THE EXPERIENCE OF CAREGIVING: A QUALITATIVE STUDY OF OLDER WOMEN WHOSE HUSBANDS HAVE PARKINSON'S DISEASE

By

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ABSTRACT

This phenomenological study was designed to explore and describe the experience of older women who are caring for husbands with Parkinson's disease.

The study was conducted with a sample of seven caregivers ranging in age from 50 - 74 years who had lived with husbands with Parkinson's disease for 9-38 years. Data were collected by intensive interviewing usually at the home of the caregiver. The data were analyzed for common themes.

The findings revealed that each wife experienced three phases during the course of caregiving. The three phases were: coping with illness, taking over, and separating life paths. These phases occurred in relation to the changes due to the illness, that each wife perceived in her husband, her marriage and herself. Each phase developed as the disease progressed and was meaningful to each wife because of her personal perceptions.

Understanding the nature of caregiving in this way may help health care workers to provide more appropriate support for caregivers. Implications for practice are discussed.
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CHAPTER ONE
INTRODUCTION

Nurses will increasingly encounter older women in their practice because a rapidly increasing proportion of the population is not only elderly but female. In 1981 in Canada, the elderly comprised about 9.7% of the population (Government of Canada, 1983). By the year 2001, the elderly could constitute 14-17% of the population. Since wives outlive their husbands and are usually younger, (Peron & Strohmenger, 1985) they are likely to be involved in their husband's decline and death. So many women outlive men that if present trends continue, demographers predict that the ratio of older women to older men in Canada will be two to one by the year 2001 (Government of Canada, 1983, p. 20). In considering these factors, one must conclude that the patterns of aging for men and women are developing significant differences (Robinson, 1986). It follows that in order to understand the needs of this growing segment of nursing clientele, there is a need for nurses to study older women.

Nurses will also encounter in their practice an increasing number of individuals who have a chronic illness. Over the last thirty years, health surveys have shown a general trend of increasing disability in the Canadian population (Peron & Strohmenger, 1985, p. 128). In all age groups, but particularly among the elderly, chronic illnesses are becoming more prevalent than acute illnesses as health problems that cause disability (Peron & Strohmenger, 1985, p. 164). The longterm nature of chronic illness is such that its effects are handled over the years by the individuals themselves, primarily at home. Other family members are the single most important emotional and physical resource available to a chronically ill individual at home. Family members become deeply involved in the daily lives of chronically ill individuals when they begin to need psychological and physical support.
(Dimond & Jones, 1983; Strauss, Corbin, Fagerbaugh, Glaser, Maines, Suczek & Weiner, 1984). For nurses to provide useful service to this increasing population, they need to understand the problems and needs of caregivers, as well as the problems and needs of chronically ill individuals.

In our society, the social role of caregiving will usually be assumed by women. As spouses, older women are frequently called upon to assume the role of caregiver. This study will focus on how older women view their role of caring for a spouse who has a specific chronic illness – Parkinson's disease.

Parkinson's disease is a chronic neurological illness that affects 120 per 100,000 people in the North American population. The mean age of onset is about 58 years although it can begin anywhere from age 25-85 years (Teräväinen, Forgach, Heitanen, Schulzer, Schoenberg & Calne, 1986). Like many other chronic illnesses, Parkinson's disease causes increasing disability as it advances. Its major symptoms are muscle rigidity and bradykinesia which cause an individual to have increasing difficulty in moving with agility. Eventually these symptoms cause the individual to need increasing amounts of help to accomplish activities of daily living. As symptoms progress, speech and facial expressiveness become distorted and social interaction becomes inhibited. As a result, families and the individual must become adept at maintaining communication between each other. In addition, progressing symptoms cause difficulty swallowing which leads to drooling and choking. As symptoms become more visible, they become more embarrassing, and ultimately lead to social isolation.

Like other chronic illnesses, Parkinson's symptoms can be controlled to a degree with a medication regime that grows more complex as the disease progresses. The chronically ill individual and the family must develop considerable skill at managing the symptoms and the medication regime within the structure of their ongoing lives (Duvoisin, 1984). In addition, the
slow progression and long duration of Parkinson’s disease ensure that the disease becomes an integral part of the lives, not only of the ill individual, but also of family members involved. Since the age of onset of this disease makes it a disease of old age, the most available individual to be caregiver in an aging family is likely to be the aging spouse.

Some literature is available to help nurses begin to understand the problems of caregiving in general. Caregiving has been examined in relation to the home care of handicapped children (Wright, 1983); of the mentally ill (Brown, Birby & Wing, 1972; Thompson & Doll, 1982); and more recently, of the elderly - primarily the cognitively impaired (Poulshock & Deimling, 1984). Consensus in the literature is that caregiving causes stresses that become burdensome. Researchers have attempted to isolate and relate factors in the caregiving situation that cause caregiver stress. However, they have generally concluded from the studies available that caregiver stress is a complex and subjectively determined phenomenon (Poulshock & Deimling, 1984). Therefore, there is a need to develop a body of literature that examines caregiving circumstances from various subjective viewpoints. This study proposes to examine one such viewpoint, the caregiving circumstances of individuals at a specific lifestage experiencing a specific illness.

Although the experience of the ill individual, of the couple dealing with a chronic illness, and of the daughter as the middle-aged caregiver have been studied, there are few studies of elderly women who are spouses in the caregiving role (Crossman, London & Berry, 1981). No specific research has been located on the older woman’s experience of caring for a spouse with Parkinson’s disease. Therefore this study will employ a qualitative method of inquiry in order to understand how such individuals give structure and meaning to their experience. Since phenomenology seeks to “understand human experience from the individual perspective” (Knaack, 1984, p.108), this
is the method of choice.

Statement of the Problem

The purpose of this study is to explore and describe elderly women's experiences of living with, and caring for, a male spouse with Parkinson's disease. There is a lack of knowledge and understanding of the nature of the caregiving experience for older woman living with and caring for a disabled spouse as articulated by the women themselves. Specifically, the research questions are the following:

1. What are older women's experiences as caregivers?
2. What meaning do older women assign to their role as caregiver for a spouse with Parkinson's disease?

Definition of Terms

Caregiver: An individual who engages in cognitive and/or behavioural activities with the intent of enhancing the welfare of another.

Caregiving role: Activities and behaviours performed by an individual to enhance the welfare of another individual.

Older women: Women who are over 50 years of age.

Parkinson's disease: A chronic neurological illness that causes problems with mobility, with social interaction, often causes depression and possibly causes dementia.

Caregiving wives: Women who identify themselves as spousal caregivers.
Methodological Perspective

Phenomenology is an interpretive science that studies the experience of individuals with the goal of understanding the meaning the experience has for individuals (Davis, 1978). Phenomenology is based in the philosophy that people are not acted upon as objects in nature, but live interactively with the world. Individual experience is not only unique but is also significant and integral to a person's mode of being in the world (Knaack, 1984). Knowledge of this significance, then, is essential to understanding the individual (Knaack, 1984).

Several characteristics of phenomenology indicate its appropriateness to answer the research question (Knaack, 1984). Phenomenology studies the most direct source of a phenomenon, the individual experiencing it. Because phenomenology is faithful to the phenomenon as lived, the researcher must set aside theories and preconceptions in order to hear perceptions and meanings as interpreted by the person experiencing the phenomenon. These perceptions and meanings become the data. Phenomenology uses a descriptive approach that views the lived-in situation as the basic unit of research. In addition, phenomenology has a biographical emphasis “because all human phenomena are temporal” (Knaack, 1984, p. 109). The research question set forward here intends to discover from the caregiving older woman herself, her perceptions of her role, the meaning she ascribes to it and the place this role occupies in her life.

The qualitative research methodology of phenomenology, then, considers the meaning an individual's behaviour has for that individual and the reality the individual lives because of that individual's interpretation of his/her own situation (Davis, 1978). A detailed descriptive account of the viewpoints of a group of study participants is the product of this method of
research.

The information gained by this study will be useful to nurses who must understand clients' and their families' responses to illnesses and other life events in order to provide care that individual clients will perceive as relevant (Davis, 1978). Nurses widely accept the principle that as health professionals they need to understand the client's illness experience and use this understanding to tailor their interventions individually (Abdellah, Beland, Martin and Matheney, 1960; Sundeen, Stuart, Rankin & Cohen, 1981). Furthermore, nurses must understand clients' interpretations of their own health needs in order to assist clients to attain their individually defined optimum level of health (Oiler, 1982). When dealing with chronic illness, understanding the experience as it is lived by the client and caregiver is necessary for nurses to predict and identify problems and plan appropriate interventions (Lynam & Anderson, 1986).

Our beliefs and attitudes as nurses about the older woman caregiver may differ from the findings of this study. Consulting older women themselves as experts is the most direct way of reaching an understanding of these women. Phenomenology provides the most appropriate disciplined method of inquiry. The understanding that is gained by research concerning the experience of older women caring for husbands with Parkinson's disease may be useful to help nurses develop informed attitudes and assumptions about older women who are caregivers. Knowledge such as this will enable nurses to tailor empathetic care for these women and to know that the women will perceive it as helpful.
Assumptions

1. The researcher assumes that close examination of this particular caregiving situation will produce useable knowledge.
2. The researcher assumes that caregiving has an impact on the life of an older woman.
3. The researcher assumes that these women will be willing and able to talk openly and honestly, thereby giving an accurate account of their perception of reality.

Limitations

1. Because of time and logistical constraints, the researcher studied a limited number of participants who were English-speaking and lived in or near Vancouver. Consequently, the participants were city dwellers all of Anglo-Saxon background. Moreover, the subjects were obtained through a single clinic. Therefore, the study sample may represent a unique group of older women who are caregivers.
2. The study participants may also comprise a unique group of older caregiving women because they were accessible and articulate. The experiences of the women who participated may differ from the experiences of women who were unable or unwilling to participate.

Conclusion

Informal caregiving in the home is an important service to society. Caregiving is recognized in the literature as imposing a significant burden that affects the
wellbeing of caregivers. Although literature exists on objective factors relating to caregiver burden, there is a consensus that it is a subjective experience which requires further study. Parkinson's disease is a chronic neurological illness occurring more commonly in aging individuals. Thus the spousal caregiver is likely to be aging herself. Because there is a lack of literature describing an older woman's experience of caregiving for a disabled spouse, a qualitative phenomenological approach will provide meaningful descriptive data for nurses. The study results will assist nurses to provide care that is perceived to be relevant and helpful by older women caring for their spouses at home.
CHAPTER TWO
BACKGROUND TO THE PROBLEM

This chapter reviews current literature on the experience of older women caring for a spouse with Parkinson's disease. Since there is a scarcity of literature specific to this topic, the author has drawn on related literature about caregiving, chronic illness, Parkinson's disease, the social roles and the developmental stage of older women. Reviewing the literature in this way will place the research problem in a social context. Since phenomenological research is concerned with phenomena observed from the individual point of view, it is important that the social context of the phenomena be explored.

First this chapter will review the problems of chronically ill individuals, in particular, their need for caregivers. Then it will describe Parkinson's disease as one chronic illness that leads to a need for a caregiver in the home. Once the need for caregivers is established, the chapter will discuss how society assigns the role of caregiving and how it is likely to be older women who are caregivers. Then this chapter will examine how societal and developmental factors may influence the experiences that older women may have in the caregiving role. The chapter will examine literature about interventions for caregivers written by health care providers to see how they understand the caregiving experience for older women. Finally the chapter will examine research that provide insight into the caregiving experience of older women.

Chronic Illness and Care Needs of the Chronically III

Traditionally the health care system has focused on treatment of acute illness. However the increasing prevalence of chronic illness, with its associated problems of disability, is becoming a growing concern to the health care system. Better public health practices, medical advances in the treatment of acute health crises, and life style changes have caused death rates to fall
dramatically in the last 60 years. As a result, more people live to an older age (Peron & Strohmenger, 1985, p. 112) and are more likely to spend several years of their lives with the disability of a chronic illness. Wilkins and Adams (1983) estimated that on the average, women spend 15.5 years and men spend 11.6 years of their lives with some degree of ill health. Over the last thirty years, health surveys in both Canada and the United States show a trend of increasing disability in the population (Peron & Strohmenger, 1985, p.128).

Internationally, the World Health Organization (W.H.O.) also recognizes this trend and has attempted to create a better understanding of this class of health problems by developing a taxonomy of graded distinctions of the ability or inability to function independently and to fit into the surrounding social milieu (W.H.O., 1980).

The health care system in Canada is not well equipped to handle chronic illnesses. Presently our health care system is best equipped to handle the acutely ill. The acutely ill patient with infection or trauma, in need of surgical intervention, or experiencing an exacerbation of chronic illness is treated briefly and sent home, well out of danger. Usually, acute illnesses cause only temporary absence from societal roles and obligations. Thus the role of health care personnel has been to quickly return the individual to her/his previous healthy state at home. Health care personnel have measured the success of their care by the speed of recovery of their patients.

Chronic illnesses, on the other hand, are progressive and require longterm care. Most often the chronically ill are cared for at home. For this reason, a strict division has evolved between a highly technical hospital environment which is the precinct of health care workers and the low technology home environment where families are in control (Strauss et al, 1984).

The problems of chronic illness contrast sharply with those of acute illness. An acute illness has a period of acute disability that resolves quickly.
Chronic illness is longterm. A chronic illness has periods of progression and quiescence. It often causes decreasing independent function as disability increases. For example, heart or respiratory diseases, limit physical activity more and more over the years by decreasing strength and endurance. Arthritis limits mobility and energy because it causes years of joint stiffness and pain. Chronic neurological diseases limit usual activity by decreasing muscular coordination either temporarily and suddenly, as in epilepsy or slowly over the years as in Parkinson’s disease or multiple sclerosis. The effects of chronic illnesses often cause visible disability, and as a result, individuals with a chronic illness often feel stigmatized (Dimond & Jones, 1983). Eventually they lose contact with society as their decreasing energy levels and increasingly visible handicaps make it awkward to blend into normal social activities (Strauss et al, 1984). Finally, chronic illnesses are experienced, for the most part, at home as an ongoing part of every day life.

Health care personnel usually see chronically ill patients only when they are in hospital for acute episodes (Skelton, 1973; Strauss et al, 1984), for an acute episode unrelated to their chronic disease, or for terminal palliative care. Because of the temporary nature of most acute illnesses, the personal concerns of acutely ill individuals can be set aside during their illness. Consequently, personal concerns are not the focus of hospital care. In addition, the medically oriented structure of the hospital environment, with its emphasis on tasks associated with medical treatments, makes it difficult for nursing personnel to focus on the personal concerns of these patients.

On the other hand, because of the longterm nature of chronic illness, the personal concerns of chronically ill individuals become intertwined with their illness. In addition, medical technology is not the focus of care for the chronically ill because it cannot provide a cure. Moreover, chronically ill individuals have a long experience with their own symptoms and an awareness
of the inability of medical technology to cure their disease. It is usually the chronically ill who are experts on their illness, not the health professional. Because chronically ill individuals do not necessarily respond as predictably to treatment as acutely ill individuals, and because chronically ill individuals often have less than complete trust in the care being given, health care personnel do not obtain the same sense of success and gratification (Strauss et al, 1984) as they do from acutely ill patients.

With the chronically ill, it is not health care professionals but the family members who are the caregivers and who have a better understanding of chronically ill individuals. By virtue of living with them, the families become aware of and become involved in the problems of chronically ill individuals who continue daily life despite their symptoms. Families must accommodate their chronically ill members' fluctuating limitations, take on roles left vacant, and assume caring activities (Anderson & Bauwens, 1981; Golodetz, Evans, Heinritz & Gibson, 1969).

The caring activities which families assume are considerable if one takes into account the amount of support chronically ill individuals need to adjust to an unpleasant diagnosis, to increasing disability and to the prospect of giving up roles important to their identity (Strauss et al, 1984). For the chronically ill individual, the onset of chronic illness can provide the ingredients for a major life crisis (Westbrook & Viney, 1982). For the caregiver, giving psychological care on a day to day basis is very strenuous. Bowers (1987), for example, describes the energy that caregiving daughters invest on a day to day basis, in the "invisible" caregiving task of preserving the dignity of a mother whose dementia is progressing.

The physical care is as strenuous as the psychological care involved in dealing with the multiple daily problems experienced with a chronic disability. For example, a family must have intimate knowledge of the daily problems of
impaired mobility. Family members must become skilled at such things as lifting the cared for individual up from falls, or helping the cared for individual to a bathroom in restaurants and theatres (Equal Opportunities Commission, 1982; Strauss et al, 1984).

Caregivers are a social necessity in that they provide the ongoing home care for many chronically ill individuals. Home caregivers are usually the central emotional and instrumental resource for disabled individuals. With the increasing prevalence of chronic illness in our society, people who provide free care in the home are essential in keeping health care costs from becoming insurmountable (Evans, 1984). The significance of home caregivers as a community resource has been apparent to both health care personnel and government policy makers in Britain (Isaacs, 1971), the U.S. (Bowers, 1987; Cantor, 1983; Stephens & Christianson, 1985) and in Canada (Aronson, 1985; Chappell, Strain & Blandford, 1986). To all those concerned, it would seem that the best solution for individualized and humane care of chronically ill individuals is care at home. This assumes, however, that there is a caregiver at home willing and able to take on the caregiving role.

**Parkinson's disease**

Parkinson's disease is a chronic neurological illness. Its prevalence ranges from 23.3/100,000 people in Vancouver to 120/100,000 people in North America and Europe (Teräväinen, Forgach, Hietanen, Schulzer, Schoenberg & Calne, 1986). Figures in an American population over forty years of age may be as high as 217/100,000 for men and 267/100,000 for women (Schoenberg, Anderson, & Haerer, 1985). The disease has several major manifestations. Muscle rigidity and bradykinesia affect posture and gait, making mobility slow, difficult, and strenuous (Gibberd, 1986). Muscle rigidity and bradykinesia also affect an individual’s capacity to carry out activities of daily living by making all movements painstaking. The same symptoms affect social interaction
since they inhibit speech and facial expressiveness. A noticeable resting tremor is also characteristic of Parkinson's disease. Parkinson's disease is frequently associated with depression (Duvoisin, 1984). Furthermore, in later stages of the disease, one third or more of the population show signs of cognitive impairment (Ball, 1984; Godwin-Austen, 1984; Hornykiewicz & Kish, 1984). Duration of the disease can be from 4 to 35 years (Godwin-Austen, 1984).

Although the disability associated with the disease may tax the individual and the caregiver enough to require institutionalization, many individuals live most of the rest of their lives at home. Thus an older woman may spend years of her life caring for a husband who might become very dependent. His condition might change dramatically, and he might become very different from the person she married. The author will examine the role from the sociocultural perspective in the next section in an attempt to understand the caregiver in this circumstance.

In summary, Parkinson's disease has many characteristics in common with other chronic illnesses. It develops slowly. It eventually causes social isolation because its symptoms become increasingly visible and obstructive to social interaction. It causes disability, making the individual increasingly dependent on a caregiver to carry out daily activities. The slowly developing symptoms of Parkinson's disease affect the individual's daily life both physically and psychologically, but not enough to force the individual to enter hospital. Therefore, the effects of Parkinson's disease are usually managed at home, and family members will become increasingly involved as the disease progresses. Because many chronic illnesses cause progressive disability requiring daily care, and because the prevalence of chronic illnesses such as Parkinson's disease is rising, society ultimately will have to bear the cost of caring for disabled individuals. The present system assumes that care will be provided free in the home and that someone is willing and able to do so. With
these issues is mind, the next section will examine the literature on caregiving.

