INSTITUTIONALIZATION OF A SPOUSE WITH ALZHEIMER'S DISEASE: A PHENOMENOLOGICAL STUDY OF THE EXPERIENCE OF THE ELDERLY WIFE CAREGIVER

By

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ABSTRACT

INSTITUTIONALIZATION OF A SPOUSE WITH ALZHEIMER’S DISEASE: A PHENOMENOLOGICAL STUDY OF THE EXPERIENCE OF THE ELDERLY WIFE CAREGIVER

This study describes the experience of the elderly wife caregiver during the initial period of institutionalization of her husband with Alzheimer’s disease. Phenomenology was the research method used because of its unique focus on revealing an experience from the perspective of the participant. Because problems in health care arise from the differing perspectives of professionals and lay persons, discovery of the caregiver’s perspective was considered to be essential in order for professionals to provide care which is sensitive to caregiver needs.

Data were collected through 16 interactive interviews with 8 wives who were between 64 and 78 years old, and whose husbands with Alzheimer’s disease had been living in an institution for between 4 and 13 months. Reflective analysis proceeded concurrently with interviews and continued following interview completion. The insights achieved were synthesized and integrated into a consistent description of the experience.

Throughout the accounts of the experience, uncertainty was the pervasive and unifying theme. The uncertainty which the wives experienced was described as having its source in two forms of separation. These two forms of separation, separation of husband from home, and separation of husband
and wife, had parallel structures which included expressions of uncertainty, factors influencing uncertainty and management in the state of uncertainty. Uncertainty was the way in which wives experienced both continuing responsibility for their husbands' well-being and lives as married widows. The summary description of the total experience for the wives was that it was worse than death.

The findings confirm that the wives' burden is not relieved by institutionalization of their husbands. Thus they also confirm the continuing need for caregiver care. The findings also demonstrate that failure of professionals and others to understand the experience from the wives' perspective contributes to caregiver burden following institutionalization of husbands with Alzheimer's disease.
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Chapter 1
INTRODUCTION
Background to the Problem

Alzheimer's disease is an irreversible disease of unknown etiology which results in unexpected and premature decay of central nervous system tissue and function (Whitney, 1985). Because of this decay the essential feature of the disease is dementia with characteristic loss of intellectual abilities of sufficient severity to interfere with social or occupational functioning (American Psychiatric Association cited in Whitney, 1985)

It has been estimated that approximately 10% of the population over the age of 65 is affected by dementia (Robertson & Reisner, 1982), and while Alzheimer's disease is only one of several possible causes, it is estimated that half of all of those who suffer from dementia suffer from Alzheimer's disease (Williams, 1986). By 1983 approximately 100,000 to 300,000 Canadians were affected by Alzheimer's disease, and these numbers can be expected to increase along with the steadily increasing elderly proportion of the Canadian population (Hirst, 1983). The significance of Alzheimer's disease as a health problem, therefore, is clear.

The course of Alzheimer's disease is described as progressive, involving three stages (Gwyther & Mattison, 1983; Williams, 1986). The first stage, lasting 2-4 years is characterized by memory loss, time and space disorientation, mistakes in judgement and affect changes. The second and
longer lasting stage (from 2 - 12) years includes increasing disorientation and aphasia, restlessness at night, forgetting of socially acceptable behaviour and progressive physical disability. The third and generally terminal stage is the stage during which the individual becomes bedridden, incontinent, and withdrawn, and suffers loss of motor and sensory performance. It is during this third stage that the patient is usually institutionalized (Whitney, 1985; Williams, 1986).

Patients who have dementia account for approximately 50% of all nursing home occupants (Rowe, 1985). Still, research has shown that in spite of the immense problems which result from mental and physical deterioration during the course of the disease, the majority are cared for in the home by family members, often for many years (Robertson & Reisner, 1982; Mann, 1985; Chenoweth & Spencer, 1986). Recent recognition of the tenacity of family caregivers in maintaining patients at home, and current emphasis on keeping the elderly out of institutions to maintain their quality of life and contain health costs, has stimulated considerable research (Brock & O’Sullivan, 1985; Davis, 1980; Fengler & Goodrich, 1979; Gilhooly, 1984). Much of this research is directed towards identification of ways of providing support needed to preserve the difficult caregiving role. In this respect the caregiver performing the caregiving role is recognized as being as much in need of care as the patient.

However, the possibility that the need for care for the
caregiver continues to be important during the initial period of institutionalization has not been reflected in the literature. As Colerick and George (1986) said, "a caregiver’s decision to relinquish care to professionals is frequently difficult due to an intense and exclusionary bond with the patient, and it most often follows a period of cumulative strain and fatigue" (p.493). It is not surprising, therefore, that caregivers have expressed the feeling that much more could have been done to make the experience of transition to an institution easier for them and their relatives (Chenoweth & Spencer, 1986).

No definite guidelines were found in the literature regarding the duration of the initial period of adjustment to institutionalization for either the patient or the family members. However, Locker (1981) describes the first month of institutionalization as the most difficult, while Chenitz (1983) suggests that crisis resolution is achieved in about eight weeks. In one study newly institutionalized is defined as having been admitted to a care facility for not more than three months; however, no rationale was given for this definition (Brock & O’Sullivan, 1985).

It has been the researcher’s experience during several years of clinical experience in nursing that interactions between staff and caregivers, particularly during the early period of placement in a facility, frequently involve conflict. Some have suggested that this conflict arises as a result of professional tendency to focus on the needs of the
afflicted member while overlooking the family caregiver (Annett, 1986; Linn & Gurel 1969; Mann, 1985; Schmidt, 1987).

The researcher's interest in institutionalization of a spouse with Alzheimer's disease was stimulated by the surprising revelation of an elderly wife caregiver who, in looking back on her experience at the time of institutionalization of her husband, described the suffering she had experienced. Much of her suffering was due to her intense feeling of being misunderstood by the staff of the facility to which her husband was admitted.

Desire to study the experience of elderly wives was reinforced by the researcher's awareness of the numbers of wives who encountered this experience. The fact that caregiving has traditionally been defined as a woman's role and that women live longer and tend to marry older husbands means that most demented males are cared for at home by their wives (Colerick & George, 1986; Fengler & Goodrich, 1979; Zarit, Todd & Zarit, 1986). Understanding of the experience of elderly wives, therefore, would seem to be of great significance to those caring for patient's with Alzheimer's disease.

Conceptualization of the Problem

Within the nursing profession, the importance of studying health problems from the client's perspective is being recognized (Hayes & Knox, 1984; Lynam & Anderson, 1986, Robinson, 1985). It has been suggested that such a perspective promotes clinical practice which is responsive to
the client's needs by facilitating professional definition of problems and prescription of solutions which are congruent with the client's point of view (Anderson, 1985).

One conceptualization of health and illness which is helpful in explaining the differences between nurses and clients with respect to their explanations and interpretations of health and illness comes from the work of Kleinman in the field of medical anthropology (Anderson 1981, 1985). According to Kleinman (1978), health care professionals belong to a specific cultural and social system having its own system of meanings and behavioural norms, while clients of health care professionals belong to different cultural and social systems and thus have their own systems of meanings and norms. As a result of differences in meanings and norms, members of each cultural group understand and explain reality in different ways. These explanations of reality are what Kleinman (1977, 1978) calls explanatory models. They form the basis for the explanatory model approach to health care (Kleinman, 1978, 1982) which provides the framework for conceptualization of the problem in this study (see Figure 1).

Within the health care system, Kleinman (1978) suggests that there are three distinct sectors in which sickness is experienced and reacted to: the popular sector (individual, family, society and community), the folk sector (self-help groups, religious practitioners, heterodox healers) and the
EXPLANATORY MODEL FRAMEWORK: HEALTH CARE RELATIONSHIPS
AS TRANSACTIONS BETWEEN EXPLANATORY MODELS

Adapted from:
professional sector (doctors, nurses and other health care professionals). Interactions between professional and lay persons which occur in health care relationships are transactions between the explanatory models of the sectors. During health care transactions, because explanatory models are determined by specific systems of knowledge and values centered in the different sectors, differences between the models frequently occur, often resulting in problems in clinical communication and in clinical management.

Differences in explanatory models arise from differences in the perspectives between the sectors. Within the professional, popular and folk arenas, Kleinman (1978) contends that sickness is viewed in distinctively different ways. Professionals, he says, usually focus on the diagnosis and treatment of disease which involves "abnormalities in the structure and function of body organs and systems", while those in the popular and usually the folk sectors deal with "illness". Kleinman and associates (1978) have described illness as "experiences of disvalued changes in states of being and in social function; the human experience of sickness" (p.251). Problems arise when professionals provide care which is responsive to the disease while neglecting illness.

Differences between explanatory models of professionals and their clients also occur because of differences in personal beliefs and values (Anderson, 1987; Kleinman, 1981). Sources of personal perspectives are diverse,
including economic background, social background, life experiences, interests and other aspects of the day-to-day world of the individual. Problems arise when personal views of the professional are in conflict with those of the patient and family.

Eliciting the patient's explanatory model provides the professional with "knowledge of the beliefs the patient holds about his illness, the personal and social meaning he attaches to his disorder, his expectations of what will happen to him and what doctors (professionals) will do and his own therapeutic goals" (Kleinman, Eisenberg and Good, 1978, p.256). The direct influence of the explanatory model on all client decisions regarding health care makes it essential that the professional understands the client's own model.

Thus Kleinman's explanatory model framework indicates that the suffering experienced by the caregiver as a result of perceived staff misunderstanding, and the conflict observed by the researcher and others between family caregivers and professionals, can be understood as the outcome of differences in explanatory models. The greater the level of professional understanding of the explanatory model of caregivers through discovery of the caregivers' own experience, the greater the possibility of negotiating care which is appropriate for the caregiver and satisfying for both caregiver and professional (Anderson, 1981, 1987).
Problem Statement

The initial period of institutionalization is potentially a time of extreme difficulty for the elderly wife caregiver; yet no research could be found which documents the experiences of these individuals during that time. Because the decision to institutionalize is a difficult one, often experienced at a time of physical and emotional exhaustion, the likelihood that caregivers continue to require care during this time must be considered. Failure to provide care which is sensitive to their needs can result in suffering for the caregiver and conflict between caregiver and staff. Therefore, if nurses are to provide optimal care to caregivers throughout this period in the course of Alzheimer’s disease, it is essential that they recognize and understand the caregivers’ experience of institutionalizing their spouses.

Purpose

The purpose of this study is to describe the experience of the elderly wife caregiver during the initial period of institutionalization of her spouse with Alzheimer’s disease.

Research Question

What is the experience of the elderly wife caregiver during the initial period of her spouse’s institutionalization with Alzheimer’s disease?
Theoretical and Methodological Perspective of the Study

According to Field and Morse (1985), "For each question, there is a best or most appropriate method, and selecting the method is the most important decision in the research process" (p. 29). This view has been widely supported (Colaizzi, 1978; Giorgi, 1970; Rist, 1979). Phenomenology was the research method chosen for the study because it is believed to be the best and most appropriate approach for answering the research question posed. The following brief description of the philosophical and methodological perspectives of phenomenology will reveal the reasons for this decision. An account of the way in which the phenomenological method was implemented in the study will be presented in Chapter 3.

The research question for the study developed as a result of identification of a problem in nursing practice. This problem was conceptualized with guidance from Kleinman's explanatory model as a problem arising from differences between professional and lay caregiver explanatory models of an experience. The researcher thus identified the need to explore the experience of institutionalization of a husband with Alzheimer's disease in a way that would reveal the explanatory model of the elderly wife caregiver from her own perspective, while at the same time contributing results that would be significant to the nursing profession. Phenomenology is a theoretical perspective and a research method ideally suited to both exploring the experience from
the wife's perspective and contributing results that are significant for nursing.

Phenomenology is a qualitative research method that, unlike the more familiar quantitative method, is guided by the perspective that not all that is human can be measured in the mathematical sense, and further, that much of human experience cannot be revealed through a research method which isolates it from the lived in world (Giorgi, 1985; Lofland, 1971; Omery, 1983; Rist, 1979). Spiegelberg (1975) adds that the objective of phenomenology is to describe phenomena "without theories of their causal explanation and as free as possible from unexamined preconceptions and presuppositions" (p.3). For these reasons, when human experience is the focus of study, qualitative research methods such as phenomenology are most often viewed as an alternate form of inquiry to quantitative or traditional scientific methods (Sandelowski, 1986).

The goal of phenomenology was considered to be congruent with the study of a question about what an experience is like. The explicit goal of phenomenological investigation includes discovery and description of the essential structure of an experience from the perspective of those who have lived it (Merleau-Ponty, 1964; Psathas, 1977; Spiegelberg, 1970). Essential structure has been described by Psathas (1977) as "descriptions of those elements which are necessary to produce the appearance and recognition of an event" (p. 93), and by Merleau-Ponty (1964) as, "that which cannot be varied
without the object (concrete experience) disappearing" (p. 70). Thus the validity of the essential structure of the experience as described by the researcher, rests on the recognition of the experience by those who have lived it. The outcome then is what Psathas refers to as an "intersubjectively verifiable" account of the experience (p.93).

In order to achieve the stated goal, the phenomenological method requires the researcher to be involved subjectively in the entire research process. The researcher gathers data by engaging in total and active interaction with those who have lived the experience; collects and analyses data in a simultaneous, non-linear process, and derives conceptual and categorical explanations from in-depth analysis and interpretation of the data themselves (Bruyn, 1970; Filstead, 1970; Giorgi, 1985; Lofland, 1971; Watson, 1985). Objectivity in phenomenology does not arise from objective behaviour of the researcher but from "fidelity to the phenomenon" (Colaizzi, 1978, p. 52).

The fact that phenomenology reveals the account of the experience through interaction with the subjects themselves was perceived as an essential requirement for discovery of the explanatory model of the experience of family caregivers. Phenomenologists recognize that behaviour that is interpreted by an objective observer may have for the behaving subject "a very different meaning or no meaning at all" (Schutz, 1971, p.210) and that the individual and his
behaviour cannot be understood without asking how he appears to himself (Spiegelberg, 1975).

In addition to its suitability for answering a question about experience, phenomenology has the potential to contribute results significant for nursing. Nursing is frequently described as a profession that embraces a holistic approach to patient care (Capra, 1982; Oiler, 1982; Tinkle & Beaton, 1983). Oiler maintains that this approach requires the researcher to go "to people in their circumstances where they are involved in the world" (p. 179). The phenomenological method is consistent with this description of holistic approach.

Nurses place a high value on the subjective internal experiences of individuals. Caring, which is often referred to as the essence of nursing, involves an interactive, intersubjective and collaborative human to human relationship (Leininger, 1985; Oiler, 1982; Omery, 1983; Tinkle & Beaton; 1983; Watson, 1985). "The subject of phenomenological research is human experiences - their types, and their structures, along with their subjective meaning, essence and relationships" (Watson, p. 80), phenomenology therefore was determined an appropriate research method for this study.

Definition of Terms

The following are operational definitions of terms used in the research question of this study:

1. Elderly: Persons of 60 or more years of age.
2. Alzheimer's Disease: An irreversible disease of unknown
etiology which results in unexpected and premature decay of the central nervous system tissue and function (Whitney, 1985).

3. Experience: "An actual living through an event; personally undergoing or observing some thing or things in general as they occur" (Friend & Guralnik, 1958).

4. Caregiver: The family member providing care in a care-giving dyad consisting of the care-receiver (husband) and the individual providing care (wife) (Cantor, 1983, p.599).

5. Institutionalization: permanent placement in a facility which provides care and supervision 24 hours a day.

6. Initial period of institutionalization: approximately the first three months of permanent placement in a care facility.

Assumptions

This study was based on the following assumptions:

1. The initial period of institutionalization of her spouse constitutes a significant experience for the elderly wife caregiver.

2. The elderly wife caregiver who institutionalizes her spouse is able to describe that experience.

Limitations

The participants in this study were considered to be qualified representatives for elderly wives who have experienced institutionalization of a spouse with Alzheimer's disease. Only those caregivers who were willing and able to
describe the experience of institutionalizing their spouses were selected. Since the reality of the experience of the wives is constructed within the context of their own lives, they were able to reveal only the experience of the cultural and social systems to which they belong.

Summary

This chapter has presented a description of the background to the problem, a framework for the conceptualization of the problem, and a statement of purpose. Definitions, assumptions and limitations of the study were also described. A brief rationale for selecting the phenomenological method was provided.

The rising incidence of Alzheimer’s disease in an aging society has resulted in increasingly frequent interaction between professional and lay caregivers when its victims are institutionalized. The conflict which frequently results between these two cultures has been conceptualized with guidance from Kleinman’s explanatory model as a problem arising from differences in explanatory models of the experience. The resultant need for professionals in nursing to understand the lay experience from the perspective of the caregivers themselves was identified. Because of its unique focus on human experience from the subjective viewpoint of those who have lived the experience, phenomenology was selected as the research methodology most appropriate to contribute the knowledge about the caregivers’ experience which is needed in nursing.
Chapter 2

REVIEW OF SELECTED LITERATURE

In this chapter, a review of selected literature provides an overview of current knowledge contributing to understanding the experience of caregivers who institutionalize their spouses with Alzheimer’s disease. The review is divided into two sections. The first section relates to the caregiving experience itself. In this section, literature concerning the caregiving experience in chronic illness and in Alzheimer’s disease, and the experience of spouses and of wives as caregivers is reviewed. In the second section a review of literature about the caregiver’s experience of institutionalization is presented. Literature related to the decision to institutionalize and to the caregiver’s experience following institutionalization is included.

The Experience of Caregiving

Caregiving in Chronic Illness

For many years, literature pertaining to caregiving in chronic illness focused almost exclusively on chronically ill individuals since meeting their needs was seen as prerequisite to maintaining them at home. More recently, family members who maintain these individuals in the home have received recognition. Several studies have contributed to awareness of the significance of the lay caregiver’s role and of the demanding nature of this role.

In an early descriptive study of chronically ill and
disabled patients requiring home care, the role of lay caregiver was labelled the "responsor" role because lay caregivers were expected to respond to and be responsible for patient needs (Golodetz, Evans, Heinritz and Gibson, 1969). Furthermore, these authors identified the role as "an important resource in the problem of medical manpower" (p. 385).

Isaacs (1971) provided support for this assertion and added recognition of the onerous demands of the caregiving role on caregivers. He studied reasons for admission of 280 patients from home to a geriatric unit. Contrary to common belief that institutionalization often occurs because of family neglect, most individuals were cared for at home "until they became so disabled and made such heavy demands that their helpers could no longer cope" (p.284). "Intolerable strain" which was identified as the frequent cause of the patient’s admission to hospital was described as "a burden of care arising from the patient’s illness which threatened either the physical or mental well-being of the relatives or both" (p. 283). Patient problems most often related to intolerable strain included immobility, incontinence and mental abnormality.

The results of a later study by Sanford (1975) provided support for Isaac’s work. Caregivers in the process of admitting their dependent member were asked to identify problems which would have to be alleviated in order to restore a tolerable situation at home. Sleep disturbance
(due to night wandering and immobility), and fecal incontinence were problems most often identified. All of these problems are characteristic of the Alzheimer patients.

Research concerning caregiving in chronic illness thus has contributed to awareness of the significance of the caregiver's role in maintaining home care of the chronically ill, recognition of the hardship inflicted by the caregiving role and identification of patient symptoms considered to be sources of greatest hardship.

**Caregiving in Dementia**

Growing awareness of the essential contribution of lay caregivers in keeping the chronically ill, the disabled and the elderly out of institutions has guided researchers concerned with dementia in general and Alzheimer's disease in particular to explore the effects of caregiving on the caregiver. One of the expectations guiding this research was that relief from problems such as immobility, incontinence and sleep disturbance would reduce caregiver burden and make continued home care more tolerable. Such studies have not succeeded in identifying factors which could ease burden. They have, however, contributed significantly to awareness of the immediate and long-term impact of caregiving on the caregiver and on caregiver health.

Zarit, Reever, and Bach-Peterson (1980) conducted a study of 29 people with senile dementia and their caregivers for the purpose of identifying interventions which would reduce sources of burden. Caregivers responded to a "burden
interview" designed to measure the degree of emotional, physical, social and financial suffering which resulted from caring for their relative. Degree of burden was related to measures of social support, quality of the relationship and severity of the illness. None of the behaviour variables, including those patient problems identified as contributing to intolerable strain in earlier research, correlated with perceived caregiver burden. The authors concluded that subjective factors were more important than severity of illness in determining the degree of burden.

Gilhooly (1984) adopted a different approach to studying the effects of the caregiving experience on the caregiver but found similar results. Rather than focusing on caregiver burden, she focused on correlates or mediators of caregiver well-being. She examined relationships among variables such as level of impairment, duration of support, marital status, age, sex, role relationship and quality of the relationship, and measurements of morale and mental health. Contrary to researcher's expectations, level of patient impairment was not significantly associated with morale and mental health of caregivers. Although the researcher assumed that the impact of caregiving for a demented person would be negative, the support for this assumption was marginal. At the same time, however, "caregivers expressed severe distress during interviews and reported experiencing considerable burden" (p.40). Gilhooly's results, like those of Zarit and associates demonstrate that there is a significant subjective
component which mediates the impact of other variables on the caregiving experience.

