UNDERSTANDING THE EXPERIENCES OF SPOUSAL CAREGIVING FOR SURVIVORS OF A STROKE: A PHENOMENOLOGICAL STUDY

URSULA EILEEN COOMBS

National Library
of Canada

Acquisitions and
Bibliographic Services

395 Wellington Street
Ottawa ON K1A 0N4
Canada

Bibliothèque nationale
du Canada

Acquisisitons et
services bibliographiques

395, rue Wellington
Ottawa ON K1A 0N4
Canada

Your file Votre référence
ISBN: 0-612-93020-3
Our file Notre référence
ISBN: 0-612-93020-3

The author has granted a non-exclusive licence allowing the National Library of Canada to reproduce, loan, distribute or sell copies of this thesis in microform, paper or electronic formats.

L'auteur a accordé une licence non exclusive permettant à la Bibliothèque nationale du Canada de reproduire, prêter, distribuer ou vendre des copies de cette thèse sous la forme de microfiche/film, de reproduction sur papier ou sur format électronique.

The author retains ownership of the copyright in this thesis. Neither the thesis nor substantial extracts from it may be printed or otherwise reproduced without the author's permission.

L'auteur conserve la propriété du droit d'auteur qui protège cette thèse. Ni la thèse ni des extraits substantiels de celle-ci ne doivent être imprimés ou aturement reproduits sans son autorisation.

In compliance with the Canadian Privacy Act some supporting forms may have been removed from this dissertation.

Conformément à la loi canadienne sur la protection de la vie privée, quelques formulaires secondaires ont été enlevés de ce manuscrit.

While these forms may be included in the document page count, their removal does not represent any loss of content from the dissertation.

Bien que ces formulaires aient inclus dans la pagination, il n'y aura aucun contenu manquant.

Canada

Understanding the Experiences of Spousal Caregiving for Survivors of a Stroke:

A Phenomenological Study

by

Ursula Eileen Coombs

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

October 2003

St. John's Newfoundland

Abstract

Caregiving has multidimensional effects on the lives of spousal caregivers that in turn have an impact upon the care they provide to the individuals who have survived a stroke. It is important to examine the experiences of spousal caregivers from their perspective. This is a phenomenological study on the experiences of spousal caregivers for survivors of a stroke. Eight spouses (five females, three males) participated in the study. van Manen's (1997) approach was used to examine the spousal caregivers' experiences. Data were collected through audio-taped unstructured interviews. The interviews were transcribed verbatim to form textual descriptions of the caregivers' experience with caregiving. From data analysis six themes were explicated which together form the essence of the experience of the spousal caregivers. These interrelated themes were 1) experiencing a profound sense of loss, 2) adjusting to a new relationship with your spouse, 3) taking on new responsibilities, 4) feeling the demands of caregiving, 5) having to depend on the support of others, and 6) maintaining hope and optimism. This study contributes to health care providers' understanding and knowledge of spousal caregivers for survivors of a stroke and supports the need for continued research in this area.

This thesis is dedicated to my parents, Magdalen and Edward Coombs, whose love and care have added meaning to my life, and has given me the courage to make the dream of doing this thesis, a reality.

This thesis is also dedicated to the late Eileen Nugent, my grandma, who watches over me from heaven. I love you, grandma, and miss you terribly. To the late Roy Naessen, the mere thought of you still brings a smile to my face, and joy to my heart.

Acknowledgements

I would like to thank numerous people for their support in completing this project:

To my thesis supervisor, Dr. Shirley Solberg, thank you for your expertise and patience during the whole process of writing this thesis.

To my thesis co-supervisor, Professor Doreen Dawe and thesis committee member Ms. Carla Wells, thank you for your expertise and encouragement as I was challenged to do this study.

To my parents, Edward and Magdalen Coombs, for their support throughout my life, particularly during graduate school and the writing of this thesis.

To my eight brothers, sister, and their families for their encouragement and support in all my endeavours.

To Dolores, Peggy, Kelsey and Kevin who help me keep life in perspective.

To my friends and other supporters, I thank you for your encouragement and continued interest in me, my studies, and undertakings.

To the spousal caregivers who participated in this study, thank you for your time and for sharing your story with me.

Table of Contents

Appendices

CHAPTER ONE

INTRODUCTION

This is a phenomenological study on the experience of caregiving for survivors of a stroke from the perspective of a group of older spousal caregivers. Stroke is a major cause of disability and handicap in all societies (Clark, 2000). Cardiovascular disease, specifically heart disease and stroke, is the third leading cause of premature death in Canadians under age 75 (Health Canada, 2000). Many adults will continue to experience disability because of cardiovascular disease and will require some type of care. Approximately 10-30% of all persons who have a stroke require institutional care after discharge from an acute care setting, and the remaining two-thirds return to a home setting with family caregivers (Dorsey & Vaca, 1998).

Family caregivers form the largest category of caregivers for a person who has suffered a stroke. Within the family, caregiving for survivors of a stroke is most frequently a spousal responsibility. It has been reported that 36% of all caregivers of older adults in general are spouses; 23% wives and 13% husbands (Pruchno & Resch, 1989). The presence of a spouse has been found to be important to the stroke victim's recovery (Baker, 1993). In the absence of a spouse, the next primary caregiver of an older adult is usually an offspring or other relative, followed by a neighbour, and lastly formal resources - nurses or respite workers (Pruchno, 1990). Since a stroke frequently results in some disability, the length of caregiving is usually long term and the responsibilities can be extensive.

Background

In July 2002, 12.7% of the total population of Canadians was aged 65 and older; 5.4% were males and 7.3% were females. In Newfoundland, 12.1% of the total population was in that age group; 5.4% were males and 6.7% were females (Statistics Canada, 2002). The number of seniors in the year 2031 is predicted to be greater than 20% of the total population. The figure will continue to rise and by 2041, 23% of the total population will be aged 65 and older, nearly double that of 1995 figures (Statistics Canada, 1998).

With the aging of the population and in the absence of greater prevention of cardiovascular disease, mortality and morbidity due to this category of diseases is expected to rise. The incidence of cardiovascular disease in Canadians is presently extensive, and with three quarters of the population having at least one risk factor, there will not be a substantial decline in this incidence rate in the immediate future. The risk factors for stroke include high blood pressure, high cholesterol, regular smoking, and sedentary lifestyle. In 1999, heart disease and stroke claimed 78,942 lives, accounting for 35.9% of all deaths (Heart Disease Quick Facts, 2002).

There are gender differences in the incidence of stroke and, therefore, gender implications for the caregivers of survivors of a stroke in Canada (Heart Canada, 2000). More women (~60%) than men (~40%) are affected by stroke. There is also a gender difference in mortality with a higher death rate from stroke among women. The Heart and Stroke Foundation reported that in 1999 stroke accounted for 8.5% of deaths among all women and 5.6% of all deaths in men. There are greater gender differences in recovery and rehabilitation. Women tend to have better recovery than men in the area of language loss. Men have also reported greater behavioural changes in their spouses after a stroke than women have in their husbands in the same situation (Santos, Farrajota, Castro-Caldas, & de Sousa, 1999). Additionally, women have a longer stay in the hospital post-stroke because of both medical and social factors. Women get transferred to chronic care units more frequently. Men tend to be discharged home or go to rehabilitation. More frequently women who have had a stroke do not have a spouse to take care of them whereas men do. It is not unexpected then that women are more frequently caregivers to a spouse with a stroke than are men.

The high incidence of stroke creates a situation that demands a greater number of caregivers because of the number of those who survive this cardiovascular event. This demand for caregivers suggests that a stroke cannot be seen as an "individual phenomenon" (Jongbloed, 1994). Caregiving is a huge responsibility. Caregiving has been reported to have a detrimental effect on the spouse who assumes that responsibility (Blake & Lincoln, 2000; Bugge, Alexander, & Hagen, 1999). Caring for a spouse who has had a stroke may predispose the caregiver to chronic stress. Having a stroke can impair the survivor physically, emotionally, and cognitively with resultant behavioural changes. The behavioural and cognitive impairment of the care recipient may be more stressful to the caregiver than the actual physical impairment (Anderson, Linto, & Stewart-Wynn, 1995). Some common emotional reactions of caregivers to their caregiving situations are anger, insecurity, loneliness, resentment, depression, and bitterness (Holicky, 1996). These reactions have been found in caregivers of those who survived a stroke (Anderson et al.). The demanding physical aspects of caregiving, such as transfers to and from wheelchair, bed, or toilet, caused an exacerbation of medical conditions such as arthritis, hypertension, or cardiac disease in the caregiver.

The effects of caring for an ill person at home have been referred to as caregiver stress, burden, or role fatigue (Pearlin, Mullan, Semple, & Skaff, 1990). Caregiver burden is defined as "the broad range of negative phenomena associated with the caring for victims of illness or injury" (Chwalisz & Kistler, 1995, p.88). Burden can also be a response to the stressors of caregiving and may result in deterioration of the caregiver's physical health, functioning, and mental health (Bull, 1990). Much of the research on caring for older adults with a chronic illness has been conducted using caregiving burden measures.

Social support is believed to help the caregiver with some of the negative aspects of caregiving. However, studies on the degree to which social support helps to alleviate some of the stresses of caregiving have shown conflicting results (Dennis, O'Rourke, Slattery, Staniforth, & Warlow, 1997; Mant, Carter, Wade, & Winner, 2000; Stewart, Doble, Hart, Langille, & MacPherson, 1998; van den Heuvel, de Witte, Schure, Sanderman, & Meyboom-de Jong, 2001). The amount of support required would more than likely vary by severity of the stroke and how much the survivor is capable of doing. In addition it may not be the actual support but the perceived support that is significant to the caregivers (Keeling, Price, Jones, & Harding, 1996). Research with caregivers of victims of a stroke has indicated that 88% of caregivers reported adverse effects to their lives despite receiving additional help from other family members and community services (Anderson et al., 1995).

Nurses who work with patients and their families following a stroke are in a good position to identify "at risk" caregivers and by finding acceptable solutions to assist them with their increased risk of physical and emotional problems. The unaffected partner is also in an at-risk situation (Holicky, 1996). Addressing the concerns of caregivers helps to ensure that better care will be given to the care-recipient. Working with caregivers is also cost effective because if caregivers are unable to provide care, the alternative is more expensive formal care in the home or in a long term care setting. Caring for caregivers may also be considered a preventive measure that may reduce the risk of caregivers requiring care secondary to their caregiving role. A supportive approach to caregivers assists the family, as the family members share in the illness experience, and in addition could help keep the family unit intact (Holicky).

The experiences of caregivers across a variety of conditions have been well researched, both quantitatively and qualitatively, and widely reported in the literature. A limitation in some of the quantitative research on caregivers is that many of the measurement instruments have not been tested using a population that consists of caregivers in the context of a stroke (Anderson et al., 1995). Additionally, most quantitative research looked at the caregiving experience at one specific time rather than examining it over time or they have examined specific aspects of the caregiving experience, such as burden or needs of caregivers, rather than looking at the experience as a whole (Scholte op Reimer, de Haan, Rijnders, Limburg, & van den Bos, 1998). Some qualitative research has been employed to examine aspects of caregiving (Simon & Kumar, 2002) as well as the overall experience of caring for a spouse who has had a stroke (Robinson-Smith & Mahoney, 1995), but work in the latter category has been limited.

Rationale

I have observed from my extensive clinical practice that caregiving for a person who has had a stroke is very stressful for most spousal caregivers. Caregiving for these affected individuals is stressful because the survivor often has cognitive and functional deficits that the caregiver must contend with on a daily basis. In addition the caregiver has to assist with physically demanding tasks such as transferring his/her spouse from chair to bed, as well as dealing with his/her spouse's forgetfulness or inappropriate behaviours. The behaviour of many people who have a stroke is difficult to deal with on a daily basis. Some of the behaviours I have observed that are most stressful to caregivers are the care-recipient's irritability, dependency, and immature behaviour. These behaviours have been reported in the literature on stroke survivors as a source of stress (Williams, 1994).

Researchers have usually focused on the needs of the survivor with less attention to and understanding of the role of the survivor's spouse (Robinson-Smith & Mahoney, 1995). I believe it is important to examine the effects of caregiving on all aspects of the spousal caregivers' lives from their perspective. The daily stresses of the caregiving experience may not only affect the physical and psychological health of the caregiver, but also may ultimately affect the health and care of the survivor and other family members. This negative impact on the well being of caregivers can have a negative impact on the health care system in the future. Nurses involved in the care of survivors of a stroke and their families can assist caregivers to prepare for the caregiving experience, find meaning in the experience, and learn strategies to cope with the stress of caregiving.

I chose to study the experiences of spousal caregivers of survivors of a stroke using the qualitative method of phenomenology. This approach was selected because it has the potential to give me and other nurses' insight into the ways in which being a family caregiver is meaningful. The meaning that caregivers place on their caregiving experience can only be discovered by listening to the caregivers tell of their experiences through their own words and their subjective interpretation of that experience. I selected spouses because they are the main sources of care for elderly people (Pruchno & Potasknik, 1989). They provide the most extensive and comprehensive care, are typically responsible for the most disabled older people, maintain the role of caregivers longer than other categories of caregivers, and are more likely to be the providers rather than overseeing the care of the survivor. The spousal caregivers involvement in the care of the survivor of a stroke improves the adaptation of the survivor to the consequences of a stroke and increases his or her independence (Baker, 1993).