**The Caregiving Role in Society: Older Women as Caregivers**

This section will review how society assigns the role of caregiving to women - frequently to older women. This section also examines social and developmental considerations that affect older women in order to better understand the social context of the caregiving role. Finally, this section speculates on the personal meaning that caregiving may have for older women accepting society's assignment, that is, caring for their chronically ill husband.

Role theory describes the structure, context and development of social roles. Of the two major theories about social roles - structural role theory and symbolic interactionism - symbolic interactionism is more useful for this study because it considers the individual's personal meaning to be a major influence. Since the purpose of this study is to explore older women's experiences of caregiving, it makes sense to use a theory that incorporates the individual perspective to guide a literature review. If one examines the social roles that individuals assume in society from the symbolic interactionist perspective, there are two major sources of influence affecting the person carrying out a role (Hardy, 1978, p. 20). One source of influence is the behaviour of others toward the person in the role. Such behaviours reflect society's perception of the role. The other source of influence is the individual's interpretation of the internal cues of biology and enculturation, and of the external cues received from others. These influences can be further differentiated by examining the interaction of societal expectations and biological development at various stages of a person's life cycle.

This section will examine what societal and individual expectations and attitudes may influence the personal meaning that caregiving may have for
older women.

**The Tradition of Women as Caregivers**

Traditionally, caring for ill family members has been viewed as a family obligation (Aronson, 1985; Brody, 1981; Litman, 1974; Sommers, 1985; Walker, 1983). This view is reflected in social policy and in the expectations of such professional caregivers such as nurses, social workers and physicians (Aronson, 1985). Nurses teach families home care activities. Social workers assess families to determine suitable home supports. Physicians choose patients with family at home for early discharge. Entitlement to carefully rationed home support services is given only when there is no family to draw upon. Professional caregivers base their decisions on who is available to give care in the home (Aronson, 1985; Sommers, 1985). However, although family caregiving in the home is a social obligation that fulfils a social and economic need, the caregiver does not receive the social or financial rewards or the status of paid employment (Aronson, 1986; Colliere, 1986). In addition, many social policy makers do not consider the private cost to the caregiver of assuming the caregiving role (Rimmer, 1983, p.136). These costs include lost opportunities such as inability to maintain paid employment because of home commitments, and the physical and psychological burdens such as role overload and fatigue. Moreover, most caregivers have very little choice about whether or not to assume the role (Oliver, 1983).

The family obligation to care for ill family members is generally viewed in society as the obligation of the closest female relative, most commonly the wife or daughter (Sommers, 1985; Springer & Brubaker, 1984; Walker, 1983). Indeed for women, until recently, "the care and welfare of the family was their major occupation" (Sommers, 1985, p. 9). According to Brody (1981), women have continuous careers as caregivers first for their children, then for their aging parents, and then for their spouses no matter what their other activities
may be. Most caregivers have little choice about whether or not to care for ill family members. Oliver (1983) and others assert, however, that spouses have even less choice (Golodetz, Evans, Henritz & Gibson, 1969).

This section has discussed in detail how society assigns the role of caregiving to women, often older women. The next section will examine social and developmental considerations that affect the way older women might view the caregiving role.

**The Older Woman as Caregiver**

This section continues the discussion of how society views women as caregivers and how women view themselves as caregivers. Social factors affect the way society and older women themselves view the role of caregiving may be changing. For example, a growing vocal concern for the welfare of older women who are caregivers is being expressed by social organizations involved with caregivers, and feminists. Furthermore, developmental factors may also affect views of the caregiving role. Developmental theorists are pointing out significant differences in male and female patterns of aging.

**Social Factors.** The previous section has raised questions about the welfare of the caregiver. Because society expects women, particularly spouses, to be caregivers, older women are likely to feel great pressure to become their husbands’ caregivers. Furthermore, demographics reveal that she is probably the most available family member. Social organizations involved with caregivers have begun to express concern about the welfare of wives who are under great pressure to carry out the caregiving role. In Britain, the Association of Carers established in 1981, reports that wives of disabled husbands are a widely ignored group (Oliver, 1983). For example, they receive no financial support while other caregivers do. Furthermore, the government does not supply support services until the wife takes initiative to ask for help. The Association describes how governmental agencies ignore not only the
needs of the caregiving wife but the needs of a marital relationship. For example they will not provide funding for home adaptations that ensure a couple has private sleeping arrangements, or a double bed. In the U.S., the Older Womens' League has lobbied for government recognition of the problems of older caregiving spouses (Coleman, 1982). Authors such as Finch and Groves (1983) in Britain, Sommers (1985), and Coleman (1982) in the United States have also written about the problems caregiving older women similar to those described by the British, lack of respite, recognition and support.

Moreover, there are other social forces acting to shape the opinions and obligations an individual may feel in assuming the caregiving role such as attitudes and values. The attitudes and values of the feminist movement form part of the growing concern and protest about the welfare of women who are caregivers.

The feminist movement challenges unconditional acceptance of the traditional caregiving roles women have assumed. The assumption that women are unconditionally available to assume the caregiver role as necessary may no longer be valid (Brody, 1981; Finch & Groves, 1982). Older wives have assumed those roles without question (Oliver, 1983). They have, however, launched their own daughters into new social roles that conflict with traditional caregiving (Brody, 1981). One must ask whether these new attitudes have changed the older woman's expectations and perceptions of herself. We do not know how such relatively recent social values influence an older woman's perspective of her roles. We do not know how this woman perceives life accomplishments, what contributes to her respect for herself and to her sense of belonging in society or whether these issues affect the meaning an older woman assigns to her caregiving role or her desire to assume it.

Other social forces such as attitudes and values about aging women help to
shape the meaning women assign to their roles in society. At present, three groups of social attitudes and values about aging women make it difficult for older women to view themselves positively (Cohen, 1984; Faulkner, 1980; Matthews, 1979). First, in a society that values youthful women as beautiful, older women are showing undesirable signs of aging (Faulkner, 1980; Robinson, 1986). By contrast, similar signs of aging in men, such as greying hair, signal that they have reached a period of power and high status in their careers (Robinson, 1986, p.153). Second, in a society that does not value singledom, older women are reaching a time in their lives when they will likely be widowed (Faulkner, 1980, p. 59). Finally, in a society that values productivity and independence (Dimond & Jones, 1983), women and the elderly are seen as dependent and burdensome (Walker, 1983). That older women do not, or can no longer, embody the qualities valued in society, may explain in part why there is a high incidence of depression in middle aged and older women (Faulkner, 1980, p. 67). The qualities regarded as feminine in our society such as dependence and helplessness, are not useful for survival. But society expects older women to be self sufficient when they care for their husbands and when they live alone as widows. It is not surprising that studies of successful aging note that older individuals who blur their sex roles by becoming androgenous are likely to experience greater life satisfaction (Sinnott, 1986, p. 43).

**Developmental Factors.** As noted earlier, examining the developmental stages that individuals are experiencing may add to our understanding of how they view themselves in their roles. Individuals evolve through consecutive stages in their lives with each stage presenting them with another set of developmental tasks. Developmental tasks are adjustments individuals must make to adapt to social forces and biological changes they are experiencing (Ostrovski, 1979). The ease with which individuals adjust to their present stage
is a function of an individual's specific situation, age, gender, social class, and the timing of life events (Ebersole, 1979, p. 302).

Differences in male and female biology and in gender roles cause men and women to differ developmentally in later life. For example, Ebersole (1979) tells us that men, having performed masterful activities outside the home, are ready to focus on more personal interests at home, at the time of retirement. This may be the reason why some studies show that older men take on the caregiving role with less stress and resentment than women (Fitting & Rabins, 1985; Marcus & Jaeger, 1982; Zarit, Todd & Zarit, 1986). In contrast, women, because they have produced and cared for children, have generally worked in the home. By middle age, women are ready to take more active roles outside the home (Lowenthal, Thurnher, Chiriboga and Associates, 1975; Neugarten & Gutman, 1968; Zarit, Todd & Zarit, 1986). Most often these women have married older men and will live to be an average of eight years older (Robinson, 1986). Because these women will usually outlive their husbands by about eleven years, perhaps, at some level of consciousness, they may have started preparing for separation from their husband and for life as a single person. If this is true, older women may be experiencing role conflict when they are expected to take on a caring responsive role in the home once again (Brody, 1981). There may other differences in the way men and women, as a spouse, assume the role of caregiver.

Differences in work habits developed throughout their lives may cause men and women to have different views of the caregiving role. Men are likely to bring to their retirement, work habits and skills acquired in their working lives (Fitting & Rabins, 1985). Thus the male caregiver could view the caregiving role as a job that requires delegation, teamwork, and vacations, a view based on work habits and attitudes acquired in the outside world (Fitting & Rabins, 1985). While the husband may be unaccustomed to taking vacations
alone, he is accustomed to a daily routine of leaving the house to take up activities outside the home. In contrast, most women, in the caregiving role, have developed different work habits and a different model of caregiving than men. As young marriage partners, most wives would expect a husband to be responsible for his own health while she takes responsibility for their children (Litman, 1974). However, many women may use work habits and attitudes acquired through caring for a dependent child when their aging ill spouse requires care (Fitting & Rabins, 1985). This role interpretation could cause the woman to have a different view of the marital relationship and cause an older woman to have particular set of expectations for herself as caregiver. These expectations might include a perception that she is expected to be available at home twenty-four hours of the day, and that her dependent husband will act like or have the disciplinary needs of a child.

Furthermore, societal expectations influence individual interpretation of the roles that individuals fill at various stages of their lives. As Sommers (1985) states, when men choose to take on the caregiving role in this society, "it is an unexpected expression of compassion" (p. 10). Significantly men are more likely to exercise a choice in taking on the caregiving role than women because society does not expect them to be caregivers. As a result, men who assume the role probably receive much more positive feedback and support for their efforts. In fact, they do receive more formal help than caregiving women (Equal Opportunities Commission, 1982; Polanski, 1982). On the other hand, women have been caregiving all their lives as "an expected duty" (Sommers, 1985, p.10). Does yet another caregiving role create conflict or provide a vehicle for growth for a woman at this developmental stage? Although some studies show that a wife finds caregiving more burdensome and is more depressed than male caregiving spouses (Fitting & Rabins, 1985), there is little literature to indicate how an older woman herself interprets her caregiving
The speculations about older women in the caregiving role presented in this section point out the possibility that they may experience several sources of stress. They must deal with a husband who is ill and who is becoming dependent. The women must therefore shed their own dependency - a socially accepted feminine characteristic. In fact, they are expected and pressured by society to become masterful in caring for an ill, dependent husband. They are facing the prospect of becoming older women less valued in society, and the prospect of outliving their husbands - being alone, also less valued by society. Role incongruity may occur because these older women may be sacrificing their own development as outwardly focused independent individuals to remain in a responsive caregiving role in the home. They may experience role overload as they take on the caregiving role in addition to their independent activities (Sommers, 1985). On the other hand, the caregiving role may provide the opportunities and the vehicle for the very preparation these women need to assume an independent life in the future. Furthermore becoming a caregiver may or may not be an unexpected event. Stoller (1982) found in interviewing older individuals that half of them had thought about possibly being chronically disabled, but only one third had thought of strategies for coping with it. Whether the older woman expects to care for her husband or not, the changes she may encounter as caregiver may engender both gains and losses, requiring her to manage her psychological responses and learn new ways of coping. However we will not know how older woman feel about the caregiving role unless we ask them directly. For more information specifically about the experience of caregiving, the next section will examine literature about home care of chronically ill individuals.
Health Care and the Problems of Caregiving in the Home

Much of the literature on caring for chronically ill individuals in the home is written by health care professionals who work closely with caregivers. Their writings show a consensus that the caregiving role is a stressful one. The literature on caregiving can be divided into literature that prescribes strategies to assist caregivers in managing their stress and research that attempts to identify the sources of stress in the caregiving role. This section will examine this literature to identify the kind of information that may be useful to accurately describe the experience of older women caring for a husband with Parkinson's disease.

Prescriptive Strategies for Home Caregivers

There are advantages to keeping the recipient of care in the home. The chronically ill individual maintains daily contact with the family. He can stay in familiar surroundings and he will receive personal care from someone who knows him well. Governments perceive that home care is cheaper than institutional care. However, literature written by health care workers, indicates that they are concerned that caregiving in the home is hard work. Health care workers have written, mostly anecdotally, about various strategies they have used to help strained caregivers.

Health care workers such as nurses, social workers and physicians have identified caregiver needs such as a lack of information and a need for more strategies to handle stress. Health care workers have used various methods such as self-help groups (Crossman, London & Barry, 1981; Gilby, 1987; Safford, 1980), information manuals (Springer & Brubaker, 1984) and individual counselling (Farkas, 1980) to disseminate information to caregivers about diseases (Gates, 1986; Safford, 1980) and aging (Springer & Brubaker, 1984) and community resources available to assist caregivers (Springer & Brubaker, 1984). In addition, this body of literature focuses on prescriptive interventions
intended to help caregivers manage stress such as identifying helpful community resources, learning decision-making skills, building networks and learning conflict resolution skills (Springer & Brubaker, 1984).

However, these writings have been anecdotal and prescriptive and have not shown evidence of formal evaluation of their effectiveness. The interventions could have been application of ready-made solutions that were common in the seventies when there was popular emphasis on stress management in many areas of health care and business. Health care workers could have been responding to the distress they perceived in home caregivers with whatever they had available: some knowledge about the various diseases and techniques of stress management.

**Research on Home Caregivers**

Research on caregiving began to appear in the early seventies. It dealt primarily with caring for mentally ill family members at home (Thompson & Doll, 1982). Then a body of literature developed about home care of handicapped children (Wright, 1983). More recently, literature has been accumulating about caring for the elderly and the chronically ill. This section will focus on the latter.

Researchers have described the caregiving role as physically and emotionally strenuous. In fact, the burden of caregiving has been the focus in the literature on caregiving in the home. Caregiver burden has been defined in many ways, but most often it is associated with accumulation of stress (Ory, 1985; Poulshock & Deimling, 1984; Robinson, 1983). Several studies have examined various populations of caregivers using interviews to identify what the stresses were and scales to measure the hypothesized impact of stresses such as depression and reduced quality of life.

Golodetz, Evans, Heinritz & Gibson (1969) working as a multidisciplinary home-care team, interviewed 59 caregivers who lived with and cared for
chronically ill individuals, in the inner city of Boston. Forty-nine of the caregivers were women; thirty-three were spouses; and seventy-five percent were over sixty years of age. Golodetz and associates concluded that these caregivers were in poor health, stressed and overwhelmed by their duties.

Robinson and Thurner (1979) identified ten stressors inductively from three open-ended interviews with adult children caring for elderly spouses conducted over a period of five years. From their research, Robinson and Thurner listed ten causes of subjective stress in caregivers which generally encompass the observations of other researchers: inconvenience, restriction of caregiver personal activities, family adjustments, changes in personal plans, conflicting demands on time, emotional adjustments, upsetting patient behaviour, upsetting behaviour changes in the patient, necessary changes in employment, and feelings of being overwhelmed.

Robinson (1983) used this list of stressors to construct and validate a thirteen item caregiver strain questionnaire. Robinson studied 85 caregivers identified by patients who had been discharged two months earlier from an acute hospital admission for arteriosclerotic heart disease or hip surgery (fracture or total hip replacement). Thirty-eight percent were spouses; twenty-eight percent were daughters; the rest were sons, other relatives, neighbours and friends. The age range was 22-83 years. Robinson used scales to measure affect and mood state in the caregiver, and scales to measure mental status in the expatients. Robinson also asked caregivers to rate the expatient’s abilities in activities in daily living and to rate their own health status. Robinson concluded that the scale was valid as an indicator of a greater level of stress. No significant differences in caregiver burden were found between sexes, between relationships, between living with or apart from the expatient or between different perceived states of health. These results indicate either that the scale may not be sensitive enough to identify the population
most in need of help or that most caregiving situations are equally stressful.

Much of the research has tried to document the sources of caregiver stress in an effort to find an effective point of intervention. Stress has been related to the disabled individual's decreasing abilities. Specifically these were the decreasing ability to carry out activities of daily living, (Cantor, 1983; Poulshock & Deimling, 1984; Robinson, 1983; ), decreasing level of cognitive function (Poulshock & Deimling, 1984; Robinson, 1983), and changes in social behaviour (Poulshock & Deimling, 1984) such as disruptive or embarrassing behaviour (Poulshock & Deimling, 1984; Robinson, 1983; Thompson & Doll, 1982), and social disengagement (Rohs, 1986).

More recently, researchers have focused on caregiving relationships, confirming that though husbands, sons, and friends do assume a caregiving role, most caregivers are women, wives or daughters (Brody, 1981; Isaacs, 1971; Kinsella & Duffy, 1979; Springer & Brubaker, 1984; Walker, 1983). In examining caregiver relationships Cantor (1983) found that caregiving in the spousal relationship while living in the same house was the most stressful of all caregiving relationships.

Cantor (1983) interviewed 111 caregivers of frail elderly individuals with marginal income, at the beginning and end of 12 weeks of service from a homemaking agency in New York. About half of the population were newly discharged from hospital after an acute myocardial infarction or hip surgery. The remainder requested homemaking service because of gradual deterioration. Thirty seven of the 111 caregivers were spouses; slightly over half of them were male. Cantor asked about the quality of their relationship with their spouses, about worry and strain and about the impact of caregiving on eight (not listed) areas of private life. The study found that the closer the bond, the more stressful the caregiving role in all areas of private life. Cantor identified spouses as the caregivers who were the most at risk for severe stress.
Fengler and Goodrich (1979) evaluated the effect of husbands’ disability on caregiving wives in New Hampshire, U.S. by studying men referred to a volunteer workshop. Having determined from a literature review that perceived health and financial status were major predictors of life satisfaction, Fengler and Good used scales to measure life satisfaction, social and health indicators in the wives and their husbands, three times at two month intervals. The scores were averaged and ranked from low to high life satisfaction (LS). Low LS in one spouse was echoed in the other spouse. Health status and mobility did not differ significantly in couples with either high LS scores or low LS scores. Wives with high LS scores reported much more contact with supporters, helper and friends than wives with low LS scores. Couples with aphasic spouses all had low life satisfaction scores. Wives with high LS scores were much more likely to mention their husband as confidant than wives with low LS scores. The researchers concluded that communication between husband and wife was important to a caregiver’s life satisfaction. Maintainance of social support was also important.

Kinsella and Duffy (1979) studied the spouses of 79 aphasic stroke patients from rehabilitation centers in London, England. Seventy percent of the spouses were wives between 55 and 74 years of age. They were identified as middle and upper working class families. The researcher used a social adjustment scale, a general health scale, and a depression inventory. They found that aphasia created a significant impact on the relationship. Wives felt a loss of partnership, loss of social and leisure activities, friendships with others and support. This study indicates that caregiving wives were coping with significant losses when their spouses could not communicate easily with them and others.

Fitting, Rabins, Lucas and Eastham (1986) compared male and female spousal caregivers of persons with dementia. The study population was over
50 years of age, well-educated and middle class and it excluded caregivers who were considered to be overwhelmed with caregiving. Twenty-eight men, an average of 70.5 years of age, and twenty-six women, an average of 65 years of age, were studied. Researchers gathered data using a family environmental scale, the Minnesota Multiphasic Personality Inventory, Zarit's Burden Interview, and a scale of functional impairment. Caregivers were given three open-ended questions which asked the participant describe his/her caregiving experience. Researchers concluded that both sexes experience similar degrees of burden, but the women reported more depressive symptoms. However, these researchers noted that these results reflect the higher incidence of depression in the female population as a whole.

