THE VISITING SPOUSES OF EXTENDED CARE UNIT RESIDENTS: AN EXPLORATORY STUDY OF THEIR EXPERIENCE

by

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Abstract

The Visiting Spouses of Extended Care Unit Residents: An Exploratory Study of Their Experience

This study focused on the non-institutionalized spouses of extended care unit (ECU) residents using the UBC Model for Nursing as the conceptual framework. The purpose was to elicit the visiting spouses' perceptions of the impact on their lives of having a spouse in an ECU, the coping behaviours they used, and the factors influencing or determining their coping behaviours.

Data were collected through relatively unstructured interviews with nine visiting spouses. The three women and six men were married to disabled spouses who had lived in the ECU for an average of three years. Data analysis proceeded through the constant comparative method.

Participants saw their spouses' institutionalization as part of a process of change beginning before the actual admission. The impact of having a spouse in an ECU was felt by participants as one of enduring loneliness and continuing preoccupation with their disabled spouses. Loneliness was interpreted to arise from the absence of intimacy in their lives and their preoccupation, from continuing caring for and attachment to their disabled spouses.
The participants described a variety of coping behaviours and influencing factors. These were clustered around four aspects of their lives: the disabled spouse; painful emotions; the roles formerly performed by the disabled spouse; and social participation. Three core concepts emerged from the data. These were: perceiving mutuality in interactions with their disabled spouses; humanizing the institution; and integrating having a spouse in an ECU into the continuity of their lives. The last core concept had the greatest explanatory power.

Nurses can facilitate the development of these three concepts by respecting the individuality of residents and visiting spouses and by ensuring that caring and competent nursing care is provided. Other implications for nursing practice and education as well as suggestions for further research are presented.
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CHAPTER ONE

Introduction

A marital relationship is pivotal to the lives of many people. The elderly may place a special value on their marriages because "of an awareness that their union continues in the face of the uncertainty of life and the reality of death" (Abu-Laban, 1980, p. 126). Their spouses are a source of continuity through the years—a link between their past, present, and future. In marriages of long duration, elderly spouses have often developed an interdependence that helps them to cope with psychological and physical disabilities. The death of a spouse rather than divorce disrupts the vast majority of marriages in old age (Nye & Berardo, 1973), but there is another form of marital disruption. This exploratory study focuses on elderly people whose spouses live in long-term care institutions. Their marriages are disrupted, not by death or divorce, but by their spouses' need for institutional care.

Background and Significance

At least 2.3 million Canadians or 9.7% of the population were 65 years of age and over in 1981 (Statistics Canada, 1984). By the year 2025 their
numbers are expected to increase to about 5.5 million or 19% of the population (Statistics Canada, 1982). Most elderly live in private dwellings but a small percentage are residents of long-term care institutions. The exact figure is not known because of disagreement about what constitutes long-term care settings and about the point at which a patient acquires long-term care status (Statistics Canada, 1982). An estimate may be obtained from recent census data stating that 158,000 or about 7% of the elderly population live in institutions and nursing homes (Statistics Canada, 1984). One might then infer that few of the elderly become institutionalized, but longitudinal studies reveal that the elderly have a 25% (Palmore, 1976) or even a 50% (McConnel, 1984) chance of living in long-term care institutions before they die.

Although the widowed and the never-married constitute most of the institutionalized population, a certain proportion are still married. American data suggest that 14% of the residents of long-term care institutions are married (Locker, 1981). The same figure is obtained by extrapolating from Canadian data on elderly residents of collective dwellings (Statistics Canada, 1983). As more Canadians survive into old age, it is reasonable to assume that the proportion of married residents will increase. Indeed, this trend has already been noted in the literature (Locker, 1976; Halbfinger,
The non-institutionalized or visiting spouses of people living in long-term care institutions form a substantial group—a group that nurses will see more of in the future.