Caregiving is a process that may extend over a prolonged period of time. To capture the experience of caregiving and to help caregivers find meaning in their daily experience of caregiving, it is appropriate to use a qualitative method. In this study, I used phenomenology guided by the work of van Manen (1997) to examine the meaning of the spousal caregivers' lived experiences. Through this method I was able to work with spousal caregivers and to find out what it was like from their perspective to care for a spouse who had had a stroke.

Research Question

This phenomenological qualitative study was guided by the research question - What is it like for older caregivers to care for a spouse who has survived a stroke?

CHAPTER TWO

LITERATURE REVIEW

There is a large volume of literature on caregiving and older caregivers pertaining to a variety of chronic conditions. In this chapter I will mainly focus on the research located on the topic of spousal caregiving for survivors of a stroke. The literature review is primarily limited to this group because I wanted to focus on caregiving within that particular context, i.e., within the context of a stroke. Although similarities and differences may exist with caring for someone who has a stroke, and other caregiving situations, the extent to which caregiving for a person who has had a stroke varies from these other situations is beyond the scope of this particular study. For example, the impact of caregiving may differ if there is a gradual onset of the disease such as occurs in Alzheimer disease versus the sudden onset that usually occurs with a stroke. The 1996 National Caregiver Survey of over 1,500 family caregivers suggested a number of differences between those who cared for relatives with dementia and those who did not, on a variety of health and social indicators. The former group experienced more adverse consequences than the latter (Ory, Hoffman, Yee, Tennsledt, & Schulz, 1999).

In addition I limited the literature review to spousal caregivers because the effects of caregiving on others, such as adult children or other relatives, would be very different from spouses because of the pre-existing relationship. Some of the literature on caregiving compares caring for a survivor of a stroke with other chronic conditions and where that occurred I included these studies. Likewise I included family caregivers if spouses are represented among these family members studied, although some of the research reports are silent on just exactly who the informal or family caregivers are. The literature review in this chapter is divided into five sections: 1) the physical impact of caregiving, 2) the psychological impact of caregiving, 3) the social impact of caregiving, 4) coping strategies used by spousal caregivers, and 5) gender differences in spousal caregiving.

Physical Impact of Caregiving

There has been an increase in the research regarding the physical health of spousal caregivers which had previously been underrepresented in the literature (Han & Haley, 1999; Jackson & Cleary, 1995). Given the spousal role and usually older age among survivors of a stroke the impact of caregiving on spousal caregivers would be expected to have initial as well as long-term negative health effects (Barnes, Given, & Given, 1992). Kerr and Smith (2001) in a qualitative study into experiences of informal caregivers concluded that both physical and mental health was affected by caring for a person with a stroke. Another study on the physical health of caregivers suggested that even though they rated their current general health as moderate to good, they felt their current health status was significantly lower than their health before their relative's stroke (Williams, 1993). In Williams's study spousal caregivers reported symptoms related to sleep, fatigue, energy, pain, weight, and indigestion. In a similar study spousal caregivers reported several new or exacerbated health problems such as musculoskeletal, skin, cardiovascular, infectious, and gastrointestinal conditions (King, Carlson, Shade-Zeldow, Bares, Roth, & Heinemann, 2001). The heavy work associated with taking care of a spouse with a significant disability would no doubt take a toll on the physical health of the unaffected spouse.

In a situation where the survivor of a stroke's health is affected, the attention often turns to that person to the detriment of the spousal caregiver. The health of spousal caregivers is often neglected or at least takes lower priority than that of the care recipient (Vanetizian & Corrigan, 1995). It is found in the literature that female spouses rate the needs of the affected partner as priority over their own needs (Rosenthal, Pituch, Greninger, and Metress, 1993). These researchers asked 14 wives of stroke survivors to rate their needs. The four highest ranking needs were all related to care for their husbands, for example, what the woman needed to know to assist her husband. Those needs ranked lowest by the women were related to their work as caregivers, i.e., having someone concerned about their health and being aware of them as individuals. Within the family it is not uncommon that women's responses to illness, either their own or other family members, is to be "other" focused rather than taking care of themselves. Concern with the health of the spousal caregiver is important because if the spouse is unable to provide care, frequently formal caregiving is the only other option. Formal care puts stress on the health care system and greater stress on the affected individual who usually prefers to be maintained in her or his own home (Elmstahl, Malmberg, & Annerstedt, 1996).

Some researchers have attempted to identify the degree to which the physical health of caregivers is affected. In a study comparing caregivers with the general population, while the caregivers rated their own health as the same or worse than that of their impaired spouse, caregivers reported higher than expected rates of diabetes, arthritis, ulcers, and anaemia (Pruchno & Potashnik, 1989). Furthermore, these spousal caregivers' use of medical services was at rates similar to or lower than the general population. An explanation for the use of lower rates of medical services maybe related to the time or the lack of opportunity to obtain these medical services. The caregivers in this research also had high rates of nervousness, inertia, perspiration, heart palpations, trembling, headaches, insomnia, and bad dreams/nightmares.

The role of caregiver among older family caregivers has been identified as a risk factor for increased mortality (Schulz & Beach, 1999). Although this study was not restricted to caregivers of survivors of stroke it did compare 392 older spousal caregivers with 427 non-caregivers between 66 to 96 years of age. Possible confounding variables such as socio-demographic and health factors were controlled for in both groups. Despite this the results suggested that caregivers who experience strain were at an increased risk for death during the four-year follow-up of the participants.

Caregivers themselves recognize that the role of caregiver is stressful and this stress translates into poor health status and contributes to behaviours that might put the caregiver 's health at further risk. Stressed caregivers identified lower levels of perceived health, feelings of isolation and exhaustion, lack of rest, as well as little time for exercise, lack of rest when sick themselves, or time to see their doctor as adverse outcomes of taking on the caregiving role (Anderson et al., 1995). Stressed caregivers also had the tendency to engage in behaviours that carried higher health risks such as smoking more than usual (Schultz, Newsom, Mittlemark, Burton, Hirsch, & Jackson, 1997). As the demands for care increased and the caregiving extended over time, not only did the caregivers feel at increased physical health risk, they were also more likely to experience an acute health problem or a worsening of a pre-existing condition (Schulz et al.). The physical consequences of caregiving can be substantial and often go unnoticed.

Psychological Impact of Caregiving

Caregivers psychological well being also appears to be "at risk". One of the reasons for this is that caregiving takes a toll on the mental health of caregivers because of the stressful nature of caring for a spouse with physical and cognitive problems. Research evidence points to the stressful nature of caregiving translating into poorer mental health leading to clinically significant depression among caregivers (Han & Haley, 1999). Across all indicators of mental health spousal caregivers were more depressed, expressed greater negative effects, had more symptoms of psychological distress, and were more likely to use psychotropic drugs than the general population (Pruchno & Potashnik, 1989). Sadness, anxiety, anger, and depression were also found to be common emotions of a small sample of older spousal care givers and these emotions resulted in poor emotional health (Robinson-Smith & Mahoney, 1995). Ruppert (1996) specifically examined psychological effects of caregiving. While she did not confine her research to just the caregivers of stroke sufferers, but instead a variety of diagnoses, she found depression, powerlessness, guilt, and grief were frequently admitted emotions. The grief was related to the many losses in the caregiver's personal life.

A number of researchers have examined the psychological impact of caregiving and in particular how the survivor's condition affected the caregivers' mental health. In one such study caregivers were more likely to be depressed if the care recipients were severely dependent or emotionally distressed themselves (Dennis, O'Rourke, Lewis, Sharpe, & Warlow, 1998). Likewise Addington-Hall, Lay, Altmann, and McCarthy (1998) found that depression and anxiety among the stroke survivors had a negative impact on their carer's mental health. Other factors found to contribute to depression among caregivers were physical impairment in the care recipient, disharmony in the family, and lack of hope (Thompson, Bundek, & Sobolew-Shubin, 1990). The survivor's cognitive impairment (Thommessen, Aarsland, Braekhus, Oksengaard, Engedal, & Laake, 2002) and incontinence (Jones, Charlesworth, & Hendra, 2000) both have contributed to psychosocial burden in spousal caregivers.

Not all caregivers become depressed so it is important to try and understand what factors may contribute to a negative outcome for this group. In a comparison of depressed and non-depressed primary family caregivers, factors such as lower life satisfaction and a lack of support were important predictors of depression among the caregivers (Grant, Bartolucci, Elliot, & Giger, 2000). Various emotional reactions of the survivor such as feeling miserable, withdrawn, anxious, fearful, and irritability were also found to negatively affect the caregiver's psychological health (Anderson et al., 1995). These emotional reactions resulted in difficulty expressing concerns and anxieties and reluctance seeking help through fear that such a request would be seen as a sign of failure or inadequacy.

Research that compared the psychological health of 99 co-resident carers of elderly stroke survivors and dementia sufferers did not find differences in the psychological health of the carers by disease condition (Draper, Poulos, Cole, Poulos, & Ehrlich, 1992). They did find that both groups of caregivers had high levels of psychological disturbance and these high levels were positively correlated to caregiver burden. These caregivers found the behaviours and moods of the affected person as more difficult to handle than the physical difficulties. In another study that was limited to stroke victims, and included mainly female spouse caregivers, severe cognitive changes coupled with behavioural and emotional changes, increased the risk of caregiver burnout and decreased mental well being. (van den Heuvel et al., 2001). Older women were at higher risk for burnout.

Other researchers examining psychological or mental health of caregivers have looked at factors that influence or ameliorate the negative effects of caregiving. This is important because approximately half of caregivers reported mental or physical strain associated with caregiving (Schulz et al., 1997). Three significant predictors of caregiver's well being were appraisal of caregiving stress, physical health, and satisfaction with service provision (Hodgson, Wood, & Langton-Hewer, 1996). Spousal caregivers' strain increased when either the survivor of a stroke or themselves made an unrealistic assessment of the survivor's level of dependence (Blake & Lincoln, 2000). Knapp and Hewison (1999) found that stroke survivors rated themselves as less disabled than their primary caregivers rated them in a study on 30 pairs of carers and care recipients. The ability to make sense out of a traumatic event and the extent to which one's feelings of purpose and control are challenged by the trauma resulting from a stroke have been found to influence psychological adjustment to the experience (Thompson et al., 1990).

The number of caregiving demands has also been found to be an important factor in caregiver strain or stress and in turn can affect the caregiver's mental health. Neiboer et al. (1998) found that an increase in caregiving demands resulted in increased depressive symptoms while a decrease in these demands reduced depressive symptoms. Uncertainty about the survivor's condition and care were factors that have been noted to affect the psychological health of spousal caregivers. Spouses of survivors of a first-time stroke, at least in the first phase after a stroke, reported their greatest concerns as uncertainty about the severity and prognosis of the disease and impact on daily occupations (Forsberg-Warleby, Moller, & Blomstrand, 2002). A study by Grant and Davis (1997) found the uncertainty among the caregivers they studied was mainly related to whether or not their caregiving decisions were the best for the survivor.

Social Impact of Caregiving

Caregiving not only has physical and psychological effects on spousal caregivers, it has an impact on the social life of the persons providing care, although the extent to which the caregiver's social life is disrupted varies a great deal. There seems to be more contradictory findings on the social impacts of caregiving than there are related to physical and psychological effects. However, many of the spouses who took on the caregiving role and all that entailed, experienced major disruptions in established patterns of daily life (Thommessen et al. 2002). In one study 95% of caregivers experienced change in at least one lifestyle category among the categories of leisure activities, physical activities or exercise, participation in community activities, and church attendance, in addition to experiencing effects on their relationship with family and friends (Periard & Ames, 1993). Three-quarters of the caregivers in a study by Addington-Hall and co-researchers (1998) reported that the extent of the restrictions they had to their activities could be rated from fair to severe. They also reported these restrictions were very stressful.

Other caregivers have reported social problems such as dealing with restrictions on their time and activities, managing the older person's behaviour, dealing with the overall stress of their duties, and having little time to spend with friends and other family members as some of the consequences of their caregiving role (Kane, Reinardy, Penrod, & Huck, 1999). Other reported social problems are the inability to take vacations and restrictions in social life (Thommassen et al., 2002). Social isolation has been identified as a problem of caregivers of survivors of a stroke (Dorsey & Vaca, 1998; Williams, 1994). It is not uncommon for spousal caregivers to have feelings of distress over decreased social contacts (King et al., 2001).

Investigation of loss is another area of study that provides evidence of the social impact of caring. Mumma (1986) conducted an exploratory study among 60 couples to determine losses they perceived after a stroke. She also looked for differences in whether the right or left brain of the affected partner was involved. The spouse who provided the care ranked losses related to independence and social life as the greatest losses when the right brain was affected but ranked travel and independence as the greatest losses in a left brain stroke. There were no gender differences in the rankings by affected spouses.

