

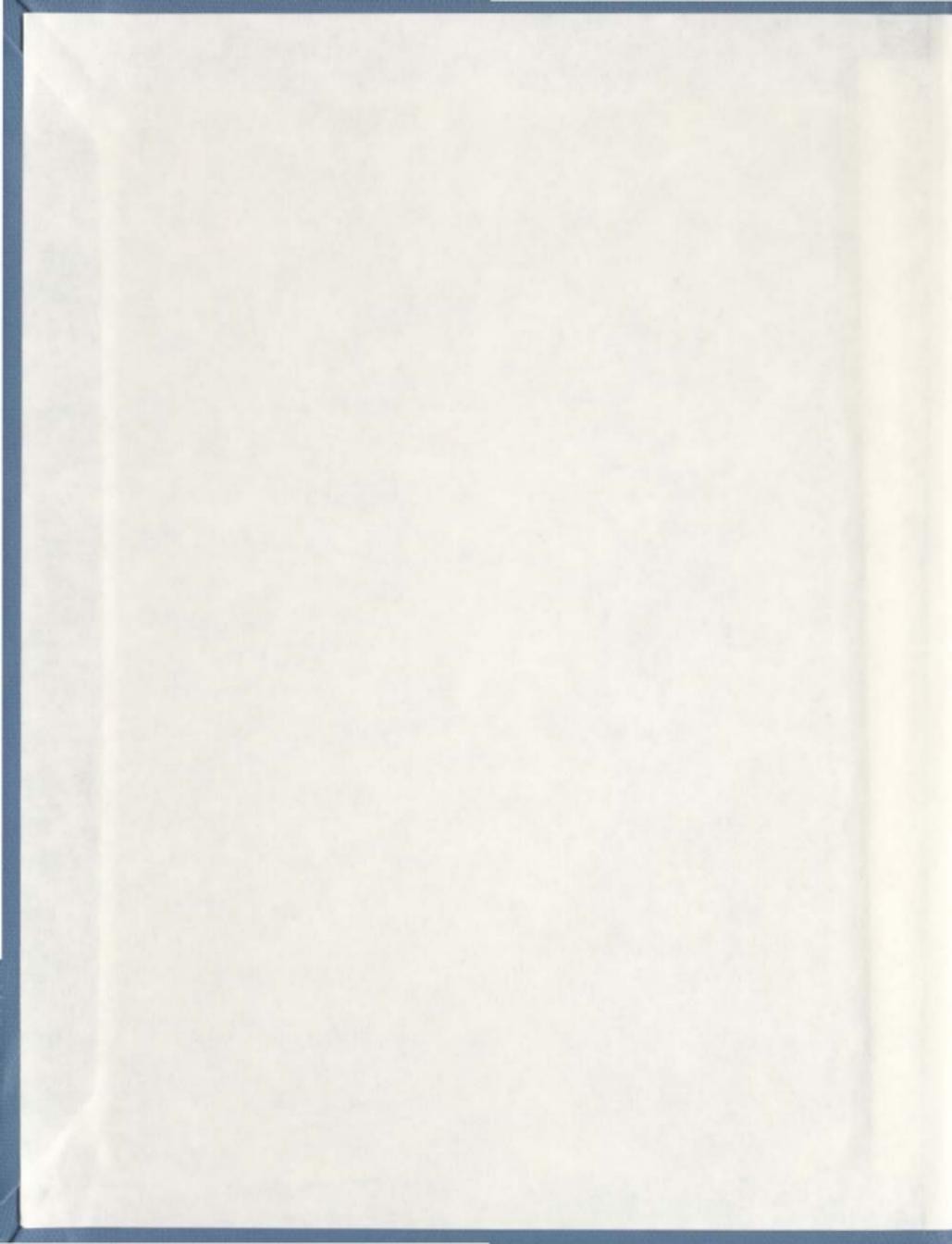
THE EXPERIENCE OF CAREGIVING FOR A FAMILY
MEMBER WITH ALZHEIMER'S DISEASE:
A MALE PERSPECTIVE

CENTRE FOR NEWFOUNDLAND STUDIES

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**The Experience Of Caregiving For A Family Member With
Alzheimer's Disease: A Male Perspective**

by

Karen Ann Parsons

A thesis submitted to the school of graduate studies in
partial fulfilment of the requirements for the degree of
Master of Nursing

School of Nursing
Memorial University of Newfoundland
St. John's, Newfoundland
August, 1994



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Dedicated to the memory of three grandparents,
Mr. John A. Parsons, Mrs. Martha Ann Parsons
and Mr. William T. Hardy, and to my grandmother,
Mrs. Irene Hardy.

ABSTRACT

**The Experience Of Caregiving For A Family Member With Alzheimer's
Disease: A Male Perspective**

There is little research in the literature on men as caregivers for a family member with Alzheimer's disease. Most of the previous work has concentrated on the burden or stress related to this type of care and has been done mostly with women. In the present study a phenomenological method was used to investigate the male experience of caregiving for a family member with Alzheimer's disease.

Eight men, five spouses and three sons were interviewed in order to find out what their experiences were like. From the analysis of the interview data nine themes were identified. The themes were (a) enduring, (b) vigilance, (c) a sense of loss, (d) aloneness and loneliness, (e) taking away, (f) searching to discover, (g) the need for assistance, and (h) reciprocity. An additional theme was identified from the experience of the son caregivers: (i) overstepping the normal boundaries. The themes were not isolated, but were interrelated to form a whole that captured the experience of caregiving for the male caregivers. The significance or essence of the experience was the disease itself, without which the caregiving experience could not have been what it was. Implications for nursing practice, nursing education and nursing research are discussed.

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I would first like to extend a sincere thank-you to all the participants who took the time to share the private thoughts and feelings of their caregiving experience with me.

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CHAPTER 1

INTRODUCTION

Despite an increase in specialized nursing homes, the family is still viewed as the major support and source of caregivers for the elderly who may be frail and/or functionally disabled (Aronson, 1990; Chappell, 1992; Jutras & Renaud, 1989). This pattern of caregiving has remained constant over the past decade or so (Shanas, 1979) as well as across cultures (Kane, Evans, & MacFadyen, 1990). Although we use the term "family caregivers", in reality it is usually only one family member who takes primary responsibility for its sick or frail elderly regardless of family size or constitution (Johnson, 1983; Stoller & Earl, 1983; Tennstedt, McKinlay, & Sullivan, 1989). These individual family members are referred to in the literature as informal caregivers to distinguish them from professional caregivers within our health and social systems (Chappell, 1992; Stephens & Christianson, 1986).

Within the family context it is women, as spouses or daughters, who are most frequently the source of informal care to the aged (Dwyer & Coward, 1992; Kramer, 1991; Stone, 1988). There are, however, clearly identifiable groups of men who are primary caregivers to frail elderly and those with physical and mental disabilities (Kaye & Applegate,

1990).

Recent changes in the demographic profile of the elderly and changes in other general social and health trends will have implications for caregiving by family members. With an increase in the population of elderly in Canada there has been a corresponding increase in chronic illness in this age group (Stone & Fletcher, 1986), which naturally translates into more care required by family members.

Dementia is one of the chronic illnesses in which there has been an increase in incidence (Kokmen, Beard, O'Brien, Olford, & Kurland, 1993). Dementia, in turn, is one of the major causes of chronic disability in the elderly, and the principle form of dementia is Alzheimer's disease (Hutton, 1991). Alzheimer's disease is a progressive dementia, characterized by profound memory loss, impairment of judgement, disorientation, decline in ability to perform routine tasks, learning difficulties, loss of language skills, and personality changes. There are various stages in the progression of the disease. In the last stage of the disease, the affected person becomes totally incapable of caring for themselves thus requiring care by others (Iqbal, 1991).

The majority of individuals with Alzheimer's disease are cared for by family members at home. Less than ten

percent of these families use formal services and they do so only for the most severely impaired elderly (Stone, Cafferta, & Sangl, 1987). As the disease progresses, individuals with Alzheimer's disease lose most of their cognitive and physical abilities and commonly display behavioral disturbances, such as wandering. Caring for such a person often generates financial difficulties, physical health problems, and emotional strain for caregivers (Cantor, 1983; Colerick & George, 1986; George & Gwyther, 1986).

More women than men are diagnosed with Alzheimer's disease which suggests that men may be increasingly required to take on the role of caregiver (Brody, 1985). Although there is increasing research and discussion on the male caregiver in general, most research on caring for relatives with dementia has focused on the female. This study explores the male experience of caregiving for a family member with Alzheimer's disease. A phenomenological mode of inquiry is used for this purpose.

The remainder of chapter one will outline the rationale and research question. Chapter two is a presentation of the literature review pertinent to the focus of the research. Chapter three contains a discussion of phenomenology as a methodology with special attention to the approach as outlined by van Manen (1990). The findings will be

presented in chapter four. Chapter five is a discussion of the findings and finally, chapter six explores the nursing implications and limitations of the study.

Rationale and Statement of the Problem

The impetus for this research comes from my nursing practice. While working as a community health nurse, I observed that caring for a family member with Alzheimer's disease was a very complex experience. Caregiving entailed more than a caregiver struggling to cope with an enormous burden. Interactions between the caregiver and care-recipient are shaped by a longstanding relationship characterized by many emotional and/or physical ties. The relationship itself, both past and present, is a part of the caregiving experience for the caregiver. The experience of caregiving is a dynamic one, involving a process of give and take between caregiver and care-recipient, other individuals such as family and friends, health professionals, and many others. These interactions may be both positive and negative and have great significance for the caregiver in forming the caregiving experience.

Caregivers are made up of individuals who feel, act, and respond differently while carrying out their various

roles. Their care-recipients, too, are individuals possessing unique characteristics that serve to frame the overall experience. With such a wide variation of personal characteristics and interaction processes taking place within the caregiving relationship there is much complexity and diversity in caregiving experiences. Yet, little research attention has been given to the experience of caregiving itself; what this experience is like for individuals who assume the caregiving role.

Most research on caring for individuals with Alzheimer's disease is based on the assumption that caregiving is costly resulting in unpleasant consequences such as burden. As a result researchers frequently have used a stress/coping framework to guide their research (Farran, Keane-Hagerty, Salloway, Kupferer, & Wilken, 1991). Generally research has focused on the types of burden experienced by family caregivers (Cantor, 1983; Colerick & George, 1986; George & Gwyther, 1986; Zarit, Todd, & Zarit, 1986), or alternatively the negative consequences of this burden (Gallager, Rose, Rivera, Lovett, & Thompson, 1989; Morrissey, Becker, & Rubert, 1990; Pruchno & Resch, 1989; Wright, 1991). Other research has looked at ways of coping with the caregiving experience, such as, the use of various support systems (Baillie, Norbeck, & Barnes, 1988; Green & Monahan, 1989; Robinson, 1990; Soldo & Mylluoma, 1983;

Zarit, Reeve, & Bach-Peterson, 1980). Still others have studied what the process of caregiving is like when caring for a family member with Alzheimer's disease (Lindgren, 1993; Watson, 1979; Willoughby & Keating, 1991). While the above research studies give some insight into caring for these individuals this researcher wanted to develop a deeper insight into the caregiving experience.

Most research on caregiving has tended to focus on the female caregiver although some research on caregiver burden has included gender differences (Barusch & Spaid, 1989; Fitting, Rabins, Lucas, & Eastham, 1986, Horowitz, 1985; Miller & Cafasso, 1992; Parks & Pilisuk, 1991). Too few studies have focused exclusively on the male experience (Harris, 1993; Kaye & Applegate, 1990). This predominance of research on women as caregivers may be due to the fact that in Western societies the role of primary caregiver in families has traditionally been performed by wives and daughters (Stone et al., 1987). However, two demographic trends suggest that this pattern may be changing. First, the trend towards smaller families reduces the probability of having a female offspring available to be a caregiver. Second, the increase in the proportion of women in the workplace decreases the time available for caregiving activities (Horowitz, 1985). As more men assume the role of informal caregivers there is a need to understand that

experience from their perspective (Gregory, Peters, & Cameron, 1990). Gender differences permeate all aspects of our lives as men and women, and when little is known about a particular gender's perspective, it is important and legitimate to study that perspective (Eichler & Lapointe, 1985). While research in this particular area is increasing, there is still a gap in the literature with regards to the experience of men who care for a family member with Alzheimer's disease and as a consequence little is known about their actual experience (Harris, 1993).

A third rationale for doing this research comes from the interaction between the demographic changes of an older population and social policy trends. As the number of older people increases, informal caregiving will increase because of financial cutbacks to health and social programs, and, therefore, increased demands will be put on informal caregivers. Although the majority of the elderly are healthy and capable of caring for themselves or needing only minimal assistance, a small proportion will require caregiving by family members. With more men undertaking the primary caregiving role, a greater understanding of their experience is essential to assist nurses and other health care professionals in helping/ assisting them as caregivers. A greater understanding of men's experience is required in order to design appropriate intervention strategies that

offer tangible assistance and emotional support.

Finally, within health promotion in Canada there has been an identified need for research on men as caregivers to investigate "men's potential to be caregivers" (Jutras & Renaud, 1989, p. 38). Hopefully, this present research will contribute in a meaningful way to that developing area. The research question that will be addressed in this study is: What is it like for a man to care for a family member with Alzheimer's disease?

CHAPTER 2

LITERATURE REVIEW

The literature on caregiving may be divided into formal and informal caregiving. Formal caregiving refers to health and other service professions and paraprofessionals who work in governmental and non-governmental agencies providing a variety of services to the public (Chappell, 1992). Over the past few decades there has been a proliferation of literature on caring and caregiving within the various professions. Because nurses form the largest single professional group within health care, it is not surprising that much of the literature on formal caregiving has focused on the nurse. This particular literature ranges from broad approaches to caring (Benner & Wrubel, 1989; Leininger, 1981; Watson, 1979) to research that has addressed the nurse as caregiver in specific health care situations (Cronin & Harrison, 1988; Larson, 1987; Swanson-Kauffman, 1986).

Informal caregiving, in contrast to formal caregiving, is the care given by family and friends to individuals whose physical and/or mental health has deteriorated (Chappell, 1992). Informal care occurs more commonly than formal care, in that most individuals receive care from family and friends. The research literature to some extent reflects this reality in that a good deal of research has been done

on informal care and caregivers. Much of the literature on family caregiving is fairly broad, addressing, for example, caregiving dynamics of family members across cultures (Phillips, Hernandez, & de Ardon, 1994). Other literature is much more specific, for example, caring for an adult child with mental illness or mental retardation (Greenberg, Seltzer, & Greenley, 1993) or a family member with AIDS (Brown & Powell-Cope, 1991).

