturation point of topics related to caregiver perceptions of the effects of giving care to a spouse with dementia has been reached by researchers. There is one topic however, which needs broader investigation. Harris (1993) and Wright (1991) have published lists of statements about coping that were derived from spouse caregivers. Until this present study, only Wright (1993) has published a frequency count of perception statements about coping strategies. A wider array of perception statements about learning to cope should be collected from experienced spouse caregivers. A Concept Map devoted entirely to this issue would be helpful to both future research and intervention.

The Concept Map presented in this study offered a unique conceptualization of perception statements data when compared with researcher generated concepts. There was a difference between researcher generated concepts and caregiver generated concepts of similar perception statements data. There is a need, therefore, for caregiver participation and feedback during all stages of the conceptualization process. This is especially true if the aim of the research is to reflect the way caregivers conceptualize the effects of caregiving on their lives.

Concept Mapping was found to be useful for providing lists of statements and clusters of statements which correlated closely with the Caregiver Burden Inventory. The Concept Map was produced in this study with only 41 participants. This is markedly fewer participants than was needed to provide perception statements and clusters of statements using factor analysis as a basis for scale development. Further research could establish whether Concept Mapping is a useful tool for development of scales and scale items based on self report.

Results from this study can also be used to advance a theory about caregivers that was first postulated by Coppel et al. in 1985. They postulated that cognitions interacted with intrapersonal and interpersonal contexts to affect the way people adjusted to stressors. The Concept Map was used to validate that a caregiver's perceptions about their sense of efficacy or lack of efficacy was an important variable which contributed toward their perceived burden. It was also observed that whether a caregiver focussed more attention on their intramarital interactions or on their extramarital interactions also determined the level of their perceived burden. From these results it was concluded that perceived burden in caregivers would be alleviated by shifting their perceptions to focus on how they are learning to cope, and especially toward the area of their extramarital interactions and relationships. More research is needed to determine how much of a shift in these perceptions would be necessary to decrease perceived burden. Another area for future research would be to establish exactly what kind and what strength of relationship exists between these variables and perceived burden.

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Appendix A: Consent Form #1

Project Title: Concept Mapping: Effects on Caregivers of People With Dementia

Researcher: David Purcell C.Ss.R., M.S.
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Purpose: What is it like for spouses to care for someone with memory problems?

Procedures: On a separate questionnaire there are spaces for you to write personal information. Then, write short sentences about how caring for someone with memory problems affects you. This will take twenty to thirty minutes. This information were combined with information from other people. It were sorted, and then analyzed.

Benefits/ Risks: This study may be useful for those who plan counselling programs. This topic may trigger uncomfortable thoughts for some people. Please contact the researcher who will arrange for counselling. He can be reached at the address and phone number above.

Confidentiality: All questionnaires were stored in a safe location. Do not put your name on the questionnaires. Any information which could identify someone will not be reported. Results from this study will help the researcher finish a Ph.D. in Counselling Psychology. Results may also be presented to professional meetings and magazines.

I voluntarily agree to participate. I may refuse to answer any questions. I am free to stop participating at any time. If I decide to stop, this will not affect present or future care for myself. It will not affect care for any member of my family.

I have read this form and the attached questionnaires. I understand my involvement in this study. I have kept a copy of this consent form.

I know I can contact David Purcell if I have further questions. He can be contacted at the phone number listed above. If I have concerns about any aspect of this study, I know I can contact the Patient Concerns Office of the Capital Health Authority at 474-8892. This office has no affiliation with the study investigator. I know I can also contact Dr. Peter Calder. I can contact him at the University of Alberta, Department of Education Psychology, 492-3696.

____
Signature of Participant Date

____
Signature of Witness Date

The person signing this form appears to understand what is involved in the study and voluntarily agrees to participate.

____
Signature of Researcher Date

PLEASE COMPLETE THIS FORM. PLEASE PLACE IT IN THE ENVELOPE LABELLED 'CONSENT FORM'. SEAL THE ENVELOPE AND RETURN IT TO THE RESEARCHER.

Appendix B: Demographic Questionnaire

QUESTIONNAIRE #1

Please fill out this questionnaire. Place it in the envelope marked "Questionnaire."Return the envelope to the researcher. **Please do not put your name on this questionnaire.**

PLEASE FILL IN THE BLANKS WITH THE CORRECT INFORMATION. FILL IN THE CORRECT BOX WITH AN X.

✍ My age is: ________________

☞ I am: ☐ Female ☐ Male

✍ The highest grade in school that I finished was grade______________.

✍ After grade school the highest level of education that I completed was

(please describe): ____

✍ My first language is __________________________

☞ The person for whom I am caring received a diagnosis of dementia from a doctor.

☐ yes ☐ no

✍ The person for whom I am caring has had problems with their memory for

__________________ months.

Questionnaire #1 (continued)

☞I am related to the person for whom I am caring in the following manner:
    ☐ married partner   ☐ common-law partner

    ☐Other (please explain):______________________________

    ✍ We have been partners for ________________ years

☞Most of the time each week, the person for whom I am caring lives with...
- ☐ me at home
    - ☐ me during the day and then with others during the night
- ☐ in a place outside our home
    - ☐ other; please explain

____

☞ At present I have a paid:
    ☐ part-time job   ☐ full-time job   ☐ no paid job

    ✍ Please describe what kind of a paid job you have.

    ____

☞ At present I am retired.   ☐ yes   ☐ no

    ✍ Before retirement I worked as
    (please describe): __________________________________

✍ Please list the services you receive that assist in caring for your partner:

    ____

    ____

Appendix C: Prompt For Collection of Statements

QUESTIONNAIRE #2

Please list the effects that caring for someone with memory problems has had on you.

1) ____________________

2) ____________________

3) ____________________

4) ____________________

5) ____________________

6) ____________________

7) ____________________

8) ____________________

9) ____________________

10) ____________________

(PLEASE USE MORE PAPER IF YOU HAVE MORE RESPONSES)

Appendix D: Letter of Introduction

Rev. David Purcell C.Ss.R., M.S.
Department of Educational Psychology (403) 450-7490 (daytime)
6-122 Education North, University of Alberta
Edmonton, Alberta T6G 2G5 (403) 474-0341 (messages anytime)

1 April 1997

Dear Sir or Madam,

What is it like for someone to care for their spouse who suffers with memory problems? That is a question I would like to answer through a formal study. If you live at home with your spouse you can help me.

My name is David Purcell. I am conducting a study through the University of Alberta. Results from this study may be useful for those who plan counselling programs. Results from this study will help me finish my Ph.D. in Counselling Psychology.

I would like to ask you about how caring for someone with memory problems affects you. I would also like to ask you for some personal information. For example, I would like to know your phone number and how to contact you. I would like to know how many years you have been with your spouse. I want to ask you how many months your spouse has had memory problems. It will take between twenty and thirty minutes to answer these and other questions that I want to ask you. I could meet with you at your home or at my office.

I will not include your name in my research. **I will treat any information** that you give me **with professional confidentiality**.

Can you help me find out what it is like to care at home, for your spouse who suffers with memory problems? Please call me at my daytime phone number: **450-7490**, or you can leave messages for me at: **474-0341**.

Thank-you for your kind consideration of this matter.
Sincerely,

David Purcell

Rev. David Purcell C.Ss.R., M.S.
Alberta Chartered Psychologist #2112

Appendix E: Statements Collected From Participants

* N=new information; N/A=did not pertain to the prompt; numbers=statements with corresponding information

#	New?*	Statement
Participant #1		
001	N	I get excited too quickly.
002	N	It's hard to explain to her what she needs to do.
003	N	I had to look for two special knives for 3 days and found them in the bathroom.
004	N	Some socks are missing and I can't find them.
005	N	I have to do it by my own, before she used to do all the banking.
006	N	If I lay down for a split second an accident may happen.
007	N	I have to get used to giving in and overlook a lot of stuff.
008	N	I can't go shopping with her anymore.
009	N	I had to buy special bedding and diapers.
010	N	We have to sleep in separate beds.
011	N	I have to always carry my keys because she might lock me out of the house.
012	N	It seems like I'm busy for 24 hours a day.
Participant #2		
013	N	Can never get out on my own - well I should qualify - very seldom on my own. But once a week I play Bridge at the local seniors.
014	N	Underfoot a lot - I never seem to get going on a project.
015	N	Eating habits leave a lot to be desired.
016	N	There are some perks though. He never checks the housekeeping money; and likes eating out (I hate cooking).
017	N	My husband is slow at walking - he take a stick but swings it or puts it over his shoulder.
018	N	My husband doesn't like the wheel-chair - most frustrating.
Participant #3		
019	N	I go some nights without sleep.
020	N	I ended up with an erratic heart and had to go to the hospital.
021	N	I would think, " now what!?", when he would ask me questions.
022	N	Off and on I have to rush him to the hospital.
023	N	He would start blaming me for so many things.
024	N	I try to discipline myself. If he starts accusing me... I just walk off and leave him.
025	N	I have to remind him about his medication and going on his machine.
026	N	It's just repeat, repeat, repeat, - you get kind of like a robot.
027	N	I have to think for both of us.
028	013	I am pretty confined.
029	N	I have to do something for myself once in awhile.
030	N	I have to help him in and out of places all the time.
031	N	It's kind of scary.
Participant #4		
032	N	I'm always very concerned that he's aware of where he is.
033	N	I try to go with him on longer trips across town when he's driving.
034	032	I always wonder, is he going to remember how to get home.
035	N	He has to have a written list of what to do. Then I don't have to prompt him all the time.
036	N	I have to supervise all the odd jobs he likes to do around the home.
037	035	I have to do all the planning ahead.
038	N	It is very stressful for me.