One of the possible reasons that the social life of caregivers is affected is because caregivers are forced to take on a variety of new roles and increased responsibilities (Dorsey & Vaca, 1998). In fact, a change in role function for caregivers is one of the first consequences of a debilitating illness such as a stroke. A pilot study of wives' early role change after a husband's stroke indicated the women's responsibilities in the household for such activities as financial management and home making, were greatly increased and this increase was accompanied by a decrease in satisfaction with their responsibilities (Enterlante & Kern, 1995). The women in this study also reported less marital happiness since their spouses had a stroke. In contrast with some of the studies reported above these women did not report a significant decrease in their social activities.

Quality of life is another measure for examining the social impact of caregiving, but one that takes into consideration physical and psychological impacts (Dennis et al., 1998). Although conducted with younger spousal caregivers, for example, mean age of 44.5 years, there was not a marked decline in quality of life in these carers especially if they were able to make reasonable accommodation in coping with their situation (Smout, Koudstaal, Ribbers, Janssen, & Passchier, 2001). The latter study was a pilot study and, additionally, findings may differ in older spousal caregivers. Bethoux, Calmels, Gautheron, and Minaire (1996) did a preliminary study of the quality of life of spousal caregivers with nine stroke survivors and their spouses. Spouses reported changes in their life relating to the physical burden they had. Their psychological, social, and economic circumstances, as well as their marital relationships were altered. Some of the studies located did not directly measure quality of life but similar indicators such as sense of coherence (Nilsson, Axelsson, Gustafson, Lundman, & Norberg, 2001). In Nilsson and co-researchers' study a weak sense of coherence was associated with a higher risk of caregiver burnout and greater distress.

Changes in sexual functioning are frequently an aftermath of a stroke (Sjogren, 1983). These changes often have a negative impact on the unaffected spouse depending on functional disability and attitudes toward sexuality. A Finnish study examined the effects of a stroke on the person affected and also on the spouse (Korpelainen, Nieminen, & Myllyla, 1999). Spouses reported such negative consequences as declines in sexual interest/desire in their partners, participation in sexual activity, and sexual satisfaction. Attitudes toward sexuality, fear of poor sexual performance or impairment, and poor communication around sexuality were factors that contributed most to these sexual problems.

Coping Strategies

Degree of preparation for the role of caregiver may be a factor that could promote good physical and mental health. Getting help with their needs allowed caregivers to increase their ability to cope with the situation. (Stewart et al., 1998). Learning the strategies needed to cope with the situation is important to caregivers. However, it is also the case that emotional reaction to a partner's stroke can limit the acquisition of learning required to care effectively, especially in older caregivers (Braithwaite & McGowan, 1993). Many times the caregivers are left to discover on their own what may help the stroke survivor through a process that Brereton and Nolan (2002) identified as "seeking". In that study caregivers learned on their own what worked best in the situation.

Research into coping strategies of caregivers has identified areas where coping strategies are needed as well as how caregivers cope in this situation. Caregivers who felt they lacked the preparation and skill needed to provide good physical care found the emotional effects of stroke on the survivor particularly difficult to deal with on a daily basis (Sisson, 1998). Other skills identified relating to care for the survivor were providing emotional support and managing behavioural problems (Bakas, Austin, Okonkwo, Lewis, & Chadwick, 2002).

A second way of understanding coping strategies required by caregivers is to look at some of the difficulties experienced in caring for survivors of a stroke. Some of the difficulties and challenges that experienced caregivers identified were dealing with feelings, managing time, and adjusting to changing relationships (Kane et al., 1999). Caregivers of patients with a stroke reported they experienced many fears, which included fear of the unknown, financial devastation, inability to continue home care, and fear of another stroke (Pierce, 1994). Other problems included loss of the stroke survivor's familiar identity, managing activities of daily living, seeking and mobilizing tangible services, and obtaining emotional and social support (Grant, 1996). Identification of changes in a caregiver's spouse's life suggested the need for a good assessment of these changes and the impact they have on the caregiver (Enterlante & Kern, 1995).

Family caregivers developed several home care management strategies in the role as caregiver to a person with a stroke as a means of coping (Davis & Grant, 1994). These strategies included maintaining situational vigilance for the survivor, creating solutions for problems associated with functional losses of a stroke, constructing the reality of recovery for themselves and the survivor, and seeking to find personal meaning in the caregiving experience. The need for education into specific management strategies varies among family caregivers. Vanetzian and Corrigan (1995) studied these needs and included some spouses among their family caregivers. They looked at differences between current and future caregivers in the context of a stroke. Two important educational needs identified were how to assist with the disabilities associated with a stroke and what resources were available to assist caregivers.

The role of the nurse in helping caregivers with caring for stroke survivors has also been studied. Secrest (2002) conducted a qualitative study to find out how primary support persons for a stroke survivor experienced rehabilitation assistance from nurses. The participants did not report the nurse as an important clinician in this process. Yet nurses are frequently mentioned as the health professional that sees the family in the home and someone the family can access for advice and care.

Intervention studies and randomised controlled trials can help increase understanding about enhancing coping strategies of family members can benefit these caregivers. Families caring for victims of a stroke who received regular visits by health professionals felt their support needs were met and had more confidence in their abilities to care for their family member (Stewart et al., 1998). Carers for survivors of a stroke who received family support interventions were better able to engage in social activities and reported better quality of life on all measures than their counterparts who did not receive this intervention (Mant, Carter, Wade, & Winner, 2000). In Sweden a randomised controlled trial, in which the effects of routine rehabilitation services were compared with early discharge enhanced by continuity of rehabilitation on family caregivers, did not find significant differences in the reported well-being of the spouse nor how much time they needed to spend on spousal care (Holmqvist, von Koch, & de Pedro-Cuesta, 2000). Not surprising the stroke survivor had greater satisfaction in the experimental group.

A limitation in helping with developing coping strategies is often that the caregivers do not know what to expect of a family member who has experienced a stroke. In a grounded theory study of rural American caregivers Burman (2001) attempted to discover what these caregivers knew of the trajectory of a stroke in a relative. The core variable identified was "no idea" in that these caregivers did not know what to expect. They did however try to put specific strategies in place that they identified as helping recovery in the stroke victim, monitoring their affected relative, garnering outside help, and increasing the involvement of other family members and friends in caregiving.

Gender Differences in Spousal Caregiving

There have been studies that have looked at gender differences in caregiving and in particular among older caregivers (Wallsten, 2000). However, differences between male and female spousal caregivers in the context of a stroke have not been well investigated or reported. Perhaps because women more often become caregivers in this situation, a number of studies examined just wives (Enterlante & Kern, 1995). One area where some gender differences have been noted is in mental health outcomes. Female spousal caregivers have reported a higher incidence of depression than their male counterparts (Lieberman & Fisher, 1995). A second area is in educational needs. Vanetzian and Corrigan (1995) found male caregivers gave greater importance to how to help their family member who had a stroke with their disabilities, while females assigned a higher importance to the category defined as "health and human resources". In the latter category, female caregivers wanted to learn more about available services, and about negotiating with insurance providers. Areas affected where significant gender differences have not been reported are in the areas of psychosocial burden (Thommessen et al., 2002) and sexual functioning (Korpelainen, Nieminen, & Myllyla, 1999).

In a prospective study Kramer and Lambert (1999) were able to examine the effects on men who became caregivers to their spouses. The health conditions of the wives were not reported. These men reported higher levels of depression, less happiness, and less marital satisfaction than their cohorts in the study who did not have to assume caregiving activities for their spouses. A possible explanation for these findings is that older married men have fewer people in their caregiving networks than married women and both have fewer contacts to help than widowed or never married individuals (Barrett & Lynch, 1999).

Summary of Literature

In summary it can be seen that caregiving for a spouse after a stroke has multidimensional impacts upon the health and well being of the caregiver. Many aspects of the caregiver’s health and lives are affected. Both physical health and psychological well being are affected by the caregiving experience. Increasingly, research evidence suggests that the stroke survivor's condition and the caregiver's feeling about their spouse are factors that may mediate the health effects.

Less agreement exists on how the spousal caregiver's social life is affected. While some of the research suggested that there is a great effect, others suggested it is less so. It would no doubt depend to some extent on the nature of the spouse's social life prior to the stroke, as well as to the degree of responsibility he or she had to assume with the caregiving role. Research into the coping strategies of spousal caregivers may give some insight into the degree of physical, psychological, and social impacts that occur in this situation. In situations where good coping strategies exist, there may be lessened negative effects.

Gender difference in caregiving has not been explored to a great depth although there is some research that has explored the ways women and men may be affected. Women are more frequently the primary caregivers for stroke survivors, therefore, studies in this area mainly focus on women.

From the review of the literature and the various areas of the spousal caregivers' lives affected, it is timely to study more fully the experience of spousal caregiving for a partner who has had a stroke. Some of the outcome measures that have been used to capture caregivers' experiences, while adding to our understanding, do not do justice to this area of research (Dowswell, Lawlor, Dowswell, Young, Forster, & Hearn , 2000). Rather than examining a specific aspect of caregiving, a phenomenological study allows caregivers to identify what is important to them. If nurses are to increase their supportive role to caregivers of a spouse who has had a stroke, understanding the caregivers' experiences is very important (Moore, Maiocco, Schmidt, Guo, & Estes, 2002).

CHAPTER THREE

METHODOLOGY

This chapter describes phenomenology and the methods used in this particular research. Nursing is grounded in a holistic belief system that cares for the mind, body, and spirit. Phenomenology has at its foundation a holistic perspective of experience as lived (van Manen, 1997). It is this holistic perspective of nursing and the attributes of Phenomenology and the nature of my research question that helps support the choice of phenomenology as a useful method to investigate phenomena important to nursing practice, education, and administration such as the one selected for the present study that of older spousal caregivers to a person with a stroke. The procedural application of phenomenological methods as described by van Manen was chosen for this study. van Manen stated that the terms human science and phenomenology are interchangeable. Both terms 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" (p. 4).

Phenomenology seeks to question and understand what a particular experience is like for a person from the perspective of the person experiencing it. van Manen (1997) used the concept of intentionality to explain 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. This concept helps the researcher to question the way a participant experiences the world as a human being and helps the participant to reflect on the experience as they have lived through it. Research is a caring act, and only by intentionally attaching ourselves and caring for something can we come to understand its meaning (van Manen).

Another concept related to van Manen's philosophy of phenomenology is the study of essences: "that which makes a "thing" what it is and without which it could not be what it is" (1997, p. 10). Phenomenology attempts to reveal and describe the internal meaning structures of a phenomenon and to understand the lived experience. The researcher must attempt to understand the nature or essence of the lived experience for a particular individual in the fullness and depth of his/her everyday experience of the life world (van Manen).

The third concept important to phenomenology is phenomenological reduction. This term is defined as "a return to original awareness regarding the phenomena under investigation" (Streubert & Carpenter, 1999, p. 47). The goals of phenomenological reduction are the isolation of the phenomena and remaining as free as possible from preconceived ideas. Preconceived ideas are to be bracketed to the extent that may be possible or at least separated out of consciousness as a way for the researcher to remain neutral with respect to the belief or disbelief in the existence of the phenomenon. However, according to van Manen (1997), complete reduction is impossible.

Methods

Participants

Eight spousal caregivers who were primary caregivers to a survivor of a stroke were recruited and participated in this study. Predetermination of the number of participants for a given phenomenological study is always difficult at the outset of a study. However, I believe that the eight participants who took part in my study were sufficient because of the amount and richness of the data these participants supplied. As a novice researcher I wanted to do justice to the descriptions of their experiences. Phenomenology directed toward discerning the essence of an experience can be done with as few as six participants (Morse, 1994).

Eligibility criteria for spousal caregivers included: an age range of 50 years or older, physical and mental capacity to participate, ability to speak English, and currently caregiving at home for at least one year post stroke (See Appendix A). By the end of one year, the stroke survivor has usually completely levelled in functional ability and the caregiver has had a year of experience in the caregiving role. I wanted the caregivers to have some time to reflect on their experience before I interviewed them. Other criteria specified that the stroke survivor would be 55 years of age or older at the time of the stroke and have no evidence of coexisting terminal illness, or other rapidly progressing medical condition. I elected to focus on older spousal caregivers as the caregiving experience for this population might be significantly different from a younger caregiver population because of the physical changes that the caregiver might be experiencing. As well, younger patients with a stroke often recover better and have a more favourable prognosis than an older stroke survivor.

A rehabilitation unit in an institution in western Newfoundland and Labrador was used to recruit participants from this region of the province. The social worker of the short stay program (who assists with the co-ordination of the rehabilitation unit) was asked to identify possible participants (See Appendix B). She contacted potential participants to introduce the study and to obtain permission to release his/her name and telephone number to me as a researcher so that they could obtain further information about this study. Once permission was obtained, I contacted each potential participant by telephone. During this initial contact with me, participants were informed about the nature of the study and if the participant consented to participate in the study, an interview time was arranged. I reviewed the informed consent with the participant, asked him or her to sign this form, and gave each participant a copy of the consent including a description of the study. In total eleven caregivers agreed to be contacted, however this was reduced to eight participants who met all inclusion criteria and felt comfortable and able to participate in the study as planned.