Recognizing the conceptual confusion created by the varying approaches to measuring the effects of caregiving on the caregiver, Poulshock and Deimling (1984) proposed that the concept of burden refer to the subjective interpretations by caregivers of problems that result from caregiving, while impact refer to objective effects which are more easily measured. They were critical of studies in which combinations of subjective responses and objective measures were used in the operational definitions of the effects of caregiving. The model proposed was based on the assumption that "the burdens caregivers experience are the result of their highly personalized and individualized responses to specific caregiving contexts" (p. 231).

The results of their study of 233 elders who were mentally and or physically impaired confirmed the distinction between burden and impact. They found that burden measured as the caregivers' subjective perceptions was the mediating force between the elders' impairments and the impact of caregiving on caregivers. Their findings indicate that impairment, burden and impact resulted in both independent and additive effects on the caregiver. This explains why studies which do not differentiate these concepts, such as those of Zarit and associates (1980) and Gilhooly (1984), failed to identify variables, especially patient problems which, if alleviated, could reduce caregiver strain. The
The conclusion of the study supports the suggestion that the caregivers' subjective experience contributes significantly to the impact of the caregiving experience on caregiver lives.

The need for recognition of the subjective nature of the experience is a theme appearing repeatedly in literature concerning all aspects of the caregiving experience (Cantor, 1983; Chenoweth & Spencer, 1986; Goodman, 1986; Given, Collins & Given, 1988; Linn & Gurel, 1969). Therefore, to understand the caregiver's experience of institutionalization as part of the total caregiving experience, it is essential that the subjective perceptions of the caregivers be revealed.

**Spouses as Caregivers**

The significance of the spouses' contribution to caregiving outside of institutions has been clearly recognized in the literature. According to Shanas (1979) and Johnson (1983), a principle of substitution operates to determine who within a family accepts the caregiving role. This principle holds that support is extended most often by one family member at a time, and that, in serial order, the spouse functions as the primary caregiver; in the absence of the spouse, a child assumes the role; and in the absence of offspring, another member is responsible.

The degree of strain experienced by spouse caregivers has also been documented. Cantor (1983) conducted a study of 111 caregivers for the purpose of discovering ways of
strengthening informal caregiving capacities. Caregivers, who varied in age, sex and relationship to the patient, were asked a series of questions designed to measure strain and the impact of caregiving on private life. The relationship of the caregiver to the care-receiver contributed the greatest variance in caregiver strain. The type of caregiver at greatest risk was the spouse. All caregivers reported a negative impact on private life, but the impact was most severe in the case of spouses. Cantor concluded that "the amount of strain and disruption of daily life is very different for different groups of caregivers", and added that, "the data underscore the danger of global solutions" (p.603).

In spite of the degree of strain experienced by spouse caregivers, the literature provides support for the suggestion that these people, many of whom are old and frail themselves, are the last to relinquish care to professionals (Chenoweth & Spencer, 1986; Colerick & George, 1986; Smallegan, 1985; Soldo & Myllyluoma, 1983). The fact that spouses are first in line for selection as caregivers, are at greatest risk for strain and are most reluctant to relinquish care suggests that their need for support requires particular attention.

Wives as Caregivers

In the literature, the majority of caregivers are female, usually a wife or daughter. In fact, the prevalence of women in the caregiving role prompted Sommers (1985) to describe
caregiving as a women's issue. Accordingly, the experience of wives as caregivers has received attention.

Fengler and Goodrich (1979) specifically identified wives of elderly disabled men as a health care concern; they described the wives as "the hidden patients" (p.175). The researchers estimated that two thirds of the men in their study would have been institutionalized were it not for the care of their wives. The purpose of the study was to determine the cost of the wives' contribution by examining their special needs and problems. Results showed that depending on the degree of disability, the wives of the disabled men suffered from low life satisfaction, role overload, loss of intimacy and companionship, isolation and loss of social support. Fengler and Goodrich concluded that, "Many of the wives need help and support as much as their husbands do" (p.183). Because wives who are caregivers represent a very large number of those who are also at greatest risk for caregiver strain, they have been selected as the subjects of this study.

The Caregiver's Experience of Institutionalization

Research concerning the caregiver's experience of institutionalization has had two major foci: the decision to institutionalize and the experience of the caregiver following institutionalization.

The Decision to Institutionalize

Approaches to studying the decision to institutionalize have been directed towards finding ways of preventing or at
least delaying institutionalization. Regardless of their purpose, these studies have contributed knowledge about the predictors of the decision, resistance to the decision and the experience of deciding which in turn have contributed to knowledge about the caregivers' experience of institutionalization.

**Predictors of institutionalization.** Some caregivers care for their patient at home for many years while some decide to institutionalize their patient much more quickly. Recognition of the importance to the health care system of prevention of premature or unnecessary institutionalization has stimulated research designed to study the variability among caregivers regarding predictors of the decision to institutionalize their patients.

Two such studies, one by Colerick and George (1986) and one by Zarit, Todd and Zarit (1986) were designed to identify variables which could predict a placement decision on the part of an Alzheimer's caregiver. Structured interview methods were used in both studies to gather data about similar variables, the major difference being that Zarit and associates measured burden as a variable, and Colerick and George measured caregiver well-being. Findings of both studies indicated that subjective factors, such as caregiver perception of well-being and burden, differentiated those who decided to place their patient from those who continued to care for them at home while objective indicators of the severity of dementia did not. These findings mirror those
cited earlier regarding the importance of the subjective perception of the caregiving experience in measuring the effect of the caregiving experience on the caregiver (Gilhooly, 1984; Poulshock & Deimling, 1984; Zarit et al., 1980). The impact of subjective caregiver experience on both degree of burden and the decision to institutionalize prompted Zarit and associates to suggest that "the variability in caregiver's reactions is, in fact, of major importance for planning interventions to alleviate their stress" (p.265). These studies again point to the need for studying the caregivers' subjective experience.

Gilhooly (1986) studied factors associated with caregivers' preference for institutional care in senile dementia. Data were gathered in intensive semi-structured interviews with caregivers. Similar to the findings of Zarit and associates (1986) and Colerick and George (1986), regarding impact of the caregiving experience on the caregiver, neither the dementing dependant's characteristics nor the objectively-measured psychological well-being of the caregiver were significantly correlated with preference for institutional care. However, results did indicate that preference for institutional care was positively correlated with lower caregiver age, and with employment. Since the spouse caregivers of patients with Alzheimer's disease are generally older, and not employed, these people would most likely belong to a group with least preference for institutional care.
Gilhooly (1986) also found that the closer the blood/role relationship and the better the quality of the relationship prior to the development of dementia, the lower the preference for institutional care. She observed that "many of the spouses in the sample took their marriage vows quite literally, and said they would continue with home care 'until death do us part’" (p. 169). She also observed that while some caregivers felt unwilling to continue giving care, they strongly wished to avoid institutionalization. So strong was their desire to avoid institutionalization that caregivers often stated that the dementing relative’s death would be preferable to institutional care. Reason for resistance to institutionalization is another subject which has received attention in literature.

**Resistance to institutionalization.** Two major sources of caregiver resistance to institutionalization have been documented: attitudes toward institutional care and the meaning of the caregiving role.

The prevailing negative social attitude toward institutional care for the chronically ill has been labelled as a common belief or common stereotype (Lieberman, 1969). Davis (1980) described this stereotype in a qualitative study which included examination of the family’s decision to keep a mentally or physically disabled family member at home. A composite of the responses of 30 families to open-ended questions revealed that the families described institutions as "too regimented, breeding dependency, offering
depersonalized rather than individualized care and not meeting the patient's special needs for privacy, comfort and own developmental pace" (p. 478). Other findings frequently cite perceptions that institutions contribute to further decline in health and even hastened death, and that institutions are dumping grounds for unwanted elderly relatives (Brock & O'Sullivan, 1985; Lieberman, 1969; Shuttlesworth, Rubin, & Duffy, 1982). This negative image encourages resistance to placement and contributes to the guilt which caregivers experience following a decision to institutionalize (Annett, 1986; Mace & Rabins, 1981).

The meaning of the caregiving role for the caregiver is another major reason for resistance to institutionalization. As the role expands, dominates all other roles and is defined in a positive way by the caregiver, it becomes a role that is difficult to relinquish.

In a longitudinal study of family supports to the impaired elderly, Johnson and Catalano (1983) demonstrated the way in which the meaning of the caregiving role was influenced by what was identified as caregivers' adaptive strategies for alleviating the strain and burden of their roles. Structured and unstructured data gathered from elderly caregivers revealed that caregivers used "enmeshing techniques" (p. 617). The first technique, used mainly by couples, was social regression. As patient dependency persisted, the relationship with the caregiver intensified often to the exclusion of other relationships. As a result,
the partners were increasingly forced to depend upon each other for need satisfaction. The second technique was role entrenchment through which caregiving was accepted as a permanent, full-time role that took precedence over other roles.

According to Goldstein, Regnery and Wellin (1981), a similar situation labelled role constriction occurs when the caregiver becomes almost as housebound as the patient, all other roles and functions become subordinate, and functions of caregiving increasingly demand the caregiver's time and energy. Caregivers in Johnson and Catalano's study managed role constriction by redefining the exchange relationship as one which provided altruistic rewards of enhanced self-esteem and a sense of competence. Thus the caregiving role was seen as giving meaning to life. Similarly, Davis (1980) found that maintaining the patient at home provided some family members with purpose or meaningfulness. The relationship gave pleasure and closeness. In addition, the caregiving role fulfilled what families believed was their individual and moral responsibility.

Hirschfeld (1983) reported that "mutuality" differentiated caregivers who placed their patients from those who continued to care for them at home. Mutuality resulted from the caregiver's ability to find gratification in the relationship and meaning from the caregiving situation; it included perception that the impaired person reciprocated by virtue of his or her existence. For these
caregivers caregiving meant never being alone.

Because women, most of whom are spouses, most frequently occupy the caregiver role, the meaning of the caregiving role to them is particularly significant. Larson (1985), in a study of wives caring for elderly husbands at home, reported that the wives highly valued the caregiving role, and that accepting the role and the attendant sacrifices was "their duty as wives" (p. 62). The wife's tenacity in maintaining her husband at home revealed the values she held about her roles as wife, homemaker and caregiver. These roles had "come to constitute her life's vocation (p. 84). Similarly, Davis (1980) describes women's perception of the caregiving role as follows:

The woman in the family perceived the care-taking role as the essence of mothering, nurture, and the apex of dependency, which she accepted as mostly positive under the circumstances. She placed a high priority on interpersonal relations and a particular relationship with the disabled adult gave her a meaningful substitute for other relationships, an alternative to guilt and in many ways protected her socially and psychologically. With few exceptions she accepted the traditional female role definitions. She often felt that as long as the disabled individual stayed at home she would not be left alone (p. 480).

Thus resistance to institutional placement arises from the negative social perception of institutional care and from
the fact that the caregiving role occupies a central place in
the lives of the caregivers. The reason for maintaining the
disabled person at home for as long as possible is generally
a combination of an affective bond to the patient and an
aversion to nursing home placement (Goldstein et al., 1981).
In spite of strenuous resistance, however, institutionalization of an Alzheimer’s patient is almost
inevitable (Whitney, 1985; Williams, 1986).

The experience of deciding. Regardless of the burden and
the many problems which result from caregiving, the decision
to institutionalize appears to be a difficult one for most
caregivers. In a study designed to examine the experience of
families throughout the course of Alzheimer’s disease, the
experiences of caregivers who institutionalized their patient
were investigated (Chenoweth & Spencer, 1986). Those who had
institutionalized their relative were asked to discuss their
reasons for choosing long term care and their satisfaction
with the decision.

Reasons given for the decision to institutionalize
included behavioural problems, incontinence, combativeness,
wandering, and lack of sleep, all of which had been recorded
previously in the literature (Isaacs, 1971; Sanford, 1975;
Smallegan, 1981). Some said that the decision was forced
upon them when they became ill or injured during care.
However, almost 75% gave as their reason that they "couldn’t
take it any more" and that "24 hour care was impossible".
Some said that they "simply wore out" (p.271).
Some caregivers were convinced by the recommendation of the doctor or family members that it was time for institutionalization. This happened when most said that they "were too tired to make decision or to think clearly" (p.271). Some resented such outside decision-making while some appreciated it. For some, having others make the decision eased guilt feelings. This situation was also reported by Smallegan (1985) who found that "by the time the decision was made most patients had been cared for at home for a period of time and the people at home were so stressed that ... they were ready to decide on nursing home placement even though the decision was painful" (p.284). Consideration therefore must be given to the possibility that caregivers deciding to institutionalize under these stressful circumstances and in spite of their strenuous resistance may themselves require care.

The Caregiver's Experience Following Institutionalization

The fact that caregivers may continue to require considerable support after placement of their patient can be inferred from their reluctance to resort to placement in the first place, and from the fact that many of the problems resulting from the caregiving role are of the type that are likely to persist after institutionalization. Problems such as social isolation, loss of friendship, destruction and disintegration of family ties, giving up of leisure and volunteer activities and failure to look to the future have all been identified as results of the huge impact of
caregiving on caregivers' lives (Chenoweth & Spencer, 1986; Fengler & Goodrich, 1979; George & Gwyther, 1986; Robertson & Reisner, 1982). In spite of the fact that such problems are unlikely to be solved completely with institutionalization, little research was found which was concerned with the experience of caregivers who had decided to institutionalize their demented patients.

Two studies, though not designed primarily to examine the caregivers' experience following institutionalization, provided indications that caregivers may continue to require care. In a longitudinal study of 376 informal caregivers of older persons with Alzheimer's disease or a related disorder, Colerick & George (1986) assessed patient characteristics, caregiver characteristics, and caregiver burden, and compared the data for those who continued to care for their patients at home to those who had decided to institutionalize. Data were gathered on two occasions, separated by one year, through administration of a questionnaire. Those who had institutionalized their patients reported more satisfaction with leisure time as well as greater likelihood of using psychotropic drugs and decreased support from friends.

The researchers attributed the blending of negative and positive changes to the recency of institutionalization (which in all cases was within one year). In addition, the findings prompted the researchers to suggest that "upon institutionalization of the patient the social network dissipates, leaving the caregiver relatively isolated" and
that relinquishing care to professionals may not relieve the caregiving burden" (p.498). This is consistent with findings of Poulshock and Deimling (1984) described earlier, that the effect of the emotional burden of caregiving on the caregiver has both independent and additive relationships to the impact of providing physical care. The emotional effect may well continue even when the physical demand is relieved.

The study by Zarit and associates (1986) described earlier also indicates that the need for caregiver support continues after the dependent's institutionalization, and suggests that special consideration is needed for caregiver wives. Wives who had placed their husbands all reported minimal social support. The researchers suggested that "the prospect that some caregivers remain isolated and unsupported after placing a spouse should be considered" (p.265).

Following institutionalization, problems cited most frequently were lack of staff preparation for care of the Alzheimer's patient, and a feeling of frustration with the difficulty of the period of transition from the family's home to the nursing home.

The transition from home to institution is a difficult time for an elderly individual, frequently referred to in the literature as a crisis for those involved (Chenitz, 1983; Locker, 1982; Solomon, 1983). There is much evidence that radical environmental change may be responsible for many of the harmful psychological and physical effects often attributed to living in an institution (Lieberman, 1969).
Difficulties experienced by Alzheimer's patients during the transition from home to institution are understandable given their lack of adaptability. Mace and Rabins (1981) advise families that strange situations, confusion, and noises can trigger "catastrophic" reactions. Hall and Kirschling (1986) describe these reactions as overreactions precipitated by the brain-failed person's anxiety in "a situation in which he perceives only nameless terror and desires only escape" (p.133). Catastrophic behaviours include outbursts of noisiness, agitation and sometimes combativeness, and withdrawal from usual activities such as eating and talking (Hall & Kirschling, 1986; Mace & Rabins, 1981). Certainly, admission to a new facility has all of the components necessary to trigger such a reaction. Such a situation may reinforce common beliefs regarding the negative effects of institutionalization, thus increasing caregiver stress and guilt.

Problems faced by caregivers who institutionalize their patient have also been acknowledged. Mace and Rabins (1981) describe the adjustment as a difficult time in which the caregiver, who is tired from efforts of arranging placement is also experiencing feelings of sadness, grief and loss, and guilt that keeping the individual at home was not possible. Annett (1986) describes the experience of elderly spouses as one in which they face major reorganization of their lives while under tremendous stress. She says:

Separation of a married couple is a traumatic experience
at any age, but for the elderly ... institutionalization can be the ultimate loss among many losses experienced through the aging process (p.12).

In addition, the stress of adjustment for the elderly whose ability to cope with excessive pressure is already reduced, poses a threat to their mental health (Locker, 1982).

It has been the researcher's experience that professional staff in institutions do not always recognize the strain experienced by caregivers during the initial period of institutionalization. There is a tendency to expect that the caregiver should be happy once the burden of providing physical care has been removed. Yet situations as described by Goldstein (1983) arise in which the agitation and demands of the caregiver spouse caused "chaos on the nursing floor" (p.42).

Tremendous potential exists for the perceptions of professionals to clash with those of caregivers at the time of institutionalization. Tensions often arise because the spouse attempts to defend a threatened spousal role that is incompatible with the new setting (Schmidt, 1987). Discovery of incongruent role expectations between families prompted the suggestion that "it is conceivable that some members in either group may perceive incongruent expectations in the other group and, therefore, be less likely to perform appropriately a particular caring task" (Shuttlesworth et al., 1982, p.206).

Only one study (Brandwein, Postoff & Steinberg, 1979) was
found which investigated the caregiver's experience following institutionalization. Because the study was unpublished, complete details were not available; however, the findings provide support for caregivers' continuing need for care. The study, descriptive in design, focused on the lifestyle of spouses (N=18) who had placed their partners because of chronic illness, 40% of whom were brain damaged.

Findings related to two areas of the caregiver's lives: their lives while visiting their husbands and their lives in the community. When visiting their husbands, 50% of the spouses reported that they continued to provide physical care. Dissatisfaction with the quality of care, the need to feel needed, the need to be perceived by others as caring and devoted partners and the need to maintain marital stability for both themselves and their partners were given as the reasons. When in the community, they described themselves as being in a state of limbo, having all of the disadvantages of being widows but none of the advantages. As a result, they suffered conflict, guilt and ambivalence.

It is evident that the caregivers' burden is not likely to be completely relieved through institutionalization. Also, it is evident that the initial period of institutionalization is a time during which differing perceptions and expectations of lay caregivers and professional staff can potentially result in ineffective and inappropriate support for the caregiver. However, no studies were found which were designed to examine the experience of
the elderly wife caregiver of the Alzheimer's patient when she institutionalizes her spouse.

Summary

In this chapter, literature which contributes to knowledge and understanding of the caregiver's experience of caregiving and of institutionalization has been reviewed. Much support has been cited for the notion that the way in which caregiving is experienced depends on the caregiver's subjective perception of that experience.

Throughout the literature, the immense contribution of wives as caregivers is recognized. Wives are among the largest group of caregivers, the group most reluctant to relinquish care and the group of caregivers at greatest risk for negative consequences of caregiving. Studying their particular experience is therefore important.

Studies concerning the caregiver's experience of institutionalization have, for the most part, been concerned with the decision to institutionalize. Little has been documented about the caregiver's subjective perceptions of the caregiving experience in predicting institutionalization.

Tremendous resistance to institutionalization has been attributed to the negative image of institutional care and to the central meaning of the caregiving role in caregiver lives. In spite of this resistance, in the case of Alzheimer's caregivers, the decision must eventually be made, usually under stressful circumstances. In addition, many long-term effects of caregiving and persistent problems
indicate that upon institutionalization of their patient, caregivers themselves may require care.

The likelihood that appropriate support will be provided for caregivers is diminished by the conflict which often arises between professionals and family caregivers at the time of institutionalization. Studying the experience of elderly caregiver wives from their own perspective is therefore important to optimizing professional care to such individuals. The need for professionals to discover the caregiver's explanatory model of the experience is clear.
Chapter 3

METHODOLOGY

Phenomenology was the research method of this study. This method was considered to be most appropriate for answering the question about the caregiver's experience since the goal of phenomenology is to describe the essential structure of lived experience including the meanings that the experiences had for the individual who participated in them (Omery, 1983). In this chapter, implementation of the phenomenological approach is described including participants selection, data collection and analysis and ethical considerations.