039	N	I have to make decisions on an hourly basis - at the end of the day I am really mentally exhausted.
040	N	I have to be careful how I express decisions I make for him because it provokes anger in him.
041	N	When you live on a day to day basis you learn to adapt.
042	N	You have two jobs: your own daily chores; supervise him at all times but make it look like you're not supervising.
043	N	I find it difficult to take over finances.
044	N	Holiday planning is almost impossible.
045	N	Make sure we're close to medical help if required.
046	N	So many things are your responsibility from talking to dressing for weather.
047	N	You learn to plan ahead and make plans for them and make sure they are things they can handle.
Participant #5		
048	N	Repeated requests for date, appointments, social events, etc.
049	N	Likelihood of my wife getting lost in a hotel, shopping centre, cruise ship.
050	N	Likelihood of my wife getting lost if driving the car - in spite of travelling that route for many times over many years.
051	N	Inability of my wife to remember more than two or three simple chores at one time.
052	N	Failure to write letters. She was a good correspondent in the past.
053	N	She easily loses or misplaces letter, checks, etc. - which she fails to file in appropriate places.
054	N	She sometimes is confused as to the names of your children and grandchildren.
055	N	She cannot remember lay-out of familiar places, e.g. restaurants -is easily lost.
056	27	I am thinking for two people.
Participant #6		
057	N	Restricts ability to go anywhere anytime.
058	N	Causes more stress because don't know how she will behave.
059	N	Results in significantly fewer social interactions.
060	037	Requires a lot more planning for everyday tasks and requirements.
061	N	Gives a greater sense of being needed.
062	N	Sometimes frustrating when she can't do what she used to do.
Participant #7		
063	N	I question myself often.
064	062	Sometimes I'm frustrated because he tried to do things he can't do.
065	058	Every 3 or 4 days there is a mood change and I don't know what to expect.
066	N	How do you keep him busy?
067	064	Sometimes there are things I wish he'd leave alone.
068	N	I've always depended on him a lot. It has changed my life 360 degrees.
069	N/A	He will talk now and you can get him going.
070	N	You are always wondering, "where is he?", and "what's he doing?"
071	N	Forever having to check up on him.
072	N	The minute I'm not around, he comes looking for me.
073	N	I take him shopping with me all the time, so you don't shop very long.
074	N	I pulled a muscle in my back and I told him he'd have to make meals but it didn't ring a bell.
075	N	Sometimes he can't comprehend which pills to take now and which ones later. ... You kind of have to be always ready to be sure of what he's up to.
076	N/A	We had a camping trip to Bowden. I said we'll throw in some sleeping bags and food, and we stayed a couple of days. He didn't get his proper food but that didn't matter to him.
077	N	He gets impatient and restless then I have to argue with him and fight with him.

078	N	I've learned not to say too much unless I know something for sure.
079	N	On the way to the bank he had his cap on and asked, "can't you hurry?"
080	078	I have to learn not to say much and call him too early.
081	N	This makes it hard to think of things that he can do.
082	070	You are always on the alert for things he can do or what he might do. I'm always trying to second guess him and what he might do or why he might do something.

<u>Participant #8</u>

083	038	Stressful.
084	N/A	Memory problems.
085	N	His reasoning is problematic. He gets it fixed in his mind to do something.
086	N	He will argue about his blood sugar levels.
087	N	He's obsessed with having a normal blood sugar level.
088	N	I found him twice, had taken a big dose of insulin and then he was eating because he thinks he's having an insulin reaction. I have to lock up his insulin pump at night.
089	N	I have to tie up the fridge and cupboards at night.
090	003	I spend lots of time looking for things he misplaces.
091	N	He tidies up my stuff but not his stuff and that is stressful especially if you need something a hurry.
092	024	He gets very angry at things and I often have to walk away from it.
093	N/A	It goes in plateaus and then things change again.
094	N	I've had to start laying his clothes out and then I have to be there when he puts them on.
095	062	He's limited in what he can do.
096	N	When he gets angry I try not to take it personally. However, when he's angry a few times a day its hard to distance myself.
097	N	When things get bad I try to go off and read a book.
098	N	My sons tell me to note down any changes that I see in him.
099	N	He can't read because he can't remember what he has read between the top and bottom.
100	N	He'll say that he's seen it all before when he's seen a movie on T.V., but when asked about it he can't tell you what happened.
101	N	Before our family reunion, I couldn't calm him down. I couldn't get my work done and couldn't get enough sleep.
102	N	The doctor gave him a pill that knocked him out and he was wobbly on his feet and I was worried.
103	N	It makes life interesting once in awhile.
104	N	Its sad when this happens to someone who was so active.
105	N	When he wants to go to church, there's no stopping him, you just get in the car and go.
106	092	I get tired of fighting with him.
107	063	Sometimes I wonder if its me causing him to act like that.
108	N/A	These things you deal with.
109	029	Some days you wish you had some time to yourself.
110	N	When he's awake early in the morning, he figures you should be awake too.
111	N	Sometimes I argue with my daughters about how they treat their Dad.
112	N	My daughter has helped out a lot to get an assessment done and all that.
113	058	I don't know how aggressive he might get.
114	N	You have to keep doing these things like medical check-ups.
115	085	It bothers me that he sometimes doesn't see the necessity of shaving and changing clothes.
116	N	We get together with friends and now he gets frustrated with it. But I will say, "play a yellow card" and he enjoys that.

117	N	I find if I have a little patience and understanding it helps.
118	N	I don't know about this machinery stuff too much so I called his brother over when he was changing the oil.
119	063	Is my pride hurting me that he can't do things like he used to?
120	N	His sister was hurt when I told him not to hit the ball. She said he enjoys it. But I was afraid he would fall and hurt himself.
121	N	I just don't need no more problems.
122	N	I try to make the best of it.
123	029	I took a position in the church and decided not to let it all hold me back.
124	029	I decided I needed a little life of my own and do some things I like to do.
125	N	Sometimes he must think I'm a stubborn old woman.
126	N	Sometimes I wish his mother was alive, I'd send him to her to look after him.
127	N	I find with a little laughing and joking we can keep things going.
128	071	I got up in the night and the hot water was still running. I've learned to check a lot when he's come out of any place. You learn to double check on him.
129	N	*It's like going back to when you had children, only you have a man to answer to.*
130	N	He's a little more snoopier. He's always checking into things and I have to learn to cope with it. That's my responsibility I guess.
131	068	It does change your life in many ways.
132	06	You always have to be alert.
133	N	I'm determined to do many things I want. I hate driving on icy streets so I have called a friend to come and pick us up.
134	N	He wanted to go to a church camp. I said, I was not driving and he was so upset. A friend offered to drive us but he was disgusted. We had a nice weekend and I appreciated what those folks did.
135	N	I'm quite a religious person and that helps us both.
136	N	I say lets be thankful for the small things that we have.
137	135	God has given us lots of strength. Without that I could never make it. If it wasn't for church I don't know what I'd do.
138	N	I have a lot of good friends and they sure help. I've said to him, I sure could never repay you and he said you never know if the same thing might happen to me.
139	N	I've got glaucoma and he can't drive.
140	N	You wonder how long we'll be able to spend in our own home.

Participant #9

141	N	First awareness of abnormality in recollection was wife's extreme and untypical criticalness and unfairness
142	N	Have changed personal involvements so as to be able to spend evenings in wife's company - she is more restless
143	037	Required to take more initiative in meal planning (and most other decision making).
144	142	Find I have to be more flexible in personal involvements and commitments.
145	N	We are (together with encouragement from children) planning to move and clearing accumulated "things."
146	144	Learning patience in a new way - as appointments and commitments are sometimes overlooked.
147	N	Arrange to drive my wife as she no longer cares to drive and has been advised not too.
148	N	Subjecting my own activities - point of view - and priorities to accommodate my wife's outlook and preferences.
149	N	Try to screen any phone calls and assess messages as these are sometimes wrong or garbled.
150	N	Am finding it necessary to monitor (unobtrusively) things my wife may give away

or commits to.