Marcus and Jaeger (1982) produced similar findings. They studied 47 subjects in Montreal, Canada. Using the ethnographic approach and the Zarit Burden Interview, they obtained demographic information, and the caregivers' ratings of their own and the cared for persons' health. They found that despite receiving more help and using confidantes more, sixty-three percent of the wives and other women showed high burden scores compared to thirty-one percent of the men. Eighty-three percent of the women had been caregivers for more than ten years compared to sixty-six percent of the husbands. Marcus and Jaeger noted that caregivers who gave very personal physical care rarely reported that they found companionship in the caregiving relationship. In addition, Marcus and Jaeger found that the women, wives and others, were more likely to deny fears and were more unwilling to think about the future than the men. Marcus and Jaeger concluded that several areas needed further study: the striking differences between husbands and wives who were caregivers, the changes in relationships because one was caregiver, and the effect of ongoing restrictions on the lives of caregivers. They noted that subjective perceptions rather than situational factors might have greater
impact on caregiver’s life experiences.

Zarit, Todd and Zarit (1986) however, found that caregiving older women experienced more burden than older caregiving men only in the early stages of a spouse’s illness (p. 265). They noted that men and women experienced different difficulties in areas in which they had previously depended on their spouse. In that study, the women were on average younger than the male comparison group. Other studies have not made such specific age distinctions (Fitting, Rabins, Lucas and Eastham, 1986) as this study but they also hint that the developmental stage of older women may have an impact on caregiver stress. This study indicates that older women experience different stresses than men and that more research is needed to understand the exact nature of these stresses.

Researchers have not yet linked objective measures of stress with the subjective experience of stress. Poulshock and Deimling (1984) contend that caregiver stress is a complex subjective phenomenon that requires further research. They reviewed the literature extensively and noted that the experience of burden did not correlate significantly with objective factors such as the number of symptoms, or the duration of caregiving. As a result they concluded that the burdens caregivers perceived were “the result of their highly personal and individualized responses to specific caregiving contexts” (p.231) and were a mediating influence between the impairment of the cared for person and the impact caregiving had on the life of the caregiver. This study clearly indicated there is a need to research the exact nature of what individuals caregivers find stressful.

The studies reviewed revealed that caregiving is a complex experience. Objective measures of stress may assist health care professionals to identify high risk populations of caregivers, caregivers needing intervention and factors which particularly might be causing the stress. However knowledge
about the subjective experience of stress may be more useful to develop the understanding needed to devise therapeutic interventions. The subjective experience of caregiving is significant to each caregiver and it is to these individual experiences and to each individual's distress that nurses must respond.

**How Home Caregivers Interpret their Situation**

Less research has addressed how individual caregivers interpret their situation, but studies to help health care workers understand individuals' experiences with caregiving are beginning to accumulate. Studying the experience of caregiving from the individual's perspective is likely the best way to understand the problems of caregivers and to develop effective interventions. To understand how individual caregiving situations and their meanings vary requires knowledge of what it means to experience a certain life stage, what it means to experience a particular disease, including what it means to live in society with that disease, and what it means to experience caregiving with that disease. With such knowledge, different conceptualizations about the experience of chronic illness and caregiving can be developed. Several studies do examine the experience of various chronic illnesses but the author has located none examining the experience of Parkinson's disease. This section will discuss these studies in detail because they reveal important information about the meaning caregivers attribute to different aspects of their situations and the motivations guiding their behaviour.

In a qualitative study, Bury (1982) identified how young chronically ill individuals with rheumatoid arthritis handled the effects of their disease. These individuals carried on, well aware of the limits of medical knowledge and professional help. They and their families continually adapted to the limitations that the illness produced in their lives while they attempted to
maintain normality in their lives. According to Bury, these individuals continually reworked their identity and their coping strategies as it became more difficult to "keep up," as normally functioning individuals. Bury concluded from his study that the chronic illness, rheumatoid arthritis, was managed by these individuals, as a biographical disruption. These individuals handled their disease by managing its ongoing interference with their lives as normal individuals.

Issues faced by chronically ill individuals must also have an impact on the perceptions and behaviour of their caregivers. Indeed Strauss and associates (1984) found in their study of various chronically ill individuals and their families, that caregivers also developed strategies to assist the ill individual to maintain a sense of normality and identity. For example, Bowers (1987) found that adult female children, in caring for their moderately impaired elderly parent, developed elaborate plans to protect the dignity and self respect of their parent. These caregiving tasks took significant time and energy.

Understanding how chronically ill individuals experience their illness provides important insight into how they and their caregivers manage its effects. Different diseases cause different limitations. Therefore patient's management strategies and family member's caregiving tasks can vary even though they are working toward the same goals - a normal lifestyle, for example. In Bury's study, individuals managed the effect of pain and low energy so that they could lead normal lives. Chenitz (1986) studied emphysema patients and discovered that the central organizing factor in their lives was the fact that they had to budget their breath and their energy to complete their normal daily activities. Roth (1963) studied how individuals with tuberculosis managed the major impact of their disease - the enforced period of time spent out of normal society - by dividing the time into
recognizable benchmarks - a timetable to gauge the progress toward a return to normal society. By using the phenomenological method of inquiry into the subjective experience of angina, Kent (1985) was able to describe specifically how individuals interpreted and incorporated their experiences of managing their angina into their normal lives.

Finally, some illuminating research exists on how chronically ill individuals and their caregivers maintain normal family and particularly spousal relationships in spite of the stresses which chronic illnesses impose. Corbin and Strauss (1984) examined how sixty couples managed when one spouse had heart disease. They found that couples developed collaborative coping strategies. Specific issues emerged as important to family harmony and efficiency. Couples who had collaborated, and had developed mutual perceptions of the duration and trajectory of the illness, helped each other manage the impact of the illness on each other's lives.

However, while the literature does contain some excellent personal accounts of the experience of Parkinson's disease (Dorros, 1981; Holman, 1985) and a few guides, written by physicians, for handling Parkinson's disease as a patient (Duvoisin, 1984; Godwin-Austin, 1984), the author has not located qualitative research on the experience of Parkinson's disease itself or the experience of caring for someone with Parkinson's disease.

This section has reviewed the literature on caregiving. It has examined literature that prescribes strategies to manage the stresses of caregiving and it has examined research attempting to isolate and relate factors causing stress in caregiving. The major conclusion from this literature review is that the stress of caregiving is subjectively determined. With this in mind, the author has examined literature on how caregivers dealing with Parkinson's disease might interpret their situation. No studies about caring for victims of Parkinson's disease were found but there were related studies of caregiving of individuals
with other diseases. The information these studies supplied indicated the value of understanding the effects of a specific disease on caregiving relationships. The author concludes that studying the experience of older women caring for spouses with Parkinson's disease will yield the kind of specific knowledge that will be useful to nurses in planning the particular kind of care that may be needed for this clientele.

Summary

This chapter has reviewed literature about chronic illness, Parkinson's disease as a chronic illness, the importance of caregivers to the chronically ill and society, and the experience of caregiving, in order to provide a background to the research question, "What is the experience as a older woman of caring for husband with Parkinson's disease?"

The literature shows that there are increasing numbers of chronically ill individuals, including those with Parkinson's disease who require the help of a caregiver in the home. This epidemiological trend indicates that home caregivers are becoming increasingly important as a social and economic resource. Most individuals with disabling chronic illnesses are cared for in their homes, usually by women. Parkinson's disease usually occurs in older individuals so home caregivers are likely to be in their sixties or seventies.

The chapter then examined the literature on how society assigned the caregiving role and literature on how caregivers might respond to the role. The literature indicated that women of all ages were assigned caregiving roles throughout their lives. Women cared for young children as young adults, for aging parents as middle-aged adults, and for spouses as older adults. The literature indicated that the experience of caregiving, particularly for older women, may have many negative implications in our society. The author concluded that these speculations would best be validated by the women
themselves.

Examination of the literature on the experience of home caregiving revealed that from the observations of health care professionals and researchers, caregiving is a stressful role. Research to the present has identified caregiving as stressful and burdensome. Attempts have been made to explore caregiver perceptions: the nature of the stresses of the caregiving role and the work of the role. Attempts have been made to relate objective and subjective factors isolated from caregiving situations. The author has concluded, along with other authors, that caregiver stress is individually determined.

Studies are beginning to accumulate on how individuals interpret their illness and how caregivers interpret their particular role. Most successfully, the qualitative research perspective has revealed the importance of seeking an understanding of the caregiving role from the caregiver's perspective in order to discover exactly how and when caregiving was stressful, to know how caregiving strategies evolved and why such knowledge is necessary, in order to allow health care personnel to align their purposes with family caregivers more effectively. No studies were found that described the experience of caring for someone with Parkinson's disease. This study of the experience of older women caring for husbands with Parkinson's disease is designed to add to the literature describing specific caregiving relationships in relation to specific diseases.
CHAPTER THREE
METHODOLOGY

The phenomenological research paradigm was used to study the experience of older women caring for husbands with Parkinson's disease. Because phenomenology is concerned with understanding human experience as it is lived, data are collected in the natural setting from individuals who can share their first hand knowledge. Therefore, the researcher must set aside theories and preconceptions in order to understand the perceptions of the person experiencing the phenomenon (Knaack, 1984). For the data to be valid, the study participants must actually be experiencing the phenomenon and they must understand that the researcher is seeking information about the participants' experience as it is truly lived. If they are to be candid in their accounts, study participants must feel that their experience is as important as the experience of others and that their accounts will be treated with respect and confidentiality. Finally, steps must be taken to ensure that interpretations of the data remain grounded in the participants' accounts, so that study results are a valid representation of the phenomenon as it is lived.

Chapter Three will describe how the researcher conducted this phenomenological study. It will discuss sampling, data collection, data analysis and methods of determining validity and reliability.
Sampling

When research of this nature is conducted, participants are viewed as knowledgeable informants who discuss their experiences with the researcher, clarifying data and verifying the researcher's ongoing analysis (Knaack, 1984). The subject is a participant, who is aware of the intent of the study, and who contributes on an equal basis with the researcher. To be valid sources of data, participants must recognize that they are experiencing the phenomenon under study and be willing and able to communicate their experiences to the researcher. Study participants are purposely selected for their ability to articulate the experience under study (Schwartz & Jacobs, 1979). Accordingly, study participants were selected when they met the following criteria:

1. Participants over the age of 50, were selected if they identified themselves to be caregiving spouses who had been caring for husbands with Parkinson's disease, in their own homes for several years.

2. Participants had to be able to speak English fluently in order to communicate their thoughts and feelings about their caregiving experience to the researcher.

3. Participants had to be accessible to the researcher in the Victoria or Vancouver metropolitan areas.

4. Participants had to freely choose to share their experience.

Selection Procedure

Potential study participants were recruited from the practice of a neurologist (letter Appendix 1). Thirty Letters of Information describing the study and the nature of participation requested, were sent to these women
under the physician's letterhead (Appendix 2). The women were asked to contact the investigator by telephone if they were interested in participating.

When potential participants contacted the researcher, they were given further information if they requested it. The researcher verified that the respondent met the selection criteria, and set an initial appointment, usually in the participant's home.

At the first interview, the researcher explained the study and the reason for recording interviews in more detail, answering questions until the participant seemed satisfied. The participant was then asked to read and sign a prepared consent (Appendix 3).

**Description of the Respondents**

There were nine responses to the thirty letters sent. Over the period of the following month, eight responded by telephone. The eighth respondent declined to participate saying that her husband had been diagnosed only three years ago; that they were closer than ever since retirement; that they were not yet experiencing serious effects from the disease; and that they did not want to think about the disease as yet. The ninth respondent lived outside the research area but had been contacted in the hopes that she might be in the area for an appointment for her husband. She responded regretfully three months later saying the trip had been postponed but asked if she could reply to questions in writing. She was not included in the study because the research method relies on interactive dialogue between study participants and the researcher.

Seven subjects finally participated in the study. They reported duration of the illness to be 9, 10, 12, 15, 20, 20, and 38 years. Many caregivers reported
duration from the time that they noticed onset of the symptoms, rather than diagnosis. Although manifestations of the disease varied, all spouses experienced muscle rigidity daily. All but one spouse experienced "freezes" daily, that is, periods of time when a husband would be incapacitated by his symptoms. To control their symptoms all spouses took one or more antiparkinsonian medications. All spouses required some degree of assistance and supervision in their everyday lives. One spouse required continuous supervision. Three spouses could be left alone not more two hours and three could be left alone for three or four hours.

By the time of the study, all participant's husbands had retired and now spent the majority of their time at home. The spouses ranged in age from 64 to 74 years of age. They had worked at a variety of occupations: book publisher, bank manager, executive, sales manager, construction manager, travelling salesman, and church minister. All had supported wives and families during their working lives. All had owned houses. All but one couple were financially comfortable.

All caregiver spouses were Caucasian and at least second generation Canadian. Before marriage they had worked and/or had had some career plans. One spouse was a teacher and two were nurses. One had planned to study journalism. Another spouse had business secretarial training; another was a hairdresser; and the last spouse had been a clerk. All participants had chosen to put their husbands and families first in their lives. All participants had raised from two to five children; one participant still had one child living at home. All the wives now spent the majority of their time at home. Only one wife continued in part-time employment. Each of these wives had lived with their husbands since the disease had begun.
The participants were aged 51, 62, 63, 66, 67, 70, and 72 years. Current calculations by demographers indicate that in British Columbia, males die at an average age of 71.5 years (Peron and Strohmenger, 1985). Based on the marriage norms for this cohort, the wife is usually five years younger than her husband (Peron and Strohmenger, 1985). On the average, she will be age 66 if she survives her husband. Therefore, if she is his caregiver before his death, she will begin caring before she is 65. In fact she could begin caregiving as early as age 52 since demographers have computed that men are likely to begin experiencing disablity around age 57. Based on these figures, the age spread of this group of older women, did mirror the societal patterns.

All but two participants had been married for twenty to forty years. One of the others had been married to her second husband for fifteen years. The other was a caregiver in her first 35 year marriage. She had now lived with and cared for another partner for nine years. Because this woman considered herself a spousal caregiver, the researcher decided to include her in the study. For the rest of the study, this woman will be referred to as caregiving wife along with the other study participants.

Most of the women gave similar reasons for participating in the study: they were anxious to tell their story; they wanted to hear the stories of others; and they wanted to learn from others to see if it would “lighten the load a little”.

The size of the study sample in phenomenological research is usually small because of the intensive nature of data collection. In addition, this study sample was small because the data elicited was rich and because the researcher’s time and resources were limited.
Ethics and Human Rights

A study such as this involves face to face contact between study participants and the researcher. The type of data elicited is of a personal nature. One wants to take precautions to ensure that participants do not feel coerced to participate, that they feel free to withdraw, and that they feel unharmed. Accordingly, ethical considerations were addressed through the following provisions:

1. Participation was voluntary with written consent (Appendix 3).

2. All potential participants were informed in writing (Appendix 2 and 3) that refusal to participate or withdrawal at any time would in no way jeopardize any of their own or their spouse's health care.

3. Prior to consenting, participants received a description of the study and an explanation of their role in it.

4. Prior to each interview, the participant was reminded that she was unconditionally free to withdraw at any time or to refuse to answer any question without any jeopardy to her own and her family's health care.

5. Confidentiality was maintained. Only the interviewer knew the identity of the participants. After all studies of the data are completed, the tapes will be erased.

7. The role of the researcher was explained. However, the researcher was prepared to refer a caregiver (with her knowledge) to appropriate healthcare personnel, if it appeared that a participant required professional assistance. This was not necessary in the course of the study.

8. The benefits to the participant were the opportunity to contribute to nursing knowledge (Hayes & Knox, 1983) and possibly the cathartic benefit of telling her story.
9. Finally, participants were offered a summary of study results if they were interested.

Data Collection

The role of the researcher in phenomenological methodology is to enter the phenomena being studied, recognizing that the researcher's bias becomes part of the interactive process of data collection (Oiler, 1982). However, the researcher must discipline her bias to promote collegial exploration of the participant's caregiving experience. Data was collected in two intensive interviews. The researcher began each initial interview by asking two sensitizing questions formulated to set aside the researchers bias and leave the participant to be the expert (Appendix 4). The researcher then followed the participant's lead in the interview, encouraged free expression of thoughts and feelings but clarified her perceptions of the points the participant was making. The data were analyzed concurrently with data collection so the researcher could validate her perceptions and pursue analytical hypotheses with the study participants in each subsequent interview.

Subsequent interview questions clarified the interviewer's perceptions. For example, one caregiver wife reported that for twenty years they had not wanted to use medication. This contradicted the part of her account in which she related how diligent and patient they had been about visiting and following their physician's instructions. A further question revealed that this behaviour was prompted by a well thought-out decision. After a few trials with drugs, they had told their physician that, for their lifestyle, tolerating the symptoms was preferable to the side effects of the drugs.

Setting the study participant at ease in each interview involved
overcoming some barriers such as having the interview audiotaped and trusting a stranger to hear their thoughts and feelings. After some initial self-consciousness about the tape recorder, study participants settled into the interview without visible discomfort. Participants were reminded at the beginning of each interview that the contents of the interviews were confidential and that all references to the data obtained would maintain their anonymity.

The interviews were conducted at the participants' homes, although the participants were given the option of choosing alternate arrangements if they wished. Only one participant chose that option. She asked to come to the interviewer's apartment for both interviews because she did not feel she could speak freely with her husband in the house. All other participants' husbands were present in the house during at least one of the interviews. Several husbands wanted to meet the researcher. Other husbands were busy with some activity and left their wives free for the interviews. To the researcher's knowledge, no husband actively avoided meeting the researcher or objected to his wife's participation.

The interviews each lasted one to one and one half hours. The first interviews were longer, lasting an average of ninety minutes and were conducted over a period of two weeks. Field notes were made immediately after each interview, giving some detail about the circumstances of the interview and the researcher's reactions. In this study all first interviews were concluded before the second round was begun. The second interviews lasted an average of one hour. They were conducted four weeks later over a period of two weeks.

There were four sources of data for this study. Most of the data came
from verbatim transcriptions of the audiotaped interviews and from field notes of the researcher's perceptions during the interviews. A small amount of data also came from telephone calls with respondents and participants and from a followup telephone call to one participant to validate interview data.

In summary, data were collected primarily through intensive interviews. The researcher used various strategies to enhance the validity of the data and promote the comfort of the study participants.

Data Analysis

Phenomenological research aims to understand the subjects' experiences from the data elicited during interviews, both the verbal data supplied by the participants and data supplied by the perceptions of the researcher. The researcher validates her perceptions with the study participants and continually tests her analytical hypotheses against the data obtained. Interpretive understanding is inferred in data analysis by comparing the accounts of the participants (Sandelowski, 1986). Lynam and Anderson (1986) assert that the essence of the phenomenological method is "the subjective construction of meaning within the context of an interpersonal encounter" between the researcher and each study participant. Phenomenological research, then, produces an intersubjective description of the phenomenon under study. This section will outline the process of data analysis in this study.

The following points will illustrate the point of view from which the researcher was working. This study was conducted because the researcher experienced a need for a greater understanding of how older women found meaning in their lives. The researcher therefore resolved to study the day to
day experience of older women encountering a phenomenon common to many of them - caring for an aging husband with a chronic illness - in an attempt to understand how these women derived meaning from these circumstances. The literature review in Chapter Two describes and develops many of the views the researcher has about chronic illness, older women and caregiving – that is, that all these phenomena have many negative implications for individuals who experience them in this society.