The visiting spouses' presence and activities benefit their disabled spouses' lives in the institution. The literature suggests that family members help to humanize the institution (Bowker, 1982) and to prevent the isolation of residents from the community and family life (Dobrof & Litwak, 1977). They also provide material, social, and emotional "extras" unobtainable from the institution (Dobrof & Litwak, 1977) and contribute to individualizing resident care (Strow & Mackreth, 1977). Visiting spouses, of all family members, are the closest emotional ties for married residents and in this researcher's experience they are usually the most frequent and concerned visitors.

The quantity and quality of their involvement depends, in part, on the staff's attitude and approach to families. The relationship between staff and family members can be fraught with conflict if the staff view family members as interlopers in the institution (Dobrof & Litwak, 1977; Strow & Mackreth, 1977). Because residents of long-term care institutions usually live there until they die, the involvement of family members is also long-term. Ideally, staff and family members see
themselves as partners in a joint enterprise (Strow & Mackreth, 1977). The integrity of this partnership rests on the understanding and support received by family members from staff. Of all health care professionals, nurses interact most frequently with residents and families. Therefore, they have many opportunities to provide visiting spouses with understanding and support. In order to do this nurses need to know something of what it is like to have a spouse in an institution.

Yet, this researcher's review of the literature and experience in a long-term care institution revealed that little is known about visiting spouses. A number of studies and papers dealt with the family of the institutionalized elderly without differentiating between visiting spouses and other visiting family members. Others concentrated on the adult children of residents. Only a few focused on visiting spouses alone and most of these were accounts of support groups formed by social workers. Thus, there is lack of empirical research on the experience of visiting spouses that can be used to enrich nursing practice. The basic question, "What is it like to have a spouse in a long-term care institution?", remains unanswered.
Conceptual Model

The University of British Columbia (UBC) Model for Nursing (1980) provided the perspective for studying the visiting spouse's experience. The UBC Model (1980) regards the individual as a behavioural system which is continually reacting to and acting on its environment. According to the model a behavioural system consists of nine subsystems, each interacting and interdependent with the other subsystems. Behavioural system balance results when the "subsystems are in a balanced relationship with each other and the system is in a balanced relationship with its environment" (UBC Model, 1980, p. 3). Each subsystem is responsible for the satisfaction of one basic human need and is associated with a need-related goal (see Appendix A). The individual experiences these needs as tensions.

The behavioural system attempts to reduce tensions by the use of coping behaviours. When coping behaviours are suitable, tensions are reduced and needs are satisfied. When coping behaviours are unsuitable, tensions increase and needs are not satisfied. Behavioural system imbalance results, threatening the individual's growth or survival.

Coping behaviours are determined by the individual's cognitive (thinking and knowing) and executive (doing) abilities and are influenced positively or negatively by
forces internal and external to the system. Forces "may arise from the needs and abilities of the subsystems (personal); from other behavioural systems (sociocultural); or from impersonal aspects of a situation (impersonal)" (UBC Model, 1980, p. 8). A coping behaviour in one subsystem may act as a force in another.

Using this framework, the institutionalization of a spouse is seen primarily as a sociocultural force affecting or influencing the visiting spouse's satisfaction of basic human needs. If tensions increase as a result of having a spouse in an institution, the visiting spouse uses coping behaviours, suitable or unsuitable, in an attempt to satisfy basic human needs and, thus, to maintain behavioural system balance. Factors (forces and abilities) influence or determine the efficacy of these coping behaviours.

**Statement of the Problem**

Visiting spouses form an increasingly significant group of family members seen in long-term care institutions. In order to empathize with them and to support their involvement, nurses need to know more about their experience. Specifically, this study is concerned with how their lives are affected by having a spouse in an extended care unit (ECU).
Purpose of the Study

The purpose of this study is to explore and describe (a) the impact on the visiting spouse's life of having a spouse in an extended care unit, (b) the coping behaviours used by the visiting spouse, and (c) the factors influencing or determining coping behaviours.