Participant #10

151	N	It is very hard to admit to yourself that your own life has changed at least to the same extent as has that of the person you love as you have for the last thirty-four years.
152	N	It takes far longer to admit it to yourself until you must hide until the shaking stops and you no longer cry.
153	N/A	Growing up is never exactly as you thought it was.
154	N/A	My wife as long as she talks or looks at picture or objects the memories for periods of time make her feel much better.
155	N	One of the worst parts of my day is that she forgets what taps and water is. Sometime it has become so bad that I cannot allow her to use the bathtub, or to shampoo herself.
156	N	Every morning before breakfast I make her soak her feet.
157	N/A	Eating for her in the morning is easy because a bowl of cereal and milk is all she has ever had for breakfast.
158	N	It is getting hard to persuade her to stop eating for the next 3 or 4 hours.
159	N	I have never been a good sleeper, but now it takes much longer and I find myself walking around often in less than half an hour.
160	071	I even find myself checking the hot water pipes and checking the balcony and the windows. Sometimes it make me feel sneaky especially when I wake her up and I must explain to her what I am doing.

Participant #11

161	117	At times I have to be very patient about the things he does.
162	N	I have to do the things that I ask him to do - as he doesn't remember.
163	N	He doesn't remember some things - so I just carry on and do my work
164	N	Someone came and took him curling - I felt relaxed.
165	N	I've grown used to the way he carries on over a period of time.
166	N	He walks very slow.
167	N	He lost interest in reading the paper.
168	044	I would like to go to Hawaii, but he won't remember so what's the use of going.
169	N	He used to do all the shovelling and sweeping outside and I do that now.
170	147	I do all the driving now that he does not drive any more.
171	N	When I tell people about him they will tell me about their problems that I never knew about before referring to A.D..

Participant #12

172	N	One evening he came up to me and asked me when his wife had died. It was like he had stabbed me, but then I realized it was the Alzheimers and I said what am I your maid.
173	N	We have been married for 35 years and we renewed our Vows, but he says we should get married so I tell him we are married and he says we have to do it the next day but by the next day he has forgotten.
174	N	The children do not come to see us very often and he quite often asks if we have any and I tell him yes and I have to name them and tell him how old they are and where they are.
175	N	I some times cry after he goes to bed wondering how am I going to keep going but I have a poem that I read and it gives me the strength to keep going.
176	N	He used to help me knit but it is another thing he cannot do so I have not been doing much even though I have plenty of yarn.
177	N	I have learned a lot in the eight years of looking after my husband and I have grown up a great deal in that time and sometimes I am very amazed at myself that I've had the strength to keep going.
178	N	I've managed not to put him in a nursing home and that makes me feel good.

Participant #13

179	115	Feelings of frustration and anger with patient's memory loss and lack of insight.
180	N	Coping with patient's denial has forced me to change my approach, e.g. less confrontation.
181	N	Patient believes he is now 30 years younger and well - this goes against my honesty because I cannot humour him.
182	129	Everyday life is like caring for a young child e.g. have to repeat, simplify sentences.
183	N	Need to enforce enduring power of attorney, take full financial responsibility, monitor his spending.
184	062	Feel frustrated when patient is impatient, e.g. because he can no longer drive and wants to go somewhere right away.
185	N	I have difficulty understanding changes in his personality - e.g. anger, impatience.
186	N	I need to cue him often -e.g. dressing, shaving shovelling walks.
187	N	Sense of hopelessness - he will get worse, uncertainty of future, progression of disease.
188	N	Have to keep patient busy.
189	N	Anger at need to handle junk mail, magazines and items ordered by patient
190	N	Fear of patients' compulsion to take herbs to get better.
191	059	Have a few close friends -find the time to cultivate new ones is difficult.
192	038	Feel very stressed and tense.
193	057	Number of outings has decreased.
194	N	Feel like my hands are tied because patient doesn't want me to tell anyone he has AD.
195	N	Whole load of caregiver falling on me - patient's sons have disowned him.
196	N	Taking one day at a time.

Participant #14

197	N	Slept for 24 hours at one time. I worried that he was not getting enough stimulation.
198	N	Ate poorly - worried about him losing weight and poor nutrition.
199	N	Drank very little - worried about dehydration.
200	N	Couldn't decide what he should wear. I wished he could make this simple decision.
201	N	Didn't like to bath. I found it very stressful wondering how I was going to get him in the bathtub.
202	N	Didn't like to get up in the morning. Found it very stressful talking him into getting up.
203	N	Repeated the same question over many time. Found this very frustrating - could never satisfy him.
204	N	Every day it seems like a big struggle trying to get him to do the simplest things.
205	N	Would stay up without sleeping 48 hours at a time. Worried he was not getting enough sleep. I didn't sleep well.
206	205	Woke me up many times at night.
207	N	I became very tired and it made it difficult to do the necessary day to day things.
208	N	Remove the dishes from the cupboard at puts them on dinning room table during the night. Couldn't stop him from this - made extra work when I was tired and frustrated me.
209	N	Told his one remaining brother that I had to put Malcom in a long term facility because I couldn't look after him. It was obvious to me he hadn't understood what I told him. It made me feel hurt.

Participant #15

210	N	I have to do the banking now.

211 147 I don't like driving in winter and night or great distances but I have to do all the driving.
212 026 I have to repeat thing if we're doing something different - repeat over and over.
213 096 I get upset a little when I see him getting upset with things and I have to try not to show it.
214 N I leave him a note to tell him where I'm going, what time I'll be home and a phone number when I go out.
215 116 We still go out to play bridge and play gin.
216 N I'm not fussy about it but I can't do everything now and we have homecare come in a few times a week.
217 N I have to answer all the telephone calls now.
218 N I have to accept that he doesn't follow a conversation anymore and he withdraws when we go out with friends.
219 N I worry about what will happen to me if he can't live at home anymore.
220 N I am frustrated because having to look after him kind of hangs over you all the time.
221 N It is a worry to think of the future not knowing what will happen and now I'm having trouble sleeping.

Participant #16

222 N I had to tell my neighbours that he was diagnosed with Alzheimer's. It was very upsetting when a neighbour started telling him there was nothing wrong with him
223 N I always have to run when he calls me or else he will come and start screaming at me.
224 N I block things off when people do not believe me and say there is nothing wrong with him.
225 N I get uptight and very nervous when I am around him because I know how he will react and I can't stop him when he runs off.
226 N He's threatened me with a knife and that makes me scared.
227 N I would go and call his cousin to come over because my husband was so angry.
228 N It takes two people to care for someone who is violent. One to care for them and one to control him when he gets upset.
229 N I had to put up a high fence in the back yard.
230 N I felt helpless and hopeless because I didn't know where to turn.
231 N I felt trapped at times. He couldn't be alone and I was a pole that he could lean on all the time.
232 029 I just have to get out for a few days. My whole life has been around him.
233 N For the last two years there has been no conversation and I became very quiet in the house.
234 169 The outside used to be his job but I started doing those things; I started learning to garden and enjoy it.
235 198 He stopped eating and drinking and that got me very concerned.
236 235 I have tried making soups and that worked for awhile but then he stopped eating soups.
237 N I found some cheese the other day that he hid away. It makes me wonder how many other things I will find that he has hidden away.
238 N I try to keep the good memories in mind. He loved camping and we loved sitting outside feeding the squirrels. So I will go to the garage and look at the camp stove.
239 N I felt embarrassed by him a number of times in public - one time he even yelled at me in church.

Participant #17

240 N I have to ride in the car every time he drives.

241	230	I felt like I had everything sucked out of me at first - helplessness
242	N	It's like a horror at first. Slowly I adjusted.
243	N	I always make a point of telling people about his memory problems. I find that a benefit - to tell people.
244	222	At first I was unable to make people believe what I knew.
245	127	I have an upbeat nature so I try to laugh a lot, and tell jokes.
246	N	I was put on anti-depressants and that has made a difference in my coping.
247	183	He always looked after bills and banking and I had to learn to do that.
248	N	When we bought the house I had to do the arrangements because of his memory problems.
249	N	We never go on our own anymore at a mall because we have trouble meeting up again.
250	N	It feels like a tie around my neck.
251	233	One of the hardest things is lack of communication. After 30 some years it is like a turn around because we were always yakking.
252	N	We and our children are more demonstrative about hugging and saying "I love you."
253	N	Our friends all know that he has memory problems. We still get together with them twice a week.
254	N	He and I have had trouble losing the car at the mall.
255	N	We got a bracelet and a care that says Alzheimer's on it.
256	063	I'm never sure what is best.
257	N	I have a hard time getting him to wear enough clothes.

Participant #18

258	221	If something happened to me I'm worried about what would happen to her.
259	046	There is a great dependence on me for her care.
260	048	There is a great strain on me because I have to answer the same question over and over.
261	237	Things get lost and I never know where they'll be.
262	027	I am not only responsible for what I do but for what she does, like checking the stove, doors locked, setting the alarm.
263	175	I am bothered, worried about how much longer I can do these things.
264	049	I have to initiate everything and keep her doing things.
265	040	It is difficult to take control of her life without ruffling her feather.
266	042	I have to give her directions about how to do things all the time.
267	026	I get exasperated about giving directions over and over.