Selection of Participants

Criteria for Selection

Criteria for selection of participants were as follows. They:

1. were women aged 60 years or older.
2. were of Anglo-Canadian ethno-cultural background.
3. had cared for husbands with Alzheimer's disease at home.
4. had husbands who had been living in an institution for one year or less.
5. were willing and able to express their feelings about institutionalizing their husbands

Rationale

One specific group of caregivers (wives over the age of 60) was selected for study since the literature indicates that mixing of groups, for example, daughters and wives,
tends to obscure differences in the experiences each may be having (Cantor, 1983). Caregivers of this age, sex and relationship to the patient were selected since they have been identified as the largest group of caregivers and, as spouses, are among those most reluctant to relinquish care to professionals and at greatest risk for strain.

Anglo-Canadian wives were selected because cultural variations might influence the experience of institutionalization. Comparison of caregivers who differ in age, sex, cultural background and relationship to the patient was beyond the scope of this study. The criterion of willingness and ability to express feelings about institutionalization of their husbands was necessary to obtain "the most insightful data possible" (Morse, 1986, p. 183).

Recency of the experience should be considered in phenomenology (Omery, 1983). Chenoweth & Spencer (1986) agree: "the passage of time is likely to affect perceptions of experience" (p.272). Furthermore, the first three months of institutionalization has been identified as the most difficult for those involved (Brock & O’Sullivan, 1985; Chenitz, 1983; Locker, 1982). Therefore, time since institutionalization was restricted to one year or less. During this time period, caregivers were expected to be experiencing the initial period of institutionalization or to have experienced it recently enough to ensure accurate and vivid memory of the experience.
Selection Procedure

In qualitative research, because of the volume of data which must be analyzed the number of participants is small (Omery, 1983; Morse, 1986; Sandelowski, 1986). The exact number is not decided in advance but is determined by the theoretical needs of the research (Morse, 1986). Initially participants are selected because they are able to illuminate the experience being studied, then additional participants are selected until understanding of the experience is coherent and confirmed and no new information is being provided (Sandelowski, 1986; Morse, 1986). Adequacy of sampling is evaluated by quality, completeness and amount of information rather than by number of subjects (Morse, 1986).

The participants were not known previously to the researcher. They were contacted through the Alzheimer’s Society support groups and through one long term care facility in the greater metropolitan area of a western Canadian city. After obtaining approval for the study from the agencies, the researcher met with agency representatives and support group leaders to explain the study further.

Support group leaders, a social worker from one long term care facility and an Alzheimer’s Society volunteer distributed letters (see Appendix A) explaining the study to potential participants who fit the criteria. Attached to these letters of explanation were forms for individuals to indicate their interest in hearing more about the study and willingness to have telephone contact with the researcher.
(see Appendix B). The researcher contacted each of the 10 individuals who returned the forms, explained the study in detail, answered any questions and, when appropriate, arranged an appointment for an interview. In this stage of the research convenience sampling was employed; the participants were not selected based on ability to contribute but on ability to meet selection criteria, availability to the researcher and willingness to participate (Morse, 1986).

Two of those contacted did not fit study criteria and so were not interviewed. The remaining eight agreed to participate in the study. Participants recruited in this manner included six who were contacted through leaders of Alzheimer's Society support groups, one who was contacted through the Alzheimer's Society office and one who was contacted through the long term care facility in which her husband lived. During the first visit participants were again provided with information explaining the study and were asked to sign a consent (see Appendix C). Once written consent was obtained and a brief demographic data sheet was completed (see Appendix D) the interview began.

When the eight participants originally recruited had been interviewed twice, no new information was being given, the data were coherent and preliminary meaning units were confirmed. Therefore the theoretical needs of the research were satisfied and no further participants were recruited. **Characteristics**

Participants ranged in age from 64 to 78 years with an
average age of 72 years. Their husbands ranged in age from
72 to 81 years with an average age of 75 years. All but one
of the wives in the study had been married only once. This
was the second marriage for one whose first husband had
died. The marriages had been long-lasting, seven of them
lasting for more than 40 years. The longest was 54.5 years
and the shortest was the second marriage of 14 years.

Seven of the couples had adult children. The children of
one couple were the husband’s from his first marriage. All
but this one couple had at least one child living in the same
metropolitan area. None of the children, however, lived at
home. All of the wives lived alone in their own homes.

Although the wives were all retired at the time of the
study, all but one had worked outside of the home in various
occupations. Four had worked in offices, one was a teacher
and while none of them had been professional caregivers
before their husbands illness, three had had occupations such
as therapeutic recreation or office work which had brought
them into contact with the health care industry. The
husbands’ occupations included two farmers, an auto mechanic,
a maintenance man, an engineer, a man who ran his own
business, a salesman and a policeman.

When asked when their husbands were diagnosed with
Alzheimer’s disease the wives were able to give a date when
the diagnosis was made; however, the approximate date when
the symptoms began was more important to them. The length of
time since that date ranged from 2 to 9 years. The date of
diagnosis was more recent, usually long after the symptoms had begun. All wives had cared for their husbands at home from the time of onset of the disease until his placement in a facility. At the time of the first interviews, the length of time since their husbands’ admissions ranged from 4 months to 13 months. All husbands were living in health care facilities.

Data Collection and Analysis

In phenomenology, the researcher searches for subjective meanings through participation in social communication with people who have had the experience being studied (Bruyn, 1970). The methodology of this study was therefore not a linear process but one which integrated data collection and analysis while placing emphasis on allowing the subjects to speak for themselves (Bruyn, 1970; Lofland, 1971). In order to gather data in this manner, the ethnographic approach to interviewing was utilized (Anderson, 1981b).

Allowing subjects to speak for themselves required that they be considered the researcher’s teachers with respect to their common experience. Spradley (1979) suggested that the word "informant" conveys this special relationship (p.25). Thus the wives who participated are designated "informants" in their accounts of the experience.

The mechanism for discovery was unstructured interviewing with an interview guide (Lofland, 1971; Spradley, 1979). Prior to the first interview, open-ended questions were developed (see Appendix E). These were intended to elicit
accounts or narratives from the perspective of the individuals being interviewed (Field & Morse, 1985). These questions were used only as a guide since the intent was that the subjects be encouraged to tell their own story, and questions were expected to arise throughout the interaction. This expectation was confirmed. In every case one question, often from the demographic data sheet stimulated the telling of the individual's story. As has been described in the literature, the wives seemed to have a definite need to tell their story (Cutler, 1985; Bloomfield, 1986). Thus, answers to questions were given without questions being asked and new questions arose as the researcher responded as openly as possible to accounts of the experience.

Interviews with each of eight participants were conducted in the participants' homes over a period of three months. Interviews were audio-taped and transcribed verbatim. Participants were allowed to describe the experience as it existed for them in an unbiased way, ensuring a "naive description" (Giorgi, 1975, p. 74). Throughout the interviews, which lasted from 45 minutes to two hours each, the researcher maintained an openness to the total interaction through a phenomenological attitude requiring openness, readiness and willingness to receive (Spiegelberg, 1970). Oiler (1982) has referred to this openness as "empathetic and intuitive awareness" (p.179) and Colaizzi (1973) describes it as "listening with the totality of his being" (p.58).
Upon completion of the interviews informants often shared important information, sometimes when the researcher was saying good-bye at the door. When possible, tape recording was resumed but frequently this information was recorded in written notes at the time or immediately following the interview in order to minimize loss of detailed and important data.

Once the interviews had been transcribed, they and the written notes were analyzed according to the phenomenological method described by Giorgi (1975). First, the entire interview was read for sense of the whole. The same description was then read again more slowly to identify transitions or units of experience called meaning units. Meanings are not simply descriptions of behaviours but are interpretations of behaviour among participants in a social world (Lofland, 1971).

Meaning units that repeated one another were integrated, and the remaining units were clarified or elaborated by relating them to each other and to the whole. These meanings, as they were still expressed in the concrete language of the subject were subjected to "reflection and imaginative variation" (Giorgi, 1985, p.17). This required that the researcher move back and forth between the concrete transcriptions of the interviews and her own abstract thought as she searched for meanings, categories and relationships.

As each of the initial eight interviews was analyzed new questions arose and the need to confirm or clarify the
meanings and relationships identified through reflection was identified. Therefore, a new set of questions was developed for each informant and second interviews were arranged. In these interviews, the beginning analysis was validated and clarified and gaps were filled by asking the subjects if the analysis described their experience and by asking further questions as necessary (Lofland 1971; Colaizzi, 1973). Again, interviews were taped and transcribed and analyzed as before.

The meanings, categories and relationships discovered were synthesized and integrated into a consistent description of the experience. The result of this process is a description of the essential structure of the experience of the elderly wife caregiver who institutionalizes her spouse. This essential structure is derived from meanings given by the wives through interaction with the researcher, and therefore constitutes their explanatory model of the experience.

Ethics and Human Rights

Approval from the University of British Columbia’s Screening Committee for Research Involving Human Subjects preceded the research. Participants were recruited through the Alzheimer’s Society and through one long term care facility; approval was obtained from these agencies as well.

Subjects were contacted by the researcher once they had given written permission for her to telephone them regarding the study. Before any interviews took place, subjects were
given written information and verbal explanations of what the study was about, what would be expected of them and how confidentiality would be maintained. They were assured that their decision to participate or not would in no way affect their husbands' care, and they were informed that they could withdraw from the study or request that any information be withdrawn from the study at any time. No subjects withdrew from the study but one subject did request that specific information be excluded. This was done according to her request.

Once subjects had signed consents the interviews began. All interviews were coded so that participants' identities were known only to the researcher, and all names were removed from the transcripts. All participants expressed interest in receiving a final report of the results of the study.

Summary

In this chapter, the phenomenological method as it was implemented in this study has been described. Participants were considered to be the experts because they had lived the experience of institutionalizing their husbands with Alzheimer's disease. Data were gathered and concurrently analyzed through intensive interactive interviews, and analysis was conducted by the researcher through abstraction and reflection. The result of this process is the collaborative description of the essential structure of the experience of the elderly wife whose husband is institutionalized with Alzheimer's disease.
Chapter 4

THE WIVES' ACCOUNTS

The findings presented in this chapter are composed of the meanings which were essential to the experience of the initial period of institutionalization of husbands with Alzheimer's disease. While each wife's account of the experience was unique, embedded within the accounts were common meanings. The relationship between and among these meanings constitute the essential structure of the experience for the wives.

Throughout the accounts, the wives described the experience of the initial period of institutionalization of their husbands as one of uncertainty. The theme of uncertainty was pervasive. It was expressed in the language of all informants. Words such as "probably", "might", "maybe", "seems", "if", and "may", and expressions such as "you never know", "you're guessing", "I wonder", "I believe" and "whether I should" and "maybe I could have" were used by the wives to describe their experiences. As well, personal feelings such as anger, fear, anxiety, ambivalence and most commonly guilt accompanied accounts of uncertain experiences, while peace of mind, satisfaction and other positive feelings accompanied reduction of uncertainty experienced by the wives.

Uncertainty as the unifying theme provides the framework for the essential structure of the wives' experience. Within this theme the wives described the source of their
uncertainty, expressed what they felt uncertain about, told of factors which influenced their uncertainty and related the ways in which they managed their uncertain state. The nature of their total experience was "worse than death". A model of this structure is provided in Figure 2.

Separation described what happened to the wives and to their husbands at the time of institutionalization. Furthermore, separation had two distinct forms: separation of husband from home, and separation of husband and wife. Each of these forms of separation was a source of uncertainty for the wives and each had a parallel structure consisting of expressions of uncertainty, factors influencing uncertainty and management in the uncertain state.

The organization of the presentation of findings reflects the wives presentation of their experience. They began their description with what happened when husbands were separated from home, proceeded to describe what happened when husbands were separated from wives and summed up the total experience as "worse than death". Therefore, the presentation begins with a section about uncertainty arising first from separation of husband from home, proceeds with a section about uncertainty arising from separation of husband and wife and concludes with the description of the total experience as worse than death.

Separation of Husband From Home

Separation of husband from home: A source of uncertainty

Separation from home removed husbands from the care of
Figure 2.

EXPERIENCE OF INSTITUTIONALIZATION OF HUSBAND WITH ALZHEIMER'S DISEASE

IS UNCERTAINTY

SOURCE OF UNCERTAINTY IS

OF HUSBAND FROM HOME

OF HUSBAND AND WIFE

EXPRESSIONS OF UNCERTAINTY
ABOUT DOING THE BEST THING:
  Entrusting care to others
  Role in husband's care

EXPRESSIONS OF UNCERTAINTY
ABOUT BEING MARRIED WIDOW:
  Living as married widow

FACTORS INFLUENCING UNCERTAINTY
ABOUT DOING THE BEST THING:
  Admission process
  Quality of care
  Staff response to wife as caregiver
  Reaction of other patients
  Husband's responses

FACTORS INFLUENCING UNCERTAINTY
ABOUT BEING MARRIED WIDOW:
  Social responses to role
  Husband's recognition of wife

MANAGING IN STATE OF UNCERTAINTY
ABOUT DOING THE BEST THING:
  Ensuring husband's well-being
  Taking him the comforts of home
  Vigilance
  Managing uncomfortable feelings
  Being thankful
  Seeking support
  Finding humour
  Distancing

MANAGING IN STATE OF UNCERTAINTY
ABOUT BEING MARRIED WIDOW:
  Maintaining attachment
  Scheduling visits
  Being there just in case
  Reaching husband
  Adapting to being alone
  Being strong
  Seeking support
  Keeping busy
  Being thankful

TOTAL EXPERIENCE IS WORSE THAN DEATH
their wives and from their desired home environment. This situation was a source of uncertainty for the wives.

The wives' recognition of the significance of their adopted caregiving role made them uncertain about their husbands' security without their care. Adjustment to their husbands' gradual cognitive regression backwards through childhood dominated the wives' accounts of life at home for their husbands before admission. The following is one of many descriptions of their husbands' childlike behaviour:

I: It's childlike in a simple reason, he lets you take his hand, and he lets you dress him. And like in the first place I used to put his undershirt the way he was supposed to put it on, you know, so he wouldn't get it back to front or something like that, and I'll put his socks on the bed, like lay his clothes out. ... But it got to the point he had no idea what to do with them. Also evident in the above description is the accompanying development of a caregiving role closely resembling that of

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I = informant
R = researcher
H = husband’s name
W = wife’s name
Facility A = first facility to which husband was admitted
Facility B = second facility to which husband was admitted
Facility C = third facility to which husband was admitted
mothers of children, which was experienced by all of the wives. However, looking after an adult with the cognitive presence of a child was much more difficult than looking after an actual child as the following informant suggests. The husbands' adult size and physical skill meant that the wives had to be alert at all times frequently necessitating 24 hour-a-day care:

I: And I said, you’re absolutely tied in, just like with a little child, except with a little child you can put a lead on a kid when you walk with them, you know, you see them at expos. You know a little kid is going to do things so you kind of run after them. On the other hand when you’re looking after little children you’re not 75 either.

As caregivers, the wives accepted responsibility not only for the demanding level of their husbands' physical care but for protecting them socially as well. In an effort to shield their husbands from the disapproval of others the wives withdrew from social contact with those who might not understand the childlike behaviour:

I: And uh, it just gets to the point, you can’t have somebody come in and visit.
R: Why is that?
I: Well, he was apt to do a striptease in there ... Come out of the bathroom without any clothes on. I could handle H. with eating, and my family could. It’s difficult for someone who hasn’t been exposed to seeing
someone slobber and, and not be able to control the liquid that they’re putting in their mouth or else pick up the spoon and turn it the wrong way. And I think you get very protective. You don’t want somebody to see this, because you don’t want them to, think badly of your husband ... not, not of yourself. You’re protecting your husband, just like you would protect your child.

Furthermore, while the wives withdrew from social contact with others, others often withdrew from them:

I: ... you lose your friends when your husband has Alzheimer’s. So many men are very good hearted but, you know it’s only human nature, if they come out for the evening they can’t talk to their opposite number, it’s very dull.

The consequence of social withdrawal was the increasing domination of the caregiving role in the wives’ lives in a context of social isolation.

In spite of its difficulties, the caregiving role was a responsibility which seemed natural to the wives. In fact, they viewed it as an extension of the role they had always performed in making a home for their husbands:

I: I think though a wife is kind of the homebody and that, and looks after the husband more than a husband looks after a wife.

Moreover, the changes in their husbands happened so gradually at first that the wives had scarcely been aware of the adaptations in their familiar roles:
I: Yeah, you can't put specific times because these things happen, gradually. The Alzheimer's happened gradually with him regressing and you keep doing things that you ... You don't realize that you changed your habits until all of the sudden when you look at it and you think, my gosh, I have to do all this.

They described their acceptance of the caregiving for their childlike husbands as "mothering instincts" taking over. In the end giving up the caregiving responsibilities was difficult for them:

I: And you have to let go, but you don't let go easily. You know, that is your responsibility. And as your responsibility it's hard to let go of those responsibilities. As I said, the only way I can do it is liken it to when your children leave home that this is another period of your life and you have to accept it. You talk to yourself a lot.

Giving up their roles as caregivers was made more difficult by the realization that the one-to-one care and personal attention which they provided for their husbands would not likely be possible once husbands were separated from homes.

The care the wives provided not only ensured physical and social security but had allowed the husbands to remain in their desired home environment. Indeed, both husbands' and wives' views of institutionalization made separation from home seem unacceptable:
I: We had one (an institution) that was right next to my mother's home where we lived in P. And my mother always called it the vegetable bin and that was I think was what I had in my mind. And I have seen abuse in an institution. You get all walks of life working in this and you know that at times there is abuse.

One husband had expressed his views about living in an institution before he became ill with Alzheimer's disease. Clearly, his views had contributed to his wife's reluctance to separate him from his home:

I: He voiced his opinions that he never ever wanted to be in a nursing home. He would rather die. He hoped he didn't live long enough to go into a nursing home. So I've known what his feelings were. Which doesn't help any.

However, there seemed to be more to their desire to keep their husbands at home than simply avoiding institutional care. They believed that their husbands would be happiest at home and were committed to the caregiving role that would keep him there. The desire to avoid separating their husbands from the home environment was often given as the reason for the wives' determined resistance to institutionalization:

I: Well, I don't think I was ready psychologically. I fought it. But then you ask the health facilities what they think and they think this is the way to go and you realize you can't, if things get worse, you can't carry
on indefinitely the way they are. So it's a very hard decision to make. I know some wives feel they're putting their husband out of their own home and they go through this trauma and they're denying them the comforts of their own home. And most people as they get on in life their home is their castle and it's everything to them. They enjoy it. ... So you are torn betwixt what's the right decision to make.

The depth of feeling about being the cause of depriving their husbands of home and happiness once he was institutionalized is evident in the following excerpt:

I: ... But he couldn't get out and enjoy those, for that beautiful autumn we had last year, months of that, he was caged, you know. Having gone from this sort of environment and walks every day, you know and the trees and the parks and along the beach to that. It was really hard to take. I cried a lot on the way home. Because, you know, it just seemed brutal. Just because he was difficult in the evenings, to have landed him in there like that, because basically the family was nervous about my being alone here with him. I just didn't feel that was enough cause to have sort of imprisoned him and it really was a prison, that's the way I felt about it, an absolute prison.

Realizing how their husbands felt about home, the wives attempted to continue caregiving until they felt sure that their husbands were no longer aware of being in an
institution. However, none of the wives were able to continue caregiving for that length of time:

I: I feel, well, he’s my husband and this is our house, and I didn’t think he was ready. I really didn’t think he was ready to go in. I kept saying "no, he’s not ready to go in."

R: What did you think "ready to go in" meant, at that time?

I: Well, I thought he would be more disoriented, like, you know, like some of them are, they’re like little lost sheep, they don't understand too much. I’ve thought that he would ... And at times he seemed good, so I didn’t think he was ready.

Separation of husbands from home resulted not only in removal of childlike husbands from the physical and social security ensured by their wives’ care, but from the desired environment of home. The consequence of this separation for the wives was uncertainty that they were doing the best thing for their husbands.

Expressions of Uncertainty About Doing the Best Thing

The wives’ uncertainty about doing the best thing for their husbands centered around two themes: uncertainty about entrusting their husbands’ care to others and uncertainty about their role in their husbands’ care in the institution.

Uncertainty about entrusting husband’s care to others. The wives continued to feel responsible for their husbands’ well-being in spite of their admission to an institution.
They felt that they had delegated rather than relinquished their responsibility and their uncertainty centered around whether or not entrusting his care to others was doing the best thing for their husbands:

I: ... I needed the help I think is what I felt and I needed to know that he was being taken care of. Like I needed that assurance that things were working out all right. It was like somebody telling you, "Yes you've done a good job and you did the right thing by putting him into the hospital".

Uncertainty about the care their husbands were receiving sprang from the wives' awareness of the limitations inherent in institutional care. The wives feared that necessary care might not be provided because they recognized that the staff were busy:

I: Well I'm sure there's never enough staff to give one-on-one attention unless you're in a private home and you just hope that the nurses looking after your loved one are caring people.

Coupled with the wives' realization that staff were busy was the awareness gained through their own caregiving experience that caring for someone with Alzheimer's disease is particularly challenging. The wives felt uncertain that the staff of the facilities had the knowledge and experience with Alzheimer's disease needed to provide adequate care:

I: You need an awful lot of patience with people like that (Alzheimer's patients) and another thing is that you
can't argue with them either. You can't argue with those patients at all. They become very upset. You have to agree with everything they say, everything they do. That's where your patience comes in. You have to be very patient with them.