Definition of Terms

1. Impact on the visiting spouse's life—"influence on the visiting spouse as a behavioural system."
2. Basic human need—"a fundamental requirement of survival and growth of the behavioural system" (UBC, 1980, p. 7).
3. Coping behaviour—"a response that indicates the way in which a subsystem is attempting to satisfy a basic human need" (UBC, 1980, p. 7) and maintain behavioural system balance. Coping behaviours may be suitable or unsuitable.
4. Factors—the cognitive and executive abilities determining coping behaviours; and the impersonal, personal, and sociocultural forces influencing the coping behaviours.
5. Extended care unit (ECU)—"An extended care hospital or unit provides a special type of program for those who, because of illness or marked physical or
functional disability, require long-term hospitalization....Twenty-four hour coverage by professional nursing staff is provided" (Hospital Programs, 1984, p. 2).

6. Visiting spouse--the husband or wife who continues to live in his or her own dwelling after the admission of a spouse to an ECU and who visits the disabled spouse in the ECU at least once every two weeks.

**Limitations of the Study**

1. The participants in this study were those spouses who regularly visited their institutionalized spouses. Thus, spouses who visited infrequently, whether because they live at a great distance from the ECU or because they are emotionally or physically unable to cope with visiting, were excluded.

2. The study used a convenience sample of visiting spouses drawn from one ECU. Therefore, the results may not be representative of the general population of visiting spouses.
Assumptions

This study was based on the assumption that the institutionalization of a spouse significantly affects the visiting spouse.

Organization of the Report

In this chapter, the problem and the purpose of the study have been introduced. In addition, the conceptual model, assumptions, and limitations of the study were presented. The literature is reviewed in Chapter Two. Chapter Three contains the description of the methodology of the study. The findings and interpretation of the data are presented in Chapter Four and the summary, conclusions, and implications of the study form Chapter Five.
CHAPTER TWO

Literature Review

The purpose of this chapter is to present the research and theory which formed the background for this study. To that end, the chapter is divided into two sections. The first section reviews and critically examines the literature on visiting spouses and thus places this study within the context of current research. The second section presents two different theoretical approaches to understanding the impact on the visiting spouse's life of having a spouse in an institution.

Visiting Spouses

Two research studies were located that dealt with aspects of the visiting spouse's experience. Brandwein, Postoff, and Steinberg (1979), in an unpublished study, examined the role and lifestyle changes faced by 18 visiting spouses. Open and closed ended questions elicited information on the role assumed by visiting spouses in the institution, the role which evolved for them in the community, and their perceptions of their marriages since the separation from their disabled spouses.
Eleven of the sample had cared for their disabled spouses at home for more than two and one-half years prior to institutionalization. Even in the institution, 13 visiting spouses provided physical care. Although more than one-half of the sample said they continued to give care because of dissatisfaction with institutional care, the authors felt that the community spouse's continued involvement in the physical care could be attributed to the lack of acceptance of the placement, the inability to cope with their own feelings of guilt and anxiety, and the transition from primary care taker to a secondary position. A major factor motivating the community spouse was the need to feel needed and to be perceived as a caring, devoted partner by others (p. 6).

All but one of the visiting spouses felt that visiting was important to their partners' psycho-social well-being. The authors inferred that visiting spouses faced an identity crisis in the community. It was evident that many could identify with consequences of widowhood such as the loss of companionship and loneliness but, unlike widows or widowers, visiting spouses were not able to start a new life or to form new relationships. They felt ill at ease with friends, especially married friends. It was determined that visiting spouses were "suspended between the state of marriage and widowhood, struggling to cope with a new role...the 'married widow(er)'" (p. 7).
To the authors' surprise and concern, 16 of the 18 visiting spouses had not made plans for the future even though their partners had been disabled for years. They saw no future for themselves and expressed feelings of helplessness and hopelessness. The formation of support groups for visiting spouses was a recommended intervention.