It is not within the scope of this thesis to present the vast body of literature on caregiving. However, it is important to acknowledge this literature both for its contribution in providing a greater insight into the caregiving role and for facilitating a more informed approach to the present study. Therefore only selected findings will be highlighted in the following review; (a) literature reviews on family caregiving to elderly family members with Alzheimer's disease or other forms of dementia, (b) the process of caregiving for a family member with Alzheimer's disease or some form of dementia, (c) the consequences of caregiving for impaired elderly family members, i.e., caregiver burden, (d) mediators of caregiving, i.e., social support, and (e) the experience of family caregiving, including men as caregivers. All five areas address caregiving for an elderly family member with a functional disability, usually Alzheimer's disease.

Additionally, the fifth area addresses what is known about the experience of caregiving specifically regarding male caregivers, the focus of this research.

Literature Reviews on Caregiving

A number of authors have provided literature reviews related to informal caregiving within the family of a frail elderly family member, or a family member with Alzheimer's disease or some form of dementia (Bergman-Evans, 1994; Given & Given, 1991; Kuhlman, Wilson, Huthchinson, & Wallhagen, 1991; Mass & Buckwalter, 1991; Schultz, Visintainer, & Williamson, 1990).

In her review of studies of individuals caring for a spouse with Alzheimer's disease Bergman-Evans (1994) examined research that addressed the feelings of loneliness and depression during caregiving, and caregivers' perceptions of formal and informal social support. A predominant finding was that even though the care-recipients were still alive, these individuals had somehow been replaced by strangers. This, and the caregiver's experience of decreased social participation and isolation from the community resulted in loneliness. There appears to be a link between the chronic burdens of caregiving for a person

with dementia and the onset of depressive disorders. Feelings of hopelessness, despair, and loss of control associated with caregiving are also found to contribute to the experience of depression. Bergman-Evans (1994) also reported findings of an inverse relationship between the level of depression and the level of social support. This literature review is limited in that it does not have any conclusions or make any recommendations for future areas of research. It does, however, provide clinical implications for health care workers who will come in contact with this group of caregivers who are experiencing loneliness and depression.

Given and Given (1991) synthesized literature on the process of caring for a frail elderly individual in the home, the caregivers' reactions to the caregiving process, and the impact of caregiving on caregiver's physical health, employment, and other roles. The authors noted that studies of the caregiving process focused mainly on the specific care tasks of the caregiver, such as cooking and cleaning. They also found that reactions to caring were both positive and negative even though most research had focused on the negative impact of caregiving. Missing from this review was research on how competing role demands impinge on the caregiving process. The authors recommend that more research be done in the area of how families make decisions

about the long term care of family members, the quality of home care provided, the outcomes of home care, and the experience of caregiving.

In a synthesis of the literature on Alzheimer's disease, Kuhlman et al., (1991) addressed the nature and causes of the disease and family caregiving, specifically the incidence, prevalence, etiology, and clinical manifestations of Alzheimer's disease, family caregiving, caregiver strain and burden, caregiver support, and intervention programs. The review covering an eleven year span, highlights a number of methodological problems with many of the studies: the use of various definitions of the term caregiver, instruments and questionnaires with variant definitions of the concept of burden, lack of clarity in the care-recipient's level of dysfunction, and sample bias towards those who have contact with community services or support groups. Many of the findings were somewhat unclear, for example, the relationship among variables such as caregiver's age, gender, health status, and management ability, and how these variables affect caregiver stress. A strength of this review was that it identified areas where further research is warranted, such as, in the area of family caregiving by different ethnic and sociocultural groups, and the need for a better understanding of the experiences and practices of caregiving for someone with

Alzheimer's disease.

A literature review by Mass and Buckwalter (1991) included a broad range of literature on Alzheimer's disease and caregiving. Their review included literature addressing the disease process, effectiveness of various institutional settings, and most importantly for the present study, literature on family members as caregivers. The authors found that few investigators have specifically studied caregivers of Alzheimer's disease patients, but rather focused on the elder-caregiver relationship, feelings of burden and how nursing interventions can be provided. Several methodological issues, such as, small sample sizes, questionable reliability and validity of measurement tools, and limited generalizability of results were also noted. The author recommended that in future research we consider the types of patient behaviours associated with the various kinds of caregiver burden and stress, as well as, the positive experiences of caregivers, and cross-cultural caregiving.

Shultz et al., (1990) reviewed literature on caregiving for a family member with a form of dementia and the prolonged effects of caregiving on the caregiver's physical and psychological health. The authors found that research on caregiving often used volunteer samples which has the potential to under or over represent specific kinds of

individuals within the caregiving group. In addition they recommended that future research ought to address the benefits of caregiving rather than focusing on the negative consequence of it. The article also provided a clear synopsis in table form, of the literature reviewed, outlining patient characteristics, sample size, instruments used in data collection, and caregiver outcomes.

Gregory et al., (1990) examined literature on the elderly male's experience in the caregiving role with their spouses, specifically, the meaning of caregiving, caregiver burden, and support services. The main findings they identified were that men have definitely not been researched enough as caregivers, therefore, their specific needs and problems have not been identified. Furthermore, although studies that focus on gender differences provide some insight we have little understanding of the meaning that men ascribe to their caregiving experience. They further noted that studies comparing burden of males and females were inconclusive, the assumption that caregiving is primarily a negative experience for males is questionable, and support services for elderly male caregivers are limited.

Although the various reviews all point to a variety of methodological difficulties and limitations, several problems appear to predominate, such as, reliability and validity of research instruments and small sample size.

While these issues need to be addressed, there is an identified need for more qualitative research in the areas of the experience of caregiving, especially across cultures and groups, the positive aspects of caregiving, and the male experience.

Process of Caregiving

There have been relatively few studies seeking to explicate the process of caregiving for a family member with Alzheimer's disease or unspecified dementia. The overall process, from the beginning of caregiving to the end has been investigated by some researchers (Langner, 1993; Lindgren, 1993; Willoughby & Keating, 1991; Wilson, 1989) whereas others have addressed specific phases of the caregiving experience, such as, the process of bereavement, before, during, and after the death of the afflicted family member (Collins, Liken, King, & Kokinakis, 1993; Jones & Martinson, 1992).

Research by Willoughby and Keating (1991), using a grounded theory approach, contributed to an understanding of the process of caregiving for a family member with Alzheimer's disease before, during, and after placement of the patient in institutional care. The sample consisted of

three female spouses and seven adult children, the latter consisting of four females and three males. Analysis of interview data revealed a process of caregiving consisting of a five stage model of gaining and relinquishing control of caregiving. Although this research added to an understanding of the caregiving process, the authors acknowledged that it is not necessarily generalizable to all caregiving situations. Many caregivers keep their relative at home indefinitely and never experience the process of giving up control. No gender differences were discussed.

Using the constant comparative method to analyze interviews with 14 females and 6 male caregivers, Wilson (1989) generated a substantive grounded theory explicating the process of caregiving for a family member with Alzheimer's disease. Findings revealed that much of the caregiving experience consisted of coping with negative choices where all possible alternatives were undesirable. Three stages of caring for a family member with Alzheimer's disease were identified; taking it on, going through it, and turning it over.

In her qualitative study of caregiving for a spouse with dementia, Lindgren (1993) interviewed six females and four males and described caregiving as a fatalistic caregiver career consisting of three stages. These stages, the encounter stage, the enduring stage, and the exit stage

are very similar to those identified by Wilson (1989). These stages entail a process of learning, adaptation to role demands and restructuring of the caregiver life as occurs with any career.

Langner (1993) conducted in-depth interviews with spouses, siblings, children, and grandchildren, 78% who were female, and who were longterm caregivers of a frail elderly relative in order to explore ways in which primary caregivers manage the caregiving experience over a long period of time. Three themes were identified from the data; establishing and maintaining a routine, focusing on the present, in other words, taking it one day at a time, and retelling the reasons for caregiving. For all the themes positive aspects of the process of caregiving emerged, but there were some negative aspects as well. Caregivers discussed a need to get control of the chaos surrounding daily activities as this was the best way of maintaining a routine and managing the disruption. Although focusing on the present was felt to be very tiring for the caregivers, it did help them become more familiar with the work, and thus better able to sort out what had to be done. Retelling their experience of caregiving was found to be helpful in sorting out why and how they had assumed the caregiving role.

To understand family caregiver's experience of loss and

grief during caregiving and after the death of the elderly family member with dementia, Collins et al., (1993) interviewed 82 primary caregivers, 79% of whom were female. Six themes were identified; loss of familiarity and intimacy before death, loss of hope, grief before death, expectancy of death, post death relief, and post death reflections.

Jones and Martinson (1992) used the constant comparative method to analyse the bereavement experience of caregivers of family members with Alzheimer's disease. Two stages of bereavement were described, the first stage, during caregiving and the second following the death of the family member. The experience of bereavement before death was found to be more intense than after death. During caregiving, caregivers reported feelings of sadness and loss, a readiness to let go, and a process of detachment from the "child-like adult". Following the death of the family member, caregivers although feeling a sense of grief, experienced feelings of relief combined with tinges of guilt. They also needed encouragement to get on with their lives.

While the studies presented above contribute to an understanding of the caregiving process when caring for an individual with Alzheimer's disease, there are a few issues worthy of mention. First, most of the studies presented focus on white middle-class caregivers who are mainly

female, with men and other cultural groups being underrepresented. Second, although the literature addresses the caregiving process, identifying the different stages that caregivers go through, it fails to investigate what these stages mean to the caregivers who experience them. Furthermore, we do not know if men and women would experience the identified stages in the same way.

Consequences of Caregiving: Caregiver Burden

A large proportion of the literature on caregiving for a family member has focused on caregiving for the elderly with a functional disability. Often times the exact etiology of the functional disability is not specified and the sample is merely referred to as the frail elderly. The frail elderly are usually defined as individuals 65 years of age or older, requiring assistance with one or more activities of daily living (Cantor, 1983; McFall & Miller, 1992; Soldo & Myllyoma, 1983). Many studies, however, have narrowed their sample to elderly with a particular disability such as cognitive impairment, dementia and/or Alzheimer's disease.

Much of this literature has focused on the negative consequences of caregiving, often referred to as caregiver

burden. Several of researchers have looked at factors associated with nursing home placement (Colerick & George, 1986; Zarit et al., 1986) whereas others have focused on differences in how men and women perceive their caregiving role or cope with the burdens of caregiving (Barusch & Spaid, 1989; Fitting et al., 1986; Horowitz, 1985; Miller & Cafasso, 1992). Still other researchers have concentrated on the effects of social support as it relates to caregiver burden (Baillie et al. 1988; Green & Monahan, 1989; Robinson, 1990; Scott, Roberto & Hutton, 1986; Soldo & Myllyuoma, 1983; Zarit et al., 1990).

The term "caregiver burden" has become widely used in recent literature. Its exact definition is often dependent upon the context in which it is used. For example, Thompson and Doll (1982) define it in terms of emotional costs such as embarrassment and overload, in their study of families coping with caregiving for the child with a mental illness. With respect to family caregiving of the elderly, researchers have generally described caregiver burden as "the physical, psychological or emotional, social, and financial problems that can be experienced by family members caring for impaired older adults" (George & Gwyther, 1986, p.253). Chappell (1992) defines burden more broadly as "the configuration of potential problems caused by caring for an older person" (p.79). Caregiver burden is seen as the

outcome of stressful situations and it is a subjective measure.

Sometimes indirect indicators are used to examine caregiver burden. Kosberg, Cairl, and Keller (1990) studied informal caregivers of family members with Alzheimer's disease. The five correlates of burden examined were personal and social restrictions, physical and emotional problems, economic cost, value investment in caregiving, and the perception of the older person as the provocateur. Factors affecting these correlates varied; some were related to the caregiver, the care-recipient, the situation or the context of caregiving per se, or a combination of all three. In relation to personal and social restrictions, caregivers who lived with their afflicted family member were more likely to feel greater restrictions. For physical and emotional problems, predictor variables relating to the care-recipient were functional impairment and behavioural problems of the family member being cared for, while for the caregiver, they were self-reported mental health problems and physical health problems. Predictor variables for economic costs were higher education of caregiver, being a spouse, and living with the family member with Alzheimer's disease. Value investment in caregiving was significantly correlated with being a female caregiver and educational level. Finally, variables significantly related to the

provocateur component were being a female caregiver and behavioural problems of the family member.

Other researchers have tried to identify causes of burden (Montgomery, Gonyea & Hooyman, 1985). Perception of burden was linked to tasks of personal care involving body contact, such as bathing, toileting and dressing, as well as, tasks that confine caregivers in time and space. Caregivers who were more limited in their personal freedom and/or involved in more intimate care for the care-recipient were more likely to feel burdened.

In a study to determine the impact of family caregiving for older impaired adults, including Alzheimer's disease, George and Gwyther (1986) examined caregiver's physical health, mental health, social participation and financial resources as indicators of caregiver burden. Results of this study indicated that caregivers were most likely to experience problems with mental health and social participation. Their sample, was predominantly women with 71% of caregivers being female.

Results of the above study were somewhat consistent with a follow-up study by Colerick and George (1986) who surveyed the same sample to determine caregiver characteristics that could be potential predictors of institutionalization of the impaired elderly. Results indicated that caregivers who subsequently institutionalized

their family member were mostly female with above average incomes. What is important for caregiver burden is that the results also indicated that those who chose to institutionalize their relative felt burdened in relation to the amount of social activity in which they could participate. The questions one wonders about, however, are:

- 1) Is institutionalization an indicator of caregiver burden?
- 2) Would men and women have the same reaction to caregiver burden?

Factors associated with nursing home placement of family members with Alzheimer's disease were investigated by Zarit et al., (1986). The sample consisted of 33 wives who were caregivers for their husbands and 31 husbands who were caring for their wives. In this study nursing home placement was more strongly associated with caregivers' perceived burden than with the severity of the dementia for both male and female caregivers. In other words, the impact of stressful events are mediated by whether caregivers actually perceive them as being stressful or not. Perception of stress is dependent upon coping responses (Lazarus & Folkman, 1984).

Similar findings were reported by Neundorpher (1991) in her study of coping and health outcomes in spouse caregivers for persons with Alzheimer's disease. She found that caregivers' appraisal of stress was a significant predictor

of psychological burden, namely, depression and anxiety. However, severity of the dementia was once again not a predictor of burden.

Gallagher-Thompson, Brooks, Bliwise, Leader, and Yesavage (1992) investigated the relationship between perceived stress, rate of change of perceived stress, patients' sundowning behaviours and patients' rate of cognitive decline in 24 male and 11 female spouse caregivers. Sundowning behaviours were defined as the nocturnal exacerbations of disruptive behaviours, such as, wandering, confusion, and disorientation. Results indicated that cognitive decline and initial sundowning behaviour were significantly correlated with caregivers' perceived stress and the average rate of increase of caregivers' perceived stress was positively correlated with the incidence of sundowning behaviours.