In phenomenological research, analysis is conducted concurrently with data collection. Accordingly, the researcher began analysis immediately after the first interview with the first participant. The researcher transcribed the interviews verbatim. The researcher then examined each account to identify all shifts in the topic of discussion or the perspective from which a topic was discussed (Giorgi, 1975). This type of analysis produced a list of topics or meaning units (Giorgi, 1975) that study participants raised. Many of the topics common to the study participants’ descriptions could be grouped into categories such as changes in the husband due to the disease, the initial story of diagnosis, and the marital relationship. Some topics were not common to all participant's descriptions but they seemed to describe important facets of caregiving. These were topics such as the future scenario, and realization by the caregiver that she was totally in charge. These topics became questions to ask participants, who had not mentioned them, in the second interviews.

Six categories of topics seemed to be relevant in describing the nature of the caregiving experience. These categories are listed below:

1. the history of the relationship - roles and satisfactions
2. communication - established patterns, problems
3. how the spouse handled the disease - ability to admit vulnerability/ability
to let go of roles/sense of responsibility for caregiver's welfare.
4. caregiver's understanding of the husband's behaviour
5. caregiver's sense of mutuality in her relationship - a result of the husband's behaviour
6. caregiver's sense of her life, herself - feelings of competence, willingness to work with disease, guilt, anger.

Eventually the researcher found that these topics fit into three themes. The topics were related to either the disease, the marriage and the caregiver herself.

Furthermore, the themes the participants had talked about began to reveal patterns consistent in each account. For example, the researcher noted that, for the study participants, caregiving seemed to have a beginning, an ongoing course and an end, and the course of the illness often shaped the caregiving tasks. Moreover, the marriages seemed to be changing over the course of caregiving and the wives, themselves, seemed to be changing over the course of caregiving.

The second interviews validated the emerging themes and patterns. Although several wives reported reactions to reliving their stories so vividly for the initial interview, their trust seemed to have grown. Most wives reported more personal details than they had in the first interview. While the first round of interviews concentrated on the illness and caregiving itself the second interviews focussed more on the context of the caregiving experience—the marriage and the rest of their lives. Every woman spoke at length about her relationship in the second interview. The researcher was impressed by the range in quality of couple interaction these women reported. Their accounts validated the pattern the researcher had observed, that marriages were changing over the course of caregiving.
In addition, most women described how their husbands’ handicaps affected them both personally and socially. Each woman included descriptions about the effects of the disease on the social and relationship abilities of their husbands, on their marriages and on themselves. It appeared that the caregivers’ views of themselves and of their circumstances were also changing over the course of caregiving.

The fact that the women were managing their negative feelings about caregiving the best they could deterred the researcher from exploring these feelings overtly for fear of precipitating a crisis. The researcher arrived at this decision after one participant reported a backlash of feeling from being so candid in the first interview. “I had quite a time there for a week. I was mad at the disease. I was mad at him. Why am I making a slave of myself to this particular cause?” Although the researcher had questions about guilt and anger particularly, enough participants raised the topics themselves that these questions were partially answered. However these facets could be examined in more detail in a future study.

How were the emerging patterns and themes linked? Were the patterns common to each account? To answer these questions, the researcher mapped out each account on several continuous sheets of computer paper following three timelines: the course of the disease in the husband as described by the caregiver, the course of the marriage, and the progress of the caregiver’s own life.

From plotting these timelines the researcher realized that caregivers were talking about four themes over the course of a caregiving career and these themes arose in different patterns that shaped the caregiving career. “The initial diagnosis story”, “living with the illness”, “realization that she was in
charge”, and “changes in the relationship” were what the researcher came to view as consistent themes in their accounts. Further analysis determined that the “story of diagnosis” did not have the same profound life altering qualities of the other themes but fit into caregiver thoughts about “living with the illness.” Eventually the researcher named the three themes phases because phases seemed to describe most accurately the effect of time and the development of the three main themes of caregiving. Ultimately the phases were called coping with the disease, taking over roles, and separating life paths.

Eventually the researcher realized that the categories of six topics describing the nature of caregiving were actually three categories of perceptions that the caregivers held about their caregiving experience: perceptions related to the illness, perceptions related to the marriage, and perceptions the caregiver held of herself. The perceptions each caregiver held about each phase of her caregiving career gave each phase a unique, personal meaning. This conceptual framework related the elements of participants’ individual descriptions into a composite description of the experience of caring for a husband with Parkinson’s disease while still accounting for variations in the data.

**Validity and Reliability**

Every research study must address issues of validity and reliability. For validity, research of this nature must remain grounded in the informants’ accounts. For reliability, consumers of this research must be able to understand how the researcher arrived at the conclusions presented. Sandelowski (1986) maintains that like quantitative methods, qualitative research methods have their own rules about aims, evidence, inference and verification, but there are no clearly established rules for demonstrating rigor. Moreover, quantitative
measures of rigor do not apply in qualitative research. Accordingly, Sandelowksi advances four concepts through which rigor may be addressed for this type of research: credibility, applicability, auditability and confirmability. Three of the concepts will be discussed in relation to the study at hand. Confirmability is achieved when the others are achieved.

**Credibility**

In qualitative research, where the findings are the subjective experience as lived, credibility comes from proof that the research is faithful to the subjects' descriptions. In these studies, the researcher describes as accurately as possible the process of data collection and analysis.

Two questions that test internal validity or credibility are “Would study participants immediately recognize the analyzed research results as true to their story?” and “Would individuals reading the research report be able to recognize the phenomenon solely from having read about it?” (Sandelowski, 1986, p.). Both these questions remain to be answered when the researcher summarizes the study for the participants and presents the results to colleagues. Informal reports from colleagues have been positive.

One threat to credibility is that the researcher runs the risk of becoming too involved to be able to interpret the phenomenon in a meaningful way. The researcher countered this risk by using literature and discussion with her committee and others to expand her views and find outside validation of the issues being discussed.

**Applicability or External Validity**

In qualitative research every subject of the study population is regarded as a unique source of an equally representative perception of the phenomenon
under study. Samples are small because the time is taken to elicit a great depth of detail. Applicability of the study findings derives from the ability of the findings to fit other situations; whether the findings are useful or fitting information for others; and whether the findings do actually represent the data from which they have come (Sandelowski, 1986).

To test the applicability of the study findings, the researcher presented her analytic framework to a social worker who worked intensively with caregivers many of them older women caring for spouses with Parkinson's disease. The social worker validated the findings. In addition, a group of nurses who assessed care in homes conveyed excitement that the study described problems and seemed to validate their perceptions of the caregiving situations they encountered.

Sandelowski (1986) identifies two threats to external validity. First, the researcher may obtain rich complete accounts only from the most articulate and accessible participants, possibly missing many dimensions of the phenomenon that other individuals may experience. The researcher found some study participants to be more explicit about the effects of their experiences than others. The researcher was aware that participants expressing strongly negative emotions and strongly positive emotions influenced the direction of the analysis. Continual comparison among all accounts about each of the elements identified helped this tendency. However the researcher has included this threat to validity in the limitations of the study (Chapter One, p. 6).

The second threat to external validity is the possibility that the researcher presents the data as a more complete description than it really is. The researcher offset this possibility by encouraging study participants to tell their
story from their own points of view; by following their leads in identifying important elements through analysis; and by validating hypotheses and conclusions as much as possible within time constraints. In attempting to account for typical and atypical elements of the data, the researcher felt the study sample was too small to show all the possibilities of caregiving situations. Further theoretical sampling would have remedied the problem. A further larger study is indicated.

**Auditability**

The validity of a study is enhanced when another researcher following a similar analytical decision path, obtains similar results. In qualitative research the repeatability of a study is difficult to determine when the method emphasizes the uniqueness of individual situations, emphasizes the intersubjective construction of experience between the researcher and promotes analysis by examining variations of the experience. Therefore to ensure some possibility of repeatability, the researcher must be open about her biases and describe the basis of her decisions throughout the research process. In this way the research procedure becomes auditable.

This thesis attempts to describe as completely and succinctly as possible the process by which this research was conducted. Chapters Three and Four contain sections explaining decisionmaking throughout the process of setting the research question, data collection, and data analysis. Chapter Four will present the findings using representative examples from the data itself.

**Summary**

This chapter has discussed the process by which this phenomenological study was conducted. The chapter has described sampling procedures, has
described data collection procedures in detail, has explained the methods of data analysis used and has discussed issues of validity and reliability. The next chapter will present the findings derived from the process this chapter has discussed.

To summarize to this point in the thesis, Chapters One and Two have introduced the study and have provided a background to the problem which is: what is the experience of older women who care for spouses with Parkinson's disease. Chapter Three has described in detail how, using phenomenological research methodology, the study was constructed, how the data was collected and how the data was analyzed. Chapter Four will present the results of data analysis describing the development of an analytical framework, discussing the findings in terms of the analytical framework, and interpreting the findings.
CHAPTER FOUR
PRESENTATION OF FINDINGS

Development of an Analytical Framework

The aim of this study was to understand the subjective experience of older women caring for a spouse with Parkinson's disease. Therefore the study findings describe the participants' collective experience as the researcher understood it. Using the phenomenological research method, the researcher developed that understanding from discussing with participants the perceptions that made up each participant's unique experience of caregiving. In consultation with the study participants, the researcher then developed a composite descriptive analysis that incorporated the various perceptions of individual study participants into an analytical framework.

The purpose of data collection and analysis, then, was to elicit the perceptions of caregivers and to identify patterns among them. Accordingly, the researcher asked caregivers to tell their stories about what caregiving was like and how the caregiving situation had developed. In telling their stories, the caregivers reported perceptions that fell into three categories: perceptions about the illness, perceptions about the marriage and perceptions about themselves. It became evident that the women's perceptions in each of the three categories evolved as the disease progressed.

Perceptions of the illness evolved as the Parkinson's disease advanced causing increasing disability. Early in the illness, wives described perceptions of their husbands' loss of physical and psychological independence. Later in the illness, the wives perceived that, due to their illness, their husbands were losing competence in carrying out their roles at work and at home. As their lives became more and more handicapped by the disease, the wives perceived that their husbands were becoming less and less involved in interpersonal
relationships, socially and in their own marriage relationship.

Perceptions of the marriage also changed as the Parkinson's disease progressed. Early in the illness, the wives described their commitment and their husbands' commitment to dealing together with the disease. Later in the disease, the wives perceived a power shift in the relationship as they took over roles their husbands could no longer fulfil. When the husbands were significantly handicapped, the wives perceived that their life paths were separating from their husbands’.

Finally, the wives' perceptions of themselves changed as the Parkinson's disease progressed. Early in the illness the wives talked of adapting to and coping with the changes that the Parkinson's disease was causing in their husbands. Later in the illness, the wives talked about the challenges of taking over their husbands' roles. As their husbands became increasingly handicapped, the wives talked about how consuming the role of caregiving had been and about taking up their own lives again alone.

It became evident that the wives' perceptions evolved in a consistent pattern. That is, three shifts in their perceptions occurred consistently in all three categories. These shifts represented three distinct phases of what the researcher called the caregiving career. The phases were clearly distinguished as coping with the illness, taking over, and separating life paths. Each wife found each phase a unique experience because of her personal perceptions of her husband's illness, her marriage, and herself (See Figure 1).

The following discussion will present the findings of the study in terms of the three phases of the caregivers' experience. Quotations and anecdotes representative of the data will be used to support the analysis presented.

**Coping with the Illness**

During this phase, the wife began coping with the effects of the illness as
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Figure 1: Analytical framework
she perceived changes in her husband due to his illness. These changes in turn affected their marriage and herself.

Perceptions of the Illness

The coping phase developed as the wives perceived changes in their husbands' behaviour and began coping with them. Wives most frequently talked about three behaviour changes: slowness, freezes, and confusion. In addition to behaviour changes, the wives also reported that they found themselves coping with their husbands' psychological responses to the illness such as denial, embarrassment or depression.

Slowness The wives reported that their husbands took progressively longer to accomplish everyday tasks. "He can't do things in a hurry anymore. If he does, he has an accident. I have to slow up and sort of wait for him," one woman said. "You wait or make accommodation," said another. Wives found that they had to help their husbands keep up with the pace of everyday life. "I lay his clothes out. He could but if he did, we'd be late," one woman said. Another stated that "He needed lots of assistance to get him together to go to work." Later, wives found themselves compensating even more: dressing their husbands and planning ahead to make sure things went smoothly. As wives came to understand the disease, they added new problem-solving skills. For example, once they realized that Sinemet™ promoted temporary ease of movement, several wives encouraged their husbands to time the doses to promote movement when it was needed.

Well we wake up at six. He doesn't take medication during the night so all the medication is worn off. So he's unable to move. He keeps his pills by the bed and a drink of water so that at six he starts his medication. He has to wait 20 minutes to half an hour to get up. We get up and he's okay until about nine o'clock. He's able to cook breakfast and do the dishes until about twenty-quarter to nine.

Usually we time it. We know we're going out. He'll take
his medication early or take part of it so we can go down to the car.

Clearly, these wives were aware of the adjustments they were making to accommodate their husbands’ changing behaviour, and many became skillful at facilitating their husbands’ daily activities.

**Freezes** The second common behaviour change was a temporary inability to move, which the wives called freezes. “A freeze is like if you come to a doorway or that gateway or a narrow passage, you’re immobilized to the spot,” one woman said, “Your feet won’t go at all. They can be moments or they can last for quite a while.” Wives initially experienced uncomprehending, helpless frustration. They did not know what to do. “Well we just panicked. Oh no, we’re ready to go and here he can’t walk. What are we going to do?”

Later, however, wives and their husbands learned to predict and even avoid freezes.

It’s like we can predict some of his freezes throughout the day now. He has a little pill box so I don’t have to go and get that. One time it happened in the bath so you know I have to assist him in that direction if that happens. But he usually tries to avoid that because he does get some kind of warning. Sometimes I can see it starting to happen, he gets a funny look.

Eventually, the wives and their husbands learned that with medication, the freezes passed or could be overcome.

**Confusion** Confusion was the third behaviour change that several wives described. On several occasions many of the wives found their husbands disoriented and lost, or hallucinating in a drug-related, acute confusional state.

It’s the confusion that is the hard part for me. It has happened four times, I guess. It’s scary because he lost everything - He couldn’t think or do anything and he wouldn’t want to be like that. There is nothing you can do
other than the comfort thing.

Just talk, talk talk all day and night when he was really wild. He’d go, he’d nap and when he got up he’d be clear as a bell and he’d be fine. He’d nap and wake up and be gone again. I never knew which way he’d be so I couldn’t leave him.

Initially wives coped by being vigilant over their helpless husbands. For some women, their husbands were developing dementia and not much could be done. Other women, with the help of their doctors, learned that the confusion was drug-related and learned to adjust the medication.

I dole out the pills. Once in a while we’ve had disastrous results because I didn’t. Too much is what threw us. Actually, it was a combination with another medication that didn’t work. It was really something.

I thought the Serax™ that he was on was maybe disorienting him a little bit so he wasn’t aware of what was happening. I cut it out for a little while and then he was fine.

Some wives became sophisticated caregivers, good at coping with behaviours and medications. They read about the disease, learned from their experiences and learned from the specialists. “I think we know more about Parkinson’s disease than our family doctor,” said one wife after counselling at a multidisciplinary movement disorder clinic.

Psychological responses All of the wives were affected by their husbands’ psychological responses to their Parkinson’s disease. They described three major responses: depression, denial and embarrassment. Although the husbands demonstrated all three of them, one response was usually more prominent than the others.

Some wives talked at length about their husbands’ depression. To them, this response represented psychological distress that they described as deep
unhappiness and apathy. Some wives felt that their husbands had "given up," that they were "not trying" and they felt responsible for helping them to control their depression.

It was not really the disease as much as the depression that was very hard to deal with, from my point of view, because sometimes I get so tired. I didn’t have the kind of energy to bring him up out of his depression.

Many wives expressed exhaustion and deep frustration when they felt that their efforts to help their husbands control their depression were unsuccessful. On the other hand, one wife said she felt sorry for her husband and rather than pushing him, she tried to keep him as "comfy as possible." One husband managed to conquer his depression to the great satisfaction of his wife.

Wives also talked about the way their husbands denied all or certain aspects of their illness. Complete denial of the disease made it difficult for the wife to offer help when the husband obviously needed it.

I think one of the more difficult things to deal with was my husband’s refusal in the beginning to accept the fact that he actually had it. It wasn’t that he refused assistance. He was hurt, I guess, that I was offering it. There was always a reason why he couldn’t do something. I understand but it makes it difficult to give the amount of assistance required when it is not accepted very easily. He still refuses to ask to go to the bathroom. [He needs help to urinate.]

Some husbands selectively denied aspects of the disease. For example, one husband consistently failed to take charge of his medications. His wife coped by making sure that he took his pills, coming home from work at lunch to do so in the beginning of the illness. Now she had to stay home to give him his daytime pills; the doses were only one or two hours apart. Not taking his medication was part of a larger denial system which had worked successfully
for him for many years. "We'll do as long as we can get away with it," he said. His wife reported that her husband had "surprised himself and all of us." Her husband was not as deterred by his symptoms as others had been. She was quite aware that no matter how frustrating his denial tactics were, they had worked well for him.

All of the wives mentioned that their husbands were embarrassed over public exposure of their handicaps. For one wife, embarrassment was the cause of her husband's sudden, complete and permanent withdrawal from social activities. "I think he became terribly self-conscious," she said and described how she helped him manage to be unobtrusive at his workplace. "I made lunch for him so he could eat without having to go to the cafeteria."

Embarrassment about being handicapped in public became more and more significant, for both spouses, as the disease progressed. Ultimately, this embarrassment was a major contributor to social isolation.

As the disease progressed, each wife perceived that her caregiving role increasingly occupied her time. However there were also periods of improvement and concommittantly a lesser need for help. Several wives said that adjustments in medication or in one case surgery, significantly improved their husbands' behaviour. Some husbands returned to near normal one or more times during the course of the illness. For their wives this phase of coping with the effects of the illness waxed and waned. But the wives soon learned that the improvement was transitory. "You go up and down like a yoyo and soon you realize that they don't know the answer," said one wife about the issue. Many wives closely followed whatever new research they could find about new treatments to make sure all that could be was being done for their husbands.

Perceptions of the Marriage in Relation to Coping

All wives talked at length about their marriages. This was not surprising,
because, without exception, they had given their marriage priority in their lives. In coping with the effects of the disease, wives talked about two things: first, about their perceptions of a marital obligation to take care of their husbands, and secondly, about their perceptions of partnership in coping with the disease.

All the caregiving wives reported feeling some kind of obligation to care for a husband who was ill.

When we were growing up, you were the ones that had to take care of the family and when the family was gone - your husband.

The way I was brought up, you were expected to do the right thing. The right thing was when my husband was sick, I would look after him.

This commitment was conveyed by all the participants.

Despite these statements, however, wives reported varying perceptions about their commitments. Some wives questioned their commitment at times. For example, when one caregiver's husband became depressed, the wife began to drift away. She became involved with her female friends and thought of leaving the relationship. However, she recommitted when her husband rallied from his depression and took her on a trip to Europe to talk things over. At the time of the interviews, she remained committed to the marriage.

Wives expressed other reasons that supported their commitment to caring for their husbands. For example, one wife wished to leave her marriage situation, but she remained because she was committed to the wifely caregiving role. "I am so used to doing it, I do it automatically...I would have to think of something to make my days worthwhile if I was not in this relationship," she said. Other wives stated that they were committed because they could not conceive of leaving the financial and temporal investment they had already
made in their marriage.