Participant #19

268	049	I have a few scary moments when I have him out, if he happens to wander away from me and I can't find him.
269	026	I do get frustrated at times after telling him a number of times and he does not appear to hear, or does not listen.
270	N/A	His hearing is getting much worse, but he says it is O.K. as a hearing specialist told him that about 10 or 12 years ago.
271	N	In some ways he is easier to get along with now, as formally he was quite stubborn and thought his way was right.
272	271	He is now quite easy to cook for, as he has forgotten all of the things he didn't like, and now will eat anything.
273	N	I feel quite guilty at times at the thought of putting him in a care home, but my children all tell me, I mustn't feel that way, as he brought this on himself, as he has alcoholic dementia.
274	127	Sometimes we have a laugh about things, when he says something, entirely out of context, than what we have been speaking about.
275	N/A	I am quite fortunate in one way, as he does not go out on his own and wander

off, as he does not like to walk, and cannot walk very far now.

Participant #20

276 077 We argue an awful lot.
277 169 I have to look after things I've never done before.
278 077 We disagree about things more than we ever did.
279 179 It makes me seethe when he doesn't do the things I ask him to do.
280 080 I pray to God to help me keep my mouth shut sometimes.
281 177 My faith has really gown through all of this.
282 201 I wonder how I can handle him.
283 077 I have to be tough with him at times.
284 164 I am glad when he sleeps a lot.
285 104 I feel sorry lots of times when I see him going downhill.

Participant #21

286 033 I always have to tell him to slow down - turn here - or drive this way in the car.
287 031 I am always thankful when we get out of the car. My stomach is in a knot.
288 008 I am always limited in going out because I can't leave him alone.
289 152 Sometimes I was mad or disappointed but I tried not to show it.
290 116 I am a social person and he isn't comfortable with anybody.
291 019 If I am sleeping, sometimes he wakes me up.
292 019 Sometimes I have to stay up with him all night.
293 114 I had to take him 5 times in one week to the doctor's.
294 126 I have to shave him and bathe him. It is like when I had a baby in the house.
295 023 He would tell me that things I did for him were all wrong.
296 061 He would tell me he was lucky to have me. Not too many women would do what I did - that made me feel good.
297 195 He is often hanging on to me. I would pray to God that if I have to die he will take my husband and hour before me.
298 104 I would like a shoulder to cry on as well, but I am getting used to it.

Participant #22

299 104 Emotional lability- I sat down on the stairs and cried one day.
300 068 Dependence and Independence - radical change.
301 169 Household became my problem completely.
302 169 Have to develop memory for trivia. Cannot rely on being reminded anymore.
303 020 Since October 96, unable to play squash together. Weight increased despite treadmill exercise. Exercise routine ruined.
304 003 Daily hunt for misplaced articles!
305 033 Losing way when driving
306 081 I awake every morning wondering how to organize her day. The last thing to go was music. When reading ability deteriorated it was very difficult to occupy her mind.
307 063 Difficulty handling the "baffle gabble." Should one agree or disagree with statements wife makes that have no sense or reality.
308 006 Can't leave her alone - she wanders around and liable to switch on electric apparatus, and fawcets, etc.

Appendix F: Statements Edited for Essential Meaning

*N denotes new information;
*numbers denote statements with redundant information
**letters "a" and "b" denote parts of original statement separated into one idea

Participant #	Statement #**	New?*	Statements Edited For Essential Meaning
07	068	N	changed my life
08	103	068	life is interesting
08	131	068	your life changes
10	151	068	life has changed
22	300	068	change my life
09	145a	N	clearing out some possessions
09	145	N	planning to move
01	009	N	buy special supplies
17	255	009	got special supplies
08	130a	N	learn to cope with odd behaviours of spouse
11	165	130a	growing used to spouse's behaviours
17	242a	130a	slowly adjusted
21	298a	130a	getting used to it
04	041	N	live day to day
13	196	041	take one day at a time
13	189	N	anger at spouse's actions
16	239	N	I feel embarrassed by spouse's actions
01	001	N	I get excited
06	061	N	Caring for spouse gives a good sense
12	178	061	caring for spouse makes me feel good
21	296	061	caring for spouse made me feel good
19	273	N	I feel bad not caring for spouse
08	121	N	feel helpless about problems
17	241	121	felt helpless
10	152	N	hide when upset
15	213a	152	try not to show upset
21	289	152	try not to show feelings
13	187	N	sense of hopelessness about disease
16	230	187	feel hopeless about where to turn
17	242	N	like a horror
03	026a	N	get like a robot
11	164	N	feel relaxed when spouse is not around
20	284	164	feel glad when spouse is not around
16	225	N	get nervous in spouse's presence
08	104	N	feel sad
16	225a	104	I cry
20	285	104	feel sorry
21	298	104	feel like crying
22	299	104	sat and cried
03	031	N	scary
16	226	031	makes me scared
19	268	031	have scary moments
21	287	031	I am scared
10	160a	N	feel sneaky
12	172	N	like I was stabbed
16	231	N	felt trapped
17	250	231	like a tie around my neck
15	213	N	get upset with spouse
08	102	N	worried about spouse

08	120a	102	worry about spouse getting hurt
13	190	102	worry for spouse's health
14	197	102	worried about spouse's health
14	198	102	worried about spouse's health
14	199	102	worried about spouse's health
14	205	102	worried about spouse's health
16	235	102	worry about spouse's health
09	141	N	spouse's unusual behaviour made me aware of abnormality
06	058a	N	don't know how spouse will behave
07	065	058a	don't know what behaviour to expect
08	113	058a	don't know how spouse will behave
07	078	N	not say too much
07	080	078	not to say much
09	149	078	screen phone calls
20	280	078	have to control what I say
01	002	N	hard to explain things to spouse
07	074	002	hard to communicate with spouse
08	100	002	can't communicate with spouse
09	149a	002	hard to understand spouse's messages
15	218	002	cannot have conversation with spouse
16	233	002	has been no conversation with spouse
16	233a	002	I became quiet in the house
17	251	002	lack of communication with spouse
03	023	N	spouse would argue
04	040	023	I have to be careful how I express decisions
07	077	023	I argue with spouse
08	086	023	spouse will argue
08	134	023	my decision upset my spouse
16	223	023	spouse will scream
18	265	023	decisions that I make will get spouse upset
20	276	023	we argue
20	278	023	we disagree
20	283	023	have to be tough with spouse
21	295	023	spouse argues
16	222	N	had to tell people about spouse's memory problems
17	243	222	telling people about spouse's memory problems helps
17	253	222	people know about spouse's memory problems
08	098	N	some people don't notice changes in my spouse
16	222a	098	people did not believe my spouse had memory problems
17	244	098	unable to make people believe that spouse has memory problems
03	024	N	walk away from spouse's accusations
08	092	024	walk away from spouse's anger
08	097	024	go off from spouse's anger
13	180	024	do not confront spouse's disagreement
01	012	N	busy for 24 hours a day
14	208a	012	made extra work
01	008	N	can't go shopping with spouse
04	044	008	difficult to holiday with spouse
06	057	008	restricts ability to go anywhere with spouse
07	073a	008	difficult to go out with spouse
08	116	008	difficult to get together with other people
08	139	008	can't drive with spouse
11	168	008	what's the use of a holiday with spouse
15	218a	008	difficult to go out with friends
17	249	008	trouble going out with spouse
21	290	008	difficult to go out socially
02	013	N	seldom get out on my own
03	028	013	I am confined

13	193	013	outings have decreased
21	288	013	I am limited in going out
06	059	N	fewer social interactions
09	142	059	changed personal involvements
13	191	059	difficult finding time for friendships
02	014	N	cannot get going on work
08	101a	014	cannot get work done
12	176	014	not been doing much work
12	177b	N	amazed at my strength
02	016	N	some things are easier
19	271	16	spouse is easier to get along with
19	272	16	spouse is easier to cook for
19	275	16	spouse is easier to supervise
02	013a	N	do things that I like to do
03	029	013a	do something for myself
08	109	013a	need time for yourself
08	123	013a	did something I liked to do
08	124a	013a	do some things I like to do
08	133	013a	determined to do things I want to do
16	232	013a	get our for time on my own
08	122	N	make the best of problems
08	136	122	focus on things for which I am thankful
11	163	122	carry on with work
12	175a	122	focus on something positive
16	224	122	block out people's denial of memory problems
16	238	122	try to keep positive things in mind
12	177	N	learned a lot
12	177a	177	grown up a great deal
20	281	177	have grown
08	127	N	laughing helps us
12	172a	127	try to use humour
17	245	127	try to get us laughing
19	274	127	we laugh about things
08	096	N	try not to take things personally
08	123a	N	decided not to be held back
08	124	123a	I need a life of my own
08	117	N	have to be patient
09	146	117	learn patience
11	161	117	have to be patient
08	135	N	religious practice helps
08	137	135	belief in God helps
08	137a	135	church helps
15	215	N	still got out to socialize
17	253a	215	still get together with friends
17	252	N	family shows affection more often
08	111	N	family argues about how to treat spouse
08	120	111	family disagrees about how to treat spouse
14	209	111	family disagrees about how to treat spouse
12	174	N	do not see family members as often
13	195a	174	do not see family members
01	007	N	give in to spouse
09	144	007	have to be more flexible
09	146a	007	need to be flexible
09	148	007	accommodate spouse
02	015	N	frustrated by spouse's limited ability with tasks
02	017	015	frustrated by spouse's slow ability
05	052	015	frustrated by spouse's failure with tasks
06	062	015	frustrated by spouse's failure to do things