To explore the relationship between meaning, psychological well-being and caregiver burden, Snow-Lono (1993) investigated 45 family caregivers of institutionalized patients with Alzheimer's disease. She found that decreased psychological well-being was the only predictor of caregiver burden. Psychological well-being was predicted by purpose in life, existential vacuum, age, length of illness, number of visits, and relationship to care-recipient.

Deimling and Bass (1989) in a study of caregivers for the cognitively impaired elderly found that cognitive incapacity had less effect on caregiver burden than disruptive behaviour and impaired social functioning. Cognitive incapacity indirectly affected caregiver burden through its influence on disruptive behaviour and social functioning.

In a study to determine the impact of the caring role on quality of life for caregivers of frail elderly family members with a functional disability, Jones and Peters (1992) found that caregivers reported adverse effects to health, social life, family life, and occupational life. Their sample, consisting mostly of daughters and daughter-in-laws, reported high levels of anxiety and depression. Caregivers reported that the more dependent the elderly person, the more detrimental the adverse effect.

McFall and Miller (1992) tested the hypothesis that caregiver burden is related to nursing home admission of frail elderly family members with both physical and mental disabilities focused on the social problems experienced by family caregivers, as well as disturbed relationship patterns with the care receiver. Their hypothesis was supported in that caregiver burden was related to admission of the family member to a nursing home. Again, as found by Zarit et al., (1986) cognitive impairment of the dependent

family member had no significant impact on risk of admission.

Several studies have shown that cognitive impairment of care recipients contributes to higher caregiver stress than physical impairments, especially when there is more severely disturbed behaviour (Draper, Poulos, Cole, Poulos, & Erlich, 1992; Given, Stommel, Collins, King, & Given, 1990; Nygaard, 1991; Worcester & Quayhagen, 1983). Moritz, Kasl, and Berkman (1989) in their study of elderly couples, found that the level of cognitive impairment in wives was significantly associated with psychological burden such as depression in husbands. In contrast, cognitive impairment in husbands was only weakly associated with depression in wives.

Caregivers of spouses with cancer were compared with caregivers of spouses suffering from dementia to determine the similarity of caregiving responses for the two groups (Clipp & George, 1993). Overall the two groups were statistically very different. Caregivers of spouses with dementia reported significantly more visits to the physician, a lower positive affect, a higher negative affect, almost twice as many stress symptoms, and lower life satisfaction than caregivers of individuals with cancer.

In her study of caregiving for a frail elderly family member, Cantor (1983) found that the overriding burden of the caregiver was the health of the dependent person, with

the greatest strains being physical and financial. The extent of impact on the everyday life of the caregiver appeared to be related to the kinship bond. The closer the bond, the more stressful the caregiving role. Primary caregivers in the study were either spouses, children or other relatives, or friends and neighbours. Children caregivers consisted mainly of married women.

In other studies, caregivers of family members with Alzheimer's disease reported high levels of depression, physical health problems and decreased well-being (Abraham & Berry, 1992; Cohen & Eisdorfer, 1988; Haley, Levine, Brown, Berry, & Hughs, 1987; Pruchno & Resch, 1989). The majority of these caregivers were female, and seniors with health problems of their own, which may seem to be, in itself, a contributing factor for experiencing burden.

Caregivers who were caring for their spouse with Alzheimer's disease or other forms of dementia were compared with general population norms on the impact of caregiving on mental and physical morbidity (Pruchno & Potashnik, 1989). Results of interviews suggested (as no simultaneous control groups existed) that spouse caregivers were more likely than the general population to experience psychological disturbances such as depression, and have more physical health problems such as ulcers, anemia, arthritis, and diabetes.

Interviews conducted with elderly caregivers (65% female) of spouses with either a physical problem or dementia, identified that their most prevalent problems as the psychological and emotional burdens of caregiving (loneliness, depression, resentment, guilt and grief over the loss of the spouse they once knew) (Barusch, 1988). Coping responses included seeking help with care management and health-related problems, however most preferred to manage on their own when possible.

The psychosocial burdens of caregiving have been found to be related to a loss of identity that results from engulfment in the caregiving role (Skaff & Pearlin, 1992). The men and women caregivers in this study reported a loss of social contact and social roles as a consequence of caregiving for their frail elderly family members, leading to a loss of their identity and role engulfment.

Gabow (1989), a Registered Nurse in Community Services, described from her professional experience, her perceptions of the impact of Alzheimer's disease on family caregivers. Problems identified for family members include decisions regarding institutional placement, guilt and ambivalence regarding such a decision, and physical, emotional, psychological, and financial burdens. This article is important in that it acknowledges the valuable insight of professional caregivers such as nurses, who often work very

closely with informal caregivers. Nurses and other health professional can make very important contributions to an understanding of the caregiving experience, as well as, recommendations for interventions to assist the caregivers.

Many researchers have attempted to compare men and women on how they respond to the stressors of caregiving for cognitively impaired family members. In some studies, gender differences in aspects of caregiving was the primary focus of the research, while for others it was a secondary interest. Results are fairly consistent with researchers reporting that women experience more anxiety and depression than do men (Barusch & Spaid, 1989; Fitting et al., 1986; Horowitz, 1985; Miller & Cafasso, 1992).

Researchers have put forward a number of theories as to the nature of the differences in men and women caregivers. For example, Barusch and Spaid (1989) suggest that men may possibly be harder to care for than women, thus women caring for men may experience greater burden. Fitting et al., (1986) postulate that the differences may be due to role change. They feel that women experience greater burden because they are now generally older and no longer feel compelled to be caregivers as they did years ago when raising small children. This theory of role change, however, fails to acknowledge the role change of the male caregiver, who in most cases has taken on a completely new

role. Miller and Cafasso (1992) may have captured the nature of the differences more appropriately when they suggested that the gender differences in response to caregiving may be the result of differences in the socialization of men and women. For example, men are socialized to be less expressive of emotion than women. Therefore, the differences that exist may actually be attributed to women reporting their feelings more than men.

From the literature it is clear that there is diversity in what causes stress, and thus burden, in caring for family members with dementia. All caregivers do not find the same problems stressful. Several studies show that caregivers report feeling burdened due to interruption in social participation, while others report more burden related to the physical and financial stresses of caregiving. Although discrepancies exist in the literature, overall, severity of cognitive impairment has not been found to be a good indicator of how much burden caregivers will experience. What appears to be an important indicator of the burden caregivers experience is how they perceive the burden, which is often dependent upon their individual coping responses.

Few studies of family caregivers have focused on the role of gender in caregiving. Most have a reference to whether or not caregivers were men or women without examining how gender contributes to differences. These

studies have relied on psychological and/or sociological perspectives to account for the differences in behaviour between men and women caregivers. These perspectives treat gender as a variable, not a theoretical orientation, and fail to acknowledge the ideology of caregiving as women's work and the lack of alternatives women are often faced with.

Once again, the literature on caregiver burden, as was evident from literature on the process of caregiving, underrepresents men and minority groups as caregivers to the elderly. Sample sizes are usually small and there are very few qualitative studies which could explore in greater depth the burden experienced by caregivers, both men and women. It is not clear whether caregiver burden increases with the patient's increased dependence and exaggeration of symptoms. We do not know if males define caregiver burden in the same way as females as their roles in caregiving may differ. Furthermore, we do not know if responses to caregiver burden are the same for men and women, as different resources may be available or different patterns in using resources may take place by gender.

Mediator of Caregiving: Social Support

Social support as it relates to caregiver well-being can be divided into two types, instrumental and emotional. Instrumental support involves providing assistance to the caregiver with the day-to-day care of the family member, such as assisting with bathing. Emotional support is the support gained from others who offer encouragement, advice or understanding. Social support can be informal, such as that received from family or friends, or it can be formal, coming from health care agencies or support groups (Zarit, Orr, & Zarit, 1985).

Both types of social support, instrumental and emotional can assist in alleviating the negative consequences of caregiving. Zarit et al., (1980) in their study of factors contributing to feelings of burden in caregivers of elderly persons with dementia, found that burden was inversely related to the frequency of visits paid to the patients with dementia by other relatives. Also, the extent of burden was not related to the behaviour problems caused by the illness. All but four of the 29 caregivers in the study were female. The sample included 18 spouses and 11 daughters. Similar findings were reported by Scott, Roberto and Hutton (1986) who examined the instrumental and

emotional support provided by families to the primary caregivers of those with Alzheimer's disease. Family support was positively associated with the caregiver's coping effectiveness and negatively associated with caregiver burden.

In addressing caregiver needs of those caring for the frail elderly, Soldo and Myllyuoma (1983) found that the presence of another unimpaired adult has the potential to reduce the direct responsibilities of the primary caregiver. By assisting with competing demands, such as shopping for food and doing laundry the negative consequences of caregiving are buffered.

The caregiver's perceived amount of social support tends to be negatively related to depression in caregivers for impaired elderly family members. Those who felt that they had adequate levels of social support were less depressed than those who felt that they were lacking social support. Additionally, depression tends to be positively related to the length of time in the caregiving role and the severity of the illness of the care recipient (Baillie et al., 1988).

According to Moritz et al., (1989) the psychological burden of husbands caring for their cognitively impaired wives is influenced by perceived availability of financial support from friends and relatives. It is not, however,

influenced by activity of daily living limitations of the wives, household responsibilities or, contrary to previous studies, lack of social participation.

Group support can have a mediating effect on caregiver burden. A caregiver support group programme produced a statistically significant reduction in anxiety, depression, and sense of burden among family caregivers of frail elderly persons (Green & Monahan, 1989). Caregivers in this study were predominantly women (86%) and 47% were providing care to a spouse.

Spouse caregivers also cite the recipients of care as a major and important source of support (Lawton, Moss, Keblan, Glicksman, & Ravine, 1991; Motenko, 1989). The recipient's response to the caregiver often makes the caregiver feel needed and provides some satisfaction for the caregiver. This in turn aids them in fulfilling their role demands. Motenko (1989) conducted interviews with elderly women caring for their husbands with dementia. She found that the continuity of marital closeness was important in sustaining the caregiving role despite the burdens these women endured. Wives who provided care based on reciprocity derived more gratification from caregiving than wives who provided care out of responsibility and duty. It is possible that this reciprocity is a form of social support. This is surprising in lieu of the fact that all of those being cared for were

suffering from some form of dementia, including Alzheimer's disease. According to Motenko (1989) caregivers view caregiving as one way of continuing some form of meaningful relationship with their husbands.

Robinson (1990) studied how the health of caregivers, past and present marital adjustment, and social support affected objective and subjective burden of wives who care for their husbands with dementia at home. Results indicated that past marital adjustment was the best predictor of subjective burden. Caregivers with happy past marriages desired less support and received less direct guidance. The best predictor of objective burden was social status. Those of higher social status reported less burden.

Despite the increase in research on social support and caregiving there are still gaps in this aspect of the literature. One of the gaps noted was that because of the cross-sectional nature of most of the studies, it is difficult to determine whether support came as a result of caregiving or as an antecedent to it. A second omission seemed to be the point that support can be stress-producing rather than stress-relieving (Thoits, 1982).

Family Caregiving Experiences

While much attention has been given to the consequences of caregiving for an elderly impaired family member, this researcher has been able to find comparatively little published research on the male experience (or indeed the female experience) of caregiving for an elderly frail family member with Alzheimer's disease. Existing studies focus predominantly on women and when men have been included they are generally outnumbered by women in the sample.

Using a grounded theory approach Beach (1993) looked at the experience of family caregivers for frail elderly individuals. Although men were included in the sample, women predominated (80%). From their analysis, three categories emerged; role strain, sense of self, and problem solving/coping. Caregivers in the study felt role strain even though they had a system of family support in place, however, they reported that they rarely used it. They also felt role strain in that they felt such caregiving became an extension of their normal family roles, and was done mainly out of a sense of responsibility to these elderly persons. With regard to the category, sense of self, female caregivers reported more social limitations than did the male caregivers. But both men and women caregivers reported

significant work conflicts. As a part of their problem solving behaviour most of the participants reported considering institutionalization only when they were no longer able to handle the responsibility. Participants found it very difficult to cope with the personality changes of the affected family member.

A secondary analysis of seven published personal accounts on caring for a family member with Alzheimer's disease using a phenomenological mode of inquiry was performed by Lynch-Sauer (1990). Study samples included both men and women. Nine themes were identified from the analysis; an unending attempt to put the family member in touch with his or her surroundings, the experience of asynchrony with the person being cared for often leading to sleep disturbance and exhaustion, a sense of always trying to stay ahead of the family member, the feeling of loss of mutuality, a loss of reciprocal relationship, a progressive loss of diversity in the relationship to the family member, others, and the environment, the experienced narrowing of the horizons felt as resentment, anger and depression, an attempt to attribute meaning to the family member's illness, and an ever-present search for personal connectedness.

To explore the impact of a diagnosis of Alzheimer's disease on caregivers caring for their spouses in the first six months following the diagnosis of the disease, Morgan

and Laing (1991) studied nine male and female caregivers using grounded theory. From their data two categories emerged; grief and role strain. The informants for whom grief became an important part of their lives had previously shared a close, loving relationship with their spouse. They experienced anticipatory grief and mourned the loss of their spouse and their relationship with that person. As time passed these caregivers achieved a high degree of acceptance to the situation and wanted to continue providing care. They felt that they were motivated by love for their spouse and experienced gratification from their role. Informants who experienced role strain consisted of caregivers whose past relationships with their spouses had been less intimate and stable. Those experiencing role strain did not show signs of bereavement as did those experiencing grief. The caregiving demands created a high level of stress, such that it often overshadowed the grief. They also only received minimal gratification from their role and were often frustrated.

Gubrium (1991) studied the frail elderly and their families, both within and outside of institutions, in order to better understand how the lives of these individuals are organized. He used an ethnographic approach to his study and attempted to represent the diversity and complexity of family care to the elderly through case studies or stories.

His case studies did include individuals with Alzheimer's disease. Although behavioural and interactional patterns were examined, he also considered the "meaning" of conduct, interpersonal relations, and issues of living" (Gubrium, 1991, p.153). He described caring as a "mosaic" rather than a linear process, because the mosaic captured the distinct and complex interpersonal experiences of caring.

Men as Caregivers

There were few studies which specifically examined men as caregivers to frail elderly or relatives with dementia/ Alzheimer's disease. These studies included only men as subjects and are an important subsection under family caregiving experiences as they represent what is known about the male experience on caregiving as opposed to gender differences which frequently examines being male as a variable.