In coping with the effects of the illness, the wives also talked about their sense of partnership with their husbands. They either described its presence, or they complained of its absence.

Women who perceived a sense of partnership in coping with the disease, reported four perceptions about their relationship with their husbands. First, their husbands talked with them about the illness, which allowed them to work together on the problems that resulted from his changing abilities. For example, both spouses shared their feelings and observations, learning together to anticipate freezes. Second, these wives talked of making decisions as a couple in anticipation of their changing needs due to the Parkinson's disease. For example, one couple moved to cheaper housing to prepare for his early retirement from a physically demanding job. Third, three wives mentioned that their husbands expressed appreciation and thanked them for their efforts. "He says without you it would be a lot harder to deal with...He always seems to give the credit for being behind him and helpful to him," said one wife. Finally they were satisfied with their relationships.

Getting our lifestyle together and handling it [Parkinson's disease], I think we're doing really well. We can rely on each other, we're both that way. If he needs me I'm there. If I need him, you know, though he has his limitations now, he's still very supportive of me.

Clearly these wives found their relationships to be meaningful. Their roles were clear and rewarding.

Wives who did not report a perception of partnership, complained of a lack of communication.

If you could tell me then I could help. If you don't tell me then I have all this trouble finding the right question! Like he won't say to me "I feel badly that I'm not able to read any
more.” He just can’t do it.

This wife articulated the feeling well. To the wives, communication, no matter what it was, was necessary to help them understand and support their husbands. “I’ve told him many many times I don’t care how badly crippled or whatever he is as long as he will communicate,” said another wife emphasizing how much the wives valued interaction with their husbands.

Wives ascribed the lack of communication to three causes. First, some of these wives observed that a lack of communication had existed before the disease and was part of a longstanding problem in their relationship.

One thing that used to bother me was that he would not communicate. He would not tell me what he was planning. So I guess it is still having effect on our present situation because he won’t tell me if anything is bothering him.

Second, the wives reported that progression of the disease would physically interfere with communication.

His speech is so slurred...that we might be having a conversation but after it is over I don’t know what the subject of the conversation was.

Third, the wives also reported that the disease would interfere emotionally with communication.

We used to be able to talk things over and now we can’t. If he has any inkling that anything is wrong with me, then he has to admit that I am having trouble, then he has to admit that he is worse than he hopes he is.

Whatever the reasons for lack of communication, it was unanimously identified as a crucial lack in managing the effects of Parkinson’s disease.

In summary, the wives had two categories of perceptions about their marriage in relation to coping with the illness. They perceived that caring for
their husbands was part of their marriage obligations, but they had varying perceptions of their commitment within their own relationships. The wives were also aware of a presence or a lack of partnership with their husbands in coping with the disease. When they could talk with their husbands about the disease and plan for their future, and when they perceived that their efforts were appreciated, they expressed satisfaction. When the wives perceived a lack of communication, they expressed frustration in their wish to help, anger at his willfulness and sadness at the loss of a confidante. It appeared that when the husbands' behaviour fit with the expectations the women all seemed to have of their husbands, they expressed satisfaction with the caregiving role.

Perceptions of self

All of the wives talked of perceptions about themselves in relation to coping with the illness. The perceptions fell into three categories. First, the wives described uncomfortable feelings at various times during the course of the illness. Second, many described judgements about their performance as caregivers. Finally wives all indicated their perception that the downhill course of Parkinson's disease made caregiving a longterm commitment.

Uncomfortable feelings

Three feelings arose during the course of the illness and were common to most accounts: anger and resentment about having to cope in the face of disappointments about the loss of future expectations, sadness about those losses, and frustration with aspects of coping with the illness. Less frequently, caregivers expressed other feelings such as anxiety, worry or guilt.

All of the caregivers experienced disappointment. Coping with the disease made it difficult to carry out expectations they might have had for the future. "The hardest thing is not to be able to do the things we wanted to do," said one woman. "The horrible thing is the bitterness, the waste of two lives," said another wife. For some wives, the effects of Parkinson's disease had been
destroying life plans and expectations since their forties. Wives alternated sadness and anger with neutrality. Many caregivers talked about having distinct periods of sadness and depression about their life situation. “I had some flat, flat feelings and being negative all the time,” said one woman. “Sure I’ve been down,” said another. Many wives were candid about their disappointment that things had not gone the way they had wished. Some were able to handle this feeling philosophically saying things like “everyone has something you don’t like about them, for me he has this problem.” Many women stated that on a day to day basis, they did not allow themselves to think about the issue. However, many had to face the issue head on periodically, and reconstruct a kind of peace with themselves. Said one wife, “It seems every few years, I have to do it all over again.” Many wives successfully managed their disappointment by taking one day at a time and facing their anger and sadness periodically.

Caregivers also experienced frustration with various aspects of coping with the illness. They reported frustration when they did not know what to do. “I am in this great frustration because I don’t know how I’m supposed to help him.” They found this helplessness extremely uncomfortable, especially when they perceived that it was their responsibility to help a sick husband. Others described frustration with their husbands’ psychological difficulties. One woman described the feeling accurately saying that she spent a lot of time trying to guess or imagine what he might be experiencing so she could decide how to help or evaluate the help she had already given. Some wives were also frustrated that their husbands were unable to overcome their handicaps. “If he would just try, it would be a lot easier,” said one woman because her husband’s behaviour seemed to result from stubbornness, rather than Parkinson’s disease. Even when the wives knew the frustrating behaviour was directly due to the disease the frustration remained. “I have to keep
reminding myself that he is not doing this deliberately.”

The women reported two other feelings significant to many in the gestalt of caregiving. The first was fear/anxiety when faced with new aspects of the disease. “It was scary at first. I just didn’t know what to do with him.” “We just panicked at first.” The caregivers felt at a loss. They felt responsible. They did not understand the situation, and they felt alone in their distress. Some caregivers experienced immense relief when, through the local movement disorder clinic, they received practical explanations of what was causing their husbands’ behaviour and practical advice in managing the symptoms. One woman conveyed the gratitude these women felt by saying, “They give me this calmness I love. They’re so helpful; they understand; they care.” One woman stated that she felt guilty that her husband had the disease and not she. This woman mentioned this feeling to her husband, and he agreed! Eventually she realized that this was not a logical viewpoint. “I took a stress course and realized it was not my fault that he had the disease.” With relief, she then gave herself permission to view the situation differently.

Judgements of performance Most caregiving spouses judged their own performance as caregivers. Their judgements were based on various personal standards caregivers held about their role. “My family and friends say I’m doing a good job,” said one woman. Some women were content to accept their friends’ confirmations that they were doing a good job of caregiving. Other women seemed to use broader criteria to judge themselves. For example, one woman judged the quality of her care by her attitude toward her husband which seemed inseparable from her satisfaction with their relationship. Her resentment towards her husband appeared to be related to events in the past however this seemed to be translated into stringent expectations of how she should feel about the role.

There is almost a sense of guilt there as if I think I could do
it well if I could fight down some feelings of resentment about some of the things that come broiling up from the past. In other aspects I've done the best I could.

Another woman was critical of herself because she expected different results for her efforts.

I just feel I'm not making any progress at all. I can't control the disease. I can't control how he handles it. I really can't and this is what upsets me. I haven't been able to motivate him.

She felt responsible for managing her husband's psychological responses to the illness and she felt she was failing as a caregiver if she could not do so.

**Caregiving as a longterm commitment**  
All caregivers knew that the downhill course of Parkinson's disease made caregiving a difficult, longterm commitment. "Things don't get better. I knew that from the beginning," said one wife. Other women also intimated that they perceived a future in which their husbands' increasing disabilities would make their caregiving responsibilities increasingly demanding. "Things will get hard when he has difficulty walking and I can't have a peaceful night," said one woman whose husband was deteriorating rapidly. The wives also predicted that when their caregiving role would become increasingly demanding, it would increasingly limit their own lives. One woman said, "I don't know how I'll be when I won't be able to take breaks. I don't think about it."

However, despite these perceptive statements about the future, several caregivers, whose husbands' disease was far advanced, indicated that they had only been partially aware of the overwhelming commitment caring for their husbands was to be. "Theoretically you know, but I don't think you really understand, until you experience it," said one woman. A few women indicated that if they had known how the disease would affect their husband, they might not have stayed. One woman said, "I think if I had known he
wasn’t going to fight, I might have walked away...But you’ve got to see somebody through this and hope that this...” However by cultivating a hopeful outlook and by practicing strategic denial of the future, the women said they were able to cope with the realities of caregiving. “I had no idea it would be like this, we just said we’d cope and we did,” said one woman accurately summing up the feelings many women expressed.

In summary, caregiving wives’ perceptions of themselves in relation to coping with the disease fell into three groups: feelings about coping with the illness, judgements about their performance coping with the illness, and perceptions of coping with the downhill course of the disease. Coping with the effects of the illness appeared to have two components: coping that focused on practical problem-solving in day to day life, and coping that focused on managing the impact of the illness on the wife’s own psyche.

The coping phase often occurred ahead of the other phases. Caregivers learned to cope as the effects of the disease began to become obvious. As the disease progressed, it became necessary to take over when the husbands handicaps had progressed beyond managing the daily activities of living.

**Taking Over**

As the disease rendered the husband unable to carry out his traditional role, the wife became the dominant partner in the relationship. This section discusses the wives’ perceptions of the illness, of the marriage, and of themselves during this phase.

**Perceptions of the illness**

As the disease progressed, all wives perceived their husbands’ losing competence in their jobs and at home, and they began to see the need to take over. The men retired early or persevered until their sixty-fifth birthdays, but in each case, the husband was having difficulty managing his work. At home, wives observed their husbands also losing competence in managing household
tasks, in driving, and in handling the family finances.

All of the women spoke about how their husbands had great difficulty managing their jobs at the time of retirement. Three men managed to work until age sixty-five because they had understanding employers and more flexible work situations.

He was just barely managing in the end. People would call to see him so I would let them talk. Then I would wait until they called again before I told him about them.

said one woman who worked closely with her husband. “He was lying down part of the day at work before he retired.” Three men opted to retire early because their work was becoming too difficult. One man lost his job twice because of his deteriorating performance. Instead of looking forward to a full retirement, the wives saw their husbands dealing with failing capabilities.

At home wives observed their husbands becoming unable to manage household tasks, driving, and financial responsibilities. The transfer of household tasks was least upsetting possibly because these responsibilities had been shared previously, and because these tasks are often routinely delegated to others when time or physical ability makes it difficult to do them. For example, the husband had difficulty walking on steep lawns so mowing was out of the question. In another example, standing balance became too unsteady to lift things easily. Most wives smoothly took over these tasks, or asked the help of neighbours and hired help to do the rest. They coped easily with these difficulties although some wives commented on how dependent they used to be on their husbands in managing these household matters.

Driving involved both physical competence and mental competence, and symbolized freedom and independent mobility. Many wives observed their husbands’ struggle to maintain driving skills and reported their own difficulty in discouraging their husbands when it was obvious that they were a danger on the road. Many women related graphic descriptions of their husbands’
physical difficulties with driving.

He seems to get where he is going all right. But he's a nightmare to drive with because of all his leg motions. His leg moves back and forth on the accelerator so you are always lurching forward as a passenger. The seatbelt tightens up and then you go back again. If it were up to me, I wouldn't give him a license but I can't say it should be taken away.

Wives found it even more devastating when it was obvious that their husbands' cognitive abilities were also impaired.

He used to hit barriers. Once he was on the highway in the wrong lane against oncoming traffic. He wouldn't know where he was and he grew up here. Once we were coming home on a main street in rush hour and I don't know how we got home. I was literally shaking when we got home.

Due to both Parkinson's and Alzheimer's disease, this man had not only lost his memory of a familiar city, but he had difficulty making appropriate judgements while driving. At the time, his wife felt helpless to take over because she could not drive.

Most husbands had significant difficulty giving up driving. Most wives handled the situation in a similar manner to the one described in the following quotation.

He insisted on driving. We're both adults. I thought on moral grounds I shouldn't go with him [when he was driving the car.] He lost his license [gradually] by demerits.

The women told their husbands that their driving ability was impaired but refrained from forcing the issue. Usually, however, the wives avoided driving with the husband once the issue had been discussed.

Several wives also became aware that their husbands were losing cognitive competence when they made mistakes in family finances. Some
wives had an ongoing knowledge about the family finances and their husbands often only made minor mistakes before the wife realized she had to take over. For example, one wife observed, “He couldn’t balance the checkbook anymore.” When wives were not knowledgeable about the family finances, only a large financial mistake would bring the problem to their attention. “He made a bad investment. I didn’t realize his mind wasn’t working properly.” This wife conveyed the dismay that other wives in this position felt. Usually, they had not been permitted to take part in decision-making about the family finances and now, suddenly and irrevocably, it was up to them.

Taking over the finances usually occurred late in the disease. Only one wife said that she had to take over when her husband retired. Other husbands maintained control of finances until much later. Furthermore, not all wives experienced taking over the finances as a sudden permanent change. In fact, two husbands became temporarily unable to manage for periods but rallied because of treatment and took back the role. “We handed it back and forth and I was happy to give it back every time.” These periods called for considerable adjustment in the relationship, but wives seemed more hopeful when their husbands rallied enough to take this important role back again. They were uncomfortable with the shift in power in the relationship and wanted to restore the status quo.

Not all wives were left to figure the finances out alone and not all husbands had to give up their role. Two husbands anticipated they would have to relinquish family finances to their wives; one handed them over well before he needed to do so. Both these husbands prepared their wives for managing the finances and both wives related their respect for their partners’ actions. Two husbands still managed the finances at the time of the study. According to their wives’ perceptions, these two husbands still maintained the finances with energy and mental competence. If husbands were losing
cognitive competence as well as physical competence, it made taking over more difficult for the wife in two ways. The husband was unable to help his wife take over and she found adjustment to loss of cognitive competence more difficult.

**Perceptions of the marriage**

As the disease progressed, wives became aware that their marriages were changing. They had to take over total responsibility for the planning and decision-making that the individual tasks of household maintenance and financial management required. In relating their perceptions about the marriage, the women talked about the shift of the power to themselves because of the new roles they had assumed in the relationship.

Wives talked proudly of taking over the tasks of house maintenance. "I'm pretty handy around the house. I can wire a lamp and fix the toilet," Many became quite adept at managing the household tasks. However some wives realized, eventually, that the job of home maintenance had shifted entirely to them. When this became clear, some made their first major decision alone - to move to a home that was easier to manage. "I had to be able to do it myself. He was going down so fast, I had to get rid of the house," said one woman. She articulated what these women experienced: a sudden realization that precipitated urgent action to bring the situation under more comfortable control.

When wives perceived that they were in charge, they talked about the weight of carrying the total responsibility for planning, and decisionmaking. "It is draining to be totally responsible physically and financially for this family," said one woman. "I do everything," said another. Not only did the responsibility take considerable time, initiative and effort, but it meant that the husbands depended upon them. One wife said what many conveyed, "I have to be ok for us to be ok." They were aware that the stability of the present
situation was dependent on their strength and health.

Many of the wives talked about the power shift in their relationships. Wives realized that assuming major responsibility brought with it the power that their husbands previously had. "In a strange way, our positions are reversed. I have to be the one that is in charge now. Now I have Power of Attorney. I have to do the finances. I was never allowed to do this before," said one woman articulating the sense of power and the sense of incongruity she experienced in her new roles. Wives were sensitive to their husbands' loss of status in the relationship. "Sometimes I feel a bit more powerful, but he won't let me get away with too much," said another woman. Some wives encouraged their husbands' continuing input into decisions. One wife maintained the facade that her husband was still in charge. "I just felt I had to be responsible for the chores. I do everything but I still ask him all these things. I stay with him until I have an answer." Other wives were quick to assure the researcher that they were acting in their husbands' best interest. "I'm in control now but I'm not doing anything behind his back." Their comments reflect sensitivity about the effect of their new positions on their husbands. "Sometimes I have to decide things that he doesn't like," said one woman. Clearly these women were concerned about asserting their power fairly and wisely. It was obvious that Parkinson's disease had a profound effect on marriage in the taking over phase. The disease was altering the structure of the marriage completely and irreversibly.

**Perceptions of self.**

The wives indicated that they had mixed feelings about taking over. They described perceptions of discomfort and feelings of burden. However, the wives also described feeling of growth and satisfaction.

Most of the wives expressed feelings of discomfort about taking over responsibility and the leadership initiative in the relationship. They worried.
"I'm trying hard to be calm [about it]," said one woman when discussing the new role. Wives disliked the tension that shifting roles caused in the relationship. "I don't like being the responsible one or he doesn't like it," said another woman. The women were also uncomfortable about unfamiliar tasks. "I have not enjoyed the financial responsibility - being totally responsible because I've never had any experience doing it," said one woman. They felt the burden of having to take the initiative in making changes. "I see clearly how it's going. What I don't like is if anything is going to be done. I have to do it," said another woman with a great deal of sadness and a reluctance to believe the truth that her husband's condition was deteriorating.

On the other hand, wives expressed a variety of positive perceptions of growth and satisfaction about taking over. "Possibly I was too self-reliant. Now I can't ask him to do what he can't. I think it has been good for me." This statement represents the perceptions of wives who had been forced to grow responsible largely because of their husbands' new inability to be in charge. Wives expressed satisfaction now that they had taken over and put their lives in order. "I can do most anything here. I've made it nice and easy."

They had made and acted upon major decisions for the future such as moving to homes in which they could care for their husbands as they grew older. One wife enjoyed the fact she could do things her own way for the first time in her marriage. "I always felt my way was better anyway," she said with satisfaction. Many wives implied that they had to struggle to overcome past conditioning to take charge. "My mother will never be as independent as I am, never," said one wife. For many it was a worthwhile struggle because they were gaining a sense of their own mastery, power, and autonomy.

The taking over phase occurred later in the disease when the husbands' handicaps stood in the way of carrying out the tasks in their marriages that they had traditionally assumed. The coping phase usually occurred early in the
disease when the symptoms began to interfere with activities of daily living. In the coping phase it was important to the wives to be able to communicate freely with their husbands and to work together closely solving practical problems as equals. However in the taking over phase, the wives began to initiate and make decisions when their husbands became unable to do so. Now instead of having an equal relationship, the wives became dominant. In the next phase, the husband is even more handicapped and often the coping phase and the taking over phase are already well developed. In the “separating life paths” phase, the relationship, which has withstood many changes, changes even more and the wives begin to grow apart from their husbands.

**Separating Life Paths**

As the disease progressed, wives experienced a separation of their life paths from their husbands' life paths. As the Parkinson’s disease caused the husbands to become physically handicapped, possibly cognitively handicapped, and now socially impaired, their lives became more and more limited. That is, the husbands became unable to carry out their social roles as part of a couple in society. Eventually, husbands also became unable to function as they had formerly as a marriage partners.

Furthermore, the women foresaw that supplying the wants and needs of their husbands would become more and more time consuming and conflict increasingly with their own wants and needs. The wives knew that their time would be increasingly consumed with caregiving activities. Unless they took time away from their husbands, they would be unable to maintain involvement in any of their own activities and friendships. In other words, the wives were becoming nearly as limited socially as their husbands. They were forced to make decisions about how they would obtain rest and recreation in the short-term and to realize that they would likely be living alone in the
As in the other two phases, the wives' perceptions of separating life paths fell into three categories: perceptions about the illness, perceptions about the marriage and perceptions about themselves.