07	064	015	frustrated when spouse's cannot do what spouse used to do
07	067	015	frustrated by spouse's limited ability with tasks
08	095	015	frustrated by spouse's limited ability in what he can do
08	099	015	frustrated by spouse's failure with tasks
11	162	015	frustrated by spouse's limited ability with doing things
11	166	015	frustrated by spouse's slow ability
11	167	015	frustrated by spouse's lost ability with tasks
14	204	015	big struggle with spouse's limited ability with doing things
13	185	N	difficulty understanding changes in spouse's personality
07	079	N	frustrated when spouse is focused to go somewhere
08	085a	079	frustrated when spouse gets fixed in mind to do something
08	087	079	frustrated when spouse gets obsessed
08	105	079	frustrated when there is no stopping spouse
08	130	079	frustrated when spouse keeps checking into things
10	158	079	hard when spouse gets eating fixed in mind
13	184	079	frustrated when spouse is impatient to go somewhere
14	208	079	frustrated when cannot stop spouse from doing something
16	223a	079	frustrated that have to respond to spouse immediately
16	225a	079	can't stop spouse when he gets fixed in mind to go somewhere
08	126	N	spouse is like a child that needs me to be like a mother
08	129	126	it is like being a mother to a child
13	182	126	life is like caring for a child
21	294	126	like caring for a child
02	018	N	frustrated by spouse's reasoning
05	051	018	frustrated with spouse's memory problems
05	054	018	bothered by spouse's mental confusion
08	085	018	problems with spouse's reasoning
08	115	018	bothered by spouse's reasoning
12	173	018	frustrated by spouse's poor memory
13	179	018	frustration with spouse's poor cognitive skills
13	181	018	cannot work with spouse's mental confusion
13	194	018	hands are tied by spouse's poor judgement
14	200	018	wish spouse could make decision
17	257	018	hard time working with spouse's poor judgement
20	279	018	angered by spouse's poor memory
08	101	N	could not calm him
14	203a	101	could never satisfy spouse
16	236	101	cannot satisfy spouse
07	063	N	question myself
08	107	063	wonder if its me causing the problem
08	119	063	question myself
08	125	063	wonder what spouse thinks about me
17	256	063	question myself
22	307	063	wonder how I should respond
03	021	N	frustrated by answering questions over and over
05	048	021	answer questions over and over
12	174a	021	remind spouse over and over
14	203	021	frustrated by answering questions
15	212	021	frustrated by reminding spouse over and over
18	260	021	get strained by answering questions over and over
13	195	N	whole load of caregiving falls on me
15	220	195	load of caregiving hangs over me
04	038	N	stressful for me
06	058	038	causes stress
08	083	038	stressful
13	192	038	feel stressed
14	201	038	found it stressful
14	202	038	found it stressful

03	020	N	My health worsened
17	246	20	I needed medication
22	303	20	health suffered
04	039a	N	I am exhausted
08	106	039a	I get tired
14	207	039a	I became tired
08	112	N	family helped care for spouse
08	118	112	family helped care for spouse
08	133a	112	have others to help me
08	134a	112	appreciated others' help
08	138	112	have others to help me
15	216	112	have others come in to help
16	227	112	call others to help care for spouse
16	228	112	takes others to care for spouse
03	022	N	get medical help
04	045	022	get close to medical help
08	114	022	take spouse for medical help
21	293	022	take spouse to medical help
01	003	N	look for misplaced things
01	004	003	cannot find misplaced things
05	053	003	look for things that get misplaced
08	090	003	look for misplaced things
08	091	003	look for misplaced things
17	254	003	look for things that get misplaced
22	304	003	hunt for misplaced articles
16	237	N	wonder about misplaced objects
18	261	237	never know where things will be found
11	171	N	people tell me about their problems caring for someone with memory problems
03	019	N	go without sleep
08	101b	019	could not sleep
08	110	019	wake up early
10	159	019	much longer to fall asleep
14	205a	019	did not sleep well
14	206	019	woke up many times
15	221a	019	I have trouble sleeping
21	291	019	I wake up
21	292	019	I have to stay up at night
01	010	N	We sleep separately
03	030	N	help spouse with things he/she cannot do alone.
04	033	030	supervise spouse's activity
04	036	030	supervise spouse's jobs
04	046	030	responsible for spouse's activities.
15	217	030	help spouse with things he/she cannot do alone.
17	240	030	supervise spouse's driving
21	286	030	supervise spouse's driving
08	094	N	tend to spouse's personal care
10	155	094	supervise my spouse's personal care
10	156	094	responsible for spouse's personal care
18	259	094	dependence on me for spouse's personal care
21	294a	094	responsible for spouse's personal care
01	006	N	stay alert for accident
01	011	006	stay alert for difficulty
08	132	006	have to remain alert
07	070a	N	wonder what spouse is doing
07	071	070a	check up on spouse
07	075a	070a	be sure of what spouse is doing
07	083	070a	guess what spouse is doing

08	128	070a	check on spouse
09	150	070a	monitor what spouse is doing
10	160	070a	check up on spouse
16	234	N	learn what spouse used to do
20	277	234	look after things that I have never done before
04	032	N	concerned that spouse might get lost
04	034	032	wonder about spouse getting lost
05	049	032	concerned about spouse getting lost
05	050	032	concerned about spouse getting lost
05	055	032	concerned that spouse gets lost
07	070	032	wondering about spouse getting lost
22	305	032	concerned about spouse losing way
13	183	N	take care of personal affairs
17	248	183	look after business arrangements
22	301	183	responsible for household affairs
04	037	N	plan spouse's activities
04	047	037	make plans for spouse
06	060	037	plan spouse's everyday tasks
07	066	037	wonder about things to keep spouse busy
07	081	037	think of things to keep spouse busy
07	082	037	alert for things to keep spouse busy
09	143	037	make decisions about spouse's daily activities
13	188	037	need to keep spouse busy
18	264	037	have to keep my spouse doing things
22	306	037	wonder how to occupy spouse
03	025	N	remind spouse about things
03	026	025	repeat over and over
04	035	025	prompt spouse repeatedly
07	075	025	remind spouse
13	186	025	I cue my spouse
15	214	025	remind my spouse over
18	266	025	give directions to my spouse
18	267	025	give directions over and over
19	269	025	tell spouse a number of times
08	088	N	I lock things up
08	089	088	I tie things up
16	229	088	I had to take special safety precautions
01	005	N	do things that spouse used to do
04	043	005	take over things spouse used to do
09	147	005	do all the driving
11	169	005	do things that spouse used to do
11	170	005	do all the driving
15	210	005	have to do business that spouse used to do
15	211	005	do all the driving
17	247	005	learned to do what spouse used to do
22	302	005	learned to do what spouse used to do
03	027	N	think for two people
04	039	027	make decisions for two people
04	042	027	supervising chores for two people
05	056	027	think for two people
18	262	027	responsible for two people's actions
07	072	N	spouse is always looking for me
07	073	072	spouse could not be left alone
16	231a	072	spouse could not stay alone
21	288a	072	I could not leave spouse alone
21	297a	072	spouse will not stay alone
22	308	072	cannot leave spouse alone
08	140	N	worry about our future

12	175	140	wonder how am going to keep caring
13	187a	140	uncertain about future
15	219	140	worry about what will happen
15	221	140	worry about future
18	258	140	worried about what would happen
18	263	140	worried about how long I can care for spouse
20	282	140	wonder how I can handle spouse
21	297	140	worry about what will happen to spouse

Appendix G: List of 86 Statements

"Please list the effects that caring for someone with memory problems has had on you."