To develop a greater understanding of the experiences and needs of male caregivers for the frail elderly Kaye and Applegate (1990) did an intensive study involving a national survey. The majority of the men were providing care to their spouses with a variety of physical and mental health problems, including Alzheimer's disease. Results indicated

that caregivers often described themselves in affective terms more than instrumental terms and this in turn was associated with lower levels of caregiver burden, a higher frequency of initiating affection, and a greater sense of competency in caregiving. Caregivers performed a wide range of tasks, but the provision of personal care resulted in the most burden. Most caregivers approached their tasks with an attitude that caregiving can bring considerable satisfaction. Also the care-recipients' mental and emotional health appeared to be the primary barrier to providing care. With regards to support, male caregivers tended to minimize the extent to which they would use a wide range of services. The caregivers believed that overall their other family members were very supportive. However, family assistance patterns were uneven, with only one or two family members providing of the support. Children (when caring for a spouse) and spouses (in the case of caring for a parent) were attributed with providing the main source of assistance. Many caregivers received no assistance. The need for outside assistance increased as the care-recipients' health deteriorated.

Matthew, Mattocks and Slatt (1990) explored the differences between men who care for a family member with dementia at home and men who institutionalize their family member. The differences in the two groups were relatively

small. Using the Burden Interview developed by Zarit et al., (1980) they unexpectedly found that men taking care of their relative at home perceived themselves as no more burdened than men who placed their relative in a nursing home. Differences did exist with respect to the amount of time spent providing care. The men who provided care to their relative at home spent more time at caregiving than their counterparts who had placed their family member in an institution. The men who kept their family member at home were more likely to receive help from other family members. Both groups of men described feeling very close or moderately close to their relative. These findings reveal very little about how men actually experience caregiving.

A study by Harris (1993) is more illustrative of the experience of male caregivers of spouses with Alzheimer's disease. She conducted interviews with fifteen male caregivers using a general interview schedule. Findings revealed that a dominant feature of all their caregiving experiences was the commitment of these men to caring for their wives. Other common themes included social isolation/loss of companionship; coping strategies such as control; a structured routine; a sense of accomplishment; limited expectations from their children; and the need for specialized services. The analysis of interview data also revealed four types of male caregivers. Type one, the

worker, oriented to their new role by modelling the caregiver role after their work role. Caregiving thus became a new work identity. Type two, the labour of love, consisted of men being oriented to their caregiver role by merging it with their deep feelings towards their wives. Type three, characterized their caregiving in terms of a sense of duty. Type four, at the crossroad, consisted of a group of men who were most often in crisis. These men were caring for spouses who were usually in the early stage of the disease.

Although Harris (1993) identified common themes of caregiving types of male caregivers, her findings are limited to men caring for their spouse. We do not know if such findings are also generalizable to caregiving for one's parent.

Summary of Literature Reviewed

The studies reviewed (Kaye & Applegate, 1990; Mathew, Mattocks, & Slatt, 1990; Harris, 1993) gave some insights into men as caregivers, especially, how the men perceived their roles, type of tasks performed, what some of their stresses were, level of burden, and types of support

received. The research further illustrated differences in the process of caregiving that men experienced. However, none of the studies examined the meaning of the caregiving experiences.

Despite the vast amount of research on caregiving for an elderly family member with some form of dementia, including Alzheimer's disease, we do not have a good understanding of the caregiving experience. This may be due in part, to the assumption by many researchers that caregiving is costly. This assumption has led to research that has focused on caregiver burden or ways of alleviating the burden such as social support.

Another important reason that the caregiving experience of family members with Alzheimer's disease may not be well understood is the tendency of many researchers to study caregiving of the frail elderly. This, of course, in itself is not a problem but often, the sample will consist of a combination of these frail elderly and those suffering from dementia. Results of these studies need to be analyzed with caution, as the sample is not homogeneous. One need only to consider the major differences in elderly who suffer with dementia, such as Alzheimer's disease, and those who do not to realize this.

Also of importance is that much of the research on caregiving has tended to focus on women. This is probably

the result of socialization, where we have come to believe that caregiving for others is women's work (Finch & Groves, 1983). When men have been studied, the emphasis has been on gender differences rather than specifically looking at the experience of the male caregiver. It is only recently that research efforts have begun to look at men as the primary caregiver. The limited research on men as caregivers has not focused on the unique experiences of men as primary caregivers to a spouse or parent with Alzheimer's disease.

Chapter 3

METHODOLOGY AND METHODS

The methodology used as a framework for the present research study of men as caregivers is phenomenology. Although there are a number of different phenomenological methods described in the literature, the researcher used those by van Manen (1990) for doing phenomenological human science research. This chapter will be divided into two parts; methodology and methods. The first part will present phenomenology as a methodology by describing the phenomenological mode of inquiry as outlined by van Manen (1990). The second part of the chapter will describe in detail how the researcher used phenomenology as a method to investigate the experience of men as caregivers to spouses or parents who had Alzheimer's disease.

Phenomenology as a Methodology

Phenomenology as a methodology and philosophy, and later as a method, has largely been attributed to the work of the European philosopher Edmund Husserl. Taking as his starting point, the difficulty in using research methodology from the

natural sciences to adequately explain human behaviour, the idea that human beings must be studied with new methods, began to crystallize (Omery, 1983). In more recent decades the existential philosopher Merleau-Ponty has modified Husserl's ideas and provided the framework for its practical use (Speigelberg, 1975).

van Manen's approach to phenomenology is grounded in the earlier European movement of human science philosophy with modifications influenced by certain North American developments. According to van Manen the terms human science and phenomenology are interchangeable because they both are concerned with the study of " ... 'persons', or beings that have 'consciousness' and that 'act purposefully' in and on the world by creating objects of 'meaning' that are 'expressions' of how human beings exist in the world" (van Manen, 1990, p.4).

The aim of phenomenology is to explicate the meaning of human phenomena and to understand the lived structures of meanings of everyday experience. To do this the research must begin in the lifeworld, that is "the world of the natural attitude of everyday life which Husserl described as the original, pre-reflective attitude" (van Manen, 1990, p. 7). Simply stated, phenomenology seeks to question and understand what a particular experience is like for a person from the perspective of the person experiencing it.

One of the core concepts of phenomenology is "intentionality." In keeping with Husserl's philosophy, van Manen (1990) describes this as the way an individual is connected to the world. Every thought or action is directed toward some object, either physical or ideal, although we are not conscious of our intentionality as experience. It is in retrospect that we discover this basic characteristic of consciousness. Moreover, it is only by being conscious that we are related to the world.

Use of the principle of intentionality facilitates the researcher's questioning of the way a person is able to experience the world as a human being. Because the person's world is presented through consciousness pre-reflectively we are able to have them reflect on the experience they have passed or lived through. Research is a caring act, and only by intentionally attaching ourselves and caring for something can we come to understand its true meaning (van Manen, 1990).

Phenomenology is the study of essences. An essence is "that what makes a thing what it is (and without which it would not be what it is); that what makes a thing what it is rather than its being or becoming something else" (van Manen, 1990, p. 177). Essences are composed of structures or internal meaning units which govern their particular manifestations. Phenomenological research is a systematic

attempt to discover and describe these structures and thus understand the lived experience.

Going beyond the actual state of affairs, such as the how, where, what, when or why something happened, phenomenology is concerned with the essence or nature of the lived experience for a particular individual. It is concerned with interpreting the meaning of the lived experience in the fullness and depth of our everyday experience, our lifeworld (van Manen, 1990).

Human science research as described by van Manen (1990) is a moving back and forth among six different research activities. First, the researcher must choose a phenomenon of interest and be committed to a study of that phenomenon. The nature of the phenomenon is important in that it deals with an aspect of human existence. The second activity is investigating the phenomenon as it is experienced rather than how it may be conceptualized. Third, is an attempt to grasp what gives the experience being investigated its special significance. This takes the form of reflecting on the essential themes within the phenomenon. Fourth, is an attempt to capture in a textual form, through the interplay of thought and language, as precisely as possible the experience as it has been lived. Fifth is the maintenance of a strong and oriented relation; not to be distracted from the purpose of the research. The sixth activity is to

balance the research by keeping in one's mind the parts and how they contribute to the description of the experience in its entirety.

Turning to the nature of lived experience is the starting point and the end point of phenomenological research. Phenomenology aims at turning the lived experience into a textual expression of its essence. It is not enough to simply recall experiences with respect to a particular phenomenon. Instead the experiences must be recalled in such a way that the essential aspects, the meaning structures are brought back as a possible interpretation of that experience. To do phenomenology is to ask what something is really like, and to exhaust the question to its very limit; "that we 'live' this question, that we 'become' this question" (van Manen, 1990, p.43), until its very nature has been revealed.

"Reduction" a core concept in phenomenology, involves the researcher's need to overcome subjective feelings, previous experience, theories, or scientific conceptions that would prevent the coming to terms with the phenomena or experience as it has been lived (Bochenski, 1965; van Manen, 1990). According to Husserl, to do this, the phenomenon must be placed outside of one's knowledge about the phenomenon. However, rather than forgetting or ignoring what is already known, and allowing it to creep into our

reflections, it is better to come to terms with our presuppositions and hold them deliberately at bay. Husserl called this the process of "bracketing" but according to Van Manen (1990), complete reduction is impossible. This implies that we need to work at reduction as vigorously as possible. Investigating experience as it is lived means that the researcher investigates the experience through all modalities. There are many sources of experiential material from which the researcher can draw upon. The human science researcher can make use of interviews, observations, various forms of literature, and art in the conquest of the lived experience (van Manen, 1990).

In phenomenology the interview serves very specific purposes. It serves as a way for discovering experiential narrative material that will assist in developing a deeper understanding of human phenomenon. It also may be used to develop a more intense relationship with the interviewee about the meaning of the experience. During the interview process it is of great importance for the researcher to remain oriented to the question of concern and not get easily carried away with verbatim that goes everywhere and nowhere. It is also important to be very concrete when asking the interviewee what something is like, and to explore the experience. The phenomenological interview is not structured with a long list of developed questions.

Rather, it is an attempt to gather the necessary information by prompting the interviewee to give his/her story as it was experienced. Patience or silence may be the greatest asset held by the researcher. In phenomenological research what is important is not whether the experience is factually correct, but rather, if it is plausible for the person living the experience.

Observation as a source of research material requires the researcher enter the lifeworld of the person whose experience is under study. This means that the researcher is a direct participant of the lifeworld. The researcher, while maintaining a close relation, must remain constantly alert to situations which allow for distance and reflecting on the meaning of the situation.

The works of artists, authors, and poets is of great use to the human science researcher in constructing a full interpretive description of the nature of the lived experience. It is in these works that the full possibility of human experience can be found. van Manen (1990) stresses the importance of not confusing phenomenology with poetry: "One difference is that phenomenology aims at making explicit and seeking universal meanings where poetry and literature remain implicit and particular" (p. 19). Descriptions of the preceding type are merely an access to the meaning of an experience. Artistic works are material

from which the researcher must work to grasp the essential nature of the human phenomena.

Human science research is a process in which the researcher is involved in the reflective activity of creating a text. To understand the meaning of a phenomenon in the text, the researcher must view it in terms of meaning units or themes. These themes "may be understood as the structures of experience" (van Manen, 1990, p.79). Thus, when analyzing a phenomenon the researcher tries to determine the themes that constitute the experience. The process of coming to a thematic understanding of the interview material is not governed by rules, rather it is a free act; the ability to see meaning. It is important to keep in mind some aspects of themes. They are at best a simplification, a heuristic device for capturing a meaning or a point of an experience. Themes are not objects or things but a form of capturing the phenomenon one is trying to understand. Themes are merely tools for getting to the meaning of an experience. They give shape and describe the content of the experience. Themes can never completely capture the lived experience; they are only conceptual abstractions which facilitate the phenomenological description.

Following the identification of the themes, the researcher along with the interviewee, collaborates and

reflects on the themes, to verify if indeed this is what the experience is really like. Collaborative discussion may also be conducted with other researchers in order to generate deeper insights and understanding.

Consistent with the view of scholars such as Husserl, Heidegger, Sartre and Merleau-Ponty, van Manen (1990) sees writing as the essence of human science research.

Writing fixes thought on paper. It externalizes what in some sense is internal; it distances us from our immediate lived involvements with the things of our world. As we stare at the paper, and stare at what we have written, our objectified thinking now stares back at us. Thus, writing creates the reflective cognitive stance that generally characterizes the theoretic attitude in the social sciences (p.125).

van Manen (1990) discusses Sartre's view of writing and rewriting when he says that the aim of these activities is to create depth or multiple layers of meaning of the text.

The human science researcher must maintain a strong and oriented relation to the fundamental question of concern or there will be temptations to get side-tracked. To be oriented means that one is animated in a full and human sense. The orientation to the object of concern must also be strong, rich and deep. This requires that the researcher formulate an understanding of the object that is exclusive of other interests, but the meanings of the phenomena are not exhausted in their immediate experience. Balancing the

research context by considering parts and whole is synonymous with the saying, do not lose sight of the forest for the trees. In other words, it is easy to get caught up in writing and thereby lose sight of the goal of phenomenological research. To avoid this the researcher must on occasion step back and look at the total picture, questioning and analyzing the overall design of the study.

Methods

The detailed description of phenomenology as a human science approach outlined by van Manen (1990) and presented above was important in that it served to guide the researcher in exploring the experiences of men caring for a family member with Alzheimer's disease. The researcher interviewed and analyzed the data from men who acted as a primary caregiver to a spouse or parent who had Alzheimer's disease in order to come to a better understanding of what this experience was like for these men. This section is a detailed description of the methods used for this particular study.

Participants

Participants in this study were men who are, or have been, the primary caregiver for a parent or spouse with Alzheimer's disease. The only inclusion criteria was that they were willing to participate and be able to articulate their experience to the researcher. Participants were not excluded if they lived in a different household than their mentally impaired family member. This is consistent with the literature in which the primary caregivers were judged in terms of level of responsibility and type and number of tasks.

A total of eight participants agreed to be in the study. The Director of St. John's Home Care was initially contacted by telephone to obtain the names of prospective participants for inclusion in the study. The researcher described the nature of the study and requested the names of possible participants. This was followed up by a written letter of request (see Appendix A). A total of six prospective participants were initially contacted by St. John's Home Care to determine if they were willing to be in the study. All six agreed to participate, and their names and telephone numbers were released to the researcher. The name of the seventh participant was found informally in the local newspaper by the researcher's supervisor. This man,

who in a newspaper article discussed his caregiving role, was initially contacted by the researcher, and he agreed to participate in the study. The name of the eighth participant was given to the researcher by a faculty member from Memorial University School of Nursing, who later made the initial contact with him. On contact this man agreed to participate in the study.