Setting

An interview at a time and place convenient for participants was arranged. I asked the participant to choose the location for the interview with the understanding that this location would be relatively quiet and conducive to conducting an interview. Seven participants chose to be interviewed in their homes and one participant was interviewed at his office. Home was most frequently selected because the participants did not want to leave the affected spouse alone. Affected spouses were not present during the interview. It was up to the participants whether or not they wished to discuss the study with their spouses.

Data Collection

Data were collected through audio-taped interviews with the written consent of the participants (Appendix C). Each interview lasted approximately one hour.

Demographic information for the caregivers was collected as a context for the caregiving experience and to describe the participants (Appendix D). Each participant was engaged in two separate interviews. An initial interview was used to collect most of the data. This interview lasted approximately one hour. The second interview was used as an opportunity for participants to add more information to their previous interview and to validate the themes that I had identified from the initial interviews. These second interviews were generally much shorter than the first.

In conducting the interviews, without my leading the discussion, I encouraged the participants to describe their lived experiences. I began the interview by asking each participant to tell me what it was like being a caregiver to her or his spouse after the spouse suffered a stroke. I used open-ended clarifying questions only if I felt they were needed and would facilitate the discussion of these experiences by the participants (Appendix D). Interviews ended when the participants felt that they had exhausted their descriptions and had no new information to add.

The interviews were audio-taped and transcribed verbatim. I checked the accuracy of the transcribed interviews texts against the tape-recorded interviews. This served to increase the overall accuracy of data collection. In addition, I listened to tapes on more than one occasion to become familiar with the data and to become immersed in the phenomenon under investigation.

Data Analysis

Data analysis began as soon as a transcript was available. Data analysis required that I become immersed in the data. Reading the verbatim transcriptions to identify and extract key themes facilitated immersion. In this approach, the text is read and reread several times to answer the question "What statement(s) or phrase(s) seem particularly essential or revealing about the phenomenon or experience being described?" (van Manen, 1997, p. 93).

During analysis of the data, statements were selected, highlighted, and themes developed. In the final stage of analysis and having consulted with my participants I identified central themes that taken together described the essence of the experience of the eight spousal caregivers who participated in the study.

Credibility

I used several methodological safeguards to ensure trustworthiness of the findings. Credibility was established through prolonged engagement with the subject matter. Each caregiver was asked to validate the content of his/her own interview (member checking) and was comfortable that my interpretation represented his or her experience. In addition, I worked with researchers experienced in the areas of chronic disease, caregiving, and phenomenology. The findings were considered trustworthy when themes were applicable across interviews despite variations in caregivers' age and gender.

Ethical Considerations

This study was conducted in compliance with the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (1999). Informed consent and permission to tape record were obtained from each participant (Appendix C). Approval from appropriate committees such as Memorial University Human Investigation Committee and Ethics Committee of the Western Health Care Corporation were obtained before any participants were recruited for this study

(Appendix E). Recruitment was designed so that the participants would not feel obligated in any way to take part in the study, as a person not involved in the research contacted all potential participants on my behalf. This was done to ensure free and voluntary participation in the study.

In order that participants felt free to discuss what they felt comfortable discussing I reminded them at the beginning of each interview that they did not have to answer any questions they did not want to answer. I also told them that they could withdraw from the study at any point.

I assured the participants confidentiality by presenting demographic and interview data in aggregates and by not specifying names of participants in text. Quotes from interview material were used in a manner that would not link the information to any specific individual. No written notes and tapes would be kept beyond the end of the study. Information was carefully stored in a locked file cabinet. Only myself as researcher and my co-supervisors and supervisory committee member had access to this data. I was the only person who knew the names of the participants.

In this chapter I discussed the phenomenological approach and the methods used in this study. In the next chapter I will discuss the findings of this study.

CHAPTER FOUR

FINDINGS

This chapter includes both a brief introduction to those who participated in the study, and a description of the themes that I believe best captured the caregivers' experience of caring for a spouse who had suffered a stroke. Together these themes express the essence of these spousal caregivers' experiences of caregiving.

Participants

The participants in this study were five females and three males, aged 57-81. The average age was 65.5. All participants were married and living in their own homes. Five females were homemakers, two males were retired and the third male was self-employed. They were all primary caregivers and lived in the same household as their spouses. The number of years of caregiving ranged from 1.5 - 5 years; the average length of the caregiving experience was 3.4 years. All spousal caregivers lived in semi-urban and rural areas of the province. The female spousal caregivers were the main providers of care to the survivors of a stroke. However, the male spousal caregivers had the daily help of home support workers for several hours each day. The ages of the stroke survivors ranged from 57-81; the average age was 68.5.

Thematic Analysis

Six interrelated themes were developed from the interview data that give the reader insight into the experience of the spousal caregivers for survivors of a stroke. These themes were: 1) *experiencing a profound sense of loss*, 2) *adjusting to a new relationship with your spouse*, 3) *taking on new responsibilities*, 4) *feeling the demands of caregiving*, 5) *having to depend on the support of others*, and 6) *maintaining hope and optimism.* They were all essential to the caregiving experience and the order of presentation is not indicative of their importance to the experience.

Theme One: Experiencing a Profound Sense of Loss

One of the first and strongest impressions in interviewing the caregivers who participated in my study was the profound sense of loss that they all experienced. The participants confirmed these initial impressions as they talked to me about the many losses they were required to deal with after their spouse's stroke. The losses encompassed many aspects of their lives and deeply affected the participants. A participant who reflected on the many losses summed it up very well:

> *So everything in your life just changed. Your life just changed completely.*

There were three main sources of loss that these spousal caregivers talked about throughout the interviews. These were a loss of leisure time, loss of freedom, and loss of the marital partner they had once known. Leisure time is something that many people value; it is a time to pursue hobbies and interests or just to enjoy oneself. Among older adults retirement from paid employment is sometimes precipitated by the desire to have more leisure time. Additionally when a working spouse retires from paid employment, it is a time for couples to spend leisure time together pursuing mutual interests. The spousal caregivers experienced a loss of leisure time because they were spending most of their time every day either directly or indirectly caring for their partners. This took the form of caregiving support for their partners' activities of daily living or compensating for the things their partners were no longer able to perform on their own. The latter activities included simple tasks such as wringing out a facecloth or assisting with dressing. Some of the spousal care givers admitted they limited their own activities because they felt guilty and felt they should not pursue various interests because their partners' activities were limited.

> *He's there and he was used to going out too, so now that's taken away so it's kind of taken away from me a bit too.*

This loss of leisure time limited the caregivers in their ability to exercise their freedom or pursue their own desires or hobbies outside the home. This in part was related to the fact that they did not want to leave the affected spouse alone at home, but just as frequently because they had to attend to their spouse's needs. They did not have other options available to them. This lack of free time and how it affects the well spouse is illustrated in the following remark

> *You get no spare time say to sit down. If you went to do something, like with yourself, or ... I find the only time is when* [husband] *goes to bed and then you sit back and let it all go.*

Part of the loss of leisure time was related to the demands of caregiving; how tired the spouse was after a day of caregiving. Often at the end of the day the spousal caregivers were simply too exhausted to do anything except lie down to relax before they retired for the day.

A second related loss was a loss of freedom. It was difficult for the spouses to go outside their houses. Many of the women spousal caregivers had become accustomed to coming and going as they pleased because they did not have young children to care for in the home. With their new responsibilities the spousal caregivers once again found themselves carefully structuring their activities that required them to leave their homes, because they feared that something might happen to their partners in their absence. They were worried that their spouses would fall or have another stroke while they were out of the home. A few of the spousal care givers who did leave their ill partners alone on occasion, only went out for an hour or so. The spousal caregivers described this part of the phenomenon as a loss of freedom because they often felt confined to their house, especially at night.

> *When the girls* [home help] *is gone, I got to stay pretty well in the house, look after her anyway. So I don't, you know, get out after I comes in, in the evening.*

This feeling of confinement was expressed in many different ways by the spousal caregivers. Some of the caregivers felt the confinement more acutely than others and felt it was a difficult aspect of caregiving. They used terms such as "*housebound*", "*stuck in this piece of property*" and feeling "*restricted and barred up in the house*". The restriction in their ability to come and go as they pleased was a difficult adjustment for the spousal caregivers because they were not used to having these restrictions.

> *Because I was a person, like I used to, if I felt like going I went, if I felt like coming home, I would come home.*

Thus staying at home more since their partner's stroke was a great source of frustration for the participants. It caused a marked change in their patterns of living. Lack of freedom to go out was a lifestyle that they had to get used to and it was not something that they felt was within their control. The experience of staying home is illustrated in the following comment.

> *But where he's sick, I don't go out much, I more or less stay home where I got to look after him.*

The loss of leisure time and of the freedom to come and go as they pleased were big losses, but perhaps the hardest loss to deal with was a loss of the marital partner they had once known. This was harder for some of the caregivers than it was for others and depended to a great extent on the quality of their relationship, in particular how good that relationship had been, as well as how much time and activities the couples shared together. Just how difficult the loss of a marital partner was can be illustrated in the following statement.

> *I haven't had a conversation with him for the last four or five...four years. But still for all, I'm going on like, maybe sometimes, like I'm with a stranger.*

In our conversations the spousal caregivers talked about the changes in their spouse. Some mentioned how they really no longer talked together or went out anywhere together. In these discussions the caregivers were cognizant of the losses their partners experienced. One of the aspects of this loss is that the spousal caregiver could no longer depend on the physical or emotional support from their partners. The effects of the stroke had left a number of the survivors with physical and/or cognitive deficits such as confusion, forgetfulness, or pessimistic attitudes that limited the survivors' abilities to fully and equally participate in the marital relationship.

> *He's perfectly normal and probably in an hour's time he could be, you don't know, you don't know what he's saying*

Theme Two: Adjusting to a new relationship with your spouse

A second closely related theme evident in the caregiving accounts of the participants relates to the change in the relationship with their spouse as a result of the stroke. The changes in their marital partner because of the effects of the stroke necessitated an adjustment in their relationship. Caregivers talked about their relationships with their spouses prior to their partners' strokes. For most, the marital relationship was very much a partnership. Prior to the stroke, these couples were leading busy lives where each partner fulfilled individual roles that combined to form a strong working relationship.

> *We used to go out around the house and clean up and things we did, each one of us helped each other out.*

These roles involved activities both inside and outside the home often helping each other out. Chores included housework, gardening, repair work and anything else that had to be done. They also shared recreational activities and since most were retired from paid employment, they had more plans to travel and enjoy their lives. Retirement had brought a number of the couples closer together in their leisure activities. The couples had enjoyed time together with travelling, holidays, and camping during the summer. There were tangible objects around the house that spoke to their time together and activities they both enjoyed:

> *We were always gone...in that trailer up there in the back yard.*

Moving from the usual spousal relationship to being a caregiver was a major adjustment in these individuals' lives. The participants described how when they first assumed the caregiver role for their spouse, adjusting to this role was upsetting and stressful. They were uncertain about their ability to care for their ill partner and the intricacies of the care requirements. The spouse often learned from trial and error and eventually became more confident in their caregiving role.

> *I suppose I have been supportive as much as I could where I probably never had the training...I sometimes wonder if there was other ways you could improve on what you were doing...it was all new to me.*

What seemed to be happening was that the spousal caregivers seemed to be a "caregiver" first, and then a spouse. Depending on the spouse's condition, much of the time was taken up with bathing or helping their spouse bathe and dress, helping the spouse to the bathroom, transferring to and from bed, or helping with meals. They talked about this change in relationship, how it had come about, and what type of care they needed to take on:

> *So what's happening now I get in the shower with him. I have to get in the shower with him because I can't get him out of the tub. You know I can't just get him out of the tub.*

Some of the participants told about how they had made changes in their sleeping arrangements to accommodate their affected partner or so that they could get more uninterrupted sleep at night themselves. Many had shared a common bed for years but this was no longer comfortable or feasible and necessitated an adjustment. One participant described his routine at night now that he had become a caregiver:

> *I come in and cover her up and make her comfortable and then I go back to bed. But I got to be alert at all times night time. If she sings out two o'clock, three o'clock, two thirty, one o'clock, I gotta be there, be up. So I jump up and then I get back.*

Despite these big adjustments in their lives and relationships the caregivers were very much committed to their partners and to their caregiving role. They described doing everything that they could to keep their spouse in the home and to keep them comfortable. Many tried their best to engage their partners in conversation, getting them out of the house, and even getting them to travel. They were very determined to try and establish as much normalcy as they could in their lives given the condition of their spouses:

> *It would have to come a lot worse than it is before I'd take her out of it, let her go out of it.*[referred to taking his wife out of the family home and placing her into a nursing home] *I've been with her so long…I mean, I know what to say to her, and talk…to do.*

Theme Three: Taking on New Responsibilities

The third theme related to the change in the responsibilities of the caregiver, not the least of which was that of caregiver and all that entails. This theme was identified as "taking on new responsibilities". Although the participants maintained many of their traditional roles within the home, they were forced to take on new roles and responsibilities now that the partner was no longer able to do much of what he or she had done prior to the stroke. It was the new roles and responsibilities that took up much of what had been their leisure time.