**Perceptions related to the illness**

As the disease progressed, the husbands' physical disability increased and affected their ability to participate socially in two ways: it became too difficult physically and too embarrassing socially. Problems with mobility, speaking, and eating were the most troublesome. When the disease was well advanced, these problems became so obvious that they became a significant social barrier, so much so that they even separated wives from their husbands.

Mobility problems became a significant factor that inhibited social activity. When husbands began to walk with difficulty, to fall frequently and to experience freezes regularly, many became cautious, reluctant to go out from home. Some women said they pushed their husbands to overcome what they felt was excessive caution. "He worries unnecessarily because he doesn't think he's going to make it. By the time he gets there, he is all right. Sometimes I push him a bit because I think it is good for him." She felt, as many wives did, that going out socially despite their physical limitations was important for a sense of wellbeing. Freezes also became obstacles to social involvement. Freezes reduced mobility, particularly because they made it difficult to function at all during parts of the day. "He can't do anything in the afternoon. He sits rigid and shakes and sweats." Husbands felt warning signs of impending on/off periods (or freezes) at other times also. "He can tell when an on/off is coming and doesn't stray too far way." Frequently, husbands were inclined to stay near home during those periods.

Clear, smooth speech became difficult. "He's lost his ability to make social conversation," said one woman accurately voicing the opinion of most wives.
“He slurs his words so much that at the end of the conversation I don’t know what he was talking about,” said another. Husbands spoke indistinctly and could produce little volume; some spoke haltingly or in sudden rushes.

Eating became a problem. Wives described how their husbands’ increasing clumsiness caused spills, and his drooling and tendency to choke made it difficult to eat tidily. “At mealtimes he drools badly and spills. He’s been a careful dresser and he minds how messy he is. I have knit a coverup he wears but not when we have guests.” Wives were acutely aware of their husbands’ self-consciousness about their handicaps.

As the disease progressed, the husbands’ handicaps became more visible. The women related that their husbands’ social difficulties increased when their difficulties with speaking, eating, and walking became more obvious. Eventually these difficulties made the husbands and eventually the wives want to stay home and avoid public scrutiny.

The wives were aware of the impact of their husbands’ behaviour on strangers when they were in public.

He’s having great difficulty eating. I remember being out to dinner and a radio personality was across a few tables. The memory of the look of horror on his face when he was watching my husband has stuck with me.

Wives talked of their own discomfort with public reaction to their husbands’ handicaps. “I find it very difficult being out together when people stare so,” said one wife clearly articulating the feeling. Although most husbands withdrew when their handicaps became obvious, some did not. For example, one frustrated wife described the outcome when her husband had ignored her suggestion to put on sensible shoes so he would have less trouble walking. “You literally stop traffic in a mall because he’s stumbling and crashing along.” Many women indicated that they were somewhat angered and embarrassed at
the public spectacles some husbands caused with their disabilities. As the
disease advanced, even at rest, husbands looked obviously abnormal. One
woman articulated this feeling well.

He's spastic a lot of the time, can't control his movements.
He really looks weird and when that calms down, he has
pretty good control. But he lurches and shuffles and when
he is sitting down watching TV, he is in motion all the
time.

Wives explained how they interpreted their husbands' behaviour to others.

"Oh, I'm sure I sort of protect him. You know I tell people
if they don't know. People who are not used to it will
think maybe he's drunk or something from the way he is
walking. I just tell people."

Wives became aware of how the husbands' developing physical and
social difficulties began to limit their own lives also. Most of the wives
described how, as a couple, they began to confine their activities to home and
family events.

"It's pretty well family now because he has had a couple of
accidents in restaurants the last few times we've been out. I
don't think it is fair to him and I don't think it is fair to the
people we go with to be truthful. He has great difficulty
eating and he gets stuck."

Wives noted that staying home was not ideal, but the disadvantage was
outbalanced by the stress they both felt in public. Couples became more socially
isolated as friends and some family members found it increasingly awkward to
visit them. One wife expressed the feelings that the wives conveyed. She said,
"They don't know how to act, they're embarrassed." Wives indicated that it
was only certain people with whom they could maintain social relationships,
often only family. "His colleagues can't handle it... but some good friends still
come," said one wife about this issue.

Wives differed in the way they handled the situation, largely because of the way their husbands behaved. One husband retained a lively interest in others and a sense of humour; with a little encouragement from his wife, they maintained a social circle, albeit a more limited one. In contrast, another husband frustrated his wife when he withdrew from social activities. At the last minute, he always managed to avoid the social events for which his wife had accepted invitations until she finally realized that he had withdrawn permanently. Wives described how much work social occasions became because they had to continually watch that their husbands were all right. Many said that now social occasions were more work than fun. Social isolation became the major theme of all the couples' lives.

Perceptions of the marriage

As the disease progressed and the husbands' disability increased, all of the women perceived their husbands' growing difficulty in managing their role as marriage partners. Mobility problems made trips and vacations difficult. It became awkward to host visitors at home. There were problems with communication. There were sexual changes. The changes in their husbands changed their marital relationships; they created an increasing separation.

Some wives perceived a total personality change in their husbands, while others perceived losses of valuable aspects of their relationships. Two women stated that their husbands' personalities had changed, and that they lived with a person very different from the husband they had known and loved. "It's like living with a stranger down the block. It's like you're married but you're not," said one woman. To another woman, the situation was incongruous; not only did the man seem to be a stranger, but his behaviour had become child-like. "You know really, in many ways you're living with a stranger. Sometimes you feel like you are living with a very large child and if it is someone you have
been married to for forty years, it's hard to shift gears," she said. These two husbands had changed from being a fun-loving family man, and an articulate well-read conversationalist to quiet, withdrawn, slow-moving, dependent men who kept falling asleep.

To a lesser extent, wives perceived changes in the quality of their relationship when they lost aspects of it that they valued. For example, one wife mourned the loss of her husbands' sense of humour. "One of the things that appealed to me about him was that he had a fantastic sense of humour. That's completely gone," she said. Several wives talked about their husbands' lost ability to be a confidante. "We used to talk thing over but now we can't," said one woman sadly. "Every time we have to talk about something important he chokes [and can't talk]," said another. The women talked of losing their husband as a companion. For example, they missed conversation. "There is no conversation. He can only get three words out," said one woman. They missed activities together.

We did everything together. He didn't go off golfing or with the boys or fishing... We used to go to California every winter but he can't sit in the car for that long and he won't fly. He doesn't want to even drive short distances.

In addition, wives noted that when the disease was far advanced, their husbands had difficulty attending. They were exhausted and would nap frequently. "He likes me to watch TV in the evening with him but three minutes into the news he's fast asleep," said one. "We're watching an exciting hockey game and I look over and he's fast asleep!" said another.

Their sexual patterns changed. Three wives mentioned that, for years, they had slept in different rooms. "He was so restless that I couldn't sleep. When he hit me in his sleep, I moved to the other room." The women all gave similar explanations for moving out of their husbands' room. A few
women stated that their husbands had become impotent. These husbands continued, to their wives’s discomfort, to attempt to achieve intercourse. This behaviour generated resentment in some wives based, in part, on other frustrations from the past and on their inability to satisfy him. Another wife felt so much at a loss about how to cope with her husband’s problems with impotence that she overcame her inhibitions about talking about sexual problems to ask the researcher about a solution.

These factors contributed to the diminishing degree of engagement that many women experienced in their marriages. Furthermore, many women now had to spend their leisure and vacation time without their husbands. Some had found a new confidante. The women were slowly being forced to carry on a meaningful part their lives independent of their relationship and their husbands’ lives.

Perceptions of self

In their caregiving careers, the wives experienced a great deal of change over which they had had no control. They had adapted to the changes caused by their husbands’ disease. They had faced the challenges of coping with the effects of the disease and the challenges of taking over his roles in the relationship. Now they would be regaining their own lives. During the separating life paths phase, the wives dealt with the fact that their own lives were being limited by their husbands’ disease. They began to acknowledge and eventually to assert their healthy, social selves as a necessity for continuing as caregivers, and they began to think about the end of their caregiving career.

Apart from the loss of their marriage partners as lovers, helpmates, and companions, the major impact of the disease on most wives was the time and emotional energy that the caregiving role required. All of the wives knew that caregiving would eventually be all-consuming. “I don’t know what I’ll be like when I can’t take breaks. That’s one thing I’m coming to I’m sure,” said one
wife. They knew that they would be exhausted and socially isolated and would clearly need respite from their husbands’ dependence. But they found it difficult to assert this need without feeling guilty and without upsetting their husbands. The situation began to require a shift in the focus of their initiative. They felt forced to shift the focus from planning and making decisions that favoured the couple as a unit, to planning and making decisions that favoured themselves as individuals. Some had moved from talking about “us” to “I.” This did not change their caregiving behaviour - only the way they viewed the role. One woman accurately expressed the struggle they all shared. “I think I’ll have a hard adjustment and so will he because he likes me around. I hope he will let me go and be part of social events. I think he might have difficulty and I might emotionally, but I hope I have the strength to do it because I think it will be more necessary later on you know.” Many women could not imagine making this shift, and the struggle was intensified by some husbands who viewed the shift with dismay.

Many wives perceived their husbands’ retirement as another factor that would limit their lives. One wife had predicted that her husband’s constant presence after retirement would be difficult, but she was gratified that they had grown closer in the time they now spent together. “I used to say if I had to work with him all day, I’m sure I’d kill him by the end of the day. We have a really good closer relationship than we had before, we got to know each other.” In contrast, another wife reported that she felt trapped when her husband retired because she worked and had used his time at work for many activities. “He retired and I was trapped then.” She arranged for her husband to attend adult daycare during the week so she could continue with her activities. Other wives also realized that they would have to arrange rest periods, but had difficulty making arrangements that were satisfactory to their husbands as well. “Now I have to make decisions he doesn’t like,” said one woman. Naturally,
Many husbands reacted with dismay when wives broached the subject.

Most wives stated that their husbands expected them to be together most of the time. "He feels there is nothing wrong with doing everything together," said one wife. "He wishes I would stay home and concentrate totally on him which is not right for me," said another. Many wives, sensitive to their husbands' distress, reported that they had felt guilty about taking time away.

I feel guilty about not staying home. I do try to anticipate and have everything ready so nothing unforeseen will take place when I'm gone. But if I do go, I make up for it in an other way of some sort. Take him for drives or take him to do something he wants. We sort of even things out I hope.

Another woman dealt with her need for respite in another way: she usually invited her husband on a trip, and when he refused, she went anyway. She stocked the refrigerator and freezer with food, alerted a family member, and took trips of one to two weeks alone. "If he refuses to come [along] on the trip, you can't let your conscience bother you," she said. Another woman handled the dilemma differently. She felt that she could not leave her husband for more than two hours, so she had three close friends visit her regularly. She was apologetic for imposing them on her husband but found them essential to her wellbeing. "I'm sure we disturb him a lot ... we watch the hockey games [and play cards.] I'm sure that he is sick of women but I have to have them."

Many wives felt uncomfortable about leaving their husbands alone, particularly if the husbands were significantly handicapped. "I can't leave him alone because I'm not sure he's not going to fall. He's fallen in the garden several times and I could not get him up without the next door neighbour," said one wife. These women had few other social outlets aside from family contact, telephone conversations, and only a few hours of homemaker help per week. One wife foresaw the future without relief from her present circumstances unless she made some changes.
I've got to do something...Last summer when he was falling and doing so badly, I had a man come in to shower and dress him every morning. I would go out an walk hard for an hour. That was good [then]. The new medication helped so much that he didn't need help dressing anymore. [Now] I would like him to go to adult daycare again just for one afternoon, but he doesn't like it. Now he says he will go for my benefit but he wants to know what I want to accomplish. I just need to sit on a rock and stare at the ocean to put my body and soul back together.

Her story conveys the emotional exhaustion these women experienced and the effort they had to exert to gain relief. "If anything is going to change, I've got to do it," said one woman expressing the feeling that many of the women conveyed. They knew they would not be rescued.

Several women had concluded, often with help from their physician or longterm care worker, that their present caregiving situation was approaching its end. They predicted that their husbands would be institutionalized in a year or two. However, many of them were unable to put their husbands on a waiting list because it felt too calculating.

All of the women said that they thought about the end of their caregiving role at home. Early in the disease, the end of caregiving was a distant future possibility, but thoughts about it did arise. For example, it occurred to one caregiver when her husband was briefly in hospital that she would be alone like this in future. Her husband was still able to drive, but she felt stranded when he was away because she did not have driver's license. Another wife, who was still early in her caregiving career, spoke in general terms about being alone. These perceptions contrasted with those of wives for whom the end of their caregiving career was more imminent. They were about to institutionalize their husbands, and they viewed this prospect with mixed feelings. "It seems so cold and calculating to put his name down [on
institutional waiting list] a year ahead of time." Several spoke of feeling that they were abandoning their husbands, that planning ahead was coldblooded. "It was admitting that there wasn't anything we could do to help him," said one woman. They were unanimous that their husbands would find institutionalization devastating. "When I think about how I would feel out of home base as far as I'm concerned that's the end of life. Life in hospital is so horrendous," said another woman. They were conscious that they were adding abandonment to the already long list of their husbands' losses.

The women also felt their relationships with their husbands would change when their husbands were institutionalized. One felt that their relationship would improve. "Then maybe we can be friends the way our relationship should be at this point in our marriage." Another, despite the tremendous handicaps with which she and her husband struggled, dreaded the loss of the intimacy, and companionship that had sustained them for so long. "No matter what happens we're attuned to each other," she said.

Despite these strong feelings, many women looked forward to freedom from the burden of caregiving. Many thought that they would feel relieved of their social confinement, and they looked forward with some urgency to getting on with a future which, to them, was growing limited. One woman said, "I'm tired of being in a box. I'm tired of being tied in. I'm scared I'm not going to be able to do the things I want to do." These women had disengaged from their husbands to some extent. They had thought about future living arrangements and the lifestyle they would adopt. These plans included volunteer work, dancing, courses, travel and spending time with family, especially grandchildren. Others were conscious that they would now be left with time on their hands. One woman said that she would need to find another activity to replace caregiving so her days would have purpose. Whatever future plans the women had, they all had plans to visit their
husbands regularly, usually daily. "I'm not sure how I'll run my day, but I'll probably be there once or twice a day."

During this phase of separating life paths, wives began to uncouple from a usually longstanding marriage. They had to start thinking about their future as independent women instead of always thinking about their future as a couple. The caregiving career, by demanding that they learn to take charge and learn new skills necessary for independence, was actually preparing them for that future.

Caregiving: A personally meaningful experience

Throughout their caregiving careers, each woman experienced caregiving as a unique gestalt because it was composed of her perceptions about coping with her husband's illness, her marriage, and herself. Each woman defined the impact of the illness differently, and each woman experienced the phases differently.

Each woman defined the impact of the illness on her relationship according to the timing and personal significance of events. For example, one woman's relationship changed when she was in her forties and her husband withdrew in a deep depression that for him initiated the Parkinson's disease process. After struggling for twelve years to regain what she perceived had been a happy marriage, she angrily gave up. "I am angry, yeah, it's a waste of two lives," she said. In contrast, another woman's husband had been diagnosed six years after they were married, and coping with the disease had become an integral part of their intimacy. Now, after several decades, their intimate communication continued to be a significant bond despite the husband's severe handicaps. A third woman's husband became afflicted several years before retirement and retired early, significantly handicapped. This wife talked sadly of missing the opportunity to spend time together as a retired couple. Another woman's husband did not become severely afflicted
until after they had had a chance to travel together in their retirement.
Although life was difficult now, she was considerably more content than a
woman who felt thwarted because her husband had become handicapped
when she was in her forties.

Furthermore, the women experienced the phases of the caregiving
career in different ways. The phases could occur consecutively as the effects of
the disease became more severe, or they could occur simultaneously when the
disease progressed more rapidly. On the other hand, two phases could occur
concurrently, followed by the third. For example, the separating phase had
progressed sooner and more quickly for some caregivers than for others. A
woman whose husband had been severely depressed experienced separating
life paths before the other, more physical symptoms usually associated with the
coping phase, became evident. For her, the relationship had all but ended long
before her husband needed much physical help. Thus, the separation phase
dominated her caregiving career. On the other hand, a woman whose
husband was severely handicapped maintained an intimate, confiding
relationship with him. Although she felt fatigued and trapped, she could not
entertain the prospect of institutionalizing him. For her, the separating phase
had not begun because she perceived that their lives remained intertwined.
Several wives experienced the coping and taking over phases simultaneously,
when their husbands swiftly became quite handicapped. For other wives the
disease progressed slowly. They spent many years coping with the illness, and
late in the disease, experienced the taking over and separating phases at the
same time. The meaning of caregiving evolved for each wife according to the
synchronies of the phases in her own experience.

Conclusion
This chapter has discussed the development of the analytical framework
and then has presented the data in terms of the analytical framework. The analytical framework provided a structure which represented a composite description of the wife's stories. This structure incorporated the perceptions these wives had expressed about important elements of their lives: the illness, their marriage, and themselves. The analytical framework described caregiving as a career during which the wives perceived changes due to the Parkinson's disease. Three phases evolved in relation to the changes the wives' observed: coping with the illness, taking over and separating life paths. Using quotations, the author has attempted to convey the perceptions that the wives expressed in explaining how they managed the various events of their caregiving career. The following chapter will discuss the findings in terms of the literature review in Chapter Two and theories that help to explain their significance.
CHAPTER FIVE

This chapter discusses the findings detailed in Chapter Four which presented the caregiving experiences of seven older women. Chapter Five will further explore the nature and significance of their caregiving role in the light of the initial literature review and selected theories.

A major finding was that there were three phases in the women's caregiving careers. According to Wright and Leahey (1987), the use of phases as a way of addressing the evolution of a chronic illness over time, has arisen in the literature a few times. Three factors are relevant in describing caregiving over time. First, caregivers accumulate a history of caregiving that affects their future expectations. For example, the wife predicts the husband's psychological reactions to new developments from his coping style in the past. In addition, past hurts and disappointments may color her perceptions of his present behaviour. Second, when the caregiving career is described in phases, it is possible to consider the impact of different phases starting at different life stages. Third, it becomes possible to identify behaviour that may be more useful in one phase than another. For example, denial of the future was more useful early in the disease than later when the caregiver had to cope with her husband's inability to manage their finances.

Wright and Leahey agree that evolution over time is an important factor in caregivers' experiences. They have included time as a major element in their working model of studying families adaption in coping with chronic illnesses. In studying caregiving over time we can learn about how caregivers develop coping strategies and maintain their stamina in dealing with the stresses they encounter. In fact, Lazarus and Folkman (1984) found in studying coping over time, that the effect of coping with "daily hassles" (p.314) over time was possibly more stressful than managing the effect of major life events.

The discussion in this chapter then, will develop out of the findings of the
three phases: coping with the illness, taking over, and separating life paths.

Coping with the Effects of Parkinson's Disease

The coping phase usually developed early in the disease when the husband began to experience difficulty accomplishing his usual daily activities, and it progressed further with each new development in the disease process. The key finding was that the wives were committed to coping effectively with the Parkinson's disease as their husbands changed, and that they managed their feelings about changes in their life expectations - loss of a normal husband and a normal retirement - in such a way that they could focus on solving the problems at hand. The women had internalized the social obligation to care for a sick husband that was emphasized in Chapter Two. However, several factors made effective coping difficult.