All those who indicated that they were willing to be involved in the research were contacted by telephone by the researcher. During this initial contact, participants were informed about the nature of the study and an interview time was arranged.

An additional source of interview material came from a Canadian Broadcasting Corporation (CBC) Program "Saying Goodbye to Shirley" (Steve, 1994). In this interview Steve describes his role in caring for his wife with Alzheimer's disease. His interview, conducted by a skilled interviewer, addressed, in-depth, his experiences of caregiving, and as such gives rich insights into his experience.

Ethical considerations

Permission to conduct the study was granted from the Human Investigations Committee, Memorial University of

Newfoundland, after review of the proposal. Before commencement of the first interview all participants were required to give their written consent (see Appendix B). All participants were told the purpose of the study, as well as procedures to collect data, and time required of them. Participants were assured that they could withdraw from the study at any time, and informed of measures to assure confidentiality, such as the use of codes rather than names on interviews.

The participants were reassured that all written notes and tapes would be destroyed at the end of the study. Although they may not directly benefit from the study, participants were told that the information they provided might be of help to nurses and other health care professionals to assist nurses in the future in that nurses would have a better insight into what caregiving is like for family members.

A further measure, to increase the participant's confidentiality, was not to use interview numbers or even pseudonyms in quotations from the participants in the text. This measure is taken as the participants may be easily identified if such usage had occurred.

Interview approach

The setting for the data collection was the choice of the participants. Seven of the eight participants preferred to be interviewed in their own homes. One participant preferred to be interviewed in the researcher's home. Prior to the initiation of the first interview, a detailed description of the study was given to the participants so they could decide whether or not they wanted to continue with the study. This included information regarding the purpose of the study, and data collection techniques such as the taping of the interviews and taking some hand written notes during the interview. Participants were told that they could stop the interview at any time, however, no participant chose to do so.

Participants were asked to describe their caregiving experience in terms of their thoughts and feelings and to talk about anything that would be of help to the researcher in understanding the experience. Prompts such as "How does that make you feel?", "Can you tell me more about that?", and "Is there anything more you would like to tell me?", which were not leading, but simply encouraged the participants to share their experience or clarify ideas, were used throughout the interview. None of the participants had any problem articulating their experience.

All interviews were tape recorded. During the interviews, notes regarding non-verbal communication cues or possible emerging themes were written down. The interviews took between thirty minutes to seventy-five minutes each to complete. When verbal and/or nonverbal cues indicated that the participants were tired or had exhausted the description of their experience, the interview was brought to a close.

Participants were contacted for a second interview approximately two to three months following the first. This time period was necessary to complete the transcribing of the interviews and the preliminary data analysis. A second interview was needed to clarify responses or to further explore specific areas that were omitted or needed expansion. All but one participant was interviewed for a second time, as one man could no longer be reached. The second interviews were all very brief as the participants felt that they had fully described their experience during the first interview and had little more to add. The second interview validated some of the themes identified from the first interview. Not all themes could be validated because discussion of several of them did not take place at this time. This was acceptable as many participants felt that they had exhausted their descriptions and wished to end it at this point. Further probing of the experience, therefore, by the researcher would have been inappropriate.

Data analysis

Following the completion of each interview the researcher transcribed the tapes. This transcription process helped immerse the researcher in the data and to think about what the interviewees were saying and how they were saying it. Each written transcript was read several times while listening to the corresponding audiotape to ensure accuracy of the transcribed tape and to come to a better overall understanding of each participant's experience. It also prompted additional questions for subsequent interviews. During these initial readings it was possible to reflect on the emerging themes.

The researcher took each transcribed interview and identified themes. The specific approach used to uncover the thematic aspects of the caregiving experience was the selective or highlighting approach outlined by van Manen (1990). In the selective reading approach the text is read several times and statements that appear to be revealing about the phenomenon are underlined or highlighted. Themes were identified by highlighting material in the interview text which spoke to the man's experience. Next the researcher took each of these highlighted phrases or sentences and tried to capture as succinctly as possible what meaning the sentence conveyed. Every attempt was made

to avoid a conceptualization of the sentence but rather to capture a meaning.

Following the initial reading and preliminary identification of themes in each of the interviews the researcher met with the research supervisor to discuss the identified themes and any areas that required more investigation. These meetings helped to ensure that the researcher's decision trail could be followed and the identified themes refined. The researcher next compared the themes identified in each interview, looked for commonalities and differences, and identified the overall themes which best described the experiences of these men as caregivers.

When the first interviews had been analyzed and overall themes identified the researcher met with members of the researcher's thesis committee, all of whom are faculty at Memorial University of Newfoundland School of Nursing. The purpose was to present the themes identified, discuss why the researcher had decided on these themes, and further validate the themes. This was helpful in generating deeper insights and understandings of the participants' experiences.

After the meeting with the supervisory committee the researcher reinterviewed as many of the participants as possible. These interviews were transcribed in the same

manner as the first interviews. Once again the highlighting approach was used to identify themes. No new themes were identified as a result of these second interviews but they did help the researcher to describe and understand the preliminary themes in more depth.

With the themes identified the researcher then began the writing of the themes. Each section on the themes was rewritten several times until the researcher felt the themes (parts) and the relationship among the themes (whole) described as accurately as possible how the men experienced caregiving.

Credibility

Human science research should not be evaluated against the same criteria as quantitative research. Instead qualitative research has its own criteria for precision, exactness and rigor as described by van Manen (1990). "In contrast, human science strives for precision and exactness by aiming for interpretive descriptions that exact fullness and completeness of detail, and that explore to a degree of perfection the fundamental nature of the notion being addressed in the text" (van Manen, 1990, p.17).

Sandelowski (1986) also discusses how qualitative

research should not be evaluated against traditional scientific criteria. Instead, she states one of the important criteria of qualitative inquiry is the credibility of the research findings.

A qualitative study is credible when the descriptions of the study are such that the people having the experience would immediately recognize it as their own. The researcher attempted to establish credibility by use of a second interview. In this interview the researcher identified some of what she saw as emerging themes to the participants and they confirmed these themes by such affirmative statements as "yes, as I explained before" By comparing interview material between first and second interviews it was found that descriptions of the experience from the first interview of individual participants matched the descriptions given to the researcher during the second series of interviews.

A second method by which the researcher attempted to establish credibility of findings was through giving copies of transcribed material to the supervisory committee and meeting with them after the themes had been identified. A tape recording of the session confirmed that the members of the committee were in agreement with the themes and were able to follow the decision trail as to how the themes were identified.

CHAPTER 4
FINDINGS: TOWARD AN UNDERSTANDING OF THE EXPERIENCE OF
CAREGIVING

What is it like to care for a parent or spouse who is affected by Alzheimer's disease? How did the men in this study come to understand and experience the caregiving relationship? This chapter is an exploration of their experiences as caregivers. Each participant experienced being a caregiver in different ways, yet, those ways were interrelated. Themes which emerged from the interview data captured some similarities, as well as, the differences. This chapter is divided into three parts. The first part is a description of the caregivers and their situation. The second part of this chapter is a presentation of the emerging themes supported by selected material from the interview data. These quotes were believed to capture most succinctly the theme under analysis. The themes, not presented in any order of importance are: (a) enduring, (b) vigilance, (c) a sense of loss, (d) aloneness and loneliness, (e) taking away, (f) searching to discover, (g) the need for assistance, (h) reciprocity, and for the son caregivers only, (i) overstepping the normal boundaries. In the third part of this chapter the relationship among the themes are described. The various themes identified are not

unrelated, rather they weave together to form a whole, and capture more completely an understanding of these men's experiences as caregivers. The final section examines what gave essence or meaning to these men's experiences. The overall meaning or essence being that the disease itself is not unimportant, in other words, it is the disease itself that makes the caregiving experience what it is for these men.

The Caregivers

The caregivers were all middle aged to elderly men. Three of the men had cared for their parents, and two had cared for their spouses, all of whom are now deceased. Two of the men cared for their spouses until placing them in a nursing home, where they are now residing. One man is currently caring for his wife at home.

One son caregiver was involved in his father's care over an eight year period. Although he was married, lived separately from his parents, and was not the only son or daughter in the family, his involvement was extensive. In the early stages of the disease he helped his mother watch out for his father and provide diversional activities, but as the disease progressed the son's involvement in his father's care increased. He often provided both prolonged and brief periods of respite care to enable his mother to

have a break. The father was maintained in his own home until his behaviour became so disruptive that it was impossible to care for him at home and he was institutionalized. The son's involvement in his father's care continued after institutionalization and he has gone on to be a support to others in the same situation.

A second son caregiver, who was single, cared for his mother in her home, moving in with her as her condition worsened. After this time his mother became progressively worse and was unable to care for herself, thus requiring total care. He balanced shift work and caring for his mother through limited help from some of his sisters and paid professional and paraprofessional help in the home. When he felt he could no longer continue providing care at home he placed his mother in a nursing home where she eventually died.

A third son also cared for his mother. His caregiving extended over a two year period. In the early stages, his caregiving consisted of frequently checking on his mother in her home with the help of friends. As her condition deteriorated such that she could not be maintained in her own home, he first took her to geriatric daycare each day, taking her to her home, and then his home at night, until finally he moved her completely to his home with his family. He cared for his mother in his home with some help from his wife and sons until his mother, then bedridden, died.

The first spouse caregiver cared for his wife over a six year period. At first caregiving consisted of watching her and helping her as necessary, as she was becoming increasingly forgetful. A physical illness seemed to be the trigger for his wife becoming markedly worse. For about three years he provided complete care to his wife as her condition worsened. Eventually he felt he had to place her in a nursing home where she is currently residing. He continues with minimal care and visiting at the nursing home.

A second spouse has cared for his wife over the past six years. At first his caregiving took the form of taking over household duties but about two years ago she deteriorated to the stage where she is now, unable to remember people and places, and requiring assistance with all aspects of daily living. This man lives alone with his wife, and with the exception of paid professional and paraprofessional care to assist him, he provides all aspects of her care.

Another husband has cared for his wife for six years. During the first two years of her illness he was mainly involved in caring for his wife through assistance and watching her as she was quite forgetful. During this time they even managed to travel a little. For the past four years his wife's condition has progressively deteriorated to the point where she eventually required complete care. He

continued to care for her during that time with some assistance from family, friends and professional caregivers. When he felt he could no longer care for his wife, he applied for placement in a nursing home. She is currently being cared for in the nursing home where he visits her every other day.

For a fourth spouse caregiver, care for his wife has extended over an eight year period. When the disease began, both husband and wife were working and he engaged the help of her co-workers to assist him until she finished her term's work. Shortly after, he was forced to take an early retirement to care for his wife. Eventually his wife required total care and he performed this until his adult children felt it was too much for him, and, thus, his wife was placed in a nursing home. His involvement in his wife's care continued in the nursing home where he went in three times a day to feed her. She died shortly after placement in the home and he continues to visit her gravesite daily.

The final husband interviewed cared for his wife at home for five years. This man had no family support, as his children were living away or incapable of offering assistance. He was assisted by a limited amount of paraprofessional help in the home. During the last two years the level of care required was constant because of progressive deterioration. Five weeks before his wife died she was admitted to a hospital where he visited her daily.

Steve, interviewed on CBC radio, has lived with his wife and her disease for the past four years. His caregiving became more extensive as the disease progressed and he cared for her completely for about two and a half years when she was admitted to a nursing home several kilometres from his home.

Thematic Analysis

In examining the transcribed interviews there were a number of interrelated themes which serve to move towards an understanding of the experience of caring for a parent or spouse with Alzheimer's disease.

Enduring

The first of the themes identified was that of enduring. Having to endure and being able to endure were both important sides to this theme in that throughout their time spent caring, these men were required by the caregiving situation to endure a great deal. To endure, from the latin "endurare" means to persist or hold out, but it means to do so in a way that the person is able to hold up, and not give way, and even to be strengthened by having endured (Neufeldt

& Guralnik, 1988).

All of the caregivers were able to relate specific incidences in some detail of what they were asked to endure. They described how they were unable many times to intervene to help the person being cared for:

At night she used to sit up in bed
and cry and cry, sometimes for hours.

All described how they had to wash, dress, undress, feed, and medicate their family member. Several of the men described the behaviour of their spouse or parent as being "just like children." They described how their family members would not cooperate and refused to eat, refused to take their medications, and tried to run away when being dressed. One man would put his wife to bed and she would continue to get up many times before finally settling down for the night. These men toiled, enduring the hard work, and describing it as just that, hard work:

I'm knocking myself out looking after her. I cook, I wash, I get her up, I get her out to the table. I get her out to the bath. I take her for a walk with me ...

Getting her to move when she's sitting down is very hard.

Five hard years I punched... I had to do almost everything myself and I couldn't go anywhere or do anything, and that was hard.

What made it hard on me was all the washing and dressing. I still have the pain down my leg and in my knees.

To endure as these men did places great demands on the mind and body. Energy is depleted and the body is placed under great strain. To endure is to suffer. It is to feel pain from the weight one is under. What must be endured is not only physical, but is also psychological, such as the feelings of gloom and despair. There is very little, if any relief:

But sometimes after supper I'd say,
oh God, have I got to go through
that again.

Makes me almost cry too. In my own
mind I swear and say why in the hell
do we have this.

Some of these men questioned their ability to endure although they knew they had to:

It's now the end of January. How
much longer will it be, one
month, two? I've got to hold out
(Steve, 1994).

Similarly, another man questioned his ability to further endure caregiving, indicating his prolonged suffering and despair:

My God, how much can I take?

Caregiving was also seen as very frustrating in many respects. For example, the participants explained that they could not do many of the things that most people take for granted:

It's frustrating when you can't do what you want to do, can't even run to the store unless someone is there or I take her with me.

At other times enduring caregiving caused considerable anxiety:

I did what I could even when it was nerve wrecking.

That's why I lose my temper now, because my nerves are shot.

One of the consequences of not being able to endure any longer was the need to institutionalize the one being cared for; to place the parent or spouse in a nursing home. The male caregivers who finally agreed to nursing home placement recognized that they could not go on, they had exhausted other options open to them, and they just could not endure the caregiving that they were experiencing:

... but I had no other option but to put her in a home.

I said by all means keep her because

I can't handle it anymore.

Sometimes it was another family member who questioned the caregiver's ability to endure, and encouraged their family to place their mother in a nursing home:

Well dad what you have to do [place mother in a nursing home], and there's no way we can look after her, ... so I put an application in.

What kept these men going, being able to endure as long as they did? When asked to reflect on this question the responses varied, and although there were no single all encompassing answers, most participants could give one or two key reasons why they felt they were able to keep going.

For one of the spouses it was the life learned quality of perseverance:

... never say no, never say die.