> *By the time you got up and had to see to all this, you would have to get to meals and the house work, and see to the outside, and the fire, and get out shopping...everything.*

Female caregivers described how they maintained their role as homemaker, with responsibilities for cooking, cleaning, and running the household. The new roles these female spouses assumed were roles and tasks that their partner used to do. They were mainly related to yard work or maintaining the house. These tasks varied from person to person, however all had to take on new work:

> *He used to do all the...everything around the house...like doing our income tax...making up the bills. Now I have to do everything. That all falls on me.*

Many of the women had to take on work that they really did not feel prepared to do. Some of this was outdoor work, taking responsibility for finances, or decision-making. The outdoor work could be especially demanding when there was a heavy snowfall during the winter months. Others had to try and find someone to help them with work their spouse would have done previously. One of the things that made it so hard was that they felt that they had all the responsibility.

> *Now I does it all by myself, like shovelling snow or go up on the roof or whatever needs to be done, I does it by myself which me and him used to do.*

Prior to the stroke the male and female caregivers had been involved in fairly traditional gender related work roles in the home. Men who assumed the caregiving role were in a similar situation in that they had to take on work that they were not used to doing especially within the household such as cooking and cleaning. Taking on of these new roles, especially those that were not traditional or usual for the spouses, contributed to some stress among the caregivers. One participant recalled his experience:

> *When she was well I never had to do no cooking cause she used to do it all.*

The demands of caregiving were often a twenty-four hour a day responsibility. Caregivers suffered from lack of sleep, recreation, and respite opportunities. The effects of the stroke had caused physical deficits that impaired the partner's ability to move their affected side independently. This limitation required that the spousal caregiver assist their partner with activities of daily living such as bathing, dressing, and ambulation. Because some of the spousal caregivers were elderly, often these tasks were physically strenuous for them. The repetition of tasks such as taking their partners to the washroom several times a day was physically challenging. One participant described his caregiving responsibilities

> *It was my chore at any given time I was with her to look after her needs whereby, I would get her in to have the shower or bath, help her to the washroom, help her to dress, help her undress, that sort of thing, all those chores came to me but that sort of got to be a routine after a while…*

The spousal caregivers often had to compensate for the things their partners were unable to do because of the results of the stroke. This included activities like feeding, grooming, and dressing. One spousal caregiver's partner was confined to her wheelchair when she was out of bed.

> *The only thing with it, I got to do the same for her as I do for meself. You know, if you put it that way. If she wants something,*

> *I got to go and get it for her. So it's the same as just doing more or less double duty.*

Theme Four: Feeling the Demands of Caregiving

All of the caregivers were over 57 years of age and experienced many physical and emotional demands associated with this work. The fourth theme I identified was the ways in which they felt these caregiving demands on a daily basis, especially the bodily demands. For some of the participants at least in the early days of their caregiving experience they described a "twenty four hour day". One of the most physically demanding aspects of caregiving was helping the spouse to bathe. Helping the spouse to get to the bathroom, undress, get into the shower, wash, get out of the shower, dry off and then once again get dressed. One of the spouses literally had to get into the tub with her husband in order for him to have a shower. The following is her description of the bathing event.

> *I braced his leg and put his good leg in so then I helped him lift his bad leg in... then I could get in and wash him and then I did the same thing to get him out. So then I take him in on the bed, dry him down, and get him dressed.*

The female spousal caregivers felt an overwhelming sense of responsibility for the care of their ill partners. During our conversations, comments such as "*you got responsibility for everything*", "*it is an awful responsibility*", and "*it should be my care*" were expressed by the female spousal caregivers. They felt that it was their responsibility to provide care because it was their marital partner. Their feelings ranged from feeling that they had no choice in taking on the caregiver role "*I've got no other choice, I just have to!*" to feelings of duty.

> *I figure since it is my husband, for better or for worse, so I, you know, it's like you with your job, you took it on so you have to do it.*

The spousal caregivers felt that they were caregiving continuously. There really was not much of a break. It was not something they found they could do if and when they felt like it. They always felt the demands. They also complained of feeling fatigued and of having poor, or no, sleep at night. For some the disruptions in sleep were the most difficult aspect of caregiving:

> *Like she might get up, perhaps eight, ten times a night. I got to cover her up so I got to get up with her at night. That's the worst, you breaks a lot of rest like that.*

The spousal caregivers did speak about the stress of caregiving. They experienced new feelings such as guilt and were unsure of how to express these feelings and how to cope with them. This feeling of being overwhelmed by their caregiving situation and their inability to express feelings is illustrated in this comment.

> *Oh my, I don't know what else, I know there is but I can't explain, there is stress, you know.*

Guilt was another reaction expressed by some spousal caregivers. They felt guilty because they were well and their partners were ill. They also felt guilty when they left their home because their partner was at home and felt they should stay at home also. This feeling of guilt is captured in the following remark.

> *I feel guilty myself if I go out too much*

Several of the spousal caregivers experienced fear about their affected spouse and their own ability to carry on the caregiving work. Their fear was mainly related to the unknown, and they often wondered what might happen. One of the greatest fears that they had is what would they do if their partner became ill or had another stroke. They worried about leaving their partner alone because he or she could be injured if left unattended. This was a big fear expressed by many of the caregivers. The spousal caregivers expressed feelings of uncertainty or fear of the future. This feeling of fear of the future was illustrated in this comment.

> *I was wondering what's wrong, what are we heading for, you know, what's going to be the outcome of this?*

A demand of caregiving was to watch out for and watch over the affected spouse. The spousal caregivers spoke about being keenly aware of what their partners were doing and where they were at every minute of the day. If their partners were not in the same room with them, the spousal caregivers would call out to their partner or go check on their whereabouts. At night this watching over their partner would continue until their partners were fast asleep.

> *I'll put my hand over and put my hand on his head just to see if everything is okay. I watch everything now, you're always, you're always aware.*

Theme Five: Having to Depend on the Support of Others

The work of caregiving is not possible to maintain on a sustained basis if you do not have at least some support from other family members and friends. The fifth theme captures this essential part of the caregiving experience. How much the caregivers depended on others was related to how much the stroke had affected their spouse, degree of concern they had about leaving their spouse alone in the house, and the type of activities that they wanted to help their spouses with outside the home. They felt they were fortunate in as far as they had someone they could turn to in order to help them out with caregiving and related activities.

> *So you had to depend on other people because I don't drive. So we had to depend on our neighbour. We had an excellent neighbour across the street, he is no longer there now, and the*

> *first couple of years our neighbour used to take the car and take us to* [town].

The spousal caregivers felt supported by their family and friends. Despite the fact that family members were not consistently helping with the daily demands of caregiving, the spousal caregivers felt psychologically supported by their family. They felt that their family would be available to help them with caregiving for an hour or two, if requested. However, they did not like asking for support or calling on them on a regular basis. Most of the time the participants tried to limit how much they depended on others, especially their dependency on their adult children.

Some of the spousal caregivers spoke about having to arrange going to the nearest town for shopping or to attend medical appointments when family members were not working. Depending on help from others meant they had to arrange certain activities around their son's or daughter's available time:

> *My son is home on Mondays and Thursdays, so I try to make the appointment on one of those days... so I know he will take care of his father*

Transportation was one of the biggest challenges that spousal caregivers had to deal with and upon which they depended on others for help. They lived in areas where public transportation was not readily available. Transportation issues were especially problematic for wives who did not drive before their husband's stroke and had depended on their husbands to help with many of the errands that required a vehicle. Three out of the five female caregivers did not drive a car so they depended on family members or friends to take them where they needed to go.

> *If my son don't take us out, they* (husband's brother and his sister-in-law) *will take us out, go out around to the store...*

The spousal caregivers felt that the support of family helped them continue with their caregiving. In fact if they did not have an adult son or daughter for some of the things they needed to do like trips to the doctor or getting groceries and other supplies, they were not sure they could cope. The male spousal caregivers felt that their daughters were especially supportive. The participants felt a great deal of comfort with the support that they had available to them, especially should they not be able to carry on with their caregiving role. The following comment illustrates this support.

> *I don't think any of the girls* [daughters] *would let anything go wrong.*

The spousal caregiver just quoted, was reassured that if anything happened to him and he could not continue providing care to his wife, his daughters would look after them. One of the concerns that many caregivers had was what would happen to the affected spouse if the caregiver got sick. They definitely felt more at ease if they had someone who could step in and help out with the caregiving responsibilities. The significance of family support for the spousal caregivers was expressed in the following statement.

> *For anyone in the same predicament, I would have to stress that the key to it is family support.*

Support from other caregivers was instrumental to the male spousal caregivers, as it enabled them to care for their wives at home. This support allowed the couple to stay together as they felt their partners would be happiest at home.

> *I've been with her so long and, I mean, I know what to say to her, and talk...to do.*

Another source of support for a few of the spousal caregivers was their faith and trust in God. Their relationship with God, and the use of prayer, helped the spousal caregivers to continue caregiving. This support from God is particularly demonstrated in the following two remarks.

> *So whatever happens, I usually turn to God. That's where I get my strength from. I always finds him my best friend.*
>
> *You say your prayers and ask God to give you strength to face the next day, to do what you got to do, and it seems like the strength comes from somewhere…*

The experience of having support from family, friends, formal caregivers and God was critical for the spousal caregivers to help them continue in their caregiving roles. They all readily admitted that even though they might not necessarily want to depend on help from others, they were happy that they could do so.

Theme Six: Maintaining Hope and Optimism

The ability to remain optimistic about their situation was important to all the caregivers, even though they experienced a sense of loss and the heavy demands associated with caregiving. Despite facing daily challenges and feelings of stress, guilt and fear, the spousal caregivers were grateful for many blessings. They were grateful for having their partners living with them, they were grateful that the stroke was not as severe as it could have been, and were grateful for their partner's ability to speak and/or to walk independently. The experience of gratitude was expressed in the following remarks:

> *I suppose he is here and that seems more important than just going out to the store and he could be gone, like lots before him. I am thankful for where I am at. He could have been, you know, brain dead and lying in the hospital and I'd be there every day stressed out worse than this, right.*

What enabled the caregivers to remain in the role of a spousal caregiver? It was the ability to maintain hope and be optimistic despite at times some overwhelming changes and challenges. The sixth and last theme describes this particular aspect of their experience. The Oxford Dictionary (2001) describes hope as "a feeling of expectation and desire" (pg. 684). Having something to look forward to helped a number of the spousal caregivers. Maintaining hope and being optimistic were ways that most spousal caregivers coped with the caregiving situations. They expressed hope that they would be able to keep their partner with them in their own homes. They hoped that they would be able to continue caregiving in the future. They tried to have something to look forward to, such as having a break to go see the grandchildren or to have some time for them selves. The spousal caregivers maintained an optimistic view about their future. They hoped their future would be a good one and that they would be able to do some of the things they wanted to do together, such as travelling. This sense of hope and optimism did permeate the interviews.

> *We are optimistic that we will be able to do the things we dreamed about, going visiting, doing whatever.*

The spousal caregivers explained to me that they tried to live life one day at a time, living for today, and trying to maintain an optimistic attitude "*you can't give up you got to look ahead, right.*" This attitude seemed to get them through some of the more difficult obstacles that they had to deal with in the post-stroke period. Looking forward to a few hours respite from caregiving was important to helping the spousal caregivers cope with the daily stresses of caregiving.

> *I'm going to have a few days off and go to town. You know, that helps, just to get down and go to the bank, just walk around and go visit my daughter. I think about that, and you know, I'm going to see my grandchildren.*

The spousal caregivers had hope that their caregiving experience would change for the better in the future. "*I'm hoping that things will get better.*" This hope was necessary to their ability to continue caregiving.

> *I'd love to go to her* [daughter in Ontario*] house but he says no, he can't go but I hope in time he will be able to go and we will be able to go together.*

CHAPTER FIVE

DISCUSSION

When a spouse has a stroke this has a profound effect on not only the affected person but also on the husband or wife who assumes the care and support for his or her spouse. This phenomenological study of spouses' experiences with caregiving for their partners with a stroke provides a greater understanding of what this experience is like. This chapter is a discussion of those experiences and how the findings of the study relate to the literature on spousal caregiving. van Manen (1997) proposed four fundamental life world themes or "existentials" as a guide for reflection in the research process. These four existentials of spatiality, corporeality, temporality, and relationality form an interactive unity that we call our lifeworld - our lived world - and will be used as the organizing framework for the discussion of the findings and how the findings are related to research reported in the literature.

Spatiality

Spatiality or lived space refers to the world or landscape in which human beings move and find themself at home (van Manen, 1997). The theme "*Experiencing a profound sense of loss*" while not solely related to spatiality did demonstrate how the spousal caregivers experienced their space or physical surroundings. One of the losses that the participants talked about because of their caregiving roles was that of freedom to go and come from their homes, as they had been accustomed to doing before their spouses' illnesses. Their life worlds had become much more restrictive than they were in the immediate past. For some of the caregivers I interviewed this was problematic, while for others this seemed less so. It is not surprising that loss was such a predominant theme among my participants. In comparison, to their lives as spouses who did a number of activities together, living with a spouse who could not take part in many of these pre-stroke activities represented a number of important losses. These losses greatly affected the quality of life for the caregivers.