First, not knowing what to do made it difficult to cope effectively, so over the course of the disease, the women learned by observation, and by trial and error, to manage their husbands' symptoms - often skillfully. The study supports the observation of healthcare workers mentioned in Chapter Two that caregivers need information about the disease. The data shows that caregivers need practical, specific information to solve the immediate problems occurring in daily life such as coping with slowness and freezes. The relief as well as the satisfaction the women communicated when they had mastered the situation, further supports this point. Furthermore, the gratitude of the women who received assistance underscores the fact that not knowing what to do was a significant source of stress.

Second, the husbands' negative psychological responses to the changes caused by the Parkinson' disease could also make it difficult to be an effective caregiver. When the husband was depressed or when he denied his illness, the wives found it difficult to obtain their cooperation in solving problems. The women often did not know what to do about their husbands' psychological responses and they experienced stress when they perceived that they were failing to manage the
responsibility they felt for their husbands' wellbeing as part of their wifely role.

Third, lack of communication with the husband about coping with his disease also made it difficult to be effective. The wives needed their husbands' explanations about how the disease affected them, in order to direct their actions. Furthermore, they needed feedback to validate the effectiveness of their caring activities. The women acknowledged that lack of communication was the result of the husbands' psychological responses and/or longstanding communication patterns in their relationship. No matter what caused the lack of communication, the women were unanimous about its importance to them in managing the changes they were experiencing.

Finally, wives found it difficult to cope effectively when they were disappointed in their husbands as partners. They experienced feelings of disappointment, sadness and anger when their husbands did not act as they expected husbands should. Some husbands did act as satisfactory partners, and these wives stated that they were satisfied with their caregiving role. Other wives indicated that they had to keep telling themselves that their husbands' behaviour was due to the disease and not to willfulness. Over the years, the wives found that managing one day at a time helped to cope with these feelings for the most part. However, there were times when they had to face their feelings of disappointment, reevaluate their circumstances and reaffirm their commitment to the caregiving role. Olshansky (1962) called a similar group of feelings chronic sorrow when he described the longterm coping strategies of parents caring for their mentally defective child - another longterm caregiving situation where the usual expectations about that life event would never be met.

Three theories help explain the issues the wives faced and some of the behaviour they exhibited in managing the changes the Parkinson's disease had caused. They will be presented briefly in the course of the discussion of the coping phase and they will be discussed further in the discussions of the following two
Theoretical Interpretations

Satisfaction of basic needs. One explanation of why the wives felt stressed by the difficulties in coping with the disease, is that the changes in their lives left some of their basic needs unmet. The University of British Columbia Model for Nursing, was developed from theories that explain human behaviour as coping behaviours which manage tensions caused by the necessity to meet nine basic needs (See Figure 2). Three of the basic needs could potentially be unmet in the coping phase: the need for mastery, for love and belongingness, and for self-respect. For example, managing Parkinson's symptoms required new behaviour and understanding. Wives would not experience mastery until they learned about Parkinson's disease. In addition, some wives lost part of their sense of belonging in their marriage when their husbands found it difficult to communicate - confide, problem-solve and give feedback to them. Then they also felt frustrated about mastering their changing wifely role. Finally, wives who did not receive signs of their husbands' appreciation for their efforts, lacked an important resource in bolstering their self-respect.

The wives stated that they needed more knowledge and skills to carry out the caregiving role. Knowledge and skills are two abilities that the UBC Model also identifies as necessary to develop new coping behaviours for meeting basic needs. Other forces, some manipulable and some not, inhibited attainment of need satisfaction or enhanced it: sociocultural forces, such as marriage vows, personal forces such as their own feelings of disappointment, and environmental forces such as the appropriateness of their housing. This explanation of the caregivers' difficulties indicates several possible interventions which will be discussed in Chapter Six.

Stress and Coping. Another explanation of why the wives felt stressed by the
<table>
<thead>
<tr>
<th>Subsystem</th>
<th>Need</th>
<th>Goal of subsystem behaviour</th>
</tr>
</thead>
<tbody>
<tr>
<td>Achieving</td>
<td>For mastery</td>
<td>Feelings of accomplishment; satisfaction with accomplishments</td>
</tr>
<tr>
<td>Affective</td>
<td>For love, belongingness and dependence</td>
<td>Feelings of love, belongingness, and dependence</td>
</tr>
<tr>
<td>Ego- valuative</td>
<td>For respect of self by self and others</td>
<td>Self-esteem</td>
</tr>
<tr>
<td>Excretory</td>
<td>For collection and removal of accumulated wastes</td>
<td>Absence of accumulated wastes</td>
</tr>
<tr>
<td>Ingestive</td>
<td>For intake of food and fluid; nourishment</td>
<td>Nourishment; satisfaction of hunger and thirst</td>
</tr>
<tr>
<td>Protective</td>
<td>For safety and security</td>
<td>Integrity of the system</td>
</tr>
<tr>
<td>Reparative</td>
<td>For balance between production and utilization of energy</td>
<td>Capacity for activity</td>
</tr>
<tr>
<td>Respiratory</td>
<td>For intake of oxygen</td>
<td>Oxygenation; easy respirations</td>
</tr>
<tr>
<td>Satiative</td>
<td>For stimulation of the system's senses (ie. hearing, taste, vision, touch, smell, and taste)</td>
<td>Sensory satisfaction</td>
</tr>
</tbody>
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Figure 2: The need and goal of each subsystem of the University of British Columbia Model for Nursing. This model views an individual as a behavioural system having nine basic needs. Each subsystem represents one basic need. Adapted from: “A model for nursing: University of British Columbia School of Nursing” by M.A. Campbell, M. Cruise, and T.R. Murakami, 1976, Nursing Papers, 8(2), p. 8
difficulties in coping effectively with the disease is supplied by theory about stress and coping. The literature reviewed in Chapter Two pointed out that caregiving is stressful. The literature review predicted stresses of obligation, of living with a changing husband, and of life constriction. These were all evident in the findings. The discussion in Chapter Two concluded that caregiver stress was individually defined. The findings demonstrate this point. That is, the wives found coping with the illness stressful when they could not meet personal standards or expectations they held about their own behaviour as wives, their husbands' behaviour as husbands, and about their own lives.

Lazarus and Folkman's (1984) process-oriented, phenomenological theory explains how individuals appraise situations as stressful, what makes a situation stressful to the individual concerned, and how that individual copes. Individuals appraise situations as stressful when they anticipate potential loss/harm, actual loss/harm, or a challenge (p. 32). Therefore, stress is individually defined because threat or challenge is determined by the standards and beliefs to which individuals are committed. In other words, these factors determine what is at stake for that individual (p. 56).

This view of coping helps to explain the data. For example, all of the wives were committed to looking after their sick husbands no matter what the circumstances were. The stress the wives experienced was frequently related to the threat of not being able to meet their standards of being effective caregivers. In addition, the wives talked about the stress of actual losses such as loss of their husbands' abilities to carry out their roles of managing finances and their social roles. However, the wives also perceived challenges such as the challenge to be ingenious and to develop the new skills that the caregiving role demanded.

Furthermore, Lazarus and Folkman postulated two categories of coping. Problem-focused coping attempted to alter or manage the situation. Emotion-focused coping managed the emotions involved. For example, the
women adopted a strategy of taking one day at a time, instead of continually thinking about the future burdens of caregiving as a longterm commitment and about the loss of future expectations. Since they found that their own sadness and anger made them less effective as caregivers, the women elected to focus on the problems at hand and adopt a policy of strategic denial, not to think about the future. In fact, one woman declined to join the study because her husband had been diagnosed only three years previously, and things were going well. She declined to join this study which might force her to talk about the illness.

Role Theory. Finally, role theory provides a larger sociological context in which to analyze the data. These women were experiencing extensive role changes. Since role changes can precipitate role stresses, analysis in terms of role stress and role strain may provide useful explanations of the wives' experiences. Ward (1986) postulates that role stresses such as role incompetence, role ambiguity, or role conflict can lead to role gratification or role strain depending on intervening conditions. For example, role mastery might lead to role gratification, but rigid cultural expectations or the husband's lack of reciprocity might lead to role strain (See Figure 3).

For example, the wives experienced role incompetence when they did not know what to do. This stress was reduced when their husbands helped them to understand how to be effective caregivers. These wives reported feelings of reciprocity and role mastery. Furthermore, they seemed satisfied that their husbands' behaviour fulfilled the cultural expectation that husbands provide guidance and support. This point was confirmed by the dissatisfaction of wives whose husbands did not. On the other hand, the stress was worsened when the husbands did not communicate, guide or support them. Their wives reported dissatisfaction, role ambiguity and lack of reciprocity.

Literature reviewed in Chapter Two emphasized that caregivers had little choice about taking the caregiving role. This rigid cultural expectation could
Antecedents of role strain

- Role conflict
- Role accumulation
- Role rigidities
- Role ambiguity
- Role incompatibility
- Role incongruity
- Role uncertainty
- Role intensity
- Role incompatibility
- Tedium

Role Stress

Intervening Conditions

- Amount of role pressure
- Lack of reciprocity
- Status
- Self-esteem
- Audience
- Role mastery
- Cultural factors

Role gratification

Role Strain

Properties of role strain
- Perceptive, subjective state
- Pressure of an etiological stimulus
- Undesirable or negative state

Subjective states found in role strain
- Fatigue
- Exhaustion
- Depression
- Cognitive strain
- Insecurity
- Embarrassment
- Tension
- Anger
- Hostility
- Guilt
- Indecision
- Failure
- Job dissatisfaction
- Physiological stress
- Physical damage
- Anxiety
- Threat
- Discomfort

Consequences of role strain

- Role restructure
- Increased role distance
- Role bargaining
- Concealing stressors
- Coping with stressors
- Suicide
- Role resignation
- Decreased level of involvement
- Negotiation of the meaning of the stimulus
- Converting stressors to social prestige
- Drug abuse

Figure 3. The relationship of role stress to role strain.
Adapted from: "The meaning of role strain" by C.R. Ward, 1986, Advances in Nursing Science, 8(2), p. 43
contribute significantly to role strain. Wives did report coping with feelings of anger about having to care for an ill husband without a sense of choice. The findings of this study described how some caregivers reevaluated their situation every few years and arrived at a new settlement with themselves about carrying on with the role. It seemed that even though they rarely waivered in their commitment, they did have to reestablish its meaning in their lives.

Figure 1 lists factors that predispose role strain and its consequences. This theory about role strain explains why some caregivers gave an angry account while others gave a generally more positive account. The fatigue, guilt, depression and anger associated with role strain partly explain the negative emotions the women encountered. The theory also gives give some clues about how to intervene.

This section has discussed the findings related to the coping phase of the caregiving career in which wives learned to cope with the changes in their lives caused by the effects of the Parkinson's disease. Three theories were introduced which helped explain the participants' experiences. These theories are also useful to explain the second phase of their caregiving career when they took over.

The Taking Over Phase

The women experienced another phase in their caregiving career in which their husbands lost the competence to carry out their traditional marriage roles. In this phase, the major finding was that the women took over these roles and soon realized that the power associated with those roles had shifted to them. The changes were stressful for three possible reasons.

First, the women were watching their husbands, whom they loved and esteemed, lose status as they became incompetent and dependent in a society that values competence and independence. The women were aware that competence and independence feed self-esteem. They found it difficult as loving wives, to witness this assault on their husbands' wellbeing.
Second, in taking over new roles, the women had to relinquish old ones, and during these changes, they experienced stresses that can be explained by the UBC Model as a temporary lack of satisfaction of the basic needs. The needs for mastery, dependence, self-respect and security were often poorly met until the women could find new ways to satisfy those needs. For example, the women had to develop new behaviour to master their new roles; they felt helpless and clumsy in their new roles until they developed confidence and, often, self-respect. Furthermore, many experienced a lack of satisfaction of their need to feel dependent at times because their husbands were becoming dependent on them. Many wives lost the guidance, and support from their husbands that they had previously depended upon. Furthermore, many women felt frightened and insecure about the course their lives were taking until they gained competence and confidence.

However, despite the fact that many of the stresses the wives experienced were negative, they also experienced positive stresses. The women were challenged by their new roles. Most women perceived taking over as a growth experience. Many indicated that their self-esteem rose. This does not agree with the prediction in the literature review in Chapter Two that older women experience a loss of status as they age, because society does not find aging women attractive or competent and independent. On the contrary, the caregivers experienced a rise in status in their relationship as they gained competence and mastery in their new roles. Their worth and indispensability was emphasized by their husbands' dependence.

The study findings described in the previous paragraph, are supported by the work of Lowenthal, Thurnher, Chiriboga, and Associates (1975) also reviewed in Chapter Two. The researchers concluded that women become more masterful than men in later life, following a longitudinal study of aging men and women. In addition, Sinnott (1986) indicates from his studies that women who blur sex roles, seem to experience greater life satisfaction. The work of these researchers support the author's observation that the growth and enjoyment the women were
experiencing was because the women were following a natural developmental progression.

Third, the wives were aware of the hazards of their power over their husbands. The stress of the rise in status in the relationship probably caused some role ambiguity when the wife did not feel comfortable interacting with her husband with her new status. The women valued harmony in their relationships and indicated they felt stress if they perceived that the relationship might be harmed. In their new capacity, the wives risked making decisions which their husbands might not like. Some felt an uncomfortable sense of betrayal when they made decisions, often necessarily, without consulting their husbands.

Finally, the wives saw themselves, with some degree of guilt gain status at their husbands' expense. They experienced role conflict and therefore stress when they wanted to support their husbands' self-esteem as caregivers, perceiving that taking over his tasks contributed to the erosion of his self-esteem, but at the same time, the roles had to carried out.

Furthermore, in terms of role theory, there were added stresses of role incompetence (in new roles), role incongruity (between caregiving and taking charge), role rigidity, and role accumulation which could together predispose role strain. The stress could be eased if the wife mastered the roles easily, as some did, and if the husbands exhibited reciprocity by accepting the changes and appreciating their wives in their new roles. However, when a role seemed difficult to master, such as the management of finances for example and/or when the husband was unable to tolerate the transition gracefully (role rigidity), the wife was susceptible to role strain. Some wives diffused the tension by providing the husband with opportunities to contribute to the relationship. It was easier if their husbands continued in some of their traditional counselling and guiding capacities, particularly regarding the new roles the wives had to assume.

The findings also indicated that the timing of events during the caregiving
career had significant impact on some of the wives. Wives whose husbands became ill before they had had a chance to reach and enjoy retirement together seemed to experience more anger and depression. Neugarten and Gutman (1968) observed that some individuals who experience developmental changes earlier or later than is usual for their age cohort, will experience stress.

In terms of stress and coping, most wives found a balance of threat and challenge in the taking over phase which gave it a more positive theme than the coping or separation phases. At the same, wives were experiencing losses. For example, they were no longer able to rely on their husbands to share the burdens of decision-making and longterm planning. Wives used emotion-focused coping, such as the denial to help them manage their feelings of loss and grief. Similarly, they used pep-talks to build their initiative to take over new tasks. Emotion-focused coping facilitated brisk efficient problem-focused coping. The next phase of caregiving engendered even more losses for the wives to manage.

**The Separating Phase**

During this phase the husbands usually were significantly handicapped and became unable to function as part of a couple socially or as partners in their marital relationships. The major finding of this phase was that the wives had to find new ways to meet needs which had previously been met through their intimate relationships with their husbands. Several factors made it difficult for the women to make these changes and to find new ways to meet their own needs.

First, the wives had difficulty finding new ways to meet their needs because the new ways often conflicted with the caregiving role. Furthermore, some experienced difficulty when their values about their commitment to their husbands conflicted with their commitments to their life expectations.

The wives realized that they needed diversion, and recreation; they needed social involvement; and they needed a new confiding relationship. One explanation of why the wives were stressed in this phase was because (in terms of the U.B.C.
Model for Nursing) they were experiencing temporary, possibly permanent tension from unsatisfied needs for love, belongingness, dependence and security. Social forces such as the social obligation to care for a sick husband, and the expectation of social behaviour as a married couple affected the wives' choices in developing alternative coping behaviours. Initially, the wives gave up their own activities as caregiving began to fill their time. However, they also realized that they had to remedy their lack of need satisfaction in order to carry on their responsibilities as caregivers. To do so, they had to obtain respite from their husbands' dependency and because their husbands were no longer involved in meeting their needs, the new activities often could not include their husbands. Most wives felt that leaving their husband to meet their own needs, conflicted with their commitment to stand by their husbands, providing excellent care as a wife.

Chapter Two had predicted that the women would experience role conflict when at some level they knew they would outlive their husbands and were preparing to be independent, yet they had to continue in the responsive role of caregiver. They did experience role conflict in this phase when they were forced to put commitment to their own lives ahead of their marital commitment. Yet, as caregivers, they were committed to standing by their husbands as supportive wives as long as it was necessary. Many were reluctant to relinquish that role.

On the other hand, the findings indicate that wives became increasingly disengaged from their husbands as their husbands' handicaps forced them to find other ways to meet the needs the relationship had previously fulfilled. Emotional engagement with the husband seemed to be a sustaining feature in caregiving relationships. Once wives had lost a sense of engagement with their husbands, they seemed ready to institutionalize them. Hirschfeld (1983) made a similar observation in a study that established that when a spouse had a sense that the relationship was providing mutual benefit, she was likely to want to continue in her caregiving role.

The theory of role strain also provides another explanation for the
disengagement some of the wives reported. The continous strain had led some wives to withdraw to varying degrees. A few of Ward’s (1986) terms such as role resignation (delegating care to an institution), role distancing (less involvement) and role restructuring (delegating some care to other individuals or institutions) could be used to describe this withdrawal.

Second, the wives had difficulty finding new ways to meet their own needs because they felt both sad and guilty about having to abandon their life partners. Many wives had difficulty and appraised their situations as stressful when they experienced significant losses in their marital partners and in their social roles as couples. They had lost their marriage partner, a longstanding source of intimacy and social support. They had to stop putting their marital relationship ahead of other relationships and let other nurturing relationships became important. They experienced sadness. Many experienced deficits of the support that their husbands had previously supplied such as familiar evidence of being loved, guidance, nurturance, reassurance of their value to a significant person and reliable availability in times of need. The wives had to find new sources of support although, as caregivers, they continued to provide these supports for their husbands.

Literature on social support (Dimond & Jones, 1983) maintains that social supports such as these, contribute to an individual’s well being and his or her ability to withstand stress. This body of literature maintains that social support is particularly needed in times of crisis, transition, and in situations when an individual must withstand deficits in their lives (p.147), such as lack of reciprocity. This body of literature partly explains the distress these women felt as they conducted their caregiving career. The wives experienced crises, many transitions and, in the course of caregiving, lived with many deficits in their lives.

Third, when wives attempted to meet their needs by finding new social companions, they experienced difficulty. This phase was stressful because the wives experienced role ambiguity when they had to conduct their social lives alone in a
society where in this age cohort, married couples are the norm. They were married, but they now they had to participate in social gatherings alone. At first, when the husbands became unable to manage on social outings, the wives attended social events alone or not at all because many women chose to give up social events they could not attend as a couple. They even chose to relinquish their own social involvements when caregiving began to fill their time. The net result was that they often lost contact with longterm friends and became socially isolated themselves. For a period during their caregiving career, they spent any leisure time they could obtain, alone. As their home caregiving careers were drawing to a close, their social patterns were changing. The friendships they did maintain and the new friendships they developed were mostly with other, often single, or widowed older women. They were developing strong supportive relationships with other women as independent women. Many women completing the separating phase had negotiated the transition from loyal wifehood to independent older womanhood.