For him it was the way he grew up. He felt there were rules to live one's life by, a personal creed, and you stick by this.

With two of the spousal caregivers it was the result of good marital relationships. One, reflecting on the depth of feeling he had for his wife, simply stated:

I thought a lot of her.

He cared for her because he cared about her. Yet, it went deeper than this feeling. He could put himself in the place of the other, the one being cared for, and felt that if the situation were reversed she would have taken care of him. For the second husband he said his wife had been good to him and it was time to repay that goodness.

Some of the caregivers were unsure of what kept them going. One husband asked himself the same question. He found that the strength always came from somewhere. When faced with a particular situation he knew he had to cope with it. Part of this he attributed to taking the caregiving situation one day at a time, playing it by ear:

... getting up every morning and see
what kind of mood she'd be in and
take it from that.

One spousal caregiver, in contrast to the others, endured out of a feeling of helplessness:

I felt what else can I do.

It was a sense of being so caught up in the doing that he did not have time to reflect on why he was doing it.

For all the sons who took on the caregiving role it was in the first instance, love of their mother, even in the

case where the mother was not the parent with Alzheimer's disease:

... love for her. I was always very close to mom.

... she was my mother.

In addition to the high level of affection these men felt for their mother, they also cared for her because even though there were other siblings, they felt they were the only ones who could handle it:

I was the only one in the family who could handle it.

... and nobody else would take it on.

Vigilance

A second predominant theme was that of vigilance. Watching out for the person they were caring for, especially as the disease progressed, was a major part of the caregiving experience. This went beyond keeping an eye on someone or making frequent observations, and took the form of a constant watchfulness, a vigilance.

The origin of the word vigilant, from the latin

vigilare means to be watchful, to stay awake (Neufeldt & Guralnit, 1988, p.1488). Caregiving for a family member with Alzheimer's disease meant one must always be watching out for the person, unrelentlessly, night and day, irrespective of whatever else they were doing, often forgoing rest and sleep:

Then there were nights when she was living down with me that probably at three in the morning I'd hear the shuffle down the hall. Of course I had to get up because I didn't know where she was going, bathroom or kitchen and I couldn't rest easy... Even though I'm not a light sleeper by any means. It's funny because even the lightest sound from her would wake me.

As the saying goes, these men had to 'sleep with their eyes and ears open,' forever watchful of their family member for fear that they might harm themselves or inadvertently harm someone else:

The biggest thing that worried me was her going up and down over the stairs. It was always a worry.

Being vigilant meant watching out in another sense, it meant safeguarding everything to keep the person out of danger:

We had to remove all aspirin, chocolates,

javex, any kind of household utensils or stuff like that, hide it away.

Several of the participants had to deal with their family member's wandering, and attempts to get out of the house. In being vigilant these men had to keep the doors of their houses locked. One man stated that even his neighbours joined in the watching out for his wife. The neighbours being aware of her condition, would keep an eye out for her, and bring her back home when necessary.

Several of these men worked outside of the home in the early stages of caregiving, and found that they had to find ways of being vigilant even at work, when they were not with the affected person. For example, one participant would take the knobs off of the stove when he went to work so that his wife would not be able to burn herself while he was away.

Caregivers reported that it was a "continuous worry" with "no relief whatsoever", and that they "couldn't walk away from it." The vigilance often carried over into many realms of life for the caregivers, for example, one man described how he had to go to the local store owner and ask him to credit the things purchased by his wife as she could no longer be trusted with money.

Because individuals with Alzheimer's disease, require help with all aspects of life, especially in the latter stages, the vigilance associated with caregiving was a never

ending process. One man stated:

You had to sit down and watch her all day long. And you had to ask her if she wanted to go to the bathroom, and you had to take her in, undress her, dress her, wash her and put her clothes on, take her out to the kitchen, sit her down and get her breakfast for her. And then you had to sit down on one chair and tell her to eat, and tell her take your cup and don't waste your tea. Then you had to watch her in case she did waste her tea. Now this was during the last year with her.

Even when caregivers were not actually physically doing something, they had to remain vigilant, thus the care, worry and watchfulness never ceased, day or night. With other conditions night is frequently a time when caregivers can sleep, and get rest from their caregiving activities, but not so for many of the caregivers in this study:

From last July until she went in the home, she was up all night long, wandering around. In the daytime, the same thing.

A Sense of Loss

The sense of loss was a third theme identified from the data. These caregivers experienced and felt loss in many different ways. Caring for their parent or spouse, as this

person's health deteriorated, made the participants think of their family member as they had been prior to the disease. When describing their parent or spouse, most of the men talked about the person before the illness; highlighting their accomplishments:

Here's a woman who at 50 years old went back to college ... (Steve, 1994).

She was a very smart person ... she could do it all ... She was a very smart person, now to look at her and see the end result is almost unbelievable.

Here is a vibrant woman [who], could cook and sew and crochet, who loved to go out with friends ...

The past accomplishments of the care recipients highlighted and gave a sense of the depth of the loss of these men. The person of before, the woman or man who had contributed to the family and community, was now gone. As another man explained:

You are trying to explain to this person who is or was your mother...

It was as if this man had lost his mother even though she was still alive. The men in this study felt empty and deprived of their loved ones. They could no longer effectively communicate, share their thoughts or feelings, or have any semblance of their previous relationship with

their family member. Many of the ill family members no longer recognized their caregivers, often mistaking them for someone else. This experience was very painful for the caregivers:

In other words we never had anybody to talk to anymore, mom couldn't confide in him and also she had no support. He was there physically but he wasn't there. She lost her companion, lost her friend, lost her support and similar to me, he didn't recognize who I was, I sort of lost that thing, the father-son relationship, and it was hard.

Several of the participants described their loss as being similar to that of death. Even though their wife or parent was not dead, they were basically grieving, grieving for someone they once knew, someone they no longer recognized:

Alzheimer's disease is like a death without a funeral. What's the difference if she were dead to me right now. Her clothes are hanging up there, her dresser is the same. She's not around. It's the same thing if you took a person out and put them up in a cemetery.

Not only did they lose the relationship with the person they were caring for, but also experienced a sense of loss in relationships with other family members, when siblings

and others in the family stayed away because of the disease:

And it [sisters staying away]
sort of bugged me, and I had always
thought a lot of the family, but I lost
a little bit of feeling because of it.

Because of this feeling of loss many of the participants described their lives as being in suspension. The person they once knew and loved was gone and life now had to be placed on hold. One man stated:

I had to curtail my social life,
things I wanted to do.

and another:

It's almost better if a person were
dead because it is final.

Most of the men stated that all of their life plans had been destroyed. This was especially true of spouse caregivers:

Me and the wife were going to travel
in our retirement, but instead of
travelling, my money is being used to
pay for this.

All your life plans are gone, plans
you made when you were younger.

Aloneness and loneliness

A fourth theme which also illustrates part of the experiences of these men's caregiving was their aloneness and loneliness. As the care-recipients became progressively worse and unable to communicate or be an active part of the caregiver's world, feelings of being alone and lonely also intensified. Being alone can occur in a physical sense as someone who is alone in a house, or it can occur in the sense that one stands alone in a given situation. Many of the men were not literally physically alone but this was how they experienced their world:

Now you're alone, but not alone
physically, but mentally you're alone.

It's hard at night here all alone with
no one really to talk to [wife still
present in home].

But now there is no one in the house
with me, just myself [wife still present].

For these caregivers their spouse or parent had changed so much during the course of the disease that they were left feeling alone and lonely:

Even when she was here I had no
one to talk to. Her presence was
here that was all.

I was here all day basically by
myself, looking out through the

window.

Past relationships with the family member were lost. In the case of spouse caregivers it was especially one of sadness and longing:

It's difficult to put how I really feel into words. You just don't snap your fingers and 44 years are gone.

For sons, it was the loneliness that comes from losing your parent:

I missed his companionship and friendship.

It was hard to accept that the relationship was not there anymore.

One participant felt alone, not in a lonely sense, but rather as one who stood alone in his decision to institutionalize his father. Going against the wishes of most of his brothers and sisters, this man felt alone and alienated from many of his family members. Another participant stated that he, too, felt alienated from his family. His relationship with his sisters had deteriorated and he was left alone as sole caregiver for his mother. When asked if he had anyone to talk to and share his feelings with regarding caregiving, he stated, that, "there was no one."

Taking Away

Caregiving as the word suggests is a giving of oneself, a giving of one's time, of one's effort. It is antithetical, therefore, to think that caregiving could be associated with taking away. Taking away, was a theme from the interview data. Caregivers were forced to take away from the care-recipient, and this was something that the care-givers had to reconcile with their caregiving role.

The individuals who had Alzheimer's disease had lost a great deal, their sense of identity, recognition of familiar people and places, and a healthy happy future:

If ever she could see herself, or
if she ever knew what she was like now,
she'd be so upset and angry.

She was a very good woman [wife still
alive].

It might first appear inhumane to think of further taking away things that had been, or perhaps still were, of great importance to these people. This would surely only be adding insult to injury. What if there were no choice? Indeed, what if it were a matter of life and death? The caregivers in this study were faced with this very situation. In the midst of trying to preserve what was left of their family member, the very things that mattered to how they defined the self had to be further removed.

Frequently, taking away involved taking away the person's independence. For example, one man made his mother accept outside help against her wishes, while another made his wife quit her job. Both caregivers feared for the safety of their family member. Others described their anguish at having to remove their family members from their homes to place them in a nursing home:

It was the worst thing I ever had to see because I knew mom wanted to be home, but under the circumstances she had no choice. I think she was what I would call broken hearted because she knew she was going out of the house and she wanted to be home.

Anyway she went down to the home and that was the hardest day of my life, to take her out of the door, her thinking she was going for a drive somewhere, and me knowing she may never come back through the door again. It was almost like somebody dying really.

For one man it was taking away his father's car that stood out as one of the most difficult things he had to do:

We had to take the car away. It nearly killed me because I knew it was the last time he'd ever be behind a wheel.

This man also described how he had to dress his father, a man who normally wore a shirt and tie, in jumpsuits. This

and his father's car were seen as symbols of his dignity and the caregiver felt that these symbols were being stripped away from him.

Searching To Discover

I tried to find out what I could about Alzheimer's disease once I knew that she had it, and I was told by the doctors that there was an association, and I checked into it. Then I went to some family support group meetings. That was helpful because you learn little tips about safety and how to handle certain situations and how to avoid frustrating the person and things like that.

Most participants knew very little, if anything about Alzheimer's disease. Their need for a greater understanding grew both from their desire to assist their family member and their need to better cope with caregiving. Many turned to the Alzheimer's Association while others talked with various health professionals such as nurses and physicians. Discovery helped them cope:

Once I knew about the disease, I somehow had more patience in a way because I knew she couldn't help it.

The need to discover also revealed itself when the

participants discussed their day-to-day caregiving activities. All of the men had tried to make sense of the many idiosyncrasies displayed by their family members. Many described how they had searched for clues or answers to these unusual behaviours in belief that such answers would somehow help them cope with caregiving. This search involved a close scrutiny of the family member, of their actions, words, and expressions:

... experience and always looking
for clues.

I had it all figured out you see
I had her timed.

To facilitate this search one man had a paraprofessional keep a diary.

Often times the search involved trying various things in a hit or miss fashion in order to discover what worked best. For example, one man stated that his father continuously used the laundry basket instead of the toilet. He later discovered that the reason for this unusual behaviour was the green covering that had recently been placed on the toilet seat. After the cover was removed the behaviour never occurred again. This man stated:

So then another discovery. So
what you do, you watch for changes,
you watch for clues to help you, in
everyday living.

Many participants indicated a need to discover the cause or reason for the illness. It appeared that by finding such a reason, they could somehow make sense of the illness, and why their lives had taken such a course. The participants hypothesized several reasons as to why the illness had occurred, such as blaming it on past working environments, or the worry over another illness.

The Need For Assistance

A theme underlying all the caregivers' experience was the need for some help, some assistance with caregiving. Even though the physical and psychological demands of caregiving were enormous, they were equalled in magnitude by the need for assistance to alleviate them. Recognition of this need was generally prompted by a crisis:

I realize too that after the nurse came in here in June I started to relax. Before that I almost fell apart. I wanted to sit down and cry sometimes.

The receiving of assistance from family, friends, peers, and professionals was an essential component in lightening the load of caregiving. The need for formal assistance as home care nursing served both to lighten the physical demands of caregiving as well as provide caregivers

with an emotional outlet. Support groups were also utilized by several of the participants for information and emotional assistance. Assistance from health professional and support groups was very important as many of the participants had very few other places to turn. Most men preferred not to involve their own children. As one man stated:

You don't want to talk to your own children about it. They got their own lives to lead.

Despite the use of formal support services, informal support by family and friends was also of great importance. Many of the participants felt that their siblings (in the case of son caregivers) or their wife's siblings (in the case of spouse caregivers) should assist them in alleviating the burdens of caregiving. When such help was not offered, as often was the case, conflict arose between family members.

Neighbours of several of the participants were an expected source of assistance. One man in particular felt that the help provided by his neighbours was invaluable in easing the load. This man whose wife often wandered stated:

... and the next thing I'd know, a friend up the street would turn up and say, "me and your wife have been for a walk," and he'd be after seeing her go up the street. The neighbours were always watching out for her.

Several of the participants expressed their displeasure at not receiving adequate help from their neighbours. As stated by one man:

They don't bother to come in the house, or do anything, like bake a cake or pie.

Irrespective of the source, the need for assistance was crucial in alleviating the stress of caregiving. Caregiving for a family member with Alzheimer's disease without some form of assistance would be devastating to health and life, if not impossible.

Reciprocity

An eighth important theme was that of reciprocity. The relationship that has been established between caregiver and care-recipient is partly due to the fact that the care-recipient was once the caregiver in the relationship. Although true for both the son and spouse caregivers, this was especially so for the son caregivers. For son caregivers, caregiving has become almost a role reversal. Whereas in years gone by it was the parent who cared for the son, the son has now assumed total responsibility for the parent. The caregiver's desire to reciprocate for this care is a final act of gratitude that symbolizes a balance of exchange between themselves and their family member at the

end of a long standing relationship:

When I was young, mom took care of me and I wasn't neglected or anything. She was sick and she couldn't help it, and I was in a position to help her as much as I could. It was a bad situation but I didn't mind it because if I were sick she would do the same for me.

He would help me in making a bit of furniture. Now I was leading him along.

Spouse caregivers as well wished to reciprocate for past care given to them from their wives. The past relationship with their wives was very different from the past relationship of the sons with their parents, thus changing the meaning of reciprocity for the spousal group of caregivers. The relationship with the spouses can be described as being on more of an even plane, therefore, caregivers did not experience the role reversal:

To me, she was good to me, and I was away from home ninety percent of the time. And when I came home my meals were on the table for me, and she raised my children, and did a good job. And when she got sick, I said well boy it's time you did something for her, and that's what I did.