Linn and Gurel (1969) studied the attitudes of 80 women whose husbands were institutionalized in nursing homes. The attitudes of the wives were classified as positive or negative immediately before the admission of their husbands. Two months later their attitudes were assessed again. Positive change in attitude was best predicted by high ratings on the cleanliness of the nursing home, the activities available, the building itself, and having had little previous experience with nursing homes. Negative change was associated with low ratings on meals, the care provided, and the frequency of visits by the physician. The authors concluded that "how characteristics of the nursing home are perceived...appears to determine change and the direction of change in how nursing home placement is perceived" (p. 371).

The study by Brandwein et al. (1979) provided insights into the visiting spouse's experience but its focus on roles meant that other aspects were not
explored. In addition, the report did not clearly
distinguish between the actual findings of the study and
the authors' interpretations of those findings. Thus, it
is difficult to know what was fact and what was
inference. While the study by Linn and Gurel indicated
the importance of the quality of care, the results
reflected attitudes shortly after admission. It is
possible that the factors influencing attitudes may
change after the initial adjustment to having a spouse in
an institution. The following discussion reviews
literature that is anecdotal in nature rather than
grounded in empirical research.

Locker (1981) saw the institutionalization of a
spouse as a major life crisis, "the ultimate loss among
the many losses experienced through the process of aging"
(p. 40). From her observations and from experience with
support groups formed for spouses of the
institutionalized elderly, she noted that the visiting
spouse faced "crucial changes in living pattern, marital
role, relationship with family and friends, and the drain
of financial resources" (p. 44). Visiting spouses felt
guilty because of their inability to care for their
disabled spouses at home and angry because of the burden
they had to carry. In addition, depression, loneliness,
and anxiety about their own health were common. They
tended to project their anger onto the staff, especially
in their expectations of nursing care. Other coping behaviours were evident among the five case illustrations given in the article. One man blamed himself for his wife's condition and visited every day. Another worked as a volunteer in order to temporarily forget his problems. One woman was overwhelmed by the separation from her husband and visiting became very important to her. Locker felt that individual and group counselling helped visiting spouses deal with the emotional problems associated with the institutionalization of a spouse. Adult children were potential sources of emotional support but some of them were unable to deal with their own feelings of loss.

Locker quoted one visiting spouse as saying that "we are the widows of the living dead" (p. 44). Halbfinger (1979) observed that the visiting spouse "is in a kind of limbo. He/she is neither a partner in a marriage nor able to come to terms with and accept death" (p. 22). Like Locker, Halbfinger viewed the institutionalization of a spouse as a loss for the visiting spouse but he focused more on the interaction between the staff and visiting spouses. Conflict often arose after the disabled spouse's admission to a nursing home. The visiting spouse "is often viewed as guilt-ridden, overprotective and overdemanding. In return, he/she perceives the staff as wanting to take over completely,
wanting to control everything and excluding them from any semblance of participating in the marital role" (p. 22). When institutionalized spouses are treated as children and visiting spouses' participation not allowed, "we encourage the view that the life now disconnected from its past held little meaning" (p. 23) and, by implication, that the life of the visiting spouse has little meaning.

Steuer and Clarke (1982) reported on three groups formed to support the caregivers of patients with senile dementia. In a group for spouses, the four women with institutionalized husbands called themselves "walking widows." These spouses visited frequently and did not take vacations for fear they would then not be available in an emergency. In group discussion, "they recognized this as fulfilling a magical need for maintaining control" (p. 91).