I. ... but when he went to the lodge I thought, 'cause I didn't realize they accepted Alzheimer's patients, that was what was getting me for a while, and they said yes they were, and they were going to have to accept more, because it was getting, you know, more prevalent. And I said, well they're never going to do that, they're never going to do this.

As well the wives feared that staff lacked the personal commitment needed to care for an Alzheimer's patient:

I: They're more likely to think of the patient as a recalcitrant child rather than someone whose brain is dying. You can't blame them altogether you know. They've got a job, some money coming in. They may have a child at home that's concerning them. And they can't get too involved and they just do what they have to do and then they go for their coffee and then they do another stint and then they go for their lunch.

Uncertainty about care also arose from the wives' difficulty in evaluating their husbands' care. In their childlike state husbands were unable to either tell wives about their care or request care for themselves:
I: But I feel different now, I feel they’re, yes I like his room and he’s ... I know they’re good to him. I know they do what they can do.

R: How do you know that?

I: Well I don’t really know, I think, I feel at times, some are very short and curt you know and then again as I say some are, have the patience and extra kindness.

Uncertainty about fulfilling role in husband’s care.

Having entrusted their caregiving role to others, the wives found that their new role within the institutions was unclear. They wanted to do what was best for their husbands but were unsure about how to accomplish that:

I: ... I just didn’t know what I could have done to help except to just visit him. Oh, they did tell me about his clothes, that was it, clothes that had to be washed and laundered that would wash, not wooly things that would shrink ... after they’d all shrunk. They did tell me about that ... so that’s about the only thing I did to help.

R: And you would have liked to do more?

I: Yes I would have liked to do more but, but they didn’t seem to want me to do anything.

I: It’s hard to put into words. I felt as if I was the person going you know, the onlooker, and that I was, you know, that was their world and you almost felt as if you asked permission to do ... that was another thing, you,
you do have to ask permission. You see you ask if you can take them out, "Is it all right if I take him out?". And that’s hard after all these years of being married. It seemed that the wives were looking to the staff for direction but the necessary dialogue between staff and wives was either inadequate or missing.

Uncertainty accompanied attempts to carry on in their roles as mothers to childlike husbands. They felt that they must act as advocates but feared staff reprisals might result:

I: You know, what they’re going through, you’re suffering too. It’s rebounding on you whether you like it or not. So you do kind of respond I guess maybe, whether its good or bad, you get kind of this motherly attitude. You fuss around him like an old hen. Maybe nurses think it’s too much. I’ve heard through my work in the hospital, one case of a lady who’s always fussing about her mother in the extended care and the nurses saying well, "She’s more problem than the mother". So I wouldn’t want that to happen but I guess you do think these people, they can’t speak for themselves, you know. You’re their advocate you might say and you’ve got to kind of be on the look out.

A combination of understanding for the staff given the realities of providing institutional care and uncertainty about staff reaction to suggestions often caused the wives to take no action on their husbands’ behalf, even when they felt
that action was needed:

R: The fact your husband lost his glasses and his dentures, and that he sometimes doesn't wear his own clothes, that doesn't seem to trouble you too much.
I: No, it did at first but I figured out well you know, these people, the staff has so much to do that they just can't keep track of all this. I'm sure that's the reason why, but I don't like to mention anything because, I don't know if it would cause a bit of friction or what. I would just as soon not mention it.
R: Friction?
I: Yeah, towards my husband, ... I thought maybe they'd take it out on him or something and I don't want that to happen. It probably wouldn't happen but this went through my mind. So I thought I'm just as well not to say anything.

Another informant revealed ambivalent feelings when speaking about the difference between herself and her husband had she been the one institutionalized. Fear was experienced if wives intervened, and guilt was experienced if they did not:

I: I don't think he'd have the guilt feelings at all.
R: Why do you think that would be?
I: Because he was a much more direct person, and less analytical about emotional things and sort of interpersonal things, much less analytical. ... He always had a distinct decision about anything. I can always see
both sides of every question. He would say, "Those people are not doing the right thing and I'm going to complain that she isn't getting for instance uh, enough vitamins in her diet. And I'm going to make that stick, by Goodness". So you see, I mean that's the sort of thing. Whereas I can see the difficulties and I don't want to make a hassle, and I feel if you make too much of a hassle and I feel if you make too much of a fuss it reacts unfavourably on the patient.

In summary, in relationship to separation of their husbands from home, the wives experienced uncertainty about whether or not they were doing the best thing for him. They were uncertain about entrusting care to others who were busy and who perhaps lacked the knowledge and commitment necessary to care for Alzheimer's patients. Fear that the roles they performed might have negative repercussions for their husbands contributed to the wives' uncertainty about doing the best thing.

Factors Influencing Uncertainty About Doing the Best Thing

Several factors influenced the wives' uncertainty about doing the best thing when they institutionalized their husbands. These influencing factors included: the admission process, the quality of care that the husbands received, staff responses to the wives, results of exposure to other patients and husbands' reactions to institutionalization.

The admission process. The admission process made a significant difference to the wives' feelings about whether
or not they were doing the best thing for their husbands. This process included the way in which the decision to admit was made, the facility chosen for admission, and the response of others to the decision to institutionalize.

Circumstances surrounding the decision to admit their husbands were critically influential. Only if the wives felt that they had coped with their husbands' care at home for as long as humanly possible did they feel some assurance that admission had been the best thing to do:

I: And everybody tells you, "Oh well, you should put them in a home, you know, you can't do this". You cannot put them in until you feel that it's time. At least this is my feeling. I had to really understand that I had to put him in, or feel that I couldn't handle him any longer because to live the rest of my life with guilt I couldn't do it.

Often the wives continued to cope for so long that doctors, sometimes nurses and family members, persuaded the wives that admission was absolutely necessary:

I: I was beat. When he left in August, I was completely beat. I was worn out completely. .... And there (at the day-care center) one of the nurses Mrs. W., L.W., she's the one that told me, "He's gotta go in pretty darn soon". And she's the one who got the ball rolling. It's because of her that we were able to get him in. 'Cause she talked to the public nurse here, and the public nurse got the attention of the doctor and that's when he came
out and told me that there was a light at the end of the tunnel. ... I did everything I possibly could. I wasn't the one that said, "Take him, here he is," and take him and drop him off there. It was the doctor and the long term (care people), they were the ones that did it for me, and I do appreciate that, and I'm happy that they did it for me. I never was upset, because they were behind it.

In contrast, wives whose husbands were admitted at a time when they felt that they could have continued to manage at home suffered increased uncertainty about doing the best thing:

I: I was very distraught by it (the admission), and I didn't think it was necessary at all. But you know friends are very strange, they only look at it from your point of view and they all said, "Oh well, you should've done it weeks ago". But I didn't feel that at all. I mean, I had managed quite well and I was waiting for a calm call to take him in and it would have been, it would have come within the next two months I feel sure. And I didn't feel, even when he was very angry with me that I was ever in danger.

Wives who experienced pressure from others to admit their husbands before they felt that they could no longer cope resented the advice of those whose point of view about the decision differed so markedly from their own. When husbands were admitted before the wives were ready, feelings of guilt
and regret lingered:

I: Then I do feel guilty about the way he's being confined, about that original sending him in there in that manner. I think I'll always regret that. But it really was taken out of my hands as everyone points out. Thus, if the decision to institutionalize was made when wives felt that they could no longer cope, they were more confident about doing the best thing for their husbands. The assistance of others in making the decision under those circumstances added to that feeling. In contrast, when the wives felt that they could have coped for a longer period of time, not even the insistence of others could help them feel sure that institutionalization was the best thing to do.

The process of selecting a facility for admission was a second component of the admission process contributing to the wives' uncertainty about doing the best thing. Admissions were governed by their husbands' placement on a waiting list; therefore the timing of the admission often did not coincide with the decision that admission was required. Sometimes wives felt pressured into admitting their husbands before they were ready; more often the result was that their husbands were admitted on an emergency basis to a facility other than the facility of choice. In either case the wives' uncertainty was increased:

I: ... he was on a waiting list and that's another thing that health care professionals can't do much about ... and I heard them say, "Well the sooner they're in an
institution really the better, but you can't always get
them in when you'd like to get that right and proper care
... like in our case, it was suggested by the long term
care nurse. I think it was her that suggested that I
have my husband sent to (facility A). So that was full
of trauma.

R: For you that was full of trauma?
I: Yes. Just the stigma of the place and not knowing
what it was like down there. And my daughter had worked
there and she knew a bit about it. This is the one
(daughter) in England. So she was phoning and the idea
seemed repulsive to her at first. But the daughter here,
I think was more concerned that something be done.

R: Why did she feel that way?
I: Well I guess that she knew that she couldn't devote a
lot of time to her dad with two small children and at one
point she thought I was, she worded it, grovelling.

When admission was necessary before the facility of
choice was available the result was heightened uncertainty
about the care. This resulted in husbands being moved from
facility to facility as wives searched for a facility where
they could feel more certain about their husbands' care. In
fact, only the three husbands whose original admission had
been to the facility their wives had selected remained in
those facilities. The next informant shared her satisfaction
with the way in which the facility was selected for her
husband:
I: They're good. Yeah. I thought they would be good. Well, L. (name) told me about this place where he was going. She suggested that this place would be very good if I could get him there ... And once the doctor decided this is it, he's going in, he put him in that place.

R: So you felt ahead of time that it was probably a good place, to have him there.

I: Yeah. I went in and had a look at it before he went in. Went and had a look at it. Noticed it was clean all the way. That meant something to me.

A third aspect of the admission process affecting the wives uncertainty about doing the best thing for their husbands was the responses of others toward the decision to institutionalize. Some individuals supported the wives in making their decision and some participated in securing admission; the reactions of others who did not understand the decision increased the wives' uncertainty. Such individuals often did not perceive the husbands as unwell because they were not in close contact with them. Lack of understanding resulted, leading to lack of support for the wives:

I: ...and they (the neighbours) don't talk to them really, or just say a "good morning", or "good afternoon", or whichever, and they don't realize that there is a problem. She'd (one neighbour) never realized there was any problem at all. And that's hard.

R: That's hard, because of what you think they're thinking about you?
I: That's right. Umhm. Yeah. Oh, I think she felt that I was a heartless so and so, you know. Just wanted to get rid of him. You know, I really do, I think that ... And I think his family felt ... They knew the doctor had said a nursing home within a year or two, and yet three and a half years later they still felt that I had put him into a nursing home long before he needed it. They never said that, but I sure got the inference.
R: How did you get the inference?
I: "Oh, in a nursing home? Oh, so soon? Oh, I didn't realize", you know, that type of thing. From a brother who is a ... his brother ... who is usually very, very tactful and when he raises his eyebrows, you know, definitely he thinks that this is wrong.

As well, comments from staff sometimes contributed to the uncertainty the wives felt. Fortunately for the next informant a negative comment by one staff member was counteracted immediately by another's positive one:

I: Well it was at the time when my husband was crying a lot, and I was feeling very badly one day going out, and she said, "Well wouldn't you cry if somebody put you in here?". So I very quietly said, "Well I would hope that I would know enough that the person loved me, and they're doing the very best they could for me" and until she had lived with an Alzheimer's victim, she should maybe read a little more about it. But she may have had a bad day at that time too. And I don't think it was two minutes.
later 'til the social worker came up and said that, you know, that they were pleased with the way that I’d looked after H. at home. All those little things are what make, make you feel as if you’ve done everything.

R: You need to, to hear that.
I: You need, you need to hear that, you need somebody to tell you that it’s all right, you’ve done the right thing.

The entire admission process including the circumstances in which the decision was made, the securing of admission to the facility of choice and the reaction of others to the eventual admission influenced the uncertainty felt by the wives about doing the best thing for their husbands.

Quality of care. Another factor influencing the wives’ uncertainty about whether or not they were doing the best thing for their husbands was the quality of care husbands received. Two components were included in the wives’ evaluation of the quality of care: physical care and personal care.

Physical care was assessed along three dimensions: outward appearance, management of Alzheimer’s disease, and prevention of premature loss of ability. Physical appearance of both the husbands and the facilities was the first dimension of physical care evaluated. Cleanliness played an important part in judgement of this aspect:

I: Well every time I’ve been there the place has been very clean. Floors are as clean as anything in the
bedrooms, everywhere I go, it's always clean. I usually
go there about one-thirty in the afternoons and a lady in
housekeeping is always washing the floors where they eat,
and I mentioned something one day and she said, "Oh, I do
this after every meal." So I know that it's kept clean.
His clothes are always clean. He always has clean
clothes on, his hands are clean. His hair, is sort of
shiny, you know I can tell he's had his hair washed, and
his nails are done. His fingernails are done. He's had
his hair cut, not as often as I'd like but he has his
hair cut. So that makes me feel good you know,
especially to know that he has clean clothes, clean
hands. That makes me feel good.

The second dimension of the quality of physical care
evaluated by the wives was the ability of the staff to manage
Alzheimer's patients. The wives had developed a great deal
of expertise during their caregiving experience and used
their knowledge to evaluate care. One approach frequently
mentioned as being effective in management of difficult
behaviour was to "take their mind off it". When this and
other approaches which the wives recognized as effective were
used the wives felt reassured about the quality of care.
When ineffective approaches were identified the wives were
disturbed by the care:

I: But anyway when I went up at supper time, sure he eat
his soup and he was just eatin' his pudding, when the
nurse come and she says, "Here's a pill", and she pushed
it in his mouth while I was still feeding him and he just
backed up and Alzheimer's patients, I mean, it scared
him. So of course, he spit it out and I got it on my
finger and I says, "He spit it out". She'd gone across
to the other bed. "Well, he's got to have it". So she
pushed it back into his mouth and she picked the water up
off his table and she says, "Here". No more or anything
else and it just run all down his face. I says, "Well,
you are a stupid lady", I says, "You don't do that".
"Oh", she says, "I assumed he was eating". I says, "You
assumed a little too much. He's just eaten today. This
is the first time for two weeks he's eaten some solid"
... But he wouldn't eat any more. ... I blame her for
gettin' him all rattled, I really do.

The third dimension of physical care evaluated by the
wives was prevention of premature loss of physical abilities,
that is, losses wives attributed to institutionalization
rather than to gradual deterioration resulting from
Alzheimer's disease:

I: It's an old, old building and some patients were
confined in their wheelchair and strapped in and some
were, you know, very far gone mentally and screaming and
all this stuff. Some that were mobile would do nothing
but pace up and down the hall, up and down the hall so
that's where H. joined the pacers. And within a week he
had lost bladder control. They all end up that way and I
was devastated.
Because medications given to husbands caused physical and mental deterioration, administration of medication contributed to uncertainty about quality of care. All of the wives shared accounts of detrimental effects of medications which had been used to manage their husbands' difficult behaviour:

I: ... but I'm not at all sure that the minute these people get into an institution in order to be handled I'm quite sure they have to be drugged to a greater extent than they would be at home. And then that sets up a whole lot of things. Incontinence among other things.
R: The drugs do?
I: Oh, yes I'm sure of it. And strange behavior too I think. You know, of course an Alzheimer's patient has strange behavior in any event so it's very hard to separate the difference. A spouse can certainly tell the difference but an ordinary person probably can't.

I: So anyway, then last night he seemed as though he was ... he appeared to be under sedation a bit, because I can tell by his eyes and the way he acted. He wanted to go to sleep, and I phoned my doctor about it because he could hardly walk one day, and then when I left him that night he had fallen in his room. So I asked my doctor who prescribed that new medication for him, because I felt it was too much. And he said, "I did, before I went away, but it takes a few days before they adjust to a new
medication."

R: Oh, I see, So he's still on it then?
I: Well I'm not ... Well I guess, yes. I don't know.
One meeting I went to Alzheimer's meeting, they said that
night, they never should be on medication to quieten them
down, and they shouldn't be on any medication. So I
don't understand that.

Prevention of premature physical loss was important to
the wives because they wanted their husbands to be as
comfortable as possible for as long as possible. Because
their husbands deteriorated mentally much more quickly than
they did physically, the wives dreaded the possibility that
institutionalization would result in an early and long state
of being bedridden, a miserable state to be avoided as long
as possible:

I: But the way he is regressed, because, he just, he can
no longer stand up straight and uh, I do know that when
he ends up in bed it will be a case of it'll be a case of
he'll go into the fetal position. ... It's just a case
of, you just hope the good Lord will take him before that
happens. That's the only feeling I can have.

Physical losses that were due to institutionalization and
not to disease made the wives doubt that they had done the
best thing in agreeing to admission:

I: So, in the end I thought, well, it was a big
decision. I sure thought and prayed about it a lot and
uh, I saw my doctor and his recommendation was to take
him back (to the institution) and maybe bring him out for weekends ... sort of have the best of two worlds. Looking back I kind of wished I had kept him home and stuck with it and maybe it would have been slowed down, especially his posture because though he was restless, he didn’t really need that third medication that bowed his head over. Because that snapped right back as soon as he was taken off of it. So though these institutions have all these drugs, its quite a ticklish balance I think. And I guess just time works out which is the best for each person but I don’t think H. had reached ... I don’t think he really needed that though he was very restless ... But the effects of his head going down ... that was devastating.

Stimulating activity, including diversions such as bus trips and physical exercise of any type were considered to be essential to prevent premature loss of ability and thus to maintain comfort. All of the wives indicated that it was particularly important that their husbands be helped to walk. One informant, when asked why walking was so important to her husband, replied:

I: Because its so important to have some exercise. And if you’re sitting in a chair all day and you’re not moving your arms and you’re not moving you legs, in no time at all you just lose that completely. Then the next step very quickly comes and that’s to be bedridden and then that could be a very long drawn out affair with
a great deal of discomfort in my opinion which I mentioned earlier. Much better as long as they are able to keep a patient active. It increases their alertness and all kinds of things. It helps their digestion of food I’m sure. It helps in the elimination process. It just isn’t right to be constantly in a chair. Now take someone like Rick Hansen, of course, he is exercising. It’s true that he’s constantly in a chair but he is exercising. But someone who has Alzheimer’s doesn’t know enough to even flex their wrists or move their ankles or anything like that. And they just become sort of leaden figures in a chair.

Another informant was very satisfied with the new facility to which she had had her husband moved because the staff were encouraging her husband to walk again. This, she reports, was a welcome "change around" from the two previous facilities where her husband had been confined to a chair:

I: And she (one of the staff) said, "Well, we just decided we were going to do something different. So they came in and he wasn’t out of bed and they got him out of bed and sat him up on his bed edge and pushed his chair in towards the bed and then put the apple way in the corner, and said, "Now H., you do like an apple don’t you?". And (he) said, "Oh yes, of course, where is it?" And she said, "There it is. And you’re to get it. Reach for it." And he looked at the girl who was standing behind the chair and he said "Would you mind getting my
apple?". And the girl said, "No, H., you're to reach it yourself." So he just looked her and he reached over and he finally inched over enough to get the apple, turned himself 'round and sat down. And that was the start of it. So now they have him walking. I guess they held him. You know, there'd be somebody with him of course. And he's gone 21 feet two times that I know of, and that's, well, it's just a complete change around.

In summary, the wives evaluated the quality of physical care through the appearance of both the facility and their husbands, through indications of staff ability to manage Alzheimer's disease and through evidence that care provided for prevention of premature loss of ability.

Personal care was the second critical component of the evaluation of quality of care which influenced the wives' uncertainty about their husbands' admission. Wives wanted some kind of individual recognition for their husbands, such as, calling the husbands by name, joking with them or doing some "little extra" for them:

I: ... they used the book that I got for him and then they put up the picture that I brought. They put it on the wall. It was a picture of him and me, our fiftieth wedding anniversary and the cake and one of his boats and some of his friends. So I was quite pleased when I saw that up, you know, it sort of identifies who you are, and then Fathers' Day cards, I brought them, the children had brought, and they stuck them up on the wall too.
R: You think identifying who he is, is really something very important.
I: Oh, oh I think, yes. It's more that he hasn't lost his identity. Yes 'cause they could all just lose themselves, a lot of sick people together.

Individualized approaches to communication such as the use of humour and teasing as well as personal contact were described by the wives as making them feel more sure that the care their husbands were receiving was good:

R: This nurse that you think is so terrific, does he light up when she talks to him sometimes?
I: Yes, yes. "Cause I was there one time and she says, "Oh there's that good looking guy again". I says, "yes," and he looks at her and he smiles, he's got this flicker of a smile you know, yeah, right away, you see he NEEDS (emphasizes this word) something like that. I think possibly if, even though people get tired and don't have to spend much time with a person, but maybe maybe some little compliment, some little thing would be better than medication.