Loss is a predominant theme associated with caregiving for stroke survivors and has been reported in different ways. The literature also supports that the loss is multidimensional. Losses of leisure time and freedom have been expressed as disruptions in leisure time and social activities (Anderson et al., 1995), lack of freedom and no personal time (Grant & Davis, 1997; Bugge et al., 1999), no time for personal care, leisure, and confinement (Periard & Ames, 1993). Other researchers have described loss as a decrease in social activities and inability to travel (Mumma, 1986; Johnson, 1998; Robinson-Smith & Maloney, 1995), and restrictions in time and activities (Kane et al., 1999; Niebor et al., 1998; Forsberg-Warleby et al., 2002).

Amongst the participants in my study, one of the greatest losses related to the loss of the marital partner they knew before the stroke. While this was not directly related to spatiality it was indirectly related. The fact that their spouse was confined to home or did not want to go outside their home, confined the caregiver as well because they did not want to leave their affected spouse unattended. Additionally many of the activities they did outside the home were joint activities and with their spouse unable to participate in the same way as previously they did not go out to take part in these activities. Travel and camping were greatly affected. Other researchers have reported that spousal caregivers they studied talked about the loss of a companion (Johnson, 1998), and loss of closeness in their marriage or independence as a couple (Mumma, 1986).

Corporeality

Corporeality or lived body refers to how we are physically or bodily present in the world (van Manen, 1997). The theme that was particularly illustrative of this part of the spouse's life world was "*Feeling the demands of caregiving*". Caregiving for an adult who is unable to take care of their activities of daily living like eating, toileting, bathing, and dressing is very demanding work at any age, but especially for an older individual. It places a great demand on the physical resources of the caregiver. For the participants in this study one of the greatest challenges was to meet these physical demands on a continuing basis. The effects of caregiving were felt bodily in the fatigue and tiredness they frequently experienced.

The physical impact of caregiving is present in the literature and reported as long term negative health effects (Barnes, Given, & Given, 1992), decreased health since taking on the caregiving role (Williams, 1993), and exacerbated health problems such as cardiovascular or gastrointestinal conditions (King et al., 2001). Other physical complaints of spousal caregivers included poor sleep, fatigue, low energy, pain, weight loss/gain, and indigestion (Williams, 1993). These researchers reported what caregivers believed were outcomes of their new responsibilities. The participants in my study talked about "how" they experienced the work of caregiving. They described the physical effort it took to help their spouse bathe, how tired they felt as they checked on a spouse during the night, or assisted them to get to the bathroom.

Emotions felt by the participants that have bodily consequences were also described. Fear was one of these emotions. Fear and uncertainty were also noted in other studies and have been reported in the literature, whether it was uncertainty about how to care for an ill partner or fear of the unknown (Pierce, 1994; Grant & Davis, 1997). Other fears of spousal caregivers present in the literature and also reported by participants in my study, were fear of another stroke (Anderson et al., 1995; Pierce, 1994) or fear that the survivor would fall or that some other adverse event would happen to them (Scholte op Reiner et al., 1998;Thommessen et al., 2002). It is understandable that fear of poorer health in the stroke survivor would be a major concern. The caregivers had learned to adjust to their present situation, and while many found the work physically and mentally demanding, they were able to carry out their caregiving roles. A worsening of their spouse's condition might be the factor that would make caregiving too difficult for them.

Temporality

Temporality or lived time illustrates our subjective experience of time in the dimensions of past, present, and future (van Manen, 1997). The theme "*Maintaining hope and optimism*" best exemplified some of the temporal dimensions of these spousal caregivers' lives. The caregivers were very much caught up in the here and now of caregiving, but they also looked toward the future with hope and optimism.

The study of hope in neuroscience populations has been examined among individuals with multiple sclerosis, spinal cord injury, and stroke (Fowler, 1995). These studies dealt with survivors of stroke rather than their spousal caregivers. However, the participants in my study talked about how important it was to maintain the hope of a better future. Morse and Penrod (1999) contend that hope facilitates going beyond present suffering and into a new perspective on life. Having hope that a caregiving situation will change can help caregivers create a more positive caring experience (Tebb, 1994). The participants in my study lived with hope and optimism that their situation would improve and they could take part in some of the activities with their spouse that they had anticipated prior to the stroke. While they were very much aware of their present situation and the restrictions in their lives the hope for the future helped them with their present situation. Davis and Grant (1994) have also reported how the use of faith and hope was important to the participants in their study. Perhaps hope and faith is what enables some of the caregivers to carry out this demanding role.

Miller (2000) also explored the role of hope in individuals and caregivers dealing with chronic illness. She maintained that hope is a necessary factor in one's life to help with adverse situations. Although her review of research on the effects of hope was mainly on the person with the illness, she did acknowledge its importance among family members. People who were able to maintain their hope had better levels of adjustment. In looking at my participants and how they talked about hope, I cannot help thinking that it was an important component in their lives and did sustain them in their caregiving work.

Relationality

Relationality or lived relations refers to the way we relate to other human beings in our lives (van Manen, 1997). Three themes "*Adjusting to a new relationship with your spouse*", "*Taking on new responsibilities*", and "*Having to depend on the* *support of others*" in particular illustrated the changed relationships of the spousal caregivers. The experiences of these caregivers who agreed to take part in my study perhaps showed most change in relationships - relationships with spouse, responsibilities, and other people within their support network. The greatest change was with their affected spouses but moved beyond that to adult children and to friends and neighbours as well.

There is a gap in the literature in terms of understanding the many relational effects of a stroke on the caregiver, as the professional's focus is usually on the stroke survivor (Robin-Smith & Maloney, 1995). However, we do have research on what may affect the relationship such as anger, role reversal, or feelings of growing distance between caregiver and care recipient (Kane et al., 1999). Spousal caregivers emphasize the emotional changes in the stroke survivor as difficult factors to contend with in their partners (Kauser & Powell, 1996). These negative consequences of a stroke in the survivor are what causes the burden perceived among caregivers and results in psychological consequences for these individuals (Draper et al., 1992). The participants in my study did talk about how difficult it was to deal with the changes in their spouses.

Changes in relationships were a major consequence for the participants in my study. There were major adjustments in all their lives. The changed relationship they talked about the most was that with their affected spouse. The change in relationship meant they were caregivers first and foremost and partners less so. The quality of the partnership had changed dramatically after the stroke. The literature does address outcomes of this changed relationship such as a decrease in marital satisfaction (Bethoux et al., 1996) and less sexual contact (Korpelaniner, 1999).

My theme relating to taking on new responsibilities and the type of work the spousal caregiver now had to assume, further expands on the change in relationships in the home. These responsibilities included assistance with walking, transfers, bathing, transportation, cooking, cleaning, finances, and supervision and help give insight into why caregivers frequently experience adverse physical and psychological health consequences. Spousal caregivers reported taking on responsibilities that were previously the domain of their partner (Denman, 1998). These increased responsibilities are factors that have been found to place spousal caregivers at health risks (Barnes, Given, & Given, 1992), and role strain (Alcock, Danbrook, Walker, & Hunt, 1998). Spousal caregivers are also at risk for caregiver strain (Bugge et al., 1999), and activity restrictions and depression (Niebor et al., 1998).

The quantity and quality of social support a caregiver receives is a large factor in successfully adjusting to this role. The literature on caregiving addresses both the type of support people want and the consequences of not getting adequate support. Caregivers have been reported to have a preference for managing problems on their own (Barusch, 1988) and older people in particular want informal support (Elmstahl et al., 1996). What is usually not addressed and what the participants in my study illustrated were the changes in relationships with other family members and friends that occurred as a result of this need for informal support.

One of the consequences of taking on the caregiving role and not having the assistance from a spouse was illustrated through the theme of having to depend on the support of others. The participants in my study described how they needed to depend on adult children and neighbours to help them especially with accessing services, allowing the caregiver to go out to look after bills, or just having a brief break from caregiving. Some of the research on social networks in older adults suggests why it was difficult for my participants to look to others for help and support (Barrett et al., 1999). Older marital couples tend to have a smaller helping network than widowed and never married older adults because they rely on each other for help. When their main source of help is no longer able to provide support, i.e., their spouse, they must develop new networks. It is important to make a distinction between helping and social networks and not conflict the two.

What was noticeably absent from the interviews was the role of health professionals in helping out the caregivers. Participants did talk about the roles of these professionals in the acute stage of their spouses' illnesses and during hospitalization but not during the period of caregiving that I focused on in this study. This finding is similar to that of Secrest (2002) who in her unstructured interviews found that primary support persons to stroke survivors did not mention any “therapeutic presence” from nurses. Brereton (1997) suggested that the needs of these families are not well understood by nurses and need greater attention. Both of these studies and my findings are consistent with the conclusion in a review of the literature on how informal caregivers are affected by a stroke in the care recipient (Low et al., 1999). These authors suggest we need to move towards research that examines how health services can help these caregivers.

CHAPTER SIX

RECOMMENDATIONS AND CONCLUSION

A study of spousal caregivers for someone with a stroke, not only helps illuminate the experience of caring in this situation, but also lets us look at some of the nursing implications of this situation. This chapter suggests a number of implications for nursing practice, education, and research made in the form of some recommendations based on my participants' experiences. First, however, I would like to present some limitations to the study.

Limitations

One of the main limitations I believe is that as a novice researcher I found the work of exploring and describing the "lived experience" of my participants to be quite challenging. I may have missed some information/themes that would have been more obvious to a more experienced researcher.

Other limitations could fall under what van Manen (1997) described as effects of the research. He points out that people involved in phenomenological research may indeed be affected by the research. Involvement may generate a number of feelings, both positive and negative, in the participants. I do not know to what extent my research affected my participants and their caregiving activities. My hope is that it had a positive effect and that the spousal caregivers were able to reflect on their commitment to their spouses who had experienced a stroke and feel satisfaction and a sense of pride in what they were doing.

Despite these limitations the research does provide some important insights into spousal caregiving. In the following section are some of the implications that my study has for nursing practice, education, and research. Some recommendations for future care to spousal caregivers of survivors of a stroke are suggested.

Nursing Practice

The study findings have implications for nurses who are already in practice both within institutions and in community settings. Nurses, as well as other health professionals, cannot assume that every spouse can take on and handle the responsibilities of caregiving. A thorough multidimensional assessment of the caregiver which includes their understanding of their new role, and an assessment of their home situation is essential. Even if spousal caregivers indicate a willingness to provide care to their affected partners, they need education, assistance, and support. These needs may be greater in the initial period of caregiving so the caregivers do not need to discover what may work best by trial and error. It was clear in the interviews with the participants in the study that they felt unprepared to take on their new role as caregivers, and had no idea how care giving would affect their lives. However, supports in these areas need to continue throughout the active caregiving experience and even beyond that period.

What seemed important is that there does need to be long term follow-up, support, and contact for both the stroke survivor and his/her caregiver. Regular contact visits by health care workers and respite care could contribute to the support base of the caregiver. Community health nurses or home care nurses could provide a key role with follow-up and support to caregivers. Regular assessment could indicate when caregiving strain is decreasing their level of freedom and they experience the stress of the increased demands of caregiving. In addition, exploring the number of responsibilities and how the caregiver feels about these could help put in place new and creative solutions. The active involvement of the caregiver would help to ensure success.

By understanding the spousal caregivers concerns and challenges, interventions to prevent such problems as feeling overwhelming loss, too many responsibilities, and excessive demands of care giving, may assist the caregivers to minimize the negative effects on their lives. Just letting the caregiver know that these are fairly common responses may be of benefit. These problems just mentioned may result in isolation for the caregiver and this isolation may be prevented. Community health nurses can also play a key role in facilitating respite opportunities for the caregiver to attend appointments, shop, attend support groups, and take essential mental health breaks from their caregiving. All of these could potentially reduce the stress of caregiving.

One of the recommendations from this research is that health care workers, especially community health nurses, become involved in greater advocacy. Health care professionals can play a vital part in the political lobbying efforts for better home support programs. Understanding experiences, such as those described in my study, can greatly inform advocacy efforts. Coalitions of healthcare professionals and caregivers can bring advocacy issues to governments to improve services to these populations.

Nursing Education

The findings from this study will add to the knowledge available about the impact of caregiving on spousal caregivers of survivors of a stroke. This knowledge can be incorporated in nursing education programs. Education will provide nursing students with preparation to understand how the stroke can have an impact on the spouse who provides care on a continuing basis. With this knowledge and understanding, they will be better prepared to provide assistance to the spousal caregiver during a caregiving experience.

From the findings it is also clear that caregivers themselves need help with their caregiving. They need some education about stroke, needs of the stroke survivor, how to give care in this situation, and the impact that a stroke may have on both the survivor and the caregiver. They need to know how to cope with their feelings and how to solve problems that may arise so that they can deal with the challenges that occur and the changes in their roles and responsibilities. Nurses can be instrumental in teaching caregivers how to develop these skills to help the caregivers reframe their perceptions of the caregiving experience. Spousal caregivers often do not appreciate their contribution to their partner's recovery. By maximizing the rewards of care giving, this will help the spousal caregivers have a more positive care giving experience.