One participant found that providing care to his wife offered its own source of gratification. In other words he not only gave care to repay for past care, but also to receive something in return:

Maybe the love and other stuff
is there even more so, because you
have to give love to get it returned.
That's what's needed now. In order
to get affection from her you have
to be willing to give it to her.

Reciprocity was also found to extend beyond the role of caregiving. Several caregivers felt that they had somehow benefited from caregiving and could now give something back to someone else. Since the death of their parent two of the caregivers have become active in supporting others in the same situation:

I feel that I've learned an awful
lot, that I've passed it on.

Overstepping The Normal Boundaries

The final theme identified from the interview data, overstepping the normal boundaries, pertained only to the son caregivers. This is probably due to the differing past relationships between sons and their parents, in contrast to

husbands and wives.

To perform the essential care needed by their parents, the men in the study sometimes had to overstep the normal boundaries of the relationship. For these men, seeing and caring for their parent without clothing, shame, or dignity, was not part of their normal relationship, but rather a taboo that when carried out was emotionally very painful:

My sister got her in the bathtub one day and couldn't get her out on her own. So I had to go in and help get her out. I said, I hate to go in there, especially your own mother.

So eventually it got to the point where I had to change her and things like that ... it was difficult ... especially when it's your own mother.

Another son had to overstep the normal boundaries of his relationship with his father when he had to take away his father's car. This is something that most sons in ordinary circumstances would never imagine doing:

Getting the car away from him was the biggest and the most hard thing to do, especially what I was doing to him ... I can imagine somebody taking my car away from me now, even at my age.

Relationship Among Themes

The themes highlighting the men's experience of caregiving for a family member with Alzheimer's disease are in themselves only parts of the whole. They are not entirely separate entities, but rather are interconnected and dependent upon each other to form a structure around which "the phenomenological description has been woven" (van Manen, 1990, p. 106). The following discussion will present the themes as they relate to each other, providing a phenomenological description of the male experience of caregiving for a parent or spouse with Alzheimer's disease.

That caregivers had to endure many demands of caregiving was without a question a predominant theme in all of the interviews. One reason for this was that eventually all the family members became fully dependent on the caregivers and constantly required total care. As one caregiver indicated, he even had to talk for his wife. What also had to be endured when providing many aspects of this care was the crossing of many personal boundaries, seeing and caring for these individuals in an entirely new way. Husbands and sons found that looking after their spouse's or parent's toileting or personal cleanliness was very difficult. For the sons this was particularly emotionally very taxing and further increased the demands of caregiving.

Significant impairment in cognitive abilities and altered behaviours of the care-recipient, required caregivers to be vigilant, continuously watching out for the person, both day and night. For many of the caregivers this taxed their endurance more than other aspects of care. Although the vigilance served a protective function in making sure the person they were caring for did not wander away or injure themselves, it served other functions as well.

The vigilance served to remind the men of their aloneness and loneliness. To sit and watch the behaviour of the person they were taking care of, behaviour which seemed meaningless and repetitive, forced the men to think of and sometimes reflect on the person who was, that is, their wife or parent before the disease began. This personal reflection added to their sense of loss experience.

The vigilance also assisted the men. It helped them to discover ways to help the care-recipient, whether it was music to soothe his wife as one man noticed or ways of dressing his father so that he was able to keep his father's clothes on and maintain his dignity. There was a continual searching, trying to discovering meaning and ways to care. The vigilance allowed them to see patterns in their family members' behaviour, monitor the progression of the disease, and make decisions about when it was time to change their caregiving approach. Caregivers also searched for clues to

assist them to make sense of their family members' behaviours, which might further serve to help them endure.

The reflection that came as a result of the constant watching and thinking of their loss helped keep these men going. When they reflected on their family member and how that person had been before the disease it also made them think of how that person had been to them, in the past. This evoked a sense of the need for reciprocity. In their caregiving they had a chance to balance past accounts of times when a wife cared for the household and the children in a way that permitted the husband to pursue his career. For the sons it was a time to repay kindness they had remembered from their childhood when their parent had taken care of them. In some ways the evoking of these memories of kindness and help, together with the desire to reciprocate helped these men endure and make the vigilance less onerous a task.

To bear the burdens of care, caregivers sought and often expected assistance from family, friends, support groups, and professionals. This not only provided emotional assistance such as the alleviation of loneliness but helped them cope with physical demands of care.

The Essence

By exploring the caregiving experiences of these men as presented in their interviews, it is possible to move closer to an understanding of the male experience of caregiving for a family member with Alzheimer's disease.

It is also possible to try and come to grips with the fundamental meaning or essence of this experience.

Phenomenologically speaking, the researcher has identified the structures that govern the particular manifestations of what makes this experience what it is. From this endeavour, the researcher believes that the essence is the disease itself; the effect that this disease has had on to the care-recipient in the form of cognitive and behavioural changes. In other words the disease is not unimportant, rather it is paramount in how these men saw their experiences. It is the prism through which all their efforts were viewed and how they experienced the world.

The characteristic features of the cognitive deterioration in Alzheimer's disease lay the groundwork for what it means to care for this person. This was clearly evident in all of the themes. Enduring, vigilance, a great sense of loss, aloneness and loneliness, searching to discover, the need for assistance, reciprocity, and overstepping the normal boundaries, are all themes which capture caregiving for a person with Alzheimer's disease.

The caregiving experience was shaped to a major extent by the changes noted in the person cared for as the disease progressed. The men acknowledged these changes, often marking them by duration or date:

Things deteriorated in stages.

This was 1990, and that fall she was deteriorating a bit more.

All of the participants talked about the disease, what it did to their spouse or parent, how they believed Alzheimer's disease differed from other disease and how they felt caregiving would be different if their spouse or parent had another disease:

I'd say it's the worst disease you can possibly have. Even if a person got [sic] cancer you can make plans. You can sit down and you can talk up to the last few days.

One of the biggest contradictions of the disease, and which made the caregiving much more difficult was that the person suffering with the disease was not perceived as the 'real' sufferer, certainly not the only sufferer, or the one suffering the most; it was the caregiver who suffered. These men, therefore, had to reconcile this suffering:

It's harder on me than it is on her, she's not there.

But she doesn't know, so I guess it bothered me more than her.

Really a person with Alzheimer's has no worry at all. It's the carer.

With a physical disease, of course, there are changes, but these are not as fundamental to the personhood of the person with the physical disease as is the case with a person who has Alzheimer's disease. With Alzheimer's disease there are major changes, and the ramifications of this for the caregiver are enormous:

At first it [the personality changes] took the life out of me, but after awhile I got used to it.

I even had to talk for her in a way. She wouldn't ask for anything.

... it's hard to hear and see your wife doing these things.

Phenomenology asks the researcher to look at the very nature of a phenomenon, to see what makes this phenomenon what it is, what makes it possible and "without which it could not be what it is" (van Manen, 1990, p.10). If the disease were any other, the experience would not have the same meaning for the caregiver. That is not to say that caring for relatives with other diseases, other than Alzheimer's disease, would all be the same, but rather, the

effect that Alzheimer's disease has on the person affected shapes the caregiving required in a fundamentally different way than other diseases. As one public speaker confirmed in addressing delegates at a conference on long-term care in speaking about her mother who had Alzheimer's disease:

Everything we loved about her, her spirit, personality, her joy of life faded and died by inches. ... It's different [Alzheimer's disease] from other chronic illnesses and it's also different from other forms of dementia (The Evening Telegram, 1994, p. 10)

CHAPTER 5

Discussion

From the analysis of interview data it was found that caregiving for a parent or spouse with Alzheimer's disease was a complex experience for the men in this study. Many of the studies in the literature, especially those researched from a stress and coping framework, illustrate the negative aspects of caregiving, especially the burden experienced as a result of the caregiving. The men in this study certainly experienced stress as a result of the level of care demanded of them, but as a result of trying to understand each of their particular experiences, a much more complicated picture emerged.

Gubrium (1991) refers to this complicated picture as "the mosaic of care", emphasizing the distinct and interpersonal experiences associated with caregiving. A mosaic is a strong visual image because it suggests that different experiences, of differing shapes and colours, go together to form the whole. Each person's mosaic is different in so far as they have different pieces of experience forming the whole. This chapter is a discussion of the caregivers' experiences, their mosaic. The first section is a discussion of the themes as they relate to the

literature. The second part of the chapter contains new insights into the male experience of caregiving for a family member with Alzheimer's disease, in an attempt to explicate their meaning for the caregiver.

Discussion of Themes in Conjunction with Literature Reviewed

A number of themes merit discussion because they shed light on previously identified areas of research. One such theme is enduring. Although positive aspects of caregiving were evident, this theme encompassed much of the negative aspects of caregiving found in previous research (Cantor, 1983; Colerick & George, 1986; Jones & Peters, 1992; Montgomery et al., 1985; Zarit et al., 1986). Enduring, however, was not an isolated theme, because what had to be endured was much more complex than that suggested by previous research, encompassing many other components of the caregiving experience; vigilance, loss, aloneness, loneliness, taking away, and overstepping the normal boundaries. All of these themes to various degrees for different caregivers, were aspects of caregiving that were very demanding. They required that the caregivers hold up, and somehow continue on with caregiving in spite of them.

The need for assistance, and/or the decision to institutionalize was often the result of a crisis for the caregivers in the present study. Such a crisis was often due to the accumulative effect of the demands caregivers had to endure rather than from a single precipitating factor. Although there were both differing and similar stressors for the different caregivers, common stressors precipitating such a crisis, were the sundowning behaviours of the care-recipients, such as the exacerbations of confusion and wandering. The literature, although addressing factors precipitating the decision to institutionalize (Colerick & George, 1986; Zarit et al., 1980), contained very little regarding such a crisis. Sundowning behaviours, even though addressed in the literature (Gallagher-Thompson et al., 1992), have not been associated with or limited to the subsequent outcomes for the caregivers that were found in the present study.

Consistent with some of the literature, both informal and formal supports, were important in alleviating the demands of caregiving for the men in this study, further enabling them to endure. The caregivers often preferred to seek outside assistance rather than call upon their own children. Similar findings were reported by Harris (1993), who found that caregivers were more likely to favour paying for services from formal providers than oblige their own

children to provide services. Lee (1985) found that contact with friends and neighbours had a greater impact on well-being than did contact with adult children or other relatives especially when it came to having someone with whom to vent frustrations and spend relaxing moments. Neighbours of several of the participants were an expected source of assistance.

As with the findings of Robinson (1990), the past marital relationship of spouse caregivers in the present study was an important indicator of how well these men were able to endure caregiving. Not found in the literature however, was the importance of the father/mother to son relationship as an indicator of how these caregivers were able to endure caregiving. The son caregivers often reflected on the closeness of their relationship with their mother or father, for example, "she was good to me," and "she always thought a lot of me." These caregivers appeared to draw upon the strength of their past relationships with their parent to help them in caregiving.

Another theme identified in previous research is reciprocity. Tennstedt et al. (1989) found that little is known about the reciprocity that elders have in their relationship with caregivers as their own health deteriorates. Social exchange theory may provide some clue as to explaining caregivers' need to reciprocate identified

in the present study. The ability to reciprocate for assistance provided is, according to social exchange theory, one way of providing a valued reward. The norm, that favours, should be returned to another from whom they were received is a very generalized form of reciprocity (Nye, 1982), and may possibly be yet another piece of the puzzle as to why caregivers continue to endure the demands of caregiving. The fact that the concept is stated as a norm suggests that reciprocity is strongly approved by society. The person will predictably be rewarded by those in society who are aware of such acts (Nye, 1982). Although this aspect of the theory may also partly account for the reason caregivers care, there is one aspect of caregiving not accounted for in social exchange theory; that caregivers provide care because they care about their family member and feel good about caring. Such was the case for the men in the present study. Similar findings were reported by Horowitz and Shindelman (1983) who found that among family caregivers, warm affectionate feelings were a major influencing factor, and defined those who went beyond the call of duty.

Much of what was found in the present study also tends to reflect some of the literature addressing the process of caregiving. Similar to the findings of Wilson (1989) and Lindgren (1993), the caregivers in this study often

described their experience in terms of phases. Most of the caregivers explicitly described how they first came to the realization that something was wrong with their parent or spouse. The next phase of caregiving described by the men in this study is consistent with Lindgren's (1993) enduring stage and Wilson's (1989) stage of going through it. Within this stage caregivers in the present study began to realize their loss. This is consistent with the findings of Collins et al. (1993), who described caregivers' experiences of loss in various aspects of caregiving, and Jones and Martinson (1992), who analyzed the experience of bereavement within the context of caregiving. The final stage of caregiving is also consistent with the findings of Lindgren (1993) and Wilson (1989). The exit stage for several of the men in the present study may be seen as a result of their decision to institutionalize their family member, while for others it came as a result of death. The problem with looking at the present experiences of caregiving in terms of stages, however, is that it is often difficult to determine when one stage ends and another begins. For example, the caregivers in this study, when describing their experiences of caregiving, often included the care they provided to their family member even during institutionalization, therefore, it is almost impossible to view caregiving within the framework of distinct phases.

New Insights Into The Male Experience Of Caregiving

The findings of the present study have revealed aspects of the caregiving experience not recognized in past research. One such area is the difference between son and spouse caregivers in how they experienced caregiving for their parent or wife. Another unrecognized aspect of the caregiving experience is how the caregivers, both sons and spouses, have come to view their being in the world since caregiving.

Differences in Sons and Spouse Caregivers

Within the present study there are some very distinct differences between son and spouse caregivers in how they experienced caregiving. One such difference can be found in the theme, overstepping the normal boundaries, which was present for sons but not for spouse caregivers. This can be explained by looking at the differences in the nature of relationships between husbands and wives as compared with those between sons and parents. Both types of relationships are normally built on love, affection and mutuality, however, they differ in how these aspects of the relationship are perceived and expressed. Sons caring for a

mother or father with Alzheimer's Disease must often cross over into areas where they would normally never even think of going, such as, in providing personal care. This perception is not usually the case for husbands, however, who have during their lifetime shared an intimate and a sexual relationship with their wives

The loss experienced by spouses and sons is also quite different. Spouse caregivers have lost their partner, someone with whom they have shared most, if not all, aspects of their lives. The son caregivers in this study, however, although having lost the parent-son relationship, have for some time developed other primary relationships, usually wives or partners of their own, with whom they now have developed an intimate partnership.