Wives felt their husbands must be treated as persons of worth and dignity. When this was not the case, they were devastated:

I: So the second time I went with my daughter he was sitting there without his teeth, without his top teeth with just a few on the side so it looked as though he had no teeth at all. The clothes that I didn't recognize.
They consisted of black drawstring pants and lumberjack socks. ... It was just absolutely traumatic to see him in these dreadful clothes that didn't fit. The pants were too small, the shirt was too large. Someone said well if they're neat and clean, they may be clean but they're not neat, if you know what I mean. And I just felt that within 24 hours he'd been reduced from someone with a very high intellect much more so than my own, far greater range of subjects that he was almost an expert on, to someone who had no property of his own, who could've been anyone just sort of dragged in from the street like a wino and stuck in a wheelchair. It, it really is absolutely difficult to accept that. ... of course his intellectual quality had gone down a great deal but he still was representative of ... But I mean you could tell, that he had had a lot of interests and so on, ... you could tell that still with H. And to suddenly see him sitting there, in the hospital setting it was, it was dreadful but it was a hospital setting and he was in hospital clothes which you'd expect, but to see him suddenly sitting in the lounge in these terrible clothes without his teeth, with people in every stage of being doddering, you know. That really broke my heart because it had just taken away all his personality and all his background and being just wiped away in a single stroke.

When the wives felt that the staff cared for their husbands
as individuals they were much more likely to attribute physical losses such as injuries during a fall and even incontinence to the deterioration of Alzheimer’s disease rather than to poor quality care. The contrast in feeling experienced by the wives is exemplified in the following account of loss of personal possessions:

I: Well one of them (jogging outfits) he had on once in that building, and then the other one I think he had it about twice and I never saw them again. But that happens at this place too, at the facility C., I was quite surprised. I bought him another one after that in there and it disappeared, and the nurses looked through all the cupboards and everything, for me and they said, "I’m afraid we have a problem. There are people that lift things, even if you have the names stuck on them all over". They take them away, isn’t that funny, to think they would do that. But I don’t feel so resentful at this place, but at that other one I certainly did.

R: Why, what do you think the difference is?

I: I don’t know. Because they are so good here, they speak so nicely to the people in the chairs and some of them, some of them are, you know they really are quite helpless. They’re really quite helpless, but they treat them so nicely and they talk to them, you know as if they were friends, not just something that has to be looked after.

Thus personal care which provided husbands with
individual recognition and respect counteracted wives' uncertainty that they were doing the best thing for their husbands even when their husbands did experience loss. It seemed that as long as the wives felt that the staff had the husbands personal interests at heart, they could trust them with their care.

Staff response to wife as caregiver. Wives continued to feel responsible for their husbands' well-being after institutionalization; however, they felt uncertain about how to fulfil this responsibility. Staff response to wives' activities was therefore influential with regard to wives' uncertainty about how to do the best thing for their husbands.

For the wives, it was important that staffs' expectations and goals regarding their husbands' care were congruent with their own. Some wives expected to fulfil their role solely by visiting their husbands and became confused when staff indicated that visiting was not enough. On the other hand, when the wives' expectation was not met that staff would appreciate working together as a "team" in which wives could share their expertise, the result was increased uncertainty. All wives expected staff response to indicate that their husbands' well-being was a shared goal:

I: ... but I think you know some things that maybe make life easier for a nurse and if they're really working to make that patient's life more happy or how long they have left, surely they would be on the look out for ways to
improve that person’s (quality of life), I would think if they were dedicated. That’s what threw me when I got this negative attitude down here, ... "Do you think he needs it (a 'flu vaccine)?" (sarcastic tone). I just ... was kind of flabbergasted when I ... but I suppose when you’ve got all kinds of patients you wish people didn’t make waves or added problems.

In contrast, the feelings of the next informant were much less uncertain. She was encouraged by the staff to provide input into her husband’s care:

I: I’ve never seen anything I don’t want to. I figure well they should do this because, as they said to me, "If you see anything you don’t like or anything that you want us to know, you tell us, and we’re glad to hear and we’ll try and remedy it".

This wife was able to share her uncertainty with the staff and felt relieved as a result:

I: I got talking to them and kind of expressed my little fears about, well would they put his socks on right, or would they do his teeth, or would you know, see to him like this way. And they says, "See we do all that", and I know they do now. So I didn’t feel quite so bad.

Feeling welcome in the facility also made the wives feel more secure in their role:

I: ... I certainly never felt that I belonged at those other two (facility A and B). But at uh, this one, see I’m getting to know the people, the nurses, they’re all
so nice to me, and it's really amazing... I'll be going up in the elevator, and uh, quite a lot of them that are (a nationality) or whatever I don't know ..., and they say hello Mrs. H., how are you today. And I'll say, "Now how did you know my name?" And they'll say, "Well of course, you're H.'s wife." So that settles that you see, so you really feel as if you're a part of them. Oh, I feel very much more at home. I used to feel as if I were intruding in those other places.

R: Intruding in what way?

I: Well, interfering in their nursing or whatever it is their ..., or their regulations or their routine, that I was interrupting their routine. I always felt like that, that they didn't, you know, didn't exactly approve, of what I was doing or what I wasn't doing.

Reactions of other patients to husband's behaviour.

Reaction of other patients to their husbands' behaviour also influenced wives' uncertainty. While their husbands were at home, wives often isolated them from others who might not understand their behaviour; once they were admitted, such isolation was no longer possible. This was a source of uncertainty for the wives because they feared that measures taken to ensure that their husbands' behaviour was not disturbing to others would be detrimental to their husbands' well-being:

I: ... so I went looking for him one day, went in the dining room and couldn't see him. One of the ladies
said, "Who are you looking for?", and I told her and she said, "Oh, he doesn't eat in here any more". So I knew of course that there was a problem somewhere, so I finally found him. And I said to the staff, "Oh, they tell me that he's not eating in the dining room any more". And she said, "No", she said, "we've had to move him. He's drooling so much that the others objected". Now I don't blame them I can see it. ... So outside the dining room, in the lounge area, they have maybe a dozen that they have to feed. And there's a little table there and him and one other man are there. But my husband gets up and walks around. And they have a table, with the dessert say for a dozen people and she said he walked over there and he was drooling and she said he actually spit into the desserts. So they're going to have to put him at mealtime, ... they haven't yet ... once or twice, but they haven't yet permanently, in one of these chairs, called a geri-chair that he can't get out of. Now that, you see because he walks so well, that's going to be terrible! And yet, how else when you're eating a meal, how else can you keep someone ... I mean I understand that, I can see that they're going to have to do it, uh, because I wouldn't want to eat ...

The problem was particularly severe if husbands with unacceptable social behaviour were admitted to facilities which served patients other than those with dementia. One wife expressed her relief that her husband had been moved to
a facility which served only those with brain dysfunctions:

I: But it's a different situation down there at the lodge. They've got different kinds of patients to look after besides Alzheimer's. People are, their memory is quite good, you know what I mean, at the lodge. And I mean, some of those people, they're old definitely, and they don't understand the Alzheimer's. So they, the people, they're the ones that make it rough for the Alzheimer's patients because they don't understand. If he walks into their room, "Get out of here. You've no business in here". Where, down there it doesn't matter. He can go into somebody else's room 'cause the other fellow, "Well if he's on that bed, I guess that isn't my bed, I'll go on to the next one". You know what I mean.

R: So everyone at facility B. has Alzheimer's is that right?

I: No, not quite I don't think. But diseases that's affected the brain that they're not really with it. It's mostly Alzheimer's.

Husband's responses to institutionalization. Because the cognitive abilities of the husbands were variable at the time of their admission, the wives were never completely certain about how much their husbands understood or cared about being separated from home. Therefore, another factor influencing the wives' uncertainty was their husbands' reactions to being in an institution. Again, this problem was particularly acute at the time of admission when the husbands reactions
were most often negative. The husbands often tried to leave the facilities and sometimes even verbally complained about being admitted. Typically, the wives felt increased uncertainty when admitting their husbands under these circumstances and felt guilty as a result:

I: When I went in first of all to look around and I agreed that facility A would be good, I agreed, and they said it would be about two years perhaps, around there you see, so I thought it was a long time. I didn’t realize it was going to come so soon. But I did feel guilty when the time came. I said the room was empty, and he said "Well, now I’ve seen everything," you know. And I thought, oh, it just was harder than ever, see.

Even when the husbands did not verbally complain about institutionalization, the fact that their varying mental acuity caused them to have "good days" and "bad days" enhanced wives’ uncertainty about doing the best thing:

I: Uh, for a long time, if, if I went down and it was a really good day, I came back with a real guilt trip you know, "Well maybe I could take him home for a little bit longer". And then you’d go down maybe three or four days later and he would, you rarely ever went where he had two good visits in a row, which is a God’s blessing. Because you do go on real guilt trips. Even yet, if they’re in good shape and able to converse with you and go out on picnics. Like I used to take him out, then you have a guilt. When you come home, you know, you figure, you
know, oh, maybe I could have coped a little bit longer.

In summary, uncertainty about whether or not the wives were doing the best thing for their husbands in separating them from their homes was influenced by several factors. The admission process, the quality of physical and personal care their husbands received, the indications of congruency of goals and expectations of staff and wives, other patients' acceptance or rejection of their husbands' behaviour and the variability of husbands' responses to institutionalization all contributed to the level of uncertainty experienced by the wives. The approaches used by the wives to manage their uncertainty will be presented in this next portion of the study.

Managing in State of Uncertainty About Doing the Best Thing

The wives managed their uncertainty about doing the best thing with two approaches: First, they carried out activities to increase their confidence that their husbands' well-being was ensured. Second, they adopted strategies to help them manage the uncomfortable feelings which accompanied uncertainty.

Ensuring husband’s well-being. The wives attempted to ensure their husbands' well-being by providing husbands with the comfort of home and being vigilant in order to identify necessary action. Providing the comforts of home in the institution involved providing "the little extras" that husbands would miss as a result of institutional life. In doing so wives hoped to bring a little happiness into
husbands' lives:

R: I am quite interested in what it was like for you to be a visitor especially at the beginning?
I: In facility A., you were just trying to make it an occasion for them, bring a bit of happiness to them. There was so little you could do. Maybe bring some food that they liked or something, your tape to play music or something to make it easier for them.

Taking their husbands' favourite food was one way in which all of the wives provided the comforts of home:
I: But as long as he's mobile and uh, you know, I can take him out occasionally or that we can, they've got beautiful picnic tables and chairs there, and I usually take down a muffin. He loves bran muffins and I take him down bran muffins and cheese, and we sit outside and have a glass of pop.

Vigilance was another way in which the wives managed their uncertainty about their husbands well-being away from home. Vigilance provided wives with the information they required to supplement institutional care, protect their husbands from disapproval of others, and if necessary, act as advocates for them. Thus, vigilance was a primary reason for their visits:

R: What would you say the purpose of your visits is then?
I: It's really hard to say. Just to make sure that everything's going along as good as it can be.
I: I felt that if there was anything I could do, I wanted to be there.

The next informant described the calculated way in which she planned her observations within the facility. Because she consistently observed good care, she felt more content:

I: I can go away from H. now there and feel quite content.

R: But you didn't at first?

I: Oh, no, no. No at first it was a case of, as I said I wasn't sure that they were going to look after him as well as I could. And that I would go down and I'd see that his hair was combed, and I never went down on the same day. I tried them out. ... I never went down on the same day or the same time. But, he was always clean, his hair was combed, he was always dressed so, I knew that he was being taken care of.

Although the wives said that they would always continue to watch to a certain extent, the intensity of their vigilance decreased when they felt that they could rely on the facility to provide good care. Conversely, their vigilance intensified as their uncertainty about care increased. Some of the wives, particularly those not satisfied with their husbands' physical and personal care, felt that the very fact that they watched helped ensure better care for their husbands:

I: And also I think my very presence and I'm sure all
the other people that go, there's a nucleus of us that go, feel that our presence there maintains a certain feeling among the staff that we are there and that we do see what's going on. Because, you know, the aides are mostly not very much trained. One that I was quite fond of she only had five months training and didn't really understand Alzheimer's. And there are casual workers you know, so I think that they need to know that the patient's relatives are observing.

Vigilance provided the wives with an indication of supplementation required in their husbands' care. When the wives discovered needs which were not being met they attempted to meet those needs themselves:

I: ... because you know he has a very strong constitution and I could foresee that it might go on ... it might not, but it could go on for years. And if he's in a bad state as far as his skin breaking and all that, it could be much worse for him. So I make sure that he gets, tomatoes, avocados and that sort of thing with his lunch which I think is certainly adequate but often lacking in those things. Fresh fruit is almost never seen. Its almost always canned. That's because of budgetary restraints.

Vigilance also alerted wives when their husbands' behaviour was becoming irritating to others. When this happened, if possible, the wives took action designed to reduce the irritation. They recognized that socially
unacceptable behaviour might result in further losses due to increased use of drugs or confinement:

I: And (I have) got to get him different shoes to wear in the hall because you can hear him walking - people complain below - and all these things I get (feel) them inside, then I worry some more ... and then I got the shoes, but you see they’re always asking for something, and this is upsetting because I can never feel that ... I want to know if that’s okay, I don’t want people to complain about him. But I can’t do much more.

I: Well it was a very nice, clean place, and uh, they were very good about cleaning and everything like that. Cause H. used to spit. I don’t know where he got that idea from, he used to spit so much, and uh, oh, I’d have to clean the window, I’d clean the windows myself, cause his bed was right beside the windows. And there were four of them in the room.

Vigilance was particularly important to the wives’ role as advocates for their husbands since the husbands were not able to tell their wives about the care they received. In this respect the husbands were like young children in hospital. Advocacy most often involved requesting a modification to their husbands’ care or treatment:

I: I did look into the drugs and he was getting a tremendous amount in the morning and he was asleep. This was last winter. Every time I went he was fast asleep.
And I asked them if it was necessary and they cut it in half. What if I hadn’t asked? What stage would he be at now?

Managing uncomfortable feelings. The wives engaged in behaviour which helped them to deal with feelings such as anger, doubt, regret, ambivalence and guilt generated by their uncertain situation. Being thankful, seeking support of others, seeing humour in an otherwise upsetting situation and distancing themselves from the situation were all approaches used to manage uncomfortable feelings.

In their attempts to feel better about their situation the wives cited many different reasons to be thankful. Having their husbands in a facility close to home and the long and productive lives their husbands had lived were just two of these reasons:

I: I mean I could be a lot worse off and have him someplace way across the river or somewhere like that. I think it would have been a terrible thing, taken more out of me if I couldn’t have gone like I had gone, you, know what I mean.

I: Well I mean the point is he is, he has reached an age at which many, many people are still alive but many people have either gone or have had strokes or (are) in some way incapacitated and it’s very sad and dreadful but you have to remember that there are a lot of very young people who are facing sort of futureless existence.
The above informant also indicated that feeling that others were worse off made her thankful since the situation could have been worse than it was. The wives often compared their husbands with others in the facilities in order to come to that conclusion:

I: And uh, there’s some of them are very tormented down there. One lady in particular, she’s just uh, bad memories and she’s just goin’ around, so upset all the time. It’s sad to see her. I feel sad for her and glad in a way that H. isn’t quite like that. Maybe he’ll get like that, I don’t know, but uh, most times he’s just more or less quiet.

To manage their feelings wives also sought support from others who understood what they were going through. Family members who understood Alzheimer’s disease often provided this much needed support. As well, Alzheimer support groups provided an opportunity for the wives to share their feelings with those who understood:

I: (At the Alzheimer’s meetings) I think it’s just that you can talk to somebody else, and listen to somebody else without talking to a bunch of strangers who always think you’re running your spouse down. Because that’s ... I think that’s what people sort of think: oh, you know, your husband can’t do this, and he can’t do that. I get the impression that .... you know ... whereas when you go to Alzheimer’s everybody else has the same problem, and you can talk. Sometimes it’s nothing ...
there's nothing really said of any significance, but
still you know that there are other people in the same
boat.

Knowing that others experienced similar feelings helped the
wives understand and accept their own:

I: Like I go to the Alzheimer's society when they have a
meeting down here, but it's off for the summer. And you
talk about different things and I think that that's
helpful.

R: In what way is that helpful?

I: Well seeing that other people have (the same problem)
.... One of the ladies said, "Do you ever get over the
feeling about feeling guilty about putting your spouse in
a nursing home?". You know you should do it. You know
it's the only thing to do. You know it's right. You
know you can't do anything else. You can't carry on
forever.

The wives also used humour to manage their feelings about
having their husbands in an institution. Sometimes they
found something to laugh at in the behaviour of other
residents of the facilities. Sometimes humour was
therapeutic in an otherwise serious situation:

I: Well, sometimes I'd better laugh than cry. My
husband did something, I can't remember what happened now
and my daughter was kind of laughing. Not when he was
there, mind you. My daughter and I were laughing. He
didn't see me in the kitchen and I was kind of laughing,
too, and my son-in-law said "You shouldn't laugh at your dad." Well, she wasn't really ... she wasn't really laughing at him, but sometimes a laugh is not a bad way to break tension ... you know. Because she's very, very sympathetic. She wasn't laughing at him at all, but there are certain things that, you know, sometimes it's better to laugh.

Finally, some wives managed uncomfortable feelings by distancing themselves somewhat from the situation. This approach was used as a way of minimizing the detrimental effects of visiting on their health:

I: ... Now for instance, one woman goes to visit her husband every day. And she says she finds it comforting and I think if she does that's fine but I don't think the staff maybe ... I don't go more than once a week unless I have a particular reason for it. I come home very, very depressed. So it's not good for me.

None of the wives chose to avoid visiting altogether; even those who had chosen to restrict visiting continued to visit at least once a week.

In summary, separation of husbands from their homes and the concomitant necessity to entrust their care to others in a less than desirable environment resulted in the wives experiencing uncertainty about doing the best thing for their husbands. Uncertainty was influenced by the admission process, the quality of care, staff responses to performance of their roles, reactions of other patients to their
husbands' behaviour and their husbands' responses in the institution. The wives managed their uncertainty by taking the comforts of home to their husbands and by being vigilant. They managed uncomfortable feelings by being thankful, seeking support from others who understood and, less frequently, by distancing from the institution.

Separation of Husband And Wife

When the wives described what happened to themselves and their husbands, in addition to separation of husbands from home they described separation of husbands and wives. This form of separation resulted in an experience of uncertainty with an equivalent structure to that of separating husbands from home. This section of the chapter includes a description of the uncertainty resulting from separation of husbands and wives, expressions of the wives' uncertainty, factors influencing their uncertainty and their management of uncertainty.

Separation of husband and wife: A source of uncertainty.

Separation of husband and wife had two components: disruption of marriage ties and loss of companionship. Together, these components of separation of husband and wife were a second source of uncertainty for the wives.

Upon admission, the marriage ties which the wives had struggled to maintain by caring for their husbands at home were broken. The poignancy was clear, not only in the words but also in the tears which almost always accompanied them:

I: Because I think, like when H. went into the lodge it
was a terrible, terrible day. It was the first time we’ve separated ... it didn’t hit me ’til after I walked out with my son, "I’m leaving H."

A change in the relationship between husbands and wives had accompanied the cognitive regression of husbands into childhood and the resultant adaptation of the wives to roles as mothers; however, the emotional ties of marriage were no less strong:

I: You develop a different love for your husband, the same love you have for a child. You know it’s not a passionate love of your first married days. It’s more of a motherly instinct you’ve developed over the years and it’s part of you. All of those lives, all those years you’ve had with that husband you just can’t wash it down the drain, can you?

Sustaining marriage ties had been one of the reasons for the wives to struggle to keep their husbands at home for as long as possible:

I: It’s love, honour and cherish, and he’d looked after me a lot of times when I was sick. And I think it was just a case of reciprocating, ... for as long as I could. You know, we had a very good marriage, and it was just one of those things. It was part of what was happening to him ... 

No matter what the degree of cognitive impairment, husbands physically continued to be representatives of the husbands they used to be, and as such were valued by their wives:
I: (I thought) I can handle it if it just goes along for a little ways I can handle it for a bit longer. Because H. had had a very keen mind. He was a realtor. He'd been president of the Lion's club and Masonic and did, went out and did all sorts of work with them, their drills and that and then to see him develop the way he is now is was pretty rough on everyone.

Marriage ties remained strong even when the marriage had been strained as is illustrated in the following excerpt from the account of one wife whose husband had become violent:

I: Oh, people wondered how I even stayed with him so long, even years back. But you don't get married and leave and of course they didn't know the half of it but what they saw they wondered why I would take it.

Institutionalization resulted in the wives' struggle to maintain marriage ties even though physically separated from their husbands. The wives had experienced partial loss of their husbands' companionship prior to institutionalization as a result of Alzheimer's disease, however their physical presence had remained important; physical separation left them feeling completely alone.

I: That's the loss I felt, I was so alone. ..... Yeah, I missed him, you know it uh, he left a void, there was a big void, you know he wasn't there any more.

They spoke of the loss of their husbands not only for the present but for the future; this feeling of loss occurred in both "good" and "bad" marriages.
Wives found it necessary to live alone even though their husbands remained alive. They were "married widows" (Brandwein and associates, 1979), a state which was a source of uncertainty about how they should live their lives.