Feelings of guilt, grief, loneliness, and isolation were described by women attending a group for wives of patients with Alzheimer's disease (La Vorgna, 1979). They benefitted from sharing their feelings with others and from the acceptance and camaraderie the group meetings provided. As a result of their participation, the author concluded that "these women are now able to feel sorry for themselves as well and to take positive action toward finding some personal happiness" (p. 221).
These papers impart valuable information about visiting spouses, their coping behaviours, and the various factors influencing or determining coping behaviours. But much of the content of these reports seems to be the authors' interpretations of visiting spouses' behaviours. Therefore, the generalizability of their conclusions is doubtful. In addition, these are mainly reports of groups formed because social workers felt that visiting spouses needed support. These groups were likely attended by visiting spouses who were having problems and not by those who saw no need to participate or who felt uncomfortable talking in groups. Therefore, the observations made in these papers may apply to only some visiting spouses. Interestingly, none of the studies and papers located was written by a nurse. From the literature, one could surmise that the plight of visiting spouses is of greater concern to social workers than to nurses. But it is nurses who have the most frequent contact with visiting spouses. This literature provides guidance for social work practice and group work but little direction for nurses in their frequent interactions with individual visiting spouses.

Impact, Coping Behaviours, and Influencing Factors

The literature described above is briefly summarized in this discussion and is supplemented by literature on
the family and the institutionalized elderly and on bereavement and divorce.

**Impact on their lives.** Visiting spouses were reported to have feelings of guilt, anxiety, depression, anger, hopelessness, and helplessness (Brandwein et al., 1979; Locker, 1981). Loneliness, a sense of loss and grief, as well as an inability to project into the future were also experienced (Brandwein et al., 1979; La Vorgna, 1979; Locker, 1981). In addition, the relationships between visiting spouses and staff members were often characterized by conflict and the relationships between visiting spouses and friends by discomfort (Brandwein et al., 1979). The main observation in the literature was that visiting spouses felt neither married nor widowed, unable to enjoy the benefits of marriage and conversely, unable to proceed with their lives as unmarried individuals (Brandwein et al., 1979; Halbfinger, 1979; Locker, 1981; Steuer & Clark, 1982).

Other studies, not specific to visiting spouses, also reported guilt, a sense of loss and grief, and helplessness as prevalent among family members of the institutionalized elderly (Berezin, 1970; Brody, 1973; Tobin & Lieberman, 1976). Indeed, statements regarding guilt were almost truisms in the literature. But the results of two studies challenge the validity of these statements. In a study of 55 family members, Johnson and
Werner (1982) found that guilt scores were low, below a neutral point. Smith and Bengtson (1979), after analyzing interviews with 100 adult children and their institutionalized parents, reported that only 10% of the adult children felt guilty. Thus, the assumption that all family members feel guilt due to the institutionalization of elderly relatives may be unwarranted.

The existence of conflict between staff and family members is another frequent observation (Miller, 1969; Strow & Mackreth, 1977) and, as in Brandwein et al. (1979), is usually attributed to inner conflicts experienced by family members.

The need to feel needed was not confined to visiting spouses. Safford (1980) reported that family members wanted to find an appropriate role in the institution. But they often experienced frustration and anger "when confronted by, and unprepared for the complexities of providing tender loving care within the structure of a large organization" (Safford, 1980, p. 659).

Loneliness, social difficulties, and identity problems were commented on only in the literature on visiting spouses. It is interesting to note that loneliness was the most common problem faced by women in Lopata's large study of widows (1973) and in another study of the bereaved, the feeling of loneliness
persisted for years after the death of a spouse (Glick, Weiss & Parkes, 1974).

The lack of planning for the future was also unique to visiting spouses. Interestingly, the findings of Chiriboga (1982a) in a study of divorced people are similar in that many of those 50 years of age and over were unable to project even one year into the future. He suggested that this reflected "not only problems in detaching from the former way of life, and not simply fewer options, but also a generally greater uncertainty about what to do next" (p. 113). He also noted that divorced individuals were in a "betwixt and between" position characterized by confusion and indecision.