01 Caring for my spouse changes my life.
02 We are clearing out some possessions.
03 We are planning to move.
04 I have to buy special supplies.
05 I am learning to cope with my spouse's odd behaviours.
06 I take one day at a time.
07 I get angry at my spouse's actions.
08 I feel embarrassed by my spouse's actions.
09 I get excited.
10 Caring for my spouse helps me feel good.
11 Not caring for my spouse leaves me feeling bad.
12 I feel helpless.
13 I try not to show that I am upset.
14 I feel hopeless.
15 Caring for my spouse is like a horror.
16 I get like a robot.
17 I feel relaxed when my spouse is not around.
18 I get uptight and nervous around my spouse.
19 I feel sad.
20 I have scary moments.
21 I feel sneaky.
22 I feel like I was stabbed.
23 I feel trapped.
24 I get upset.
25 I worry about my spouse.
26 I am aware of my spouse's abnormality through his or her unusual behaviours.
27 I don't know how my spouse will behave.
28 I control what is said to my spouse.
29 I find it hard to communicate with my spouse.
30 We argue.
31 I tell people about my spouse's memory problems.
32 People do not believe me when I tell them of my spouse's memory problems.
33 I walk away from my spouse's anger.
34 Caring for my spouse makes extra work.
35 I have trouble going anywhere with my spouse.
36 It is hard to get out on my own.
37 I have less time to spend with others.
38 I have a hard time getting work done.
39 I am amazed at my strength.
40 My spouse is easier to get along with.
41 I do some things that I like to do.
42 I focus on something positive.
43 I have grown.
44 I try to get us laughing.
45 I try not to take things personally.
46 I decided that I need a life of my own.
47 I have to be patient.
48 My religious practice helps.
49 We still get together with friends.
50 Our family shows affection more often.
51 Our family disagrees about how to treat my spouse.
52 We do not see our family members as often.
53 I have to be more flexible.
54 I get frustrated when my spouse cannot do what he or she used to do.
55 I have difficulty understanding changes in my spouse's personality.
56 When my spouse gets something fixed in mind, it is frustrating.
57 Everyday life is like caring for a child.
58 I am bothered by my spouse's mental confusion.
59 I cannot satisfy my spouse.
60 I question myself.
61 I get strained by answering questions over and over.
62 The whole load of caring for my spouse falls on me.
63 Caring for my spouse is stressful for me.
64 My health suffers.
65 I get tired.
66 I have others to help me care for my spouse.
67 I have to take my spouse for medical help.
68 I look for things that get misplaced.
69 I never know where I will find things.
70 People will tell me about their problems caring for someone with memory problems.
71 I do not sleep well.
72 We sleep separately.
73 I help my spouse with things he or she cannot do alone.
74 I am responsible for my spouse's personal care
75 I have to stay alert.
76 I check up on my spouse.
77 I do things now that I have never done before.
78 I am concerned about my spouse getting lost.
79 I am responsible for our personal affairs.
80 I plan my spouse's activities.
81 I remind my spouse over and over.
82 I take special safety precautions.
83 I have taken over things that my spouse used to do.
84 I think for two people.
85 I cannot leave my spouse alone.
86 I worry about our future.

Appendix H: Sorting Instructions

DIRECTIONS FOR SORTING

☞ PLEASE READ THE STATEMENTS ON THE SLIPS OF PAPER.

☞ PUT STATEMENTS WHICH SEEM THE SAME INTO THE SAME PILE. DO NOT MAKE PILES ACCORDING TO HOW IMPORTANT ARE THESE STATEMENTS.

☞ THERE MAY BE SEVERAL WAYS TO SORT A STATEMENT. CHOOSE THE WAY WHICH SEEMS BEST FOR YOU.

☞ YOU CANNOT HAVE ONLY ONE PILE.

☞ YOU CANNOT PUT EACH STATEMENT IN ITS OWN PILE. YOU MUST PUT SOME STATEMENTS TOGETHER.

☞ IF A STATEMENT DOES NOT BELONG WITH ANY OTHER STATEMENTS. PLEASE PLACE IT ALONE IN ITS OWN PILE.

☞ WHEN YOU ARE FINISHED, PLEASE STAPLE OR CLIP EACH PILE TOGETHER. PLACE ALL PILES INTO THE ENVELOPE MARKED "PILE SORT". PLACE THIS ENVELOPE IN THE LARGE BROWN ENVELOPE. PLEASE RETURN ENVELOPES TO THE RESEARCHER.

Appendix I: Survey Based on 76 Statements

Questionnaire #2

Please think about these effects on a person of caring for a spouse, numbered 01 through 76. Decide if these statements apply to you...

...**Not At all** ...**SLightly** ...**MOderately** ...**QUite a bit** ...**VEry much**

Please circle the letters below to show how much each statement applies to you.

NA....SL....MO....QU....VE 01. We are clearing out some possessions.

NA....SL....MO....QU....VE 02. I focus on something positive.

NA....SL....MO....QU....VE 03. We argue.

NA....SL....MO....QU....VE 04. I help my spouse with things she or he cannot do alone.

NA....SL....MO....QU....VE 05. Our family shows affection more often.

NA....SL....MO....QU....VE 06. I take one day at a time.

NA....SL....MO....QU....VE 07. I have to be patient.

NA....SL....MO....QU....VE 08. We do not see our family members as often.

NA....SL....MO....QU....VE 09. I have to buy special supplies.

NA....SL....MO....QU....VE 10. I feel like I was stabbed.

NA....SL....MO....QU....VE 11. My spouse is easier to get along with.

NA....SL....MO....QU....VE 12. I have taken over things that my spouse used to do.

NA....SL....MO....QU....VE 13. I have to take my spouse for medical help.

NA....SL....MO....QU....VE 14. I am responsible for our personal affairs.

NA....SL....MO....QU....VE 15. People do not believe me when I tell them of my spouse's memory problems.

NA....SL....MO....QU....VE 16. I feel relaxed when my spouse is not around.

NA....SL....MO....QU....VE 17. I am bothered by my spouse's mental confusion.

NA....SL....MO....QU....VE 18. I tell people about my spouse's memory problems.

NA....SL....MO....QU....VE 19. I have to stay alert.

NA....SL....MO....QU....VE 20. I check up on my spouse.

NA....SL....MO....QU....VE 21. We sleep separately.

NA....SL....MO....QU....VE 22. I get angry at my spouse's actions.

NA....SL....MO....QU....VE 23. I feel hopeless.

NA....SL....MO....QU....VE 24. I have difficulty understanding changes in my spouse's personality.

NA....SL....MO....QU....VE 25. I take special safety precautions.

NA....SL....MO....QU....VE 26. I control what is said to my spouse.

NA....SL....MO....QU....VE 27. I plan my spouse's activities.

NA....SL....MO....QU....VE 28. I worry about my spouse.

NA....SL....MO....QU....VE 29. I do things now that I have never done before.

NA....SL....MO....QU....VE 30. I remind my spouse over and over.

NA....SL....MO....QU....VE 31. I do some things that I like to do.

NA....SL....MO....QU....VE 32. It is hard to get out on my own.

NA....SL....MO....QU....VE 33. I get frustrated when my spouse cannot do what he or she used to do.

NA....SL....MO....QU....VE 34. I don't know how my spouse will behave.

NA....SL....MO....QU....VE 35. I never know where I will find things.

NA....SL....MO....QU....VE 36. People will tell me about their problems caring for someone with memory problems.

NA....SL....MO....QU....VE 37. I worry about our future.

NA....SL....MO....QU....VE 38. I try not to take things personally.

NA....SL....MO....QU....VE 39. I have less time to spend with others.

NA....SL....MO....QU....VE 40. I get tired.

NA....SL....MO....QU....VE 41. Our family disagrees about how to treat my spouse.

NA....SL....MO....QU....VE 42. Caring for my spouse is like a horror.

NA....SL....MO....QU....VE 43. I cannot leave my spouse alone.

NA....SL....MO....QU....VE 44. We still get together with friends.

NA....SL....MO....QU....VE 45. I do not sleep well.

NA....SL....MO....QU....VE 46. The whole load of caring for my spouse falls on me.

NA....SL....MO....QU....VE 47. I feel embarrassed by my spouse's actions.

NA....SL....MO....QU....VE 48. My religious practice helps.

NA....SL....MO....QU....VE 49. I feel sad.

NA....SL....MO....QU....VE 50. I have trouble going anywhere with my spouse.

NA....SL....MO....QU....VE 51. I am concerned about my spouse getting lost.

NA....SL....MO....QU....VE 52. Caring for my spouse helps me feel good.

NA....SL....MO....QU....VE 53. I have a hard time getting work done.

NA....SL....MO....QU....VE 54. I feel helpless.

NA....SL....MO....QU....VE 55. We are planning to move.

NA....SL....MO....QU....VE 56. I am learning to cope with my spouse.

NA....SL....MO....QU....VE 57. I question myself.

NA....SL....MO....QU....VE 58. I have others to help me care for my spouse.

NA....SL....MO....QU....VE 59. When my spouse gets something fixed in mind, it is frustrating.

NA....SL....MO....QU....VE 60. I walk away from my spouse's anger.

NA....SL....MO....QU....VE 61. I try not to show that I am upset.

NA....SL....MO....QU....VE 62. Caring for my spouse is stressful for me.

NA....SL....MO....QU....VE 63. I get like a robot.

NA....SL....MO....QU....VE 64. I try to get us laughing.

NA....SL....MO....QU....VE 65. My health suffers.

NA....SL....MO....QU....VE 66. I find it hard to communicate with my spouse.

NA....SL....MO....QU....VE 67. I cannot satisfy my spouse.

NA....SL....MO....QU....VE 68. I feel sneaky.

NA....SL....MO....QU....VE 69. I have to be more flexible.

NA....SL....MO....QU....VE 70. I get upset.

NA....SL....MO....QU....VE 71. I look for things that get misplaced.

NA....SL....MO....QU....VE 72. Everyday life is like caring for a child.

NA....SL....MO....QU....VE 73. I am responsible for my spouse's personal care.

NA....SL....MO....QU....VE 74. I get strained by answering questions over and over.