Expressions of Uncertainty About Being a Married Widow

Uncertainty about living as a married widow. Wives with husbands who were alive but separated mentally by the disease and physically by institutionalization lived in the state of being neither wife nor widow yet both wife and widow. In this ambiguous state the wives experienced uncertainty about how they should live their lives.

I: You know you wondered where you were going and what it was all about. So I just felt isolated as it were even though the children were really good. But when you're used to having someone with you just can't get used to it you know ... not the same way.

I: ... then when he went in, it was almost, I shut myself off. That you know, now I was going to be free and to do the things I want to do. You're unhappy and you don't want to do near the things you thought you did. Living alone, the wives experienced difficulties similar to widowhood:

I: It was difficult doing things (now) that you're by yourself and everyone else is, is with someone. And 47 years of marriage is a long time.
I: I find it hard being alone. You’re like a fifth wheel, you know. You’re like a fifth wheel when you go out with anybody.

Even though life alone made them feel like widows, after many years of being married, the feelings of still being married dominated their lives. The strength of the attachment they still felt for their husbands created ambivalence about enjoying life alone while making adjustment to their situation difficult if not impossible:

I: I would think that if he’d had a quick heart attack and gone, by now, a year later, I would have adjusted. Because, you know I’m a reasonably balanced sort of person and you have to realize that that’s life, you know. But you can’t really adjust to this sort of semi-state as well, as easily. You can’t make any new beginnings.

In the above account the informant compares her difficulty in adjusting to her husband’s institutionalization with her expected adjustment had he died. One informant, currently in a second marriage, had experienced the death of her first husband. She confirmed the notion that while adjustment to a husband’s death wasn’t easy, her present situation was more difficult as it left her not knowing what to do:

I: I know, after time, and then you make your way when my husband (first husband) died before, well, it was very hard, because he died beside me, and we had a wonderful
life. But in time you see time heals and then I’d know more what to do, how to go about things, and I wouldn’t have this constant, constant feeling that I should go and see H. today, and I wonder how he is today and ...

Uncertainty about living as married widows was compounded by uncertainty about their importance as wives to their husbands. This uncertainty was reflected in the ambivalence expressed by the wives about the importance of visiting their husbands:

I: ... because who knows what these people are thinking. They can’t verbalize it. So they may know that you’re there and they may very well miss you if you’re not and wonder why you haven’t come in. Since they don’t remember that you were in at lunch, by dinner time then they think, "I haven’t seen her for a long time and I wonder why". So, you know, "Has everybody deserted me?". That would be quite normal to think that if you couldn’t remember.

Sometimes I don’t know if he really wants you there or not. My son went up the other day and talked to him for a while and another couple - a lady that was visiting - they got up and walked away and my husband got up and walked with them - with my son sitting there, forgetting he was there. So I don’t really know how much good we do. But maybe it makes me feel better to know that I’m not neglecting him, and yet when I come home I’m always
depressed.
The next informant suggests that she was unsure about whether or not it was important to her husband that she visited every day, but she felt that she might miss him if she didn't.

I: I still been going to see my husband every day. I know, like some people say it isn't important. Maybe it isn't important to him either as far as that goes. I think I would be the one maybe more, probably to miss him.

Thus, feelings of uncertainty about how to live as married widows pervaded a situation in which the wives felt strongly attached to their husbands and yet were separated from them physically and mentally. Ambivalence about enjoying life, difficulty adjusting to the situation and uncertainty about the importance of visiting were expressions of the wives' uncertainty about living as married widows.

Factors Influencing Uncertainty About Being a Married Widow

Two factors influenced the wives' uncertainty about being married widows: social responses to their role and their husbands' responses to them as wives.

Social response to role. No recognition exists for the social status of "married widow"; consequently, social guidelines for these women were ambiguous. Ambiguity was enhanced by the confused reactions of others and by conflicting social expectations. Friends, family and others often were unsure about whether to relate to the women as
wives or as widows. Social confusion is evident in one informant's description of a neighbour's remark:

I: Unfortunately, Dad is here but he's not here. The next door neighbour said to me, "You know you should join the widows club. Oh, but you're not a widow". But you're alone. It's the same thing but you're not a widow. And she said, "I didn't mean that". You know, but actually to all intents and purposes you are.

The difficulty experienced in explaining married widowhood to others is illustrated in the following comment:

I: ... it's very difficult to explain this to somebody that, that this person really has died, your husband is gone, you're now looking after this little old man who you care for, you give a hug or a kiss when you go in, and then you walk away and you are leaving them.

The wives found themselves in a situation in which the loss of their husbands was not socially recognized or supported and yet they were expected to behave as if their husbands were gone. The wives felt like widows in many ways but lacked the social support that a widow would have received following the death of a husband:

I: Well when they're dead, they're dead, they're gone. There's nothing you can do for them. All their friends, you know sympathy cards ..., people feel sorry for you and everything. They get you over a tight spot. In a nursing home situation, a lot of people think, "Oh, she just didn't want to be bothered". And you get no
sympathy. You've got no background, nothing to fall back on. Whereas, I'm not saying I wish they were dead, I don't mean that. But I mean in comparison. I have a sister that died of cancer, a brother that died of cancer ... When they had died, at least that's a point. The family rally 'round. Everybody knows, you know, that there's problems.

The requirement that the wives obtain power of attorney in order to maintain control over their financial affairs resulted in social confusion for some wives. Fortunately, most of the wives had been advised early enough or had encountered professionals willing to sign the necessary papers despite their husbands' mental incompetence. When power of attorney could not be obtained, being caught between wife and widow was a source of anger, frustration, regret and guilt:

I: I didn't have power of attorney. Our will is so that if H. died everything is mine but without having power of attorney, I have just had to go through a committeeship and I am so angry. I think it's something that the staff should, and hospitals should realize too, that this happens to a wife far more than it will happen to a husband, because a husband's pension comes into their name, so they always have money. But the courts will step in. They wouldn't have only that I wanted to sell the house and the house is in joint tenancy. So I had to get committeeship which has cost me $1300. The
government said that all they would allow me was $500 a month out of mortgage money the rest has to be accounted for. You can't live on $500 dollars a month. I had taken money and put it in my own name out of our joint account so I was all right. But if I hadn't done that, if I hadn't had somebody saying to me, which they did, look after yourself you can always put it back in the joint account. But it makes you feel like a crook, that you're stealing, money.

An apparent contradiction existed, however, in that wives were often expected to behave as if their husbands were actually gone:

I: Well, because it was so far away and because my doctor friend said to me, "You shouldn't go every day, you know". He said most cases, these cases don't last more than a year or two and he won't know whether you're there or not since he's ..., so don't go often, but I did go about every other day.

For those informants whose marriage ties were very strong, the conflict between what they felt they must do and what others expected was a source of distress:

I: So it's always good to be there. But I have friends who have given me a very hard time about this and in fact the doctor who first sent my husband to facility A., said to me, "Twice a week is quite enough". And I don't know on what basis he said that. ... And you know, admittedly that was a terribly long way to go and I didn't go every
day. But I don’t feel that twice a week is quite enough for someone you know, who’s been very important in your life and so on. You can’t just do that. It’s funny isn’t it that people would expect you to. I don’t understand that point of view.

Doctors and nurses often offered advice about how often the wives should visit. The advise sometimes relieved wives of having to decide for themselves, and was often followed, especially initially while the husbands were exhibiting difficulty adjusting and while the wives were recovering from the exhaustion of caregiving. However, not all of the informants felt comfortable in following the advice of others. One woman could not comprehend that individuals who had not experienced a husbands’ institutionalization for Alzheimer’s disease should have felt competent to give advice:

I: I know I couldn’t have him home. But it’s hard. I don’t care what anyone says. Some people say "Oh, you should go out. Go out and do things and have a good time," and I wish sometimes people wouldn’t talk to me like that, because they don’t understand. They don’t understand how I feel, ’cause they haven’t gone through really anything in their life, as yet.

Such advice prompted the wives to avoid these friends; therefore they suffered increased isolation and lack of support.

Assuming the husbands were gone also resulted in the
tendency for others to stop visiting. Wives were convinced by even the smallest response that their visits were needed, and expressed sorrow that others were unable to see the purpose in visiting someone who did not remember the visit:

I: I wish some of his friends would go. One man in (place name), he’d known for many many years, went to see him one time, a long time ago when he was in the swing bed at (a facility). And he said, not much sense in me going, he doesn’t remember that I was there anyway. But I said, "If people would understand it’s while you were there that’s counting, not after you leave". It’s while you’re there. With the recognition, they could talk about things in the past and that’s great. But they seem to, "I’m just there, he won’t remember I was there, so why go?" you see. But I hope that people will go and visit, ’cause it’s while you’re there. And that’s to everyone that has someone, well even a friend. I would say, "Please visit", because they light up when they see you. Even if you’re there for 15 minutes, you made that person feel great.

All wives experienced withdrawal by at least some family or friends; some continued to receive much needed support. When withdrawal occurred, wives felt even more socially isolated than when they were still caring for their husbands at home. Wives then felt more alone that if they had been widowed.
Husband's recognition of wife.

The wives' uncertainty about their life situation was directly influenced by their husbands' recognition of them as wives. Because their husbands' level of cognitive ability was difficult to evaluate, any responses which indicated recognition made the wives feel that their husbands were responding personally to them and strengthened their attachment:

I: I'm a familiar face now and he, I always know when he doesn't know who I am now because he says, "Oh, it's nice to see you. I didn't expect you today and you know right then, (he's thinking) "I don't know who you are today".
R: His greeting is different when he remembers you?
I: Yeah, yeah, I uh he's always called me W. (nickname) and uh and he'll say "Hi W."

Most wives experienced a stage at the time of admission when their husbands did not want them to leave. This was an uncomfortable form of recognition which made separation from their husbands more difficult:

I: ... when I leave it's so, such a hard thing because he, he doesn't want me to go, (he asks) why can't I stay longer, why can't I stay and this upsets me and it upsets him.

The degree of recognition, when the wives came to visit, although by no means consistent, was sometimes surprising. Unpredictability of recognition enhanced the continued attachment to their husbands, but made adjustment to living
alone more difficult:

I: On the phone sometimes he says "I wish you'd come and see me. I'm lonely," you know. And I say "I can't come tonight, H., but tomorrow." - "Well, it's no good tomorrow," but tomorrow he's forgotten. But then when he says that at night I think I should've gone.

I: Although yesterday when I went down. He says, "Don't you get fed up with comin' down here?". I've been goin' every day and I thought well, "You must know", and I says "No, I come to see you". He pulled me to him and kissed me yesterday. He hadn't done that for a long time. ... it meant a lot to me yesterday. I thought, "Well I didn't come for nothing". So, he didn't mention my name, but he hugged me but right away, he kind of forgot again, he just sat and I held his hand and he dozed.

None of the wives were able to continue caregiving at home until husbands no longer recognized them, although several wives had planned to do so. Wives sadly explained that it would be easier to adjust to separation from their husbands if husbands did not recognize them any more. As long as their husbands recognized them, wives remained firmly attached and found it difficult to establish lives of their own.

I: Oh, well of course I'm always pleased (when he recognizes me) but I know so much about the disease because I've read all about it, you know and I know it's
only a matter of time. But at least it makes it worthwhile going, I do feel there’ll come a time when he doesn’t know me and it’s probably better then when I probably won’t go twice a day like this, because it really uses up your life.

In summary, inconsistent social response to the role of married widows and husbands’ varying and unpredictable responses to wives, especially in terms of recognition were factors which increased wives uncertainty about their life situation. The way in which wives managed their lives as married widows reflected the struggle to cope with this uncertainty.

Managing in State of Uncertainty About Being a Married Widow

Unlike managing uncertainty about doing the best thing, the wives were unable to directly reduce their uncertainty about being married widows. Instead, they managed by doing whatever made them "feel better". Feelings about being married were managed by maintaining attachment and feelings of being widowed were managed through adaptations to living alone.

Maintaining attachment. Managing uncertainty about maintaining married attachment required the wives to manage uncertain feelings about how much they should visit their husbands. It also required that they manage uncertain feelings about their husbands’ responses to them as wives.

All of the wives maintained attachment with their husbands by being with them in the institutions; however,
much of the wives' uncertainty was centered on the frequency of visiting. All wives established visiting schedules varying from twice a day to once a week, that helped them to sustain their marriage ties and made them feel comfortable in their role as wives:

I: (My son) thinks I go down too often. I have to go twice a week because that's what I'm comfortable doing. And I have come to a conclusion now, what I feel comfortable doing is what I'll do.

Being with their husbands was especially important on special celebration days such as birthdays, Christmas and anniversaries:

I: ... but I guess I just had to be with him because it was our anniversary. ... It was just, I can't really say, it was a rough day. It's very difficult to tell you what you feel inside. As I said, I just had to be there, you know, so, and that's for me rather than for H. Maybe next year it will be different but this year, I had to be there.

For most wives, maintaining attachment made going away any distance difficult, if not impossible:

I: I know all my grandchildren are going to be home in Saskatchewan for Christmas. Like my son's here and his wife and two kids. And I've been there every Christmas for years. They haven't been all together, like last Christmas one of them from Ontario wasn't there but she said, "I'm going to be home Grandma for Christmas so
we’re all going to be home". I said, "Well don’t count on me because", I says, "If Dad’s here I’m not coming". I said I couldn’t leave him there and me be away there.

The wives anticipated decreasing their visits when their husbands no longer recognized them. They described this time as a time when they expected to feel freer. However, they felt that maintaining attachment would be essential for their peace of mind as long as their husbands lived.

Wives also had to deal with uncertainty about their husbands’ responses to them as wives. They dealt with this by being there, just in case they were missed:

I: He has tried to say, "Why am I here?". But he couldn’t quite get that out. Something sounded like it. And I said "You haven’t been very well and you aren’t walking well and I can’t manage it dear. I can’t manage to get you in and out of the car and up the stairs at home. So until you’re able to do that you’ve got to be here". But I said, "It’s very nice and cheery and bright, isn’t it? And I come twice a day so you needn’t worry. I certainly haven’t forgotten about you".

They also managed these feelings of uncertainty by reaching the husbands "wherever they were". Husbands who had regressed toward childhood were most often living in the past. Wives who had shared that past were able to reach their husbands there. One informant offered advice about this to the husband of another Alzheimer’s victim:

I: When he goes down he says, "Well she’s not with it".
Look I said, "Well you just have to take her as she is like I take H.". I says, "If he talks to me, and tells me something, even though there's no bearing, I just have to accept it and answer him in that respect." I said, "Maybe a little while after", I said, "we'll get somewhere else. It doesn't matter".

All wives shared examples of what reaching him "wherever he was" meant. Some wives gave examples of responding to their husbands as if they were their mothers or sisters and some talked of going back with their husbands into their childhood. One wife returned with her husband to an earlier time in their marriage:

I: I can tell him things, you know, happy times and things like that. Once in a while we used to relate back a little bit and he'd, you know, remember these things. But now he's talking. He's just going back himself and if you don't get a drift of what he's talking about you've no idea of what he's saying. He talks a lot of the farm in a way. And when he's moving the furniture, I don't think he's actually moving the furniture, I think he's ... he told me something about he had to get the horses into the place. And he says he's got to make room for the cattle it's getting cold ... which we did in the winter time. We kept the cattle in and I said, "Well that's fine". I says, "I think somebody else is doin' that for you now, you may as well relax". (He said) "Do you think so?". I says, "Oh, I'm sure, I'm sure it's all
seen to". (So he said) "Oh, O.K.".

The wives managed uncertainty about their married lives by maintaining attachment to their institutionalized husbands primarily through deciding on a visiting schedule which made them feel comfortable and allowed them to be there just in case their husbands needed them. Reaching their husbands wherever they were helped the wives to deal with uncertainty about their husbands responses to them as wives. At the same time they managed uncertainty about the widowed portion of their lives by adapting to being alone.

Adapting to being alone. Wives managed feelings of uncertainty about their role as married persons living alone in four ways: being strong, seeking support, keeping busy and being thankful.

Wives were not provided with, and did not feel entitled to social support for grieving behaviour. Consequently, one way in which they managed was by being strong:

R: You said that earlier you did your crying in the car and that you wouldn't let yourself mope.
I: Well, I think it's very bad, to get into a stage of moping. I know H. wouldn't want me to. And it certainly doesn't help you to maintain your health. Also you tend more to, I suppose, want to take things to make you feel better which I wouldn't want to do. I wouldn't want to have anything to lean on, you know, so it's very important, and also I have my reputation to keep up my friends say I'm a very tough bird. So I've got to
maintain that reputation. And the children would be so hurt if they saw me terribly upset and there's a lot of, a lot of interesting things in life. You know H. wouldn't want me to do that.

They struggled to be strong, by concealing their emotions. They reported "crying alone" or "doing their crying in the car", often isolating themselves from others in the process:

I: ... but no, I'm adjusting. I mean, we maybe now just come a little you know. But I can talk about it. ... For a while there I didn't really want to go out and meet people, I didn't want to talk about it. Not because I didn't want to talk about it, I just wasn't able to talk about it. I didn't want them to ask me, because I knew they were all interested, and I knew they were all, they weren't asking out of curiosity, ... just the idea I couldn't cope. I couldn't handle it without breaking down, and I felt, very inadequate to do, you know, I couldn't do it, you know I couldn't harden myself.

The wives shared their feelings that socially they must "get going", or that they "should" or that they "planned to", but most had been unable to actually succeed:

I: However, I feel a little more content about it all 'cause I know I can't, I'd love to look after him but I know I can't. So I have to realize that but he's in good hands and I have to start looking after myself and thinking that life's going to be good after all. I'll have to make it ... it's only myself that can do it, no
one else can do it for me, I have to work at it. Frequently, the only steps taken towards reestablishing social connections consisted of seeking support from those who had experienced similar feelings. Alzheimer's groups, widowed friends or widows' groups often fulfilled this need.

Wives managed the uncertainty of life alone by keeping busy. However, this management strategy did not usually begin upon admission. Most wives went through a period when they were either too tired to do anything or when they did not feel like doing anything. The period of doing nothing lasted for varying lengths of time:

I: (Life after admission) was very vast, you know. There was something missing. It was lonely. Yes. But I was tired. I just went (MAKES COLLAPSING SOUND) you know. And it was like that for months. It took me six months to get over it. I kept telling the doctor, "I'm tired. I'm so tired. Isn't there something that can be done?". "Well," he says, "after what you've been through," he says, "it takes time to get over it." It took me at least six months to get over it. Completely, anyway --

R: What would a day be like for you during that six months?

I: Nothing. I didn't do anything. Not a thing. I couldn't do anything. I just washed the dishes and made my meals and made my bed, and that was it. I couldn't do a thing.
Once the wives recovered from the period of exhaustion, they began to cope by keeping busy. Keeping busy helped them avoid the ambivalent feelings of being at home while being drawn towards being with their husbands:

R: How would you describe a day, a typical day for you after he was admitted?
I: Well I didn’t go out of the house very much. I was busy and kept working around here. I didn’t just sit down and cry and cry and cry. I just kept myself busy. I thought well I’ll have to do this and do that and that. And I like to do these things. I even did some painting in the kitchen. I did everything I could think of you know.

When the wives spoke about their activities they spoke in a tone of resignation. They seemed to find little joy in living alone:

I: Well, uh there was just me, myself, and the house. But now I’ve kind of adjusted to that and people are good and phone and I do try and go ... well I go to church all the time and I go to the ladies meetings and I belong to two other groups and I go there once a month. So that it breaks the time and I’m not just reading the paper.

Finding ways of being thankful was another way of managing feelings about living alone:

I: But I know we had a good life and I think, most of the time that’s what’s taking me on. I figure, well, we’ve had a lot of good years, we’ve had nothing to look
back on and think well, "What'd we do that for, what'd we do this for?"

In summary, separation of husbands and wives disrupted marriage ties and resulted in loss of companionship. When combined with the fact that their husbands remained alive this placed the wives in the uncertain situation of being married widows. Varying responses of husbands toward them as wives and confused and conflicting social responses to their role contributed to this uncertainty. Wives managed their uncertain situation as wives by maintaining attachment to their husbands through visiting and reaching him "wherever he was". They managed their uncertain situation as widows by being strong, seeking support from those who understood, keeping busy and being thankful.

Total Experience is Worse than Death

"Worse than death" was the way in which wives described the total experience of institutionalizing of their husbands with Alzheimer's disease. The phrase summed the wives' feelings about all parts of the experience: the disease itself, separation of husband from home, separation of husband and wife and the encompassing theme of uncertainty. All the feelings of sadness, regret, anxiety, doubt, fear, guilt, anger and frustration generated by their uncertain state were contained within this phrase.

Having a husband with Alzheimer's disease was "worse than death":

I: It's you know, there's things in life worse than
death. And it’s hard, it’s hard to watch. That they
don’t know it, it’s a kind disease as far as the person
goes. They don’t know but it’s very hard on the family,
to watch them become this vegetable, and there’s no other
way to put it. It’s just this, with H. now, he isn’t a
vegetable, but it’s a case of this little old man that,
that you know, is incontinent. He can’t feed himself
properly. He can’t dress himself any longer, you know,
so it’s, it’s pretty rough.