Coping behaviours. The literature indicates that the coping behaviours used by visiting spouses included visiting frequently (Brandwein et al., 1979) and projecting their inner conflicts on to the staff of the institution (Locker, 1981). Visiting frequently was viewed as the means by which visiting spouses maintained the marital bond, retained their significance in their institutionalized spouses' lives (Halbfinger, 1979), and expiated their guilt (Brandwein et al., 1979). Conflict with staff members was nearly always viewed as a problem of visiting spouses. Halbfinger (1979) implied that spouses and staff members have different perceptions of
their interactions and it is the difference in these perceptions that gives rise to conflict.

Berezin (1970) commented on the importance of the concept of partial grief to understanding the coping behaviours used by the family members of the institutionalized elderly. Grief, the normal emotional and psychological reaction to loss, is the "process of realization, of making real inside the self events which have already occurred in reality outside" (Parkes, 1972b, p. 344). Berezin felt that partial grief arises from losses that are incomplete or ongoing and is grief that "cannot be worked through, when it cannot be resolved" (p. 59). He believed that the emotional problems seen in family members result from the inability to work through the grief process. Family members may subconsciously wish their elderly relatives were dead but may deal with this wish through denial, overprotectiveness, or self-sacrificing behaviour.

Influencing or determining factors. The literature indicated that a number of factors influenced or determined the coping behaviours of visiting spouses. Emotional support from others in the same predicament and from health care professionals through group work was seen as particularly influential (Brandwein et al., 1979; La Vorgna, 1979; Locker, 1981; Steuer & Clark, 1982). Adult children may or may not be helpful depending on
their own emotional reaction to the institutionalization of an elderly parent (Locker, 1981). The visiting spouses' past caregiving activities also seem to influence their coping behaviours (Brandwein et al., 1979); and their perceptions of institutional care and the staff affect their attitude to and relationships with staff members (Halbfinger, 1979; Linn & Gurel, 1969).

The literature on family members and the institutionalized elderly suggests other factors not mentioned in the literature specific to visiting spouses. Writers emphasized the importance of the institution's attitude and approach to family members. Some spoke of the institution's staff forming a partnership with family members (Strow & Mackreth, 1977), sharing functions (Dobrof & Litwak, 1977), or viewing the family rather than individual residents as the unit of service (Smith & Bengtson, 1979). Other factors centred on the state of the institutionalized elderly relatives. In two studies of family involvement, the enjoyment of visiting was associated with the relatives' mental status and ability to communicate (Moss & Kurland, 1979; York & Calsyn, 1977). Enjoyment was less if the relatives were disheveled or confused (York & Calsyn, 1977) or exhibited mood disturbances (Moss & Kurland, 1979). The physical and particularly the mental deterioration of the elderly relatives detracted from enjoyment of visits (York &
Finally, the stigma attached by society to having institutionalized an elderly relative added to the emotional difficulties experienced by family members (Safford, 1980).

Approaches to Understanding Marital Disruptions

Much of the literature on the family members of the institutionalized elderly used crisis theory either implicitly or explicitly to explain their reactions to the institutionalization of elderly relatives. But the rationale for viewing institutionalization as a crisis for family members does not appear to be based in research. Indeed, as the study by Brandwein et al. (1979) indicated, visiting spouses may have longstanding problems in meeting their own needs after the institutionalization of a spouse.

In the present study, having a spouse in an institution is regarded as a form of marital disruption and as a sociocultural force according to the assumptions of the UBC Model (1980). The possible consequences of marital disruptions are well-documented in the literature. Bereavement is associated with poor medical adjustment (Gerber, Rusalem, Hannon, Battin, & Arkin, 1975) and with increased mortality rates (Parkes, Benjamin, & Fitzgerald, 1969). Marital separation and divorce have been linked to a wide range of
psychopathology (Bloom, White, & Asher, 1979). Although Lindemann (1944/1965) argued that acute grief lasts only four to six weeks, more recent studies have determined that grieving and feelings of attachment to the deceased may continue for years after bereavement (Glick et al., 1974; Lopata, 1973).

But why is marital disruption so traumatic? In this section two