Spouse caregivers, being the closest, most intimate person in the lives of their wives with Alzheimer's disease, if able, are naturally the ones most likely to assume responsibility for caregiving. The son caregivers, however, were only one of a number of siblings, so the question is why this son for this parent? Competition between siblings as primary caregiver for a parent is not common (Albert, 1990). Generally preselection by close proximity takes place. The son caregivers in this study, by reflecting on their relationship with their affected parent, provide a greater understanding of why this occurs.

They saw themselves as the only one who was able to take on the caregiving. They also perceived themselves as able to recognize that the parent had a problem, or recognized problems earlier than others. The latter was sometimes a source of conflict among siblings.

Effect of Caregiving Experience On The Way They View The
World

Like most individuals, the caregivers in this study lived with certain values, feelings, beliefs, and expectations about the world and their place within it. The caregiving experience, however, had a major impact upon the caregivers and was of great significance in reshaping the way these men viewed their experience of being in the world. One son caregiver, although describing the difficulties of many aspects of caregiving for his father and often questioning his ability to endure, stated:

And then after he died, after the
eight years of doing that and he
died, all of a sudden I found a void
in my time.

Despite the difficulties of his caregiving experience, this man filled the void in his life by going on and supporting

others in the same situation. His life was restructured as a result of caregiving and his caregiving experience was incorporated into the way he viewed the world. Because of his experience, another son caregiver also made the decision to support others, after the death of his mother. He now devotes much of his time promoting an awareness of the Alzheimer's Association to others who might benefit from it as he did. One spousal caregiver, because of his caregiving experience, has come to a greater understanding of his life in earlier years, before the disease. Whereas in the past, support, love and affection came from his wife without him always having to make any exceptional efforts, he now realizes that this is no longer true:

In order to get love from her
you have to be willing to give
it to her.

Because of this he now reflects on his life and realizes that he owes a lot to her:

If it wasn't for her I wouldn't
have been able to have done it.
Times I should have been home I
was at meetings, doing things, and
she was very supportive.

Two other spousal caregivers, because of their

caregiving experiences, came to a greater understanding of their vulnerability as humans. For them, such an experience led them to see the potential helplessness of people in the world.

Boy it was hard. And there is
nothing you can do. Nothing at all.
It's quite an experience.

It's hard to believe you can change
so much. It's heartbreaking.

Much of what has been found in the present study does reflect what is previously reported in the literature, especially in regard to the hardships endured during caregiving (George & Gwyther, 1986; Jones & Peters, 1992). There are however, several unexplored areas that have emerged from the interview data, such as, the difference in sons and spouse caregivers, and the meaning the experience has for the caregiver.

Chapter 6

Nursing Implications, Limitations and Conclusion

The findings of this study have implications for nursing practice, nursing education, and nursing research, especially as we move toward the twenty-first century and seek to accommodate the increasing number of elderly who will be diagnosed with Alzheimer's disease. Taking care of people with Alzheimer's disease must be done in both a meaningful and cost-effective way for the benefit of the personal lives caregivers, care-recipients, and society. With more men taking on the role of primary caregivers for their parents or spouses, there is a need for increased sensitivity to the special issues they may face as men.

Nursing Practice

Phenomenological research captures the unique experiences of phenomena for a person and, therefore, may not have direct implications for nursing practice. However, this study of male caregivers has many indirect implications for nurses working with men who are informal caregivers to a

relative with Alzheimer's disease.

First of all, nurses, especially community health nurses, need to establish a therapeutic rapport with the male caregiver in order to become fully aware of the meaning of the caregiving experience for the individual caregiver. By being more aware of the meaning of caregiving, nurses are in a better position to identify problem areas, thereby offering greater assistance to the caregiver in the alleviation of such problems. Nurses will then be aware of factors that can contribute to health problems for the male caregiver, such as loneliness, vigilance and the demands of providing total care. For example, loneliness has come to be recognized as a mental health problem. It has been linked to depression, heart attack, addictions, and suicide (Bulka, 1986; Dura, Stukenberg, & Kielcolt-Glaser, 1990). In fact, Gallagher et al., (1989) found that several types of depressive disorders are more common among family caregivers than the population in general.

Nurses need to be competent in assessment and use these skills to identify men in a caregiving situation who are at risk for serious health consequences, such as, depression, burnout and addiction. It is important that the nurse be aware that health consequences may be different for men who act as caregivers than for women in a similar situation. Gender specific assessments need to be employed so that

appropriate interventions may be planned.

Nurses will then have to increase their awareness of interventions that would minimize some of the problems identified for men in this study, such as, loss and loneliness. Through their nursing skills, nurses will need to know how to help male caregivers ease the load of caregiving and increase contact with individuals and groups who are supportive. Nurses can then take an active role with caregivers, providing assistance, guidance, education, and support.

One of the strategies for health promotion identified by Epp (1986) is the creation of healthy public policy. Workplace policies which address the needs of caregivers is an area where nurses may have some impact. The nurse, through the understanding that comes from research, such as this study, will be able to inform public and private workplaces, and help them to create eldercare policies which permit caregivers to balance home and work responsibilities. The needs of men as caregivers may not be considered as important an issue as it is for women in workplace settings, given that women are more frequently expected to be the caregivers. Men, as they take on caregiving responsibilities, will also need to be considered in workplace policies on eldercare so they can continue in a less stressful way with caregiving.

Nursing Education

The findings of this study also have implications for nursing education. With the rapidly changing demographics, the population of elderly individuals is reaching phenomenal proportions. This brings with it, an increase in health concerns and diseases that are prevalent in the elderly, such as Alzheimer's disease. Future generations of nurses need to be well prepared in the areas of gerontology and gerontics in order that the public receive quality care in the future.

Nursing curriculum, both undergraduate and graduate, will be required to include course content on informal caregiving and how the nurse may assist family members to take care of relatives who have Alzheimer's disease. Special attention should be placed on men as caregivers. First, the nurse educator will need to integrate into the curriculum what is known about men as caregivers, how men and women differ in caregiving, and what are the special problems and needs of men who act as primary caregivers to spouses and parents. Specific topics to be explored are what effects caregiving has on the health of these individuals, strategies to alleviate stress in the caregiving situation, and how to help the caregivers with

the many losses they experience.

Second, nurse educators will need to teach students to be sensitive to and to try to understand the male caregiving experience. Student sensitivity to male caregivers and their experiences can be increased by students reading and discussing findings of research related to the subject. The findings of this study furnish some insights into what the experience of caregiving was like for those men and provide a foundation for nursing encounters with lay caregivers.

Third, students need to be encouraged to explore with caregivers what they are experiencing as a result of taking care of someone with Alzheimer's disease. As some of the participants in this study indicated, these men can act as valuable resources in teaching about caregiving both to formal and informal caregivers

Nursing Research

From the present study, it became apparent that future research is warranted in several areas. First of all, it is highly recommended that more research be done in the area of the meaning of caregiving, for both men and women. Secondly, research should be conducted that compares and

contrasts the experience of spouse and offspring caregivers, and male and female caregivers, to determine if the experience and resulting needs are the same or different.

Many of the male caregivers indicated that they continued to provide care after institutionalization. Men may not be thought of as an important source of assistance to their spouses or parents when they are institutionalized. Research that seeks to explore the assistance men provide and to understand the conditions and consequences under which family members continue with this care is lacking. If the family member is an important source of support to an institutionalized person, including those with cognitive impairments, we need to know more about how this support or lack of support affects that person.

Research is also needed in the area of understanding the positive and rewarding aspects of caregiving for a family member with Alzheimer's disease. In the present research there were clearly some rewards in taking on the caregiver role. What is needed is a study of these rewards in more detail and to see what impact, if any, they have on the physical and mental health of the caregiver. By having a better understanding of the positive aspects, nurses could focus on these areas when assisting caregivers.

There is a need to determine what support systems would be of maximum benefit to male caregivers in assisting them

to endure the demands placed upon them. What sources of support do men more frequently seek? What type of support is considered more helpful to these men? Lee (1985) suggested studying the help provided by neighbours versus that of family. Some of the participants in the study discussed assistance or lack of assistance from family and neighbours/friends and how they felt about these different situations. Research into the type of support men seek and find helpful would provide nurses with a greater understanding of what potential positive resources caregivers might draw upon when providing care to their family member.

Finally, it is also important that future research in the area of caregiving address other cultural groups. The care of the elderly within the context of family is likely to be highly dependent upon cultural influences, and can only be adequately understood through intensive research efforts.

Limitations

Although it is not the purpose of phenomenology, to generalize results to the larger population, it is important to mention that the participants' characteristics were not

representative of male caregivers in the province. The men in the study were all caucasian, middle class, and living in an urban area of Newfoundland with similar opportunities for receiving formal support services.

A second limitation is the difficulty men had in 'fully' describing their experiences. Although, as stated in the methods section, the participants did not have any difficulty articulating their experience, that does not mean it was an easy exercise for them to go through or, at times, to put into words exactly how they felt or what their experiences were like. They spoke freely, voluntarily taking part in the research, and really worked at exploring their caregiving experiences. However, it was difficult. As one participant explained:

You really have to go through
it to understand it.

To come to an understanding of the caregiving experience was hard work, and not easy to accomplish:

Sometimes I feel that I'm just
tired of listening to Alzheimer's.
I've heard it all, said it all,
it's tiring.

Conclusion

The primary question addressed in this study was: What is it like for men to care for a family member with Alzheimer's disease? To investigate this question, a phenomenological mode of inquiry was used as outlined by van Manen (1990). Seven men were interviewed on two occasions, and one man was interviewed once. From the interviews nine themes were identified; (a) enduring, (b) vigilance, (c) a sense of loss, (d) aloneness and loneliness, (e) taking away, (f) searching to discover, (g) the need for assistance (h) reciprocity, and for son caregivers, (i) overstepping the normal boundaries.

From these themes it was determined that the meaning or essence of this caregiving experience was that the disease itself was not unimportant. In other words, the disease shaped the experience, giving it the form it eventually took. Following this, a discussion of the findings was presented, in relation to the literature reviewed, as well as areas not identified in previous research. Implications for nursing practice, nursing education and nursing research were also presented and, finally, limitations of the study were addressed.

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APPENDIX A

Ms. Ann Crowley
Director
St. John's Home Care
St. John's, NF

Dec. 6, 1993

Dear Ms. Crowley:

I am a graduate student currently registered in the School of Nursing, Graduate Program in Community Health Nursing at Memorial University of Newfoundland. A partial requirement for the degree of Master of Nursing is a research study. This letter is to explain the purpose of my study and to seek your cooperation in selecting adult males who might be included as participants.

The immediate purpose of this study is to explore the experiences of men who are caring for a spouse or parent with Alzheimer's disease. Thus, the ultimate purpose of my study is to contribute to the knowledge that could be used by nurses and other health care workers to assist in helping/assisting the caregivers.

This is a qualitative research study which will involve two, or possibly three tape recorded interviews of male caregivers. The interviews will be guided by an interview schedule. The content of the interviews will be analyzed by the researcher and three other faculty members from Memorial University School of Nursing, to identify emerging themes. Following the collection and analysis of the data, all tapes and notes will be destroyed. There will be no names or distinguishing characteristics identified in the report. The proposed study will be reviewed by the Human Investigation Committee at Memorial University of Newfoundland. I will confirm the approval of this committee to you prior to the commencement of the study.

I am requesting that your department identify, from the records, men who are the primary caregivers for a parent or spouse with Alzheimer's disease, that could be included in the study. I ask that your department make the initial contact with these men so that you can provide me with names and telephone numbers of those who agreed to be contacted. I will then contact each man selected, to further explain the study, answer any questions and arrange a time to interview each participant.

I hope you will have a favourable response to this request. Your help in identifying participants for inclusion in this study is vital. I am available to provide further information and to answer any questions that you may have. I look forward to a reply at your earliest convenience.

Sincerely,

Karen A. Parsons
1B Tunis Court
St. John's, NFLD
Telephone 753-8140 Or
956-2647 (out of town).

Appendix B**FACULTY OF MEDICINE
MEMORIAL UNIVERSITY OF NEWFOUNDLAND
ST. JOHN'S , NEWFOUNDLAND A1B 3V6**

TITLE: THE EXPERIENCE OF CAREGIVING FOR A FAMILY MEMBER WITH ALZHEIMER'S DISEASE: A MALE PERSPECTIVE

INVESTIGATOR: KAREN PARSONS

You have been asked to participate in a research study. Participation in this study is entirely voluntary. You may decide not to participate or to withdraw at any time. You may also refuse to be audiotaped or decide not to respond to any questions asked by the researcher.

Confidentiality of questions concerning participants will be maintained by the researcher. The researcher will be available during the study at all times should you have any problems or questions about the study.

Purpose of study

The purpose of the study is to determine the meaning of the caregiver experience for men who are caring for a family member with Alzheimer's disease. The study will provide information to health care workers on both positive and negative consequences of caregiving, providing insights on the issues and concerns of the male caregiver.

Descriptions of procedures and tests

Respondents will be asked to share their caregiving experience with the researcher. The interview will be guided by an interview schedule which will involve questions about personal feelings, coping strategies, and social support.

Permission to audiotape the interview is requested. Names will not be used on either the tapes or transcriptions. Tapes and transcripts will be kept in a locked file and only the investigator and three other faculty from Memorial School of Nursing will have access to them. Upon completion of the research project they will be destroyed.

Duration of subject participation

You are being asked to participate in two or possibly three interviews. Each interview will take approximately one hour each to complete, and will be held one to two months apart. Each interview will be at a time and place of your convenience.

Foreseeable risks, discomforts, or inconveniences

There are no foreseeable risks from any of the questions you will be asked during the interview. If however you feel discomfort in answering any question or sharing any information, please indicate this to the researcher who will go on to another question or ask one that is less stressful. You have the right to refuse any question that may be asked.

Benefits which the subject may receive

There are no direct benefits from this study. However, the information you provide may help nurses and other health care professionals to assist/help other men in the caregiving role in the future.

Alternative procedures or treatments for those not entering the study

Participation in this study is entirely voluntary and you may decide to withdraw at any time.

Any other relevant information

If you have any questions, please feel free to ask before signing the consent form.

I, _____, the undersigned, agree to my participation in the research study described above.

Any questions have been answered and I understand what is involved in the study. I realize that my participation is voluntary and that there is no guarantee that I will benefit from my involvement. I acknowledge that a copy of this form has been offered to me.

(Signature of participant)

(Date)

The use of tapes and transcription materials have been explained to me. I understand that these materials will be destroyed when the project is completed. I hereby consent to be audiotaped.

(Signature of participant)

(Date)

To be signed by Investigator

To the best of my ability I have fully explained to the subjects the nature of this research study. I have invited questions and provided answers. I believe that the subject fully understands the implications and voluntary nature of the study.

(Signature of Investigator)

(Date)