Life for their husbands in the institution was "worse
than death". Watching their husbands die, little by little,
having no idea how long he would continue to live was
extremely difficult.

I: I’d much rather have a quick heart attack and it’s
over you know, I just don’t want to see him dying by
inches kind of thing. But funnily enough the things you
worry most about are more easy to handle than you think.
R: Are you thinking then of the end possibly?
I: Well, from time to time but I think it’s a long way
off. Because he had lost a lot of weight at the first
facility he weighed about a hundred pounds, but he’s back
up now to almost a hundred and thirty, and, you know,
looks reasonably well. And uh, unless he got pneumonia
or something I think we’ve got a long haul. It’s hard to
say. ... It depends what sort of condition he’s in for
the longest part. I hate to see anyone, I see enough of
them there, I see enough of them bedridden to know it’s
not pleasant you know, but I s'pose it's worse for the person looking. And truly it isn't pleasant now because he has the indignities of incontinence and the indignities of not getting his teeth brushed. The separation of husbands and wives was described as "worse than death":

I: You know and he, it's just like it's worse than death 'cause he's gone and he still isn't gone. He's still there but I can't communicate with him. I can't share nothing with him any more.

The uncertainty of the situation and it's effect on their lives were described as worse than death:

I: ... especially its a very protracted kind of illness, it is pretty hard. You don't know whether to take a holiday for instance, or get away from it all, or whether you should. And you see him kind of die inch by inch which is not ... I suppose you're kind of looking for new symptoms all the time too, and thinking, well, last year he could do this and that's denied him now and its always a step down isn't it?

When the researcher asked the following informant about this state of "worse than death" she told of her feeling of being caught between wife and widow:

I: I wouldn't want to prolong H.'s life because he's not getting very much out of it. In fact almost nothing I would say. And yet he isn't dead, you know what I mean. So you can't sort of turn over a new leaf. I don't even
like to get rid of all his clothes and things. You know. It's awkward. I've still got them ... a lot of them I've given away that were old. But some of his best things, I just can't bring myself to sort of act as though he no longer existed which would be much easier to do if he weren't alive. Of course I haven't experienced the other (having a husband die) so it's a little difficult to say.

One wife who had experienced the death of her first husband described her feelings about her husband's life and her life as worse than death:

I: Actually I lost my first husband to death and I think this is far worse.

R: In what way?

I: Well, this seems ... The other, the grief was very deep but, you know, you gradually ... you don't forget your loved one or the nice times or the life you had together but this is a kind of a living death. He's not there and yet he is there. Can you understand what I'm trying to say there? Because when they're once gone it's hard but this is very very hard, which I didn't realize how many people I spoke to that had loved ones that have Alzheimer's, what they were going through. You have to have it yourself before you can really feel what that person's going through. That's day and night it never seems to be away from you at all. It seems to be with you all the time ... And of course you can't help the
guilt feeling. I think. When he was in that other ward I couldn't stand the time, the times he wasn't too bad and he came and he just held on and he started to cry and he said, "Surely I have earned something better than this". That was hard to take.

Summary

The essential structure of the experience of institutionalization of a husband with Alzheimer's disease as it was discovered within the accounts of wives has been presented in this chapter. Uncertainty was the unifying theme which provided the framework for the essential structure and therefore for the presentation of findings as well.

Upon institutionalization, the wives experienced two forms of separation: separation of husbands from home and separation of husbands and wives. Each form of separation was a source of uncertainty, and each source of uncertainty had its own structure including expressions of uncertainty, factors which influenced uncertainty and management in the state of uncertainty. The wives summarized their total experience as "worse than death".

Separation of husband from home was a source of uncertainty because husbands were taken from their desired environment and removed from the comfort and security ensured by their wives' care. The result was uncertainty for the wives about whether or not they were doing the best thing for their husbands. Expressions of this uncertainty centered
around doubts about staff providing adequate care for their husbands. In addition, the wives were uncertain about their expected role and about what role would both meet their husbands’ needs and be accepted by the staff.

Several factors enhanced or reduced uncertainty about doing the best thing. These included the circumstances of their husbands’ admission and the facility to which he was admitted; the quality of physical care and the degree of respect shown for the husbands’ personal worth and dignity; the response of staff to wives activities in the facility; and the husbands’ responses to institutionalization.

Wives managed uncertainty directly through actions and indirectly through coping with their uncomfortable feelings. Wives managed uncertainty about their husbands’ comfort and well-being by taking them the comforts of home and through vigilance which provided information needed for supplementing care and for guiding activities as advocates. They managed their feelings by being thankful, seeking support from others who understood Alzheimer’s disease, using humour and sometimes by distancing themselves from the situation.

Separation of husbands and wives was a second source of uncertainty. This form of separation placed wives in the socially unrecognized role of married widow and caused them to express uncertainty about their life situation. Social responses to their role in the form of confused reactions and conflicting expectations contributed to their uncertainty as did their husbands’ unpredictable responses to them as wives.
Separation of husbands and wives divided the lives of the wives into two components: one in which they maintained their marriage ties and one in which they adapted to living alone like widows. Wives managed feelings of uncertainty about the married component of their lives by maintaining attachment to their husbands through visiting and through reaching them "wherever they were". The widowed portion of their lives was managed by adapting to life alone. Being strong, seeking support from those who understood, keeping busy and being thankful were all ways in which wives managed life alone.

Finally, wives described the total experience as worse than death. "Worse than death" was a summary phrase used to convey feelings about separation of husbands from home, about separation of husbands and wives, about living with Alzheimer's disease and about the whole encompassing uncertain state. Death, though not welcomed, was seen as a source of certainty in their lives.

The findings describe the wives' explanatory model of the experience of institutionalizing husbands with Alzheimer's disease. Understanding the wives' experience is valuable to both professionals and non-professionals with whom wife caregivers come in contact. Such understanding can potentially guide negotiation of effective and appropriate support for wives during the initial period of institutionalization of their husbands.
Chapter 5
DISCUSSION OF FINDINGS

Kleinman's explanatory model framework provided direction for conceptualization of the problem of this study. The perspective derived from Kleinman's framework explains the problem as one in which professional understanding of the caregivers' perception of their experience fosters negotiation of appropriate care, while lack of understanding often results in inappropriate care and conflict.

In this chapter, the findings of the study, which constitute the caregivers explanatory model of the experience, will be presented in relation to the professional perspective found in the literature. This discussion will demonstrate ways in which the study of the caregivers' perspective contributes to current knowledge about the experience of institutionalizing a husband with Alzheimer's disease. Caregiving literature reviewed in Chapter 2 as well as other literature relevant to the findings will be included.

The presentation of the discussion will follow the structure of the findings. It will begin with uncertainty as the unifying theme of the caregivers' experience. Following that, findings within each section of the uncertainty framework, including separation as a source of uncertainty, expressions of uncertainty, factors influencing uncertainty and the description of the total experience as worse than death will be discussed.
Uncertainty as the Unifying Theme

Although uncertainty is often mentioned in the caregiving literature in association with the caregiving experience (Kapust, 1982; Shuttlesworth et al., 1982), it would appear that this concept has not been identified as a significant part of the experience. Perhaps this is because little research was found regarding the caregiving experience from the caregivers' perspective and even less was found concerning their experience following institutionalization.

One suggestion of the importance of uncertainty in connection with institutionalization was found in an unpublished descriptive study of the spouses' experience following institutionalization in which the authors report that "feelings of doubt and uncertainty as to role identity create anguish" (Brandwein et al., 1979, p.2). Similarly, the wives in this study provide accounts of anguish as a result of uncertainty with regard to both their role identity in the institutions and their status as married widows. However, these findings indicate that uncertainty is not only experienced in terms of role identity but as the unifying theme of the experience as a whole.

Uncertainty is most often considered to be a perceptual state (Christman, McConnell, Pfeiffer, Webster, Schmidt & Ries 1988; Hilton, 1988; Lazarus and Folkman, 1984; Michel 1984). As a perceptual state uncertainty has been examined in various ways: as a property of a life event (Suls & Mullen, 1981) as a situation factor influencing appraisal of
a life event (Lazarus & Folkman, 1984) and as a source of stress (Michel, 1988). Regardless of the way in which it has been viewed, uncertainty has been consistently linked with stress in that it contributes to perception of an event as stressful (Lazarus & Folkman, 1984; Michel, 1984; Suls & Mullen, 1981). According to Lazarus & Folkman (1984), uncertainty forces consideration of first one possible outcome and then another, and when a decision cannot be made "fear, excessive worrying and rumination and eventually anxiety can result" (p. 92).

The stressful nature of the situation for caregivers following institutionalization is recognized in the literature (Hall & Kirschling, 1986; Mace & Rabins, 1981; Zarit et al., 1985); however, research, which has focused almost exclusively on the caregiving experience, thus far has only suggested that the caregiving burden may not be relieved by institutionalization and that there may be a continuing need for care (Chenoweth & Spencer, 1986; Colerick & George, 1986; Zarit et al., 1986). The finding of this study is that the burden does indeed continue for caregivers after institutionalization and that the burden is uncertainty with its associated stress. The need for continuing care for the caregiver, therefore, is also confirmed.

Separation as a Source of Uncertainty

Two forms of separation were found to be sources of uncertainty in this study: separation of husband from home and separation of husband and wife. Separation removes
husbands from the security of wives' care and from their desired home environment. Separation also disrupts marriage ties and results in loss of companionship for the wives. Uncertainty in separation arises from attitudes to institutional care and from the meaning of the caregiving role both of which have been documented as reasons for resistance to institutionalization.

Wives report that negative expectations regarding institutional care contribute to uncertainty once their husbands are admitted. Some of this uncertainty arises from a negative stereotype similar to that reported in the literature (Brock & O'Sullivan, 1985; Lieberman, 1969; Shuttlesworth et al., 1982). However, much of it arises from the wives' personal experience that care of an Alzheimer's patient is demanding and from the realization that the individualized care and the social protection which they provided for their husbands at home is not possible in the institution.

Davis (1980) reported that caregivers continued to keep their patient at home because they considered the disabled individual a person who had certain rights. The specific rights which the wives in this study feel are violated by institutionalization are their husbands' right to individualized care provided by their wives, and their husbands' right to live in the comfort of their own homes. The findings indicate that separation prevents wives from fulfilling commitments to keep their husbands at home. The
greater the strength of the commitment, the more vulnerable the individual is to stress (Lazarus & Folkman, 1984).

Maintenance of the caregiving role as a means to preserve marriage ties and to ensure companionship has also been recorded (Davis, 1980; Gilhooly, 1986; Hirschfeld, 1983). The findings of this study confirm that disruption of marriage ties and loss of companionship are outcomes of institutionalization. However, while it has been suggested that the better the quality of the relationship the lower the preference for institutionalization prior to admission (Gilhooly, 1986), the quality of the marriage does not appear to affect the degree of uncertainty experienced by wives following institutionalization. The findings of this study indicate that disruption of marriage ties and loss of companionship result in uncertainty for wives of both "good" and "bad" marriages. Marris (1974) contends that because human beings depend on predictability and familiarity in their environment, social change, such as that which occurs when any relationship is disrupted, results in uncertainty and arouses a conflicting "conservative impulse" (p.5).

Thus the findings of this study contribute awareness that the negative feelings towards institutionalization and the reluctance to relinquish the caregiving role because of its meaning are sources of uncertainty following admission. The suggestion is that sources of resistance prior to institutionalization become sources of uncertainty afterwards that the wives are doing the best thing for themselves and
their husbands. The fact that separation results in both disruption in commitments and significant social change provides additional evidence of the continuing burden experienced by caregivers following institutionalization and thus provides further indication of the continuing need for care for caregivers.

**Expressions of Uncertainty**

Wives experience uncertainty about doing the best thing for their husbands and about their situation as married widows. Examination of the literature on uncertainty identifies and explains the link between characteristics of the caregivers' situation and these expressions of uncertainty.

Characteristics of situations about which individuals report that they feel uncertain include vagueness, lack of clarity, unpredictability, inconsistency, probability, multiple meanings and lack of information (Michel, 1981). Lazarus and Folkman (1984) differentiate three types of uncertainty: event uncertainty, the likelihood of an event occurring; temporal uncertainty, not knowing when an event will occur; and ambiguity, lack of situational clarity. In testing a tool developed to measure uncertainty in illness, Michel (1984) found that these characteristics collapsed into two: ambiguity and unpredictability.

Ambiguity and unpredictability are characteristics of situations about which wives in this study express uncertainty. The wives report that feeling uncertain about
doing the best thing is related to uncertainty about entrusting husbands' care to others. Inability to predict the kind of care husbands will receive and ambiguity involved in evaluating care because of husbands' lack of awareness contribute to their uncertainty. Their expressions of uncertainty also center around the ambiguous nature of their role in their husbands' care in the institution and around the ambiguous nature of lives in which they feel like widows but continue to be wives. One interesting finding is that communication with staff which could conceivably reduce the unpredictability and ambiguity of their situation is often lacking in spite of recognition in the literature that families should be involved in their members' care (Annett, 1986; Goldstein, 1983; Locker, 1981).

Uncertainty About Doing the Best Thing

The findings of this study indicate that uncertainty about doing the best thing for husbands is closely related to the wives' perception that their husbands are vulnerable as a result of inability to assume responsibility for their own well-being. In fact, wives compare their situation both during caregiving and following institutionalization to that of mothers caring for children. From this perspective the literature that describes parents' experiences when they have young children in hospital illuminates the wives' situation.

A central feature of this literature concerns the "dilemma of trust" (Kirkpatrick, Futterman & Hoffman, 1974, p.169). The dilemma of trust relates to the parents'
recognition that they must rely on the knowledge and skills of health care professionals while at the same time recognizing their limitations.

Robinson (1985) has described this situation as a "double bind" or "no-win" situation in which no matter what the parents do they fear, and sometimes experience, negative consequences for the child. She reports that parents recognize the expectation that they must consider professionals to be the "experts" and fear negative repercussions for the child should they not comply. At the same time parents consider themselves to be "expert" with regard to their own child's care and fear that if they don't act as advocates their child will suffer. Thus, not only do they feel uncertain about entrusting the care of their child to others but in addition they feel uncertain about their role. Being a parent of a child in hospital had been described as "having a job without a job description" (Knox and Hayes, 1981, p.223). What parents expect is that they will share responsibility for care with the professionals and that mutually acceptable care will be negotiated, but that expectation often is not fulfilled (Knox & Hayes, 1981; Robinson, 1985).

The findings indicate that wives' perceptions of the experience of institutionalizing their husbands closely resemble the findings in the literature about parents of hospitalized children. During the caregiving experience at home, wives learn to care for their husbands and become adept
at managing most behaviour. They are uncertain about relying on staff to do all that they have learned to do, especially if staff don’t seem prepared to manage a patient with Alzheimer’s disease. They too are caught in a "double bind" as they feel guilty if they don’t intervene in order to ensure good care, but fear that actions as advocates might have negative consequences for their husbands. Contrary to suggestions in the literature that caregivers "relinquish" care to professionals (Colerick & George, 1986; Smallegan, 1985; Soldo & Myllyluoma 1983), like the parents of hospitalized children, wives do not relinquish care entirely but rather delegate it. They retain ultimate responsibility for their husbands well-being but do not know how best to fulfil that responsibility.

Uncertainty About Living as Married Widow

Wives in the study express uncertainty about the ambiguous state of living alone and yet continuing to be spouses. The fact that this role is similarly documented and descriptively labelled by Brandwein and associates (1979) as "married widow" prompted the researcher to use this term. These authors report that the spouses whose partners were institutionalized were "in limbo", or "neither here nor there", since in some aspects of their lives spouses experience the negative attributes of widowhood but at the same time they are not free to engage in new relationships or start a new life (p.7).

The married widow state described in this study may also
be described as "betwixt and between" in that wives describe feeling as if they are neither wives nor widows and yet both wives and widows. Turner (1970) has described culturally defined periods of being "betwixt and between" as transitional stages in the rites of passage from one state to another. Rites of passage or ceremonies which assist the individual to move from one culturally defined position to another include preliminal rites (rites of separation), liminal rites (rites of transition) and post liminal rites (rites of incorporation) (van Gennep, 1960). Examples of transitions which societies often recognize through rites of passage occur at puberty, marriage and death. Transitional beings in recognized states of being betwixt and between experience ambiguity, paradox and confusion since society's definitions do not allow for the existence of someone who is neither here nor there (Turner, 1970).

The uncertainty experienced by wives about how to live as married widows arises from the contradictory state of being neither wife nor widow and yet both. This uncertain state is as uncomfortable for them as it is for anyone in a transitional state; however, their particular experience of uncertainty is increased because this transitional state is not socially recognized and because it is not possible to predict when it will come to an end. The findings indicate that because friends, family and others also feel uncertain about the married widow state, they contribute to uncertainty about the role wives should perform.
Factors Influencing State of Uncertainty

Several findings concerning factors influencing the wives' uncertainty contribute to understanding of the experience as presented in the literature. Findings concerning the admission process, the quality of care, and the responses of others to the wives' roles are particularly significant in this regard.

The caregiving literature reviewed earlier describes the difficulty involved in making the decision about admission and reports that subjective factors such as the caregivers' perception of well-being or burden determines whether or not the dependent individual is admitted to an institution (Colerick & George, 1986; Zarit et al., 1986). A common reason for admission was found to be that the caregiver "couldn't take it any more" (Chenoweth & Spencer, 1986, p.271).

The findings of this study confirm the difficulty experienced by caregivers in making the decision and indicate that the admission process, including the circumstances surrounding admission, the facility chosen for admission and the reactions of others to admission, continues to influence the wives' experience following institutionalization.

One interesting finding is that the caregivers' subjective perception that they can no longer cope is necessary to reduce their uncertainty about doing the best thing. This finding suggests that "not being able to take it any more" is not only a reason for admission as recorded in
the literature but is the criterion used by the wives to decide when the time for admission has come. The feeling that they can no longer cope differentiates wives who appreciate the recommendations of others that they have their husbands admitted from those who consider such suggestions to be unwarranted. Furthermore, when wives agree to admission before they feel ready they experience lingering resentment and regret. This finding suggests that admitting husbands in order to protect wives from reaching the stage of inability to cope can contribute to long-standing uncertainty that agreeing to institutionalization was the best thing to do.

The significance of the quality of care in influencing the wives' uncertainty is not an unexpected finding. Dissatisfaction with care is one of the experiences following institutionalization identified in previous research (Brandwein et al. 1979; Chenoweth & Spencer, 1986). The findings of this study contribute to awareness of what quality of care means to wives.

The wives' confidence in health care providers is determined by evaluation of the quality of care according to certain criteria. Care which increases confidence includes cleanliness in appearance of husbands and facilities, prevention of premature loss of ability, and consideration for husbands' individual dignity and worth. Study findings also indicate that the wives expect that the goal of the staff should be consistent with their own goal of keeping their husbands as comfortable as possible in the time
remaining. When interventions such as confinement and administration of medications are used in spite of their detrimental effects on husbands, the goal of the staff is seen to be incongruent with expectations, and uncertainty is increased. Lack of confidence in health care providers and lack of congruence between what is expected and what is experienced have both been identified as factors influencing uncertainty in illness (Michel, 1988).

A striking finding is the degree to which uncertainty is increased by social reactions which demonstrate that others, either lay persons or professionals, fail to share the wives' point of view. The reactions of others during the admission process, the reactions of others toward the wives' role in the institution, and social expectations about how wives should live as married widows all have significant influence in this regard. This finding is congruent with Kleinman's explanatory model framework (Kleinman, 1977, 1978) which explains that problems arise in interactions in which explanatory models of reality differ. The wives' point of view reflects their knowledge, values, goals and expectations and constitutes their explanatory model of the experience of institutionalization of their husbands. Differences between the explanatory models of the wives and the explanatory models of others regarding this experience create the problem of uncertainty for the wives.

Kleinman's model focuses on problems in health care relationships which occur because of differences in
explanatory models between three sectors: popular, professional and folk. The findings of this study indicate that differences in explanatory models within the popular sector can cause problems for clients in the health care system as well. Wives experience enhanced uncertainty as a result of differing views of friends, relatives and others in their social world as well as differing views of professionals. Differing views are considered by wives to be indications of lack of support and result in withdrawal from those expressing them. The result for wives is an increase in already significant social isolation. Lack of social support has been found to be another factor which has been found to increase uncertainty in illness (Michel, 1988).

Management in State of Uncertainty

The strategies used by the wives to manage their uncertainty and to manage uncomfortable feelings associated with uncertainty have been documented previously as strategies of coping with stress generally and with uncertainty specifically. Since uncertainty is directly linked with stress it is understandable that ways in which wives cope with uncertainty mirror the ways of coping with stress as presented by Lazarus and Folkman (1984). These include distancing, self-control (keeping feelings to self), seeking social support, accepting responsibility, escape-avoidance, planful problem-solving and positive reappraisal (finding meaning). To this list Michel (1981) adds vigilance and information seeking as coping strategies.
specifically related to coping with uncertainty in illness. The use of similar coping strategies has also been documented in studies of individuals managing uncertainty in specific illnesses such as breast cancer (Hilton, 1988).