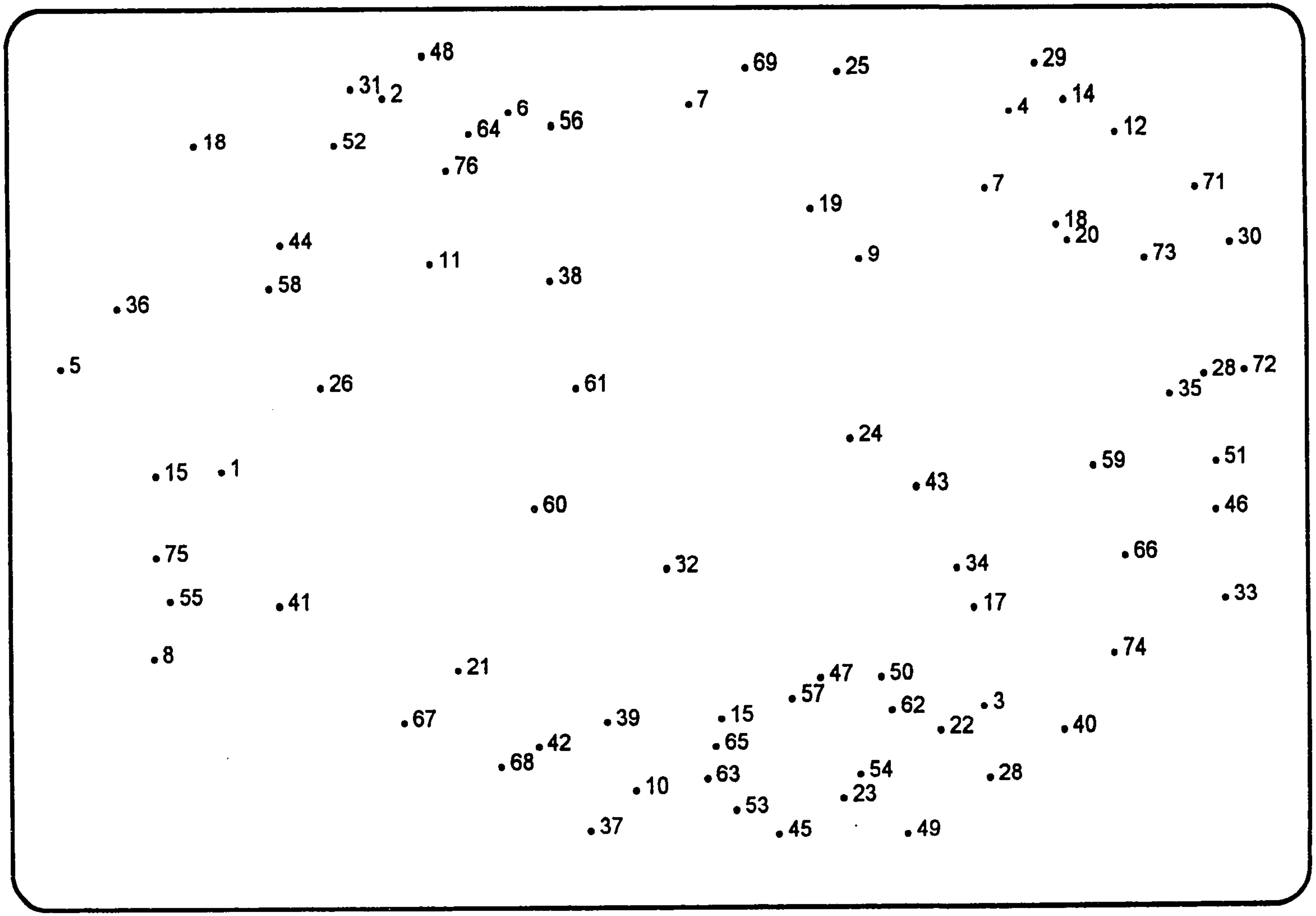
NA....SL....MO....QU....VE 75. I decided that I need a life of my own.

NA....SL....MO....QU....VE 76. I am amazed at my strength.

Appendix J: Number of Statements Collected

Participant	Collected	New Information
01	12	10
02	07	06
03	14	11
04	17	05
05	09	00
06	07	03
07	24	06
08	68	18
09	13	03
10	11	02
11	11	02
12	12	04
13	20	05
14	16	00
15	15	02
16	24	06
17	20	02
18	10	00
19	08	01
20	10	00
21	18	00
22	12	00

Appendix K
Multidimensional Scaling Point Map



Appendix L: Six Cluster Solution and Bridging Values

Please list the effects that caring for someone with memory problems has had on you.

Cluster 1
32. It is hard to get out on my own (0.24)
60. I walk away from my spouse's anger (0.35)
61. I try not to show that I am upset (0.44)
41. Our family disagrees about how to treat my spouse (0.59)
26. I control what is said to my spouse (0.65)
01. We are clearing out some possessions (0.79)
36. People tell me about their problems caring for someone with memory problems (0.79)
55. We are planning to move (0.80)
05. Our family shows affection more often (0.86)
08. We do not see our family members as often (0.95)
75. I decided that I need a life of my own (0.90)
15. People do not believe me when I tell them of my spouse's memory problems (1.00)
Cluster Average = 0.70

Cluster 2
64. I try to get us laughing (0.30)
02. I focus on something positive (0.36)
48. My religious practice helps (0.36)
56. I am learning to cope with my spouse (0.38)
06. I take one day at a time (0.39)
52. Caring for my spouse helps me feel good (0.40)
76. I am amazed at my strength (0.42)
38. I try not to take things personally (0.43)
11. My spouse is easier to get along with (0.48)
58. I have others to help me care for my spouse (0.51)
31. I do some things that I like to do (0.53)
44. We still get together with friends (0.57)
18 I tell people about my spouse's memory problems (0.90)
Cluster Average = 0.47

Cluster 3
04. I help my spouse with things she or he cannot do alone (0.33)
12 I have taken over things that my spouse used to do (0.33)
13. I have to take my spouse for medical help (0.35)
20. I check up on my spouse (0.36)
09. I have to buy special supplies (0.37)
14. I am responsible for our personal affairs (0.38)
27. I plan my spouse's activities (0.40)
73 I am responsible for my spouse's personal care (0.41)
19. I have to stay alert (0.43)
29 I look after things that I have never done before (0.45)
07. I have to be patient (0.47)
25. I take special safety precautions (0.48)
69. I have to be more flexible (0.56)
71. I look for things that get misplaced (0.68)
30. I remind my spouse over and over (0.73)
Cluster Average = 0.45

Cluster 4
34. I don't know how my spouse will behave (0.11)
17. I am bothered by my spouse's mental confusion (0.14)
43. I cannot leave my spouse alone (0.15)
24. I have difficulty understanding changes in my spouse's personality (0.25)
74. I get strained by answering questions over and over (0.36)
66. I find it hard to communicate with my spouse (0.37)
59. When my spouse gets something fixed in mind, it is frustrating (0.41)
35. I never know where I will find things (0.52)
51. I am concerned about my spouse getting lost (0.60)
33 I get frustrated when my spouse cannot do what he or she used to do (0.64)
46. The whole load of caring for my spouse falls on me (0.69)
28. I worry about my spouse (0.71)
72. Everyday life is like caring for a child (0.72)
Cluster Average = 0.44

Cluster 5
47. I feel embarrassed by my spouse's actions (0.01)
50. I have trouble going anywhere with my spouse (0.01)
23. I feel hopeless (0.04)
54. I feel helpless (0.04)
62. Caring for my spouse is stressful for me (0.06)
22. I get angry at my spouse's actions (0.06)
57. I question myself (0.09)
70. I get upset (0.28)
03. We argue (0.33)
49. I feel sad (0.34)
40. I get tired (0.45)
Cluster Average = 0.16

Cluster 6
65. My health suffers (0.00)
63. I get like a robot (0.07)
16. I feel relaxed when my spouse is not around (0.09)
45. I do not sleep well (0.14)
10. I feel like I was stabbed (0.18)
39. I have less time to spend with others (0.19)
53. I have a hard time getting work done (0.25)
42. Caring for my spouse is like a horror (0.30)
21. We sleep separately (0.44)
67. I cannot satisfy my spouse (0.48)
68. I feel sneaky (0.54)
37 I worry about our future (0.54)
Cluster Average = 0.27

Appendix M: Eight Cluster Solution and Bridging Values

Please list the effects that caring for someone with memory problems has had on you.

Cluster 1
41. Our family disagrees about how to treat my spouse (0.59)
26. I control what is said to my spouse (0.65)
01. We are clearing out some possessions (0.79)
36. People tell me about their problems caring for someone with memory problems (0.79)
55. We are planning to move (0.80)
05. Our family shows affection more often (0.86)
08. We do not see our family members as often (0.95)
75. I decided that I need a life of my own (0.90)
15. People do not believe me when I tell them of my spouse's memory problems (1.00)
Cluster Average = 0.82

Cluster 2
32. It is hard to get out on my own (0.24)
60. I walk away from my spouse's anger (0.35)
61. I try not to show that I am upset (0.44)
Cluster Average = 0.34

Cluster 3
64. I try to get us laughing (0.30)
02. I focus on something positive (0.36)
48. My religious practice helps (0.36)
56. I am learning to cope with my spouse (0.38)
06. I take one day at a time (0.39)
52. Caring for my spouse helps me feel good (0.40)
76. I am amazed at my strength (0.42)
38. I try not to take things personally (0.43)
11. My spouse is easier to get along with (0.48)
58. I have others to help me care for my spouse (0.51)
31. I do some things that I like to do (0.53)
44. We still get together with friends (0.57)
18 I tell people about my spouse's memory problems (0.90)
Cluster Average = 0.47

Cluster 4
04. I help my spouse with things she or he cannot do alone (0.33)
12 I have taken over things that my spouse used to do (0.33)
13. I have to take my spouse for medical help (0.35)
20. I check up on my spouse (0.36)
14. I am responsible for our personal affairs (0.38)
27. I plan my spouse's activities (0.40)
73 I am responsible for my spouse's personal care (0.41)
29 I look after things that I have never done before (0.45)
71. I look for things that get misplaced (0.68)
30. I remind my spouse over and over (0.73)
Cluster Average = 0.44

Cluster 5
09. I have to buy special supplies (0.37)
19. I have to stay alert (0.43)
07. I have to be patient (0.47)
25. I take special safety precautions (0.48)
69. I have to be more flexible (0.56)
Cluster Average = 0.46

Cluster 6
34. I don't know how my spouse will behave (0.11)
17. I am bothered by my spouse's mental confusion (0.14)
43. I cannot leave my spouse alone (0.15)
24. I have difficulty understanding changes in my spouse's personality (0.25)
74. I get strained by answering questions over and over (0.36)
66. I find it hard to communicate with my spouse (0.37)
59. When my spouse gets something fixed in mind, it is frustrating (0.41)
35. I never know where I will find things (0.52)
51. I am concerned about my spouse getting lost (0.60)
33 I get frustrated when my spouse cannot do what he or she used to do (0.64)
46. The whole load of caring for my spouse falls on me (0.69)
28. I worry about my spouse (0.71)
72. Everyday life is like caring for a child (0.72)
Cluster Average = 0.44

Cluster 7
47. I feel embarrassed by my spouse's actions (0.01)
50. I have trouble going anywhere with my spouse (0.01)
23. I feel hopeless (0.04)
54. I feel helpless (0.04)
62. Caring for my spouse is stressful for me (0.06)
22. I get angry at my spouse's actions (0.06)
57. I question myself (0.09)
70. I get upset (0.28)
03. We argue (0.33)
49. I feel sad (0.34)
40. I get tired (0.45)
Cluster Average = 0.16

Cluster 8
65. My health suffers (0.00)
63. I get like a robot (0.07)
16. I feel relaxed when my spouse is not around (0.09)
45. I do not sleep well (0.14)
10. I feel like I was stabbed (0.18)
39. I have less time to spend with others (0.19)
53. I have a hard time getting work done (0.25)
42. Caring for my spouse is like a horror (0.30)
21. We sleep separately (0.44)
67. I cannot satisfy my spouse (0.48)
68. I feel sneaky (0.54)
37 I worry about our future (0.54)
Cluster Average = 0.27

Appendix N: Final Cluster Solution and Bridging Values

Please list the effects that caring for someone with memory problems has had on you.

Cluster 1
41. Our family disagrees about how to treat my spouse (0.59)
26. I control what is said to my spouse (0.65)
01. We are clearing out some possessions (0.79)
36. People tell me about their problems caring for someone with memory problems (0.79)
55. We are planning to move (0.80)
05. Our family shows affection more often (0.86)
08. We do not see our family members as often (0.95)
75. I decided that I need a life of my own (0.90)
15. People do not believe me when I tell them of my spouse's memory problems (1.00)
Cluster Average = 0.82

Cluster 2
32. It is hard to get out on my own (0.24)
60. I walk away from my spouse's anger (0.35)
61. I try not to show that I am upset (0.44)
Cluster Average = 0.34

Cluster 3
64. I try to get us laughing (0.30)
02. I focus on something positive (0.36)
48. My religious practice helps (0.36)
56. I am learning to cope with my spouse (0.38)
06. I take one day at a time (0.39)
52. Caring for my spouse helps me feel good (0.40)
76. I am amazed at my strength (0.42)
38. I try not to take things personally (0.43)
11. My spouse is easier to get along with (0.48)
58. I have others to help me care for my spouse (0.51)
31. I do some things that I like to do (0.53)
44. We still get together with friends (0.57)
18 I tell people about my spouse's memory problems (0.90)
Cluster Average = 0.47

Cluster 4
04. I help my spouse with things she or he cannot do alone (0.33)
12 I have taken over things that my spouse used to do (0.33)
13. I have to take my spouse for medical help (0.35)
20. I check up on my spouse (0.36)
09. I have to buy special supplies (0.37)
14. I am responsible for our personal affairs (0.38)
27. I plan my spouse's activities (0.40)
73 I am responsible for my spouse's personal care (0.41)
19. I have to stay alert (0.43)
29 I look after things that I have never done before (0.45)
07. I have to be patient (0.47)
25. I take special safety precautions (0.48)
69. I have to be more flexible (0.56)
71. I look for things that get misplaced (0.68)
30. I remind my spouse over and over (0.73)
Cluster Average = 0.45

Cluster 5
34. I don't know how my spouse will behave (0.11)
17. I am bothered by my spouse's mental confusion (0.14)
43. I cannot leave my spouse alone (0.15)
24. I have difficulty understanding changes in my spouse's personality (0.25)
74. I get strained by answering questions over and over (0.36)
66. I find it hard to communicate with my spouse (0.37)
59. When my spouse gets something fixed in mind, it is frustrating (0.41)
35. I never know where I will find things (0.52)
51. I am concerned about my spouse getting lost (0.60)
33 I get frustrated when my spouse cannot do what he or she used to do (0.64)
46. The whole load of caring for my spouse falls on me (0.69)
28. I worry about my spouse (0.71)
72. Everyday life is like caring for a child (0.72)
Cluster Average = 0.44

Cluster 6
47. I feel embarrassed by my spouse's actions (0.01)
50. I have trouble going anywhere with my spouse (0.01)
23. I feel hopeless (0.04)
54. I feel helpless (0.04)
62. Caring for my spouse is stressful for me (0.06)
22. I get angry at my spouse's actions (0.06)
57. I question myself (0.09)
70. I get upset (0.28)
03. We argue (0.33)
49. I feel sad (0.34)
40. I get tired (0.45)
Cluster Average = 0.16

Cluster 7
65. My health suffers (0.00)
63. I get like a robot (0.07)
16. I feel relaxed when my spouse is not around (0.09)
45. I do not sleep well (0.14)
10. I feel like I was stabbed (0.18)
39. I have less time to spend with others (0.19)
53. I have a hard time getting work done (0.25)
42. Caring for my spouse is like a horror (0.30)
21. We sleep separately (0.44)
67. I cannot satisfy my spouse (0.48)
68. I feel sneaky (0.54)
37 I worry about our future (0.54)
Cluster Average = 0.27

Appendix O: Labels for Clusters

Derived by Researcher

Cluster #1: Managing the Environment
Cluster #2: Disengaging
Cluster #3: Learning to Cope
Cluster #4: Assuming New Roles
Cluster #5: Reacting to Spouse's Confusion
Cluster #6: Feeling Helpless
Cluster #7: Burning Out

Derived by Alzheimer Support Group

Cluster #1: Managing the Situation; Covering the Big Picture; Taking Control; Juggling; Managing the Surroundings.
Cluster #2: Caregiver Second; Frustration for Caregiver; Helplessness; Self-Denial; Limiting Self-Expression
Cluster #3: Discovering Coping Strategies; Taking Initiative; More Positive Outlook; Taking One Day at a Time; Finding Strength
Cluster #4: All Responsibility; Solely Responsible; Re-learning; Shifting Responsibility; Extending One's Patience; A New Set of Rules for an Old Relationship
Cluster #5: Uncertainty, Anxiety, Communication Breakdown, Anxious, Second Guessing
Cluster #6: Wholly Negative Feelings; Trapped; Depression; Confusion About It All; Helplessness
Cluster #7: Why?; Unfulfilled - Inadequate; Victimized; Burn-out; Sliding into Self-Pity; Lowliness - Resentful

Two Labels Selected by Support Group Before Final Labels Were Selected

Cluster #1: Managing Our Surroundings; Managing the Environment
Cluster #2: Disengaging; Limiting Self-Expression
Cluster #3: Discovering Coping Strategies; Learning to Cope
Cluster #4: A New Set of Rules for an Old Relationship; Shifting Responsibilities
Cluster #5: Uncertainty; Reacting to Spouse's Confusion
Cluster #6: Helplessness; Feeling Helpless.
Cluster #7: Burning Out; Burn-out