The Caregiving Career

The phase of separating life paths usually culminated late in the disease. Now the wives could view their caregiving in retrospect as a career. It had a beginning and an end. It had been long and difficult and, at some level, they had known all along that caregiving would be a long demanding commitment. The concept that caregiving was a career with an end was supported by friends, longterm care workers and physicians who predicted the need for help in the home and eventually institutionalization.

The caregiving career was paced not by time but by degree of handicap. In fact, the author observed that there were different types of caregiving careers determined by the speed of advance of the disability, the pattern of lessening and worsening disability, and by the husbands’ psychological responses. The husbands’ responses could delay or accelerate caregiving phases.

Each career shape had a different impact on the caregiver’s life depending on
the time at which the illness interfered with normal life events. Neugarten and Gutman (1968) indicated that when life events occurred that forced the individual to be out of step with the cohort of which the individual was part, they experienced stress. For example, one wife experienced the beginning of the taking over phase first, when as a middle-aged mother with teenage children, she had to cope during the severe depression that signalled the beginning of his Parkinson's disease. In addition, she experienced the beginning of the separation phase when she had to deal with his devastating withdrawal. Another wife experienced the beginning of the coping phase just as she and her husband were beginning their family. The concept that caregiving careers take various shapes may be useful in predicting the kind of caregiving career a caregiver may experience. This kind of thinking has led Wright and Leahey (1987) to incorporate a categorization of various disease trajectories into their framework for studying family adaptation to chronic illnesses.

How Much is Enough?

During the caregiving career, the women supplied care unstintingly with often little thought about the limits of what they could give. Daniel Callaghan (1988) of the Hastings Center discussed the limits of the obligation of a family member to provide care when the care demands were severe over a long period of time. The caregivers said and Callaghan agrees, that the moral claim on their energies to care for an ill husband is justifiable. However, Callaghan suggests that carrying out the obligation may not be endurable, but even if it was endurable, was it justified? How much caregiving was enough to satisfy social obligations?

This study shows that the women worked hard to develop coping strategies that made the caregiving role endurable. In addition, particularly while the women were adjusting to the changes, the husbands' contributions had great impact on the wives' perceptions of stress. The factors that reduced the stress of caregiving can be explained in part by the theories about need satisfaction, about roles, and about stress
and coping discussed in this chapter.

However, the women talked little about supports, rewards, and appreciation from individuals outside their marital relationship. Caregivers pointed out, with appreciation, the outside supports they did have. For example, in this study group, a knowledgeable clinic nurse, longterm care workers, sometimes another caregiver and a few of the physicians were the only individuals who had an understanding of the demands of the role. Particularly near the end, the caregiving role gave little reward, other than pride in workmanship and mastery.

Callaghan points out that the meaningfulness of the caregiving role might be enhanced if it was viewed by the surrounding culture "not as a stark and unpalatable moral demand but more as a moral vocation, one honored by the community and returned in kind when the caregiver herself will need care" (p.327). However, it is unlikely that the wife will ever have the advantage of being cared for by someone who knows them as well as a spouse. However if society valued, rewarded and honoured the role of caregiving, others might come forward to offer the loving considerate care most of these wives gave their husbands.

The wives performed heroically for many reasons. There was no one else to do the job. It was their social obligation as marriage partner. They did it because they loved their husbands and because they became committed to doing a good job.

Conclusion

The overall theme of the caregiving careers was that the wives were coping with change. They were dealing with Parkinson's disease, an unanticipated event, that altered many aspects of their lives, their husbands' behaviour, their marriage roles, and themselves. The discussion throughout the phases has centered on how the women perceived these changes and coped with them. Discussion of these issues has indicated implications for nursing practice, education and research to be discussed in Chapter Six.
CHAPTER SIX

IMPLICATIONS FOR NURSING AND SUMMARY OF THE STUDY

The discussion of the findings in Chapter Five indicated implications for nursing practice, education and research. This chapter will discuss the implications in terms of the three phases of the caregiving career described in the findings. Lastly this chapter will summarize the study.

General Implications for Nursing

In discussing the implications of this study, some comments about the role of the nurse in relation to family caregivers is relevant. If nurses follow two widely accepted principles of nursing, that nurses understand the client's experience of disease and that nurses give thorough individualized care, they must prepare themselves in such a way that they indeed do understand individuals' experiences with illness. It is well established in this study and in the literature (Strauss, et al, 1984) that families are integrally involved in the chronically ill individual's life. Therefore, in order to give thorough, understanding assistance in managing chronic illnesses, nurses must understand how families are involved when individual clients manage their chronic illness.

Caplan (1961), a physician specializing in community mental health, contends that nurses occupy a unique role in that they are accessible members of the health care team; they can help guide lay persons through the intricacies of medical treatment and at the same time provide knowledgeable psychological peer support. Similarly, Strauss and colleagues (1984) state that nurses can act as conduits between clients for information about dealing with particular diseases, conditions and situations.

Furthermore, health care professionals who see future trends in health care see the need for the health care system to evolve to meet the needs of the
chronically ill. Incorporating responses to these needs within the framework of present practice is a step towards meeting changing societal needs. By moving to understand the circumstances of chronic illness which include the welfare of the caregivers, nurses will develop awareness of the particular needs of these clients, a vital step towards preparing to act responsively.

**Specific Implications for Nursing**

In agreement with the literature in Chapter Two, the focus of the implications for nursing is alleviation of stress. The findings in Chapter Four have indicated what caregivers find stressful, and the discussion of the findings and relevant theory in Chapter Five has given clues about interventions. The University of British Columbia Model for Nursing (UBC Model) discussed in Chapter Five, indicates that change and loss cause tension because coping behaviours that previously satisfied basic needs are no longer effective. Individuals must devise new ways of coping. The UBC Model suggests that nurses can assist by helping individuals gain knowledge and skills; enhance positive forces such as self-esteem and a positive awareness of growth; and inhibit negative forces such as unrealistic performance expectations. Stress and coping theory indicates that enhancing individual problem-solving and self-management will help individuals appraise situations more positively and with less stress. The theory of role strain indicates that clarification of roles, reduction of role intensity, and reduction of role incompetence can lead to reduction of role strain. This theory suggests that manipulation of intervening variables such as support of self-esteem, enhancement of role mastery, reduction of role ambiguity and reevaluating perceptions of cultural factors may also assist in achieving role gratification rather than role strain.

Specific implications for nursing will be discussed in terms of the three phases of the caregiving careers of women caring for husbands with Parkinson’s disease.
The Coping Phase

Practice implications. This phase presents the most potential for nursing intervention. During this phase, caregiving wives need practical information timed to help them increase their knowledge and skills in order to reduce their stress of not knowing what to do. In consultation with rehabilitation therapists and experienced caregivers, nurses could assist caregiving wives in the practical management of daily routines and medications. To do so, nurses must have a general knowledge about the problems of caregivers and the chronically ill, and gather specific, practical knowledge about coping in daily life with the problems of Parkinson’s disease.

During this phase, nurses must be aware that caregiving wives struggle to manage their husbands’ psychological responses to Parkinson’s disease. Nurses could help wives devise caregiving strategies by using working theories about hope, depression, stigma/embarrassment and denial, powerlessness (Miller, 1984), loss and change now available in the literature.

Couple communication was important to wives during this phase. Nurses could observe its presence or absence and help the wife or the couple devise strategies to maintain or facilitate communication and provide referral if necessary.

Nurses could assist wives in managing their feelings of stress by supporting them in whichever coping mode they are using, understanding that strategic denial is a useful coping strategy. Nurses would support the emotional work of grieving when the wife is sad or angry. But when the wife exhibits problem-solving coping behaviour, the nurse would support the emotion-focused coping the wife was using to facilitate her problem-focused coping.
Group work is a common intervention to reduce stress of caregiving clientele. However, the findings indicate that groups with specific foci may be most beneficial to caregivers. Early in the disease wives should be supported to maintain their strategic denial and should receive practical information. It would be counterproductive to mix caregivers dealing with issues of separating lifepaths with individuals dealing with developing symptoms. Groups, then, should address specific practical caregiving problems and issues and have members recruited with the purpose of the group in mind.

Caregivers need interventions related to coping with the illness, in the early stages of the disease. Strauss and colleagues (1984) note that organized educational services for individuals managing chronic illnesses usually do not exist. Nurses could advocate for caregivers by finding funding and initiating community-based programs such as educational programs and self-help groups.

**Nursing education.** To give individualized care to this clientele, beginning and practicing nurses should know the natural history of Parkinson’s disease, the natural history of a caregiving career, and common caregiving problems. Parkinson’s disease associations, experienced nurses, experienced caregivers and further research of this type can supply this information since there is little available in the literature.

In addition, beginning and practicing nurses need to have working theories of how individuals can effectively cope with change, loss, hope, embarrassment and other phenomena associated with Parkinson’s disease. Nursing literature is beginning to provide these theories. To implement them, beginning and practicing nurses need to develop teaching, counselling and group facilitation skills. Nurses also need skill in working with other health care disciplines. They should have a thorough awareness of the resources available to caregivers.
Nursing research. Further research is needed on the natural history of Parkinson's disease as experienced by individuals with Parkinson's disease and their caregivers. A larger study using another method such as grounded theory will reveal information useful in assisting the general population of caregivers dealing with Parkinson's disease. Natural histories of other chronic illnesses would also be useful to compare the caregiving experiences. The timing of events and other factors may differ in other diseases and some factors may be similar to other diseases. For example, the experience of multiple sclerosis must be different because it usually begins at a much younger age. Corbin and Strauss (1984) studied couples managing heart disease. Although they described coping over time, they did not describe phases of caregiving. They did find, however, that a strong partnership was important in managing the illness satisfactorily. That finding is similar to the experience of couples with Parkinson's disease while the husbands were still able to manage their roles. Couple dynamics were the central focus of Corbin and Strauss's study. In this study, couple dynamics were the focus of the taking over phase.

The Taking Over Phase

Nursing practice. In this phase, the most significant implication for nursing practice is that the women experienced major changes in their marriage roles. To alleviate the stress associated with the taking over phase, nurses need to be aware of these changes to predict the issues with which individual wives are likely to be coping. This would allow the nurse to provide appropriate supports such as counselling and timely referrals to social work to give them assistance with finances, or decision-making. The nurse can also provide support by keeping avenues open to discuss role changes, by helping the wives clarify their roles, or renegotiate their roles reducing such stressors as role ambiguity and lack of reciprocity.

Nursing education. To provide individualized care, beginning and practicing
nurses require a knowledge of the events of the taking over phase. They require counselling and multidisciplinary teamwork and referral skills. Again, working theories of change and loss would be valuable.

**Nursing research.** Further questions to study include questions about the role of the marriage in the caregiving career where marriage is not the caregiver's lifework. Wives in other age cohorts may view their caregiving career differently. Caregiving husbands will also view their caregiving career differently. Are marital changes different with different diseases? Cognitive impairment had a significant effect on the marriage because it forced the wife to take over. However, cognitive impairment along with severe physical incapacity were even more evident in the separating phase.

**The Separating Phase**

**Nursing practice.** In the separation phase, implications for nursing practice again focus on the loss and change caregiving wives experience. The findings indicated that nurses must be alert to the individual significance of events. For example, a wife who had already disengaged from her husband would have a different mode of coping than a wife who still confided in her husband, regardless of the degree of handicap.

The nurse should be aware that in this phase of the caregiving career, the caregiving wives are likely to be socially isolated and that their social patterns were changing whether they like it or not. The nurse could assist these women to clarify their values so they can positively appraise their changing circumstances. Uhlenberg (1979) makes the point that older women may not have previously learned the skills needed to actively rebuild their lives if necessary. Groupwork would be appropriate to provide opportunities for exploration of feelings, exchanging strategies and for support. However, in this phase, caregiving demands would make it imperative to arrange a few hours respite to allow the women to attend the meeting. In fact, caregiving demands
are so great in this phase that it would be difficult for these women to organize self-help groups. These women particularly deserve respectful help and support that demands little extra effort from them.

**Nursing education.** To give individualized care to this clientele, beginning and practicing nurses need knowledge about factors such as marriage and friendship patterns for this age cohort. Nurses should be aware of the sociocultural forces older women experience and the developmental tasks they face. Again, a working theory of change and loss would be useful. Counselling skills and group skills would be useful to provide high quality care.

**Nursing research.** Studies plotting various disease trajectories will help predict the shape of various caregiving careers. Study of how these caregivers cope will help nurses become better conduits of knowledge (Strauss et al, 1984) to other caregivers. In their book about families and chronic illness, Wright and Leahey (1987) agree that we must study illness and caregiving careers longitudinally. They propose a conceptual model to guide practice and research that includes a typology of chronic illnesses whose focus is their similarities and differences and their developmental phases.

Studies of various aspects of chronic illness and caregiving will also allow nurses to become better conduits of knowledge between patients. For example, studies of the phenomenology of different kinds of disability will help explain the social stresses chronically ill individuals and their caregivers experience and will also suggest coping strategies. For example, Parkinson’s disease causes hesitancy of action and speech. Socially, hesitancy suggests lack of confidence, and possibly a lack of intelligence. Moreover, individuals with Parkinson’s disease move either stiffly in ways that make the individual seem old. Conversely, from drug effects, they move with loose swimming motions that could be mistaken for drunkeness. Caregivers and their chronically ill family member must deal with the social consequences of the perceptions such as this.
With creative thought based on an understanding of the dynamics involved, we may be able to help them ease their difficulties.

In addition, it appears that men and women have different developmental tasks at this stage of life. If so, studies are needed to determine the developmental tasks for older women. We must also find or create positive cultural archetypes of caregivers, and of aging women. We must find ways to help society handle the moral and ethical issue of the wives' obligations to care for their ill husbands. Finally, we must find ways to provide more social support, recognition and status for the social role of caregiving. These are all issues that indicate directions for further study if we are to enrich our knowledge and possibly our ability, as nurses, to ease the burdens of caregivers.

This concludes the discussion of implications for nursing practice, education and research. This section has focused on the alleviation of the stress. Possibly when the stress caregiving wives experience is lessened, their husbands may experience less stress and other complications associated with their chronic illness. One research question that caregiving research should address, is the interrelationship between the stresses caregivers experience and the resulting positive or negative effects they may have on the experience of their chronically ill husbands. The following section will summarize the study and conclude this thesis.

Summary

This study has used the phenomenological method to examine the experience of older women caring for husbands with Parkinson's disease. The purpose of the study was to help nurses understand their experience in order to provide care more relevant for these clients.

Seven women were interviewed intensively about their caregiving experiences. The interviews were transcribed and analyzed in order to develop
a composite description of their experiences.

The analysis revealed that there were three phases to a caregiving career - coping with the illness, taking over, and separating life paths. These phases often occurred chronologically beginning with coping with the illness, then accumulating, first, the taking over phase and then, the separating phase. However, the phases also occurred in simultaneous combinations depending on the progression of symptoms, the husbands' psychological responses, and the timing of events in their lives.

The discussion of the findings focused on the distress the caregivers felt about the changes taking place in their lives, how they coped, and factors that would reduce their stress.

Implications for nursing indicated that nurses using individual and group teaching and counselling skills as part of the interdisciplinary health care team, can help caregiving wives reduce their stress by assisting them to develop their caring skills, and manage their feelings. However, to do so effectively, nurses must understand the course of Parkinson's disease, and the social and developmental forces impinging on that age group. Nurses have a responsibility to find ways to enhance the social recognition and the status of the caregiving role. In addition, nurses interested in this clientele, must deliberately develop their expertise by integrating theory, with the results of research and practical experience. Nurses must then articulate and communicate their findings so they can be added to our body of professional knowledge.

The results of a study such as this one can be used to facilitate individual nurse's development of expertise because it provides information about a specific, identifiable category of clients. Studies such as this one are useful because they direct nurses to develop the kind of knowledge they need to assist this particular clientele. In this way we can build our knowledge about specific
client groups and further the professional goal of providing individualized care.
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Dear Sir:

I am a graduate student in the University of British Columbia School of Nursing. I wish to request permission to obtain subjects for my study "The Experience of Caregiving: A Qualitative Study of Older Women Whose Husbands have Parkinson's Disease," through the Movement Disorder Clinic. I am interested in learning about how older women caring for spouses with Parkinson's disease, view their role. Understanding how spouses describe and explain their role can be beneficial for nurses so that:

1. Spouses may increase their satisfaction with care by nurses because their concerns are known and directly addressed.
2. Nurses may effectively gear teaching programs to the spouses' real concerns.

I have prepared an application for ethical review and I submit my proposal for you to review. Please note the information letter, consent form and example interview questions in Appendices A, B and C. If you have any questions please feel free to contact me at the numbers above, at any time. My thesis committee chairman is Judy Lynam, Assistant Professor in the School of Nursing and you can contact her there.

I appreciate your time and interest, thank you.

Sincerely,
Appendix 2: Letter of Information

The Experience of Caregiving: A Qualitative Study of Older Women Whose Husbands have Parkinson's Disease

My name is Tilly Schalkwyk. I am a registered nurse doing graduate studies at the University of British Columbia. This letter is an invitation for you to participate in an exploratory study of what it is like to care for a husband who has Parkinson's disease, at home. The purpose of the study is to understand what it is like to be a caregiver and how it affects your life.

I have asked the nurse from the Movement Disorder Clinic to give you and other women who are caring for husbands with Parkinson's disease, this letter of information. Please feel under no obligation to participate. It is your right to refuse to participate or withdraw from this study at any time without any jeopardy to your or your family's present or future health care.

If you are interested in being involved in this study, I will arrange with you to meet in your home or another setting that is convenient for you. When we meet, I will explain the study and answer any questions you may have. I will then ask your written consent.

I would like to interview you anywhere from one to three times. In the first interview, we will discuss your experience of looking after your husband. I will be asking you questions like:

1. Please describe for me, a typical day.
2. Can you tell me how you feel about the being a caregiver?
3. Did you feel prepared to become your husband's caregiver?
4. How have your activities as caregiver developed and changed over time?

The second interview will be to clarify things you and other study
participants have told me, to make sure that I have heard you correctly and to
discuss some topics in greater depth. Everything you tell me will be treated
confidentially. I will make sure any spoken or written reports I must make do
not contain anything about you that may identify you to listeners or readers.

I will audiotape our interviews to allow me to pay close attention to what
you are saying without distracting us both with note-taking. Being able to go
back to what you have told me using the tape, will help me when I compare
what you are saying to what others are telling me. Again, all information you
share with me will be treated confidentially. I will erase any names we have
used before others hear the tapes. Other people who may listen to the tapes
(which I will have numbered) will be my teaching advisors, and my typist.
Quotes from the tapes will be included in the report I must write of this study
but I will make sure that you will not be recognized. The tapes will be erased at
the end of this study.

The benefit I can offer you is the opportunity to tell your story, to be the
expert witness of what life is like for you and in doing so contribute to nursing
knowledge and understanding about women like you. When the study is
complete, I will send you a summary of the findings, if you wish.

If you have any questions and/or would like to participate in the study,
please contact me at (home phone number). Around suppertime is the best
time to contact me. If I am not home, please leave your telephone number on
my answering machine and I will return your call.

Thank you for your attention.
Appendix 4
Examples of Interview Questions

These questions will serve as a guide in the interviews. Additional questions will be developed in response to how the women describe their experience. For example I may initially use the word caregiver, but that word and other words used may change to reflect the terms used by the women themselves.

1. What is it like for you to live with and look after a husband who has Parkinson's disease?
2. How did life get to be the way it is now?
3. What is it like to talk about your experiences as your husband's caregiver?
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