The findings from this study will also help nurses to understand the impact of the caregiving experience on spousal caregivers and other family members. It will assist them to provide meaningful care to the caregiver as soon as possible after admission of the affected spouse. Including the spouse in the entire care and discharge planning and by understanding the abilities and concerns of the caregiver, will facilitate the care giving experience. In-service education to those working in the field of stroke rehabilitation on caregiving to stroke survivors will create a stronger awareness of the needs of this population.

Nursing Research

The findings from this study support the need for further research into the spousal caregiving experience of survivors of a stroke. Such studies could follow caregivers over a longer period of time and could study the effects of the caregiving experiences on health and well being at various stages of the caregiving experience. An important question to ask is if there are phases and transitions in the caregiving experience when a spousal caregiver is more vulnerable to adverse effects on his or her health? Continued research on spousal caregivers is necessary because of the impact of the stroke survivor's care requirements on the caregiver.

Future studies could compare the similarities and differences between male and female spousal caregivers. While it was not the purpose of my study I felt that there were some differences in how the men and women experienced their caregiving situation. By studying gender differences between caregivers it might be possible to determine what interventions may be common and effective for both and what may be different. Approaches to education and caregiving could then be tailored to the needs of caregiver's and be gender specific.

Another question that arises is what makes the caregiving a positive experience for some people and not for others when the caregiving experience may otherwise seem similar. We need more research information on the long term impact of caregiving on carers. These impacts could be studied in view of health status and quality of life. Closely related to this area is what type of interventions would work best to relieve burden in caregivers?

An additional question that arises is what are the stressors related to the caregiving experience? If the common stressors are known, appropriate interventions could be implemented to help reduce those stressors and help make it a more positive and perhaps fulfilling experience. Another area of importance when studying caregiving is to look at the issue of respite care, both in the home and institution, and what this might mean to caregivers. An action research approach could be instituted to develop models of care that are acceptable and within the control of caregivers, yet contribute to our understanding of alternate care models.

Conclusion

Caregiving for a spousal partner who has suffered a stroke has contributed to many changes in the lives of the caregivers that I interviewed. Caregiving seemed to have had both negative and positive consequences on these participants' lives. What seemed to be the case was that the spousal caregivers were committed to the work of caregiving and felt it was their responsibility to care for their affected partners. Equally evident in these caregiver's accounts was that they also needed some assistance with their caregiving work. Researchers need to continue to examine the experiences of spousal caregivers and to expand the scope of this work because of the impact that caregiving has on a spouse. The population of Canada is aging and the incidence of spousal caregiving will increase as aging increases and with it the risk of chronic conditions such as stroke. Caregivers' contributions need to be recognized, valued, and financially compensated because of the many hours of unpaid labour they provide to ill and impaired family members. The cost to families for using formal supports such as home support and respite services need to be decreased so that these services are more readily available to all caregivers regardless of income. Health care providers can be instrumental in lobbying for universal access to home care for all Canadians. This study will provide additional understanding and insight into the experiences of spousal caregivers of survivors of a stroke.

References

Addington-Hall, J., Lay, M., Altmann, B.A., & McCarthy, M. (1998). Community care for stroke patients in the last year of life: Results of a national retrospective survey of surviving family, friends, and officials. *Health and Social Care in the Community,* 6, 112-119.

Alcock, D., Danbrook, C., Walker, D., & Hunt, C. (1998). Home Care clients and providers and costs. *Canadian Journal of Public Health,* 89, 297-300.

Anderson, C.S., Linto J., & Stewart-Wynn, E.G. (1995). A population-based assessment of the impact and burden of caregiving for long-term survivors of a stroke. *Stroke, 1,* 834-839.

Bakas, T., Austin, J., Ohonkwo, K., Lewis, R., & Chadwick, L. (2002). Needs, concerns, strategies, and advice to stroke caregivers: the first six months after discharge. *Journal of Neuroscience Nursing,* 34, 242-252.

Baker, A. C. (1993). The spouse's positive effect on the stroke patient's recovery. *Rehabilitation Nursing, 18,* 30-33.

Barnes, C. L., Given, B. A., & Given, C. (1992). Caregivers of elderly relatives: Spouses and adult children. *Health and Social Work, 17,* 282-289.

Barrett, A.E. & Lynch, S.M. (1999). Caregiving networks of elderly persons: Variation by marital status. *The Gerontologist,* 36, 695-704.

Barusch, A. S. (1988). Problems and coping strategies of elderly spouse caregivers. *The Gerontologist, 28,* 677-685.

Béthoux, F., Calmels, P., Gautheron, V., & Minaire, P. (1996). Quality of life of the spouses of stroke patients: a preliminary study. *International Journal of Rehabilitation Research, 15,* 291-299.

Blake, H. & Lincoln, N.B. (2000). Factors associated with strain in co-resident spouses of patients following a stroke. *Clinical Rehabilitation,* 14, 307-314.

Braitwaite, V. & McGowan, A. (1993). Caregivers' emotional well-being and their capacity to learn about stroke. *Journal of Advanced Nursing,* 18, 195-202.

Brereton, L. (1997). Preparation for family care-giving: stroke as a paradigm case. *Journal of Clinical Nursing,* 6, 425-434.

Brereton, L. & Nolan, M. (2002). “Seeking”: A key activity for new family carers of stroke survivors. *Journal of Clinical Nursing,* 11, 22-31.

Bugge, C., Alexander, H., & Hagen, S. (1999) Stroke patients’ informal caregivers. Patient, care and service factors that affect caregivers strain. *Stroke,* 30, 1517-1523.

Bull, M. J. (1990). Factors influencing family caregiver burden and health. *Western Journal of Nursing Research, 12*, 758-776.

Burman, M. (2001). Family caregivers' expectations and management of the stroke trajectory. *Rehabilitation Nursing*, 26, 94-99.

Chwalisz, K. & Kistler,V. (1995). Perceived Stress: A better measure of caregiver burden. *Measurement and Evaluation in Counselling and Development, 28*, 88-98.

Clark, M. S. (2000). Patient and spouse perceptions of stroke and its rehabilitation. *International Journal of Rehabilitation Research, 23*, 19-29.

Davis, L. L., & Grant, J. S. (1994). Constructing the reality of recovery: Family home care management strategies. *Advances in Nursing Science, 17,* 66-76.

Denmann, A. (1998). Determining the needs of spouses caring for aphasic partners. *Disability and Rehabilitation,* 20, 411-423.

Dennis, M., O’Rourke, S., Slattery, J., Staneforth, J.,& Warlow, C. (1997). Evaluation of a stroke family care worker: Results of a randomised controlled trial. *British Medical Journal,* 314 (7087), 1076-6

Dennis, M., O’Rourke, S., Lewis, S., Sharpe, M., & Warlow, C. (1998). A qualitative study of the emotional outcome of people caring for survivors of a stroke. *Stroke, 29*, 1867-1872.

Dorsey, M. K., & Vaca, K. J. (1998). The stroke patient and assessment of caregiver needs. *Journal of Vascular Nursing, 16,* 62-67.

Dowswell, G., Lawlor, J., Dowswell, T., Young, J., Forster, A., & Hearn, J. (2000). Investigating recovery from stroke: A qualitative study. *Journal of Clinical Nursing,* 9, 507-515.

Draper, B.M., Poulos, C.J., Cole, A.M., Poulos, R.G., & Ehrlich, F. (1992). A comparison of caregivers for elderly stroke and dementia victims. *Journal of the American Geriatric Society,* 40, 896-901.

Elmstahl, S., Malmberg, B., & Annerstedt, L. (1996). Caregivers burden of patients three years after stroke assessed by a novel caregivers burden scale. *Arcihives of Physicians and Medical Rehabilitation,* 77, 177-182.

Enterlante, T.M. & Kern, J.M. (1995). Wives' reported role changes following a husband's stroke: A pilot study. *Rehabilitation Nursing*, 20, 155-160.

Forsberg-Warleby, G., Moller, A., & Blomstrand, C. (2002). Spouses of first-ever stroke patients, their view of the future during the first phase after stroke. *Clinical Rehabilitation,* 16, 506-514.

Fowler, S.B. (1995). Hope: Implications for NeuroscienceNursing. *Journal of Neuroscience Nursing.* 27, 298-304

Grant, J.S. (1996). Home care problems experienced by survivors of a stroke and their family caregivers. *Home Health Care Nurse, 14*, 893-902.

Grant, J.S., Bartolucci, A.A., Elliot, T.R., & Giger, J.N. (2000). Sociodemographic, physical and psychosocial characteristics of depressed and non-depressed family caregivers of stroke survivors. *Brain Injury,* 14, 1089-1100.

Grant, J.S. & Davis L.L. (1997). Living with loss: the stroke family caregiver. *Journal of Family Nursing, 3*, 36-56.

Han, B., & Haley, W. (1999). Family caregiving for patients with stroke review and analysis. *Stroke, 30*, 1478-1485.

Health Canada. (2000). The Changing Face of Heart Disease and Stroke in Canada. [On-line]. Retrieved from: *http://www.hc-sc.gc.ca/hpb/lcdc/bcrdd/ hdsc2000/index.html. Heart and Stroke Foundation Canada* (2003). Retrieved from www://ww2heartandstroke.ca

Heart Disease Quick Facts. Retrieved from www.gmcc.ab.ca/nw/hsfacentral/eccudates/HDQikFcts.htm. November 25,2002.

Hodgson, S. P., Wood, V. A., & Langton-Hewer, R. (1996). Identification of stroke carers' at risk: A preliminary study of the predictors of carers' psychological well-being at one year post stroke. *Stroke, 10*, 337-346.

Holicky, R. (1996). Caring for the caregivers: The Hidden victims of illness. *Rehabilitation Nursing, 21*, 247-252.

Holmquist, L.W., von Koch, L., & de Pedro-Cuesta, J. (2000). Use of healthcare, impact on family caregivers and patient satisfaction of rehabilitation & home after stroke in southwest Stockholm. *Scandinavian Journal Rehabilitation Medicine.* 32, 173-179.

Jackson, D. G & Cleary, B. L. (1995). Health promotion strategies for spousal caregivers of chronically ill elders. *Nurse Practitioner Forum*, *6,* 10-18.

Johnson, P.D. (1998). Rural stroke caregivers: A Qualitative Study of the Positive and Negative Response to the Caregiver's Role. *Topics in Stroke Rehabilitation, 5(3),* 51-68.

Jones, A.L., Charlesworth, J.F., & Hendra, T.J. (2000). Patient mood and carer strain during stroke rehabilitation in the community following early discharge. *Disability and Rehabilitation,* 22, 490-494.

Jongbloed, L. (1994). Adaptation to a stroke: The experience of one couple. *American Journal of Occupational Therapy*, 48, 1006-1013.

Kane, R. A., Reinardy, J., Penrod, J. D., & Huck, S. (1999). After the hospitalization is over: A different perspective on Family care of older people. *Journal of Gerontological Social Work, 31*, 119-141.

Kauser, R. & Powell, G. (1996). Subjective burden on carers of patients with neurological problems as a consequence of precise objective symptoms (objective burden). *Clinical Rehabilitation,* 10, 159-165.

Keeling, D., Price, P. E., Jones, E., & Harding, K.G.(1996). Social support: Some pragmatic implications for health care professional. *Journal of Advanced Nursing, 23*, 76-81.

Kerr, S.M., & Smith, L.N. (2001). Stroke: an exploration of the experience of informal caregiving. *Clinical Rehabilitation.* 15, 428-436.

King, R., Carlson, C., Shade-Zeldow, Y., Bares, K., Roth, E., & Heinemann, A. (2001). Transition to home care after stroke: depression, physical health and adaptive processes in support persons. *Research in Nursing and Health, 24, 307-323.*

Knapp, P., & Hewison, J. (1999). Disagreement in patient and career assessment of functional abilities after stroke. *Stroke,* 30, 934-938.

Korpelainen, J.T., Nieminen, P., & Myllyla, V.V. (1999). Sexual functioning among stroke patients and their spouses. *Stroke*, 30, 715-719.

Kramer, B.J. & Lambert, J.D. (1999). Caregiving as a life course transition among older husbands: A prospective study. *The Gerontologist,* 39, 658-667.

Lieberman, M. A.,& Fisher, L. (1995). The impact of chronic illness on the health and well-being of family members. *Gerontologist, 35,* 94-101.

Low, J. T., Payne, S., & Roderick, P.(1999). The Impact of Stroke on informal carers: A literature review. *Social Science & Medicine, 49*, 711-725.

Mant, J., Carter, J., Wade, D.T., & Winner, S. (2000). Family support for stroke: A randomized controlled trial. *Lancet*, 356 (9248): 2196.

Miller, J.F. (2000). Inspiring hope. In J.F. Miller (Ed.). *Coping with chronic illness: Overcoming powerlessness,* (pp. 523-546). Philadelphia, PA: F.A. Davis.

Moore, L.W., Maiocco, G., Schmidt, S.M. Guo, L., & Estes, J. (2002) Perspectives of caregivers of stroke survivors: Implications for nursing. *MedSurg Nursing, 11,* 289-295.

Morse, J., & Penrod, J. (1999). Linking concepts of enduring, uncertainty, suffering, and hope. *Image: Journal of Nursing Scholarship, 31,* 145-150.

Morse, J. M. (1994). Designing funded qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds), *Handbook of qualitative research (pp. 220-235*). Thousand Oaks: CA: Sage.

Mumma, C.M. (1986). Perceived losses following a stroke. *Rehabilitation Nursing,* 11(3), 19-24.

National Caregiving Survey (1996). Retrieved from http://www.caregiving.org/National, November 10, 2002.

Nieboer, A.P., Schulz, R., Matthews, K. A., Scheier, M. F., Obmel, J., & Lindenberg, S.M., (1998). Spousal Caregivers' Activity Restrictions and Depression: A model for changes over time. *Social Science and Medicine*, 47, 1361-1371.

Nilsson, I., Axelsson, K., Gustafson, Y., Lundman, B., & Norberg, A. (2001). Well-being, sense of coherence, and burnout in stroke victims and spouses during the first few months after a stroke. *Scandinavian Journal of Nursing Science,* 15, 203-214.

Ory, M.G., Hoffman, R.R., Yee, J. L., Tennsledt, S., & Schulz, R. (1999). Prevalence and impact of caregiving: A detailed comparison between dementia and nondemential caregivers. *The Gerontologist,* 39, 177-185.

Oxford Dictionary (2001). London: Oxford University Press.

Pearlin, L. I., Mullan, J.T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the Stress Process: An overview of concepts and their measures. *Gerontologist, 30,* 583-594.

Periard, M. E. , & Ames, B. D. (1993). Lifestyle changes and coping patterns among caregivers of survivors of a stroke. *Public Health Nursing, 10*, 252-256.

Pierce, L. L. (1994). Fear held by caregivers of people with stroke: a concept analysis. *Rehabilitation Nursing Research, 8*, 69-74.

Pruchno, R. (1990). The effects of help patterns on the mental health of spouse caregivers. *Research on Aging, 12*, 57-71.

Pruchno, R., & Resch, N. (1989). Husbands and wives as caregivers: Antecedents of depression and burden. *The Gerontological Society of American, 29*, 159-165.

Pruchno, R. A., & Potashnik, S. L. (1989). Caregiving spouses: Physical and mental health in perspective. *Journal of the American Geriatrics Society, 37*, 697-705.

Robinson-Smith, G., & Mahoney, C. (1995). Coping and marital equilibrium after stroke. *Journal of Neuroscience Nursing, 27* (2), 83-89.

Rosenthal, S.G., Pituch, M.J., Greninger, L.O., & Metress, E.S. (1993). Perceived needs of wives of stroke patients. *Rehabilitation Nursing, 15, 148-153;167.*

Ruppert, R.A. (1996). Psychological aspects of lay caregiving. *Rehabilitation Nursing,* 21, 315-320.

Santos, M. E., Farrajota , M.L., Castro-Caldas, A., & de Sousa, L. (1999). Problems of patients with chronic aphasia : Different perspectives of husbands and wives. *Brain Injury, 13*(1), 23-29.

Scholte op Reimer, W. J., de Haan, R. J., Rijnders, P. T., Limburg, M., & van den Bos, G. A. (1998). The burden of caregiving in partners of long-term survivors of a stroke. *Stroke, 29*, 1605-1611.

Schulz, R. & Beach, S.R. (1999). Caregiving as a risk factor for mortality: The caregiver Health Effects Study. *Journal of the American Medical Association,* 23, 2215-2219.

Schulz, R., Newsom, J., Mittelmark, M., Burton, L., Hirsch, C., & Jackson, S. (1997). Health effects of caregiving: The caregiver health effects. Study: An ancillary Study of the cardiovascular health study. *Annals of Behavioural Medicine, 19*, 110-116.

Secrest, J. (2000). Transformation of the relationship: The experience of primary support persons of survivors of a stroke. *Rehabilitation Nursing, 25*, 93-99.

Simon, C., & Kumar, S. (2002). Stroke patients' carers' view of formal community support. *British Journal of Community Nursing, 7*(3), 158 – 163.

Sisson, R. A. (1998). Life after a stroke: Coping with change. *Rehabilitation Nursing,* 23, 198-203.

Sjogren, K. (1983). Sexuality after stroke with hemiplegia. II. With special regard to partnership adjustment and to fulfilment. *Scandinavian Journal of Rehabilitation Medicine,* 15, 63-69.

Smout, S., Koudstaal, P.J., Ribbers, G.M., Janssen, W.G., & Passchier, J. (2001). Struck by stroke: A pilot study exploring quality of life and coping patterns in younger patients and spouses. *International Journal of Rehabilitation Research,* 24, 261-268.

Statistics Canada. (1998). *The Canada Year Book.* Ottawa: Industry Canada.

Statistics Canada. Population by age group: Canada, the provinces, and territories. Retrieved from *http://www.ststcan.ca/english/Pgdb/demo31ahtm.* November 25, 2002.

Stewart, M.J., Doble, S., Hart, G., Langille, L., & MacPherson, K. (1998). Peer visitor support for family caregivers of seniors with stroke. *Canadian Journal of Nursing Research*, 30, 87-117.

Streubert, H. J.,& Carpenter, D. R. (1999). *Qualitative Research in Nursing: Advancing The Humanistic Imperative, 2nd edition.* Philadelphia J.B.: Lippincott.

Tebb, S. (1994). Creating meaning in elder caregiving. *Adult Residential Care Journal, 8*(1), 34 – 42.

Thommessen, B., Aarsland, D., Braekhus, A., Oksengaard, A.R., Engedal, K., & Laake, K. (2002). The psychosocial burden on spouses of the elderly with stroke, dementia and Parkinson's disease. *International Journal of Geriatric Psychiatry,* 17, 78-84.

Thompson, S. C., Bundek, N. I., & Sobolew-Shubin, A. (1990). The caregivers of stroke patients: An investigation of factors associated with depression. *Journal of Applied Social Psychology,* 20, 115-129.

Tri-Council policy statement: Ethical conduct for research involving humans. (2000). Ottawa: Author.

van den Heuvel, E.T., de Witte, L.P., Schure, L.M., Sanderman, R., & Meyboom-de Jong, B. (2001). *Clinical Rehabilitation,* 15, 669-677.

van Manen, M. (1997). *Researching lived experience: Human science for an action sensitive pedagogy.* London, Ont: The Althouse Press.

Vanetzian, E. & Corrigan, B.A. (1995). A comparison of educational wants of family caregivers of patients with stroke. *Rehabilitation Nursing,* 20, 149-154.

Wallsten, S.S. (2000). Effects of caregiving, gender, and race on the health, mutuality, and social support of older couples. *Journal of Aging and Health*, 12, 90-111.

Williams, A. (1993). Caregivers of persons with stroke: Their physical and emotional well-being. *Quality of Life Research*, 2, 213-220.

Williams, A. (1994). What bothers caregivers of stroke victims? *Journal of Neuroscience Nursing, 26,* 155-161.

Appendix A

Inclusion Criteria for Study

Caregivers will have to:

- be 50 years of age or older;
- be physically and mentally capable of participating;
- speak English;
- be caregivers currently;
- have been caregivers for at least one year post stroke;
- be providing care at home;
- be caring for spouse who has no evidence of coexisting terminal illness or other rapidly progressing medical condition;
- be caring for stroke survivor who is at least 55 years of age.

Appendix B

October 10, 2000

73 Elizabeth Street
Corner Brook, NF A2H 5Z8
Telephone 639-1271

Mrs. Eva Payne-Lang, Social Worker
Short Stay Program
John I. O'Connell Centre
P.O. Box 2005
Corner Brook, NF A2H 6J7

Dear Mrs. Payne-Lang:

I am a graduate student in the School of Nursing, Graduate Program at Memorial University of Newfoundland. A partial requirement for this 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 recruiting spouse caregivers of survivors of a stroke who might be included as participants. The immediate purpose of this study is to explore the experiences of spouse caregivers of survivors of a stroke. Ultimately the purpose of my study is to contribute to the knowledge that could be used by nurses and other health care workers to assist/help caregivers.

This is a qualitative study which will involve two tape recorded interviews of spouse caregivers. The interviews will be unstructured. The contents of the interviews will be analysed by the researcher and 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. No distinguishing characteristics will be identified in the report. The proposed study has been submitted to the Human Investigation Committee at Memorial University of Newfoundland and I am awaiting approval from that committee.

I am requesting that the rehabilitation unit identify from the records, spouse caregivers of survivors of a stroke who meet the inclusion criteria for the study. Please see attachment. I ask that you make the initial contact with these caregivers so that you can provide me with the names and telephone numbers of those who agreed to be contacted by myself. I will then contact each participant to further explain the study, answer any questions and arrange a time to interview each participant. 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 written reply at your earliest convenience.

Sincerely,

Ursula Eileen Coombs

Guide for Intermediator for Recruiting Participants

A graduate student currently enrolled in the Master of Nursing degree program is conducting a research study as part of her degree program.

The researcher wishes to study spouse caregivers who provide care at home to a stroke survivor and have done so for at least one year.

This study will be of no direct benefit to the caregiver; however, this study ultimately will contribute to the knowledge that could be used by nurses and other health care workers to assist/help caregivers.

Two tape recorded interviews of approximately one hour each is required (at one or two months apart). The time and location of these interviews is at the convenience of each participant.

After the study all tapes and documents will be destroyed.

There will be no names or distinguishing characteristics identified in the report.

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

Participants Name

Participants Telephone

Appendix C

Demographic Form and Sample Interview Guide

Caregiver's Sex

Age

Martial Status

Occupation

Number of Years as Primary Caregiver

Care Recipient's Age

Number of Formal Respite Hours/Week

Number of Informal Respite Hours/Week

Type of help given to Care Recipient

<u>Introduction:</u>

Thank you for agreeing to be part of my study. I would like for you to tell me what it is like to care for (a husband / wife) who has a stroke. I am interested in your experience so tell me whatever you think is important to you about your caregiving. You can start wherever you feel comfortable.

Questions for clarification and elaboration:

Describe a typical day of caregiving.

What kind of caregiving activities do you do for your spouse?

What stands out in your experience as a caregiver?

How do you feel about the caregiving experience?

Appendix D

Participant Consent Form

Title of Project: The Experience of Caregiving for A stroke Survivor: A Spousal Perspective
Name of Principal Investigator: Ursula Eileen Coombs

To be signed by participant

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 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 given to me.

(Signature of Participant) (Date)

(Signature of Witness) (Date)

To be signed by investigator

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

(Signature of Investigator) (Date)

Phone Number

Appendix E

Human Investigation Committee Consent and Western Health Care Corporation Ethics Committee Consent

Memorial
University of Newfoundland

Office of Research and Graduate Studies (Medicine)
Faculty of Medicine
The Health Sciences Centre

March 22, 2001

TO: **Ms. U. Eileen Coombs**

FROM: Dr. F. Moody-Corbett, Assistant Dean
Research & Graduate Studies (Medicine)

SUBJECT: Application to the Human Investigation Committee - #00.178

//

The Human Investigation Committee of the Faculty of Medicine has reviewed your proposal for the study entitled "**"The experience of caregiving for a stroke survivor: A spousal perspective"**.

Full approval has been granted for one year, from point of view of ethics as defined in the terms of reference of this Faculty Committee.

For a hospital-based study, it is **your responsibility to seek necessary approval from the Health Care Corporation of St. John's**.

Notwithstanding the approval of the HIC, the primary responsibility for the ethical conduct of the investigation remains with you.

F. Moody-Corbett, PhD
Assistant Dean

cc: Dr. C. Loomis, Acting Vice-President (Research)
Dr. R. Williams, Vice-President, Medical Services, HCC
Dr. S. Solberg, Co-Supervisor
Ms. D. Dawe, Co-Supervisor
Dr. S. LeFort, Associate Professor, (Graduate Program & Research)

WESTERN
HEALTH CARE
CORPORATION

January 5, 2001

Ms.Ursula Eileen Coombs
73 Elizabeth Street
Corner Brook, NF A2H 5Z8

Re: Research Proposal ~ The Experience of Caregiving for a Stroke Survivor: A Spousal Perspective

Dear Ms. Coombs:

Your research proposal was reviewed by the Ethics Committee on December 5, 2000, and no problems were found with it. This proposal was accepted by the Committee.

Sincerely,

Dr. Ian Simpson, Chair
Ethics Committee

/hb

● P.O. Box 2005 ● Corner Brook ● NF ● A2H 6J7 ●
● Telephone: 709-637-5000 ●

Operating the following sites:

◆ Bay St. George Senior Citizens Home ◆ Bonne Bay Health Centre ◆ Calder Health Centre ◆ Dr. Charles L. LeGrow Health Centre ◆ Inter-Faith Home For Senior Citizens ◆ J.I. O'Connell Centre ◆ Rufus Guinchard Health Centre ◆ Sir Thomas Roddick Hospital ◆ Western Memorial Regional Hospital ◆