One significant finding is that management strategies often place wives in conflict with others. The existence of conflict between staff of institutions and families is recognized in the caregiving literature (Brandwein et al., 1979; Goldstein, 1983; Schmidt, 1987; Shuttlesworth et al., 1982). Two possible causes for this conflict are frequently suggested: first, that the conflict results from displacement of family emotions such as anger and regret regarding the necessity to institutionalize onto staff; second, that conflict results because of the difficulty the spouse has in relinquishing the caregiving role (Brandwein et al., 1979; Kapust, 1982; Schmidt, 1987). In contrast, from the wives' perspective, conflict results when factors such as uncertainty about the quality of care increase the use of management strategies such as vigilance and advocacy.

Another perspective regarding the conflict is that doubts concerning the degree to which professionals can be trusted place families in a "no-win situation" in which their efforts at advocacy often result in them being labelled as trouble-makers (Robinson, 1985). According to Robinson & Thorne (1984), behaviours that professionals label as trouble-making are manifestations of the conflict, frustration and anxiety which are inherent in what they have
called "the stage of disenchantment". During this stage in health care relationships, family trust in the congruency of their own point of view with that of health care professionals is shaken. This perspective regarding health care relationships is congruent with the findings of this study which indicate that behaviours such as vigilance and advocacy which often bring wives into conflict with professionals are manifestations of uncertainty.

Robinson & Thorne (1984) describe the stage of disenchantment as uncomfortable and recommend that professionals encourage movement towards the stage of "guarded alliance". In this stage the strengths and limitations of health care providers are acknowledged thus opening the door for "negotiating mutually satisfying care" (p.599). Kleinman’s framework suggests that not only the strengths and limitations of health care providers but the explanatory models of both professional and lay sectors must be acknowledged in order to negotiate such care. The wives in this study who had experienced negotiation with staff did indeed report satisfaction as a result of decreased uncertainty about care.

The findings of this study also indicate that staff recognition for the personal worth and dignity of the family member would be key to entering a stage of "guarded alliance". When wives perceive that staff have the personal interest of their husbands at heart, they are more likely to believe that the staff are doing the best that they can under
difficult conditions, and more likely to attribute their husbands' physical deterioration to Alzheimer's disease rather than to staff neglect.

Maintaining attachment is a management strategy which requires further discussion. Although the strength of the marriage ties between caregivers and their spouses has been recognized (Brandwein et al. 1979; Colman, Sommers & Leonard, 1982; Gilhooly, 1986; Laurence, 1985), the findings indicate that wives attempts to maintain their marriage ties are often misunderstood. Wives are distressed by pressure from family, friends, and health care professionals to reduce the time spent with their husbands. Wives are also distressed by suggestions that they "get out and do things" as if their husband were "gone".

The literature suggests that social isolation following institutionalization may result from withdrawal of friends and family prior to institutionalization or from the failure of others to recognize the need for support once institutionalization has taken place (Colerick & George, 1986; Zarit et al. 1986). The findings of this study support both of these suggestions. An additional finding, however, is that wives withdraw from those who demonstrate lack of understanding for their need to continue attachment to husbands. Hirschfeld (1983) found that the ability to perceive impaired persons as reciprocating in relationships by virtue of their existence differentiated those who continued caring at home from those who gave up more
readily. The findings of this study indicate that this ability remains following institutionalization. Wives are able to find comfort in simply being with their husbands. They learn to utilize the past to reach their husbands and feel rewarded by any response.

In summary, management strategies such as vigilance, advocacy and maintaining attachment which are often the cause of conflict between wives, families, friends and professionals can be understood as ways of managing uncertainty. Lack of understanding of these strategies is another source of burden experienced by wives following institutionalization.

Total Experience is "Worse Than Death"

The finding that the total experience of institutionalization is "worse than death" confirms the feeling expressed by caregivers and recorded in the caregiving literature that death would be preferable to institutionalization (Gilhooly, 1986; Hirschfeld, 1983; Locker, 1981). "It's worse than death" is the phrase used by wives to sum up their experience. The literature on loss and grief helps to explain this finding.

Anticipatory grief occurs whenever the impending nature of death permits "grief work" to begin before the actual death (Gerber, Rusalem, Hannon, Battin & Arkin, 1975; Rando, 1986). Rando (1986) contends that anticipatory grief focuses on three actual losses rather than on the individual who is dying: losses that have already occurred, ongoing losses such
as progressive debilitation, and losses yet to come such as the future together.

Unfortunately, the findings of this study indicate that this form of grieving is not recognized by wives or by others. The confusion created by their married widow state stems from lack of norms for appropriate behaviour for their grief and lack of social support such as would be provided in the event of their husbands’ death (Fulton & Gottesman, 1980; Lezak, 1978). Thus wives do not allow themselves to grieve but instead manage by being strong, keeping busy, seeking support from those who understand and being thankful.

The wives consider that slow death in an institution is worse than death for their husbands. The literature supports this finding with recognition of the stressful nature of the experience of watching a spouse slowly die (Gerber et al., 1975). Slow death with Alzheimer’s disease is particularly difficult. As Toynbee (cited in Kapust, 1982) has said:

"This premature death of a human spirit in advance of the death of its body is more appalling than premature death in which spirit and body die simultaneously. It is an outrage committed by nature on human dignity" (p. 81).

Finally, the entire state of uncertainty was experienced by the wives as worse than death. "Worse than death" is a summary statement describing all of the distressing feelings which were generated by this uncertain state. These included anxiety, fear, anger, frustration, regret, depression, guilt and sorrow which have all been recorded previously as

Dealing with uncertainty has been described as a "major adaptive task" (Lazarus & Folkman, 1984, p.91). The distress experienced by wives who institutionalize their husbands is a further indication of the link between uncertainty and stress and an further indication that care needed for the caregivers involves assistance in reducing and managing their uncertain state. The wives description of the total experience as worse than death, is a clear indication of their continuing emotional burden following institutionalization.

Summary

In this chapter, the findings of this study were discussed in relation to relevant literature for the purpose of demonstrating the contribution of this study of the wives' experience to current knowledge. Findings relating to each section of the uncertainty framework which constituted the wives' explanatory model of the experience were discussed. The findings of this study of the experience from the wives' perspective, differs from, confirms and amplifies various aspects of existing knowledge.

Two major contributions to current knowledge arise from the details of the discussion. One is confirmation of the suggestion in the caregiving literature that the burden of caregiving may remain following institutionalization necessitating continuing care for the caregiver. Caregivers identify their burden as uncertainty, describe various
factors influencing their uncertainty and provide accounts of management in their uncertain state. Confirmation of the need for continuing care for caregivers following institutionalization is found in their summary of their experience as "worse than death".

A second contribution to current knowledge relates to the wives' experience of differences between their explanatory model and the explanatory models of professionals and others in their social world. As predicted by Kleinman's explanatory model framework, problems such as lack of support and conflict are experienced as a result. Wives experience increased uncertainty whenever these differences occur. Only through the study of the experience of caregivers from their own perspective can such differences be identified and taken into account.
Chapter 6
SUMMARY, CONCLUSIONS AND IMPLICATIONS FOR NURSING

In this chapter a summary of the study, the conclusions arising from the findings and the implications for nursing practice, nursing education and nursing research will be presented.

Summary and Conclusions

Most victims of Alzheimer's disease are cared for at home for lengthy periods, however, eventual institutionalization is almost inevitable. Therefore, as the incidence of Alzheimer's disease increases along with the increasingly aging population, the frequency of interaction between professional and lay caregivers will increase as well. Because elderly wives are members of the largest group of caregivers, the group of caregivers at greatest risk for strain and the group of caregivers most resistant to relinquishing their caregiving role they were selected as participants in this study.

A review of the literature provided evidence that caregiver burden was not likely to be completely relieved upon institutionalization of the patient. However, differences in perceptions and expectations between lay caregivers and professionals reduce the possibility that caregivers will receive appropriate support. The initial period of institutionalization was chosen for study since the transition from home to hospital was identified as a difficult time having great potential for conflict between
the two groups.

The problem of conflict between professional and lay caregivers was conceptualized as a problem of difference in explanatory models between cultures (Kleinman, 1977, 1978). The need to explore the experience from the caregivers' point of view was therefore identified. Phenomenology was selected as the research method because of its unique focus on revealing the experience from the perspective of the participant. This approach was consistent with the conceptualization of the problem and with the objective of contributing results which would be significant for nursing.

The eight women who participated in the study were contacted through two agencies in the metropolitan area of a western Canadian city. They were Anglo-Canadian women between 64 and 78 years old whose husbands with Alzheimer's disease had been living in institutions for between 4 and 13 months. Data were gathered through interactive interviews which were taped and transcribed. Each participant was interviewed twice.

Analysis was a non-linear reflective process accomplished by going back and forth between concrete transcriptions of the interviews and abstract thoughts of the researcher in order to discover and validate meanings, categories and relationships. The insights achieved were synthesized and integrated into a consistent description of the experience. This description constitutes the essential structure of the experience from the perspective of the elderly wife. Because
it was derived from the accounts of the wives themselves it is also their explanatory model of the experience.

Throughout the accounts of the experience, uncertainty was the pervasive and unifying theme. The source of uncertainty experienced by the wives was two forms of separation: separation of husband from home and separation of husband and wife. These forms of separation had parallel structures including expressions of uncertainty, factors influencing uncertainty and management in a state of uncertainty. The summary description of the total experience for the wives was that it was worse than death.

Separation of husbands from home was a source of uncertainty about whether or not the wives were doing the best thing for their husbands. In relationship to doing the best thing wives expressed uncertainty about entrusting husbands' care to others and about their role in their husbands' care. The admission process, the quality of care which husbands received, staff responses to wives as caregivers, reactions of other patients to husbands' behaviour and husbands' responses to institutionalization influenced the wives' uncertainty. Wives managed uncertainty by doing all that they could to ensure their husbands' well-being by taking them the comforts of home and by being vigilant. Through vigilance wives gathered information needed to be advocates for their husbands and to supplement their care. They managed distressing feelings by being thankful, seeking support of others, finding humour and
distancing themselves from the institution.

Separation of husbands and wives was a source of uncertainty because, as a result, wives became married widows. Lack of social recognition for this state and lack of norms for role performance resulted in uncertainty. Inconsistent social responses and variability in husbands' recognition of them as wives influenced their uncertainty. The wives managed uncomfortable feelings generated by uncertainty by maintaining attachment to their husbands and by adapting to being alone. Maintaining attachment was accomplished by establishing a comfortable visiting schedule, by being there just in case their husbands were aware, and by finding ways of reaching husbands. Adapting to being alone was accomplished by being strong, seeking support from those who understood, keeping busy and being thankful.

The wives' summary description of the experience was that it was worse than death. "Worse than death" described the way the wives felt about Alzheimer's disease, having husbands in institutions, living as married widows and about the encompassing state of uncertainty. Death, though undesirable, was seen as the source of certainty for themselves and for their husbands.

Two major conclusions can be drawn from the findings: one regarding the caregivers' burden and continuing need for care and one regarding the significance of differing explanatory models of the experience.

First, the findings confirm that the initial period of
institutionalization is an extremely difficult time for the elderly wife caregiver. Upon admission, the wives delegated rather than relinquished care. Thus they continued to carry the burden of responsibility. An additional burden suffered as a consequence of institutionalization of husbands was the state of married widowhood. Uncertainty was the way in which these burdens were experienced by the wives. Because of the established link between uncertainty and stress, the continuing need for support for caregivers during the initial period of institutionalization is clear.

Second, it is clear that if appropriate care and support is to be provided for caregivers it is essential that their explanatory models of the experience be recognized. The findings indicate that differing explanatory models result in conflict between professionals and lay caregivers and that these differences enhance the burden of uncertainty experienced by the wives. This was the case when the differences existed between professionals and caregivers and also when differences existed between caregivers and others in their social world. Therefore, it is imperative that the explanatory models of the experience be recognized and used as a guide for providing support which is sensitive to the caregivers’ needs.

Implications for Nursing Practice

Many implications for nursing practice arise from the findings of the study. These implications are significant not only for nurses working in the facilities to which the
husbands are admitted but to nurses in the community as well.

One important implication is that nurses must explore the individual explanatory models of those whose spouses are institutionalized with Alzheimer's disease. When explanatory models are acknowledged, care can be negotiated which provides needed reassurance, prevents conflict and reduces caregiver burden. All of the implications following are based on the explanatory models of eight wives. Their accounts had in common the essential structure of the experience as presented; however, in addition, within each of their accounts there were individual differences which should influence care.

Because of the continuing effect of the admission process on caregiver burden following institutionalization, implications for practice begin prior to admission. Following institutionalization, feeling that they could not have coped any longer is essential to reassure wives that they are doing the best thing. Awareness of the resentment, regret and guilt experienced when this is not the case should affect the way in which others attempt to influence the caregiver's decision. Nurses should be prepared to assist caregivers to identify criteria for judging when they should no longer attempt to cope but should nevertheless be prepared to recognize when caregivers are not ready. Also, because caregivers must usually be desperate before agreeing to admission, nurses should work towards establishing services which would be available on a short-term basis which could
prevent admission to a facility that is unacceptable to the caregiver or inappropriate for Alzheimer’s patients. Even when such an admission is temporary, the result can be permanent physical loss for the patient and long-term guilt for the caregiver.

The essential structure of the experience of institutionalization of a husband with Alzheimer’s disease was framed by the unifying theme of uncertainty. Wives uncertainty about doing the best thing is not surprising given their commitment to maintaining their marriages and keeping husbands in their own homes. When spouses are admitted, nurses should therefore be prepared to support caregivers who are in an uncertain state.

Supporting caregivers who are uncertain should include attending to factors which influence uncertainty. Uncertainty could be reduced if nurses demonstrated that their goal for the care of the spouse was the same as that of the caregiver: to provide not just custodial care but both physical and personal care which attends to the quality of life and demonstrates respect for individuality, worth and dignity of each patient. The use of medication should be avoided as much as possible since medications not only contribute to premature loss of ability but convince caregivers that their spouses’ well-being is not of primary concern. Communicating an attitude of caring towards the individual patient has a remarkably comforting effect on family caregivers.
Nurses should ask caregivers what is important to them about care. Caregivers should be considered to be experts about management of their spouses' behaviour and should be included as much as possible in decision-making about care. Being included in decision-making should also reduce apprehension about what will happen if others object to their spouses' behaviour. A suggested goal would be that caregiver and staff reach a stage of "guarded alliance" in which "trust that acknowledges the strengths and limitations of health care providers" is established (Robinson & Thorne, 1984, p.599). Caregivers should be encouraged to feel that they have a mutually acceptable and recognized role on the health care team.

Nurses could reduce wives' uncertainty about being married widows by recognizing the situation as caregivers see it. No matter what the quality of the marriage, and no matter what the degree of cognitive impairment, the desire to maintain the marriage ties remains strong. Caregivers do not assume that their spouses are unaware but utilize individual approaches to evaluate and appreciate their responses. As well, caregivers establish a visiting schedule that is comfortable for them. Nurses and others who criticize the amount of visiting for being either too much or too little create discomfort for the caregiver and distance themselves as sources of support.

Caregivers also experience uncertainty about living life alone. Nurses could help caregivers to understand that they
are actually grieving for losses, past, present and future, incurred by their husbands' disease and by their institutionalization, and that allowing themselves to express these feelings may be therapeutic (Rando, 1984). Although findings of the study confirm that support groups are helpful for some wives for sharing feelings, others may benefit more from contact with an individual who demonstrates understanding of their experience as they see it.

Nurses are needed as educators regarding Alzheimer's disease and its effects on caregivers. The findings of the study indicate that reactions of those who do not understand the experience significantly increase the wives' uncertainty. Information sessions could be arranged for family and friends of persons diagnosed with Alzheimer's disease. Findings indicate numerous ways in which increased awareness of the caregiver's experience on the part of family, friends and others with whom the caregiver comes in contact could be of benefit. For example, others need to know that because visits from familiar people make the patient happy, regardless of the fact that the patient doesn't remember, they are an important source of comfort for the spouse. They should also know that although the caregivers may withdraw completely for a period of time after the spouse is institutionalized, the need for support remains and friends, family and nurses should continue to be available to provide support when it is required.
Implications for Nursing Education

The findings of the study also hold implications for nursing education. The first implication is that nursing education should prepare nurses to elicit the explanatory models of clients and families and to utilize this knowledge to negotiate appropriate care. It is particularly important that nurses recognize potential differences between explanatory models of lay persons and professionals. However, nursing education should also prepare nurses to recognize that differences exist not only between but within conventionally recognized cultural groups.

Education regarding quality nursing care should include the fact that families search for evidence that professionals respect the personal dignity and individual importance of every patient regardless of the patient’s apparent state of awareness. Only in the presence of such evidence can families feel reassured that professionals can be trusted to care for their loved one. The findings of the study indicate that conveying respect for the individual does not take a great deal of time but can be achieved through approaches such as the use of humour, calling the individual by name, giving a hug, putting up personal pictures or providing something extra.

Education is needed to prepare nurses to manage patients with Alzheimer’s disease. The increased incidence of the disease ensures that nurses will come into contact with its victims at some time during their careers. Nurses who do not
know how to manage behaviours associated with the disease are likely to provide inappropriate care which is disturbing for patients and upsetting for families.

Since most Alzheimer's patients are institutionalized in intermediate or long-term care facilities where the majority of staff are care aides, courses in gerontology should prepare nurses to teach and to provide leadership regarding the care of Alzheimer's patients for whom they are responsible.

Preparation is needed within nursing education to assist nurses to support caregivers as well as patients. The uncertainty experienced by the wives in this study indicates that it would be necessary to study uncertainty as a concept in order to provide appropriate support. Understanding uncertainty, its sources, the factors that influence it and its management can help to avoid conflict and ensure effective care.

Implications for Nursing Research

Several implications for nursing research arise from the findings of the study. This study explored the experience of just one particular group of caregivers. The study of other groups, and comparisons of different groups are needed as well. Also, studies comparing explanatory models of caregivers with professionals and with family members would be helpful in identifying the source of the problem when differences occur. For example, it would be helpful to understand all points of view in situations in which
professionals and family pressure caregivers to admit their spouses while caregivers feel that they are still able to cope.

This study focused on the initial period of institutionalization. Studies are needed which reveal the experience of caregivers at different times in the experience. Experiences following lengthy institutionalization and experiences following the death of the spouse may provide further indications of necessary support.

Research designed to reveal the expertise of family caregivers could provide valuable information regarding management of difficult behaviour associated with Alzheimer's disease. The findings of the study indicate that caregivers often use great ingenuity during their caregiving experience at home. Their knowledge and experience should be utilized in professional care.

Research is needed for the purpose of finding ways of managing disturbing behaviours such as those which often occur at the time of admission. Alternatives to medication need to be explored with respect to management of all behaviour which is likely to be experienced by others as objectionable.

In conclusion, dementia has been described as a "bio-psycho-social phenomenon in which the biological aspects are not currently treatable but the psychosocial are often amenable to intervention (Kahn, cited in Zarit et al., 1985,
Nurses who are committed to a holistic approach to care of patients and their caregivers are in an ideal position to intervene. The implications for nursing practice, nursing research and nursing education reflect the significance of the responsibility.
Bibliography


APPENDIX B
Consent for Telephone Contact

INSTITUTIONALIZATION OF A SPOUSE WITH ALZHEIMER’S DISEASE: A PHENOMENOLOGICAL STUDY OF THE EXPERIENCE OF THE ELDERLY WIFE CAREGIVER

I would like to hear more about this study. I give permission for Sandra Whytock to telephone me ______

I would not like to hear more about this study ______

If you would like to hear more about this study, please provide your name and telephone number in the space provided below. Thank you.

Name: ______________________________________________________

Telephone: ____________________
APPENDIX D

Demographic Data Sheet

Initials: _______
Interview code ___________________
Interview date: ___________________
Age: __________
Birthplace: ___________________
Occupation: ___________________
Husband’s Age: ______
Husband’s Occupation: ________________
Children: ________________
Residence of children: ___________________

Other occupants of residence ___________________
Date of Husband’s Diagnosis: __________
Date of Admission to care facility: __________
APPENDIX E

Interview Guide

1. What would a typical day be like for you before your husband was admitted to a care facility?
2. Can you tell me about how the decision was made that your husband should be admitted to a facility?
3. What did you think about care facilities before your husband was admitted?
4. Can you describe what the day of your husband’s admission was like? What was it like to leave him at the facility? How did your husband react?
5. How would you describe your life (a typical day) in the first few days or weeks following your husband’s admission?
6. What was it like for you to visit him in the facility at first? What is it like now?
7. Is it different for you to have him in a facility now from what it was like at first?
8. Is there anyone or anything that was helpful when your husband was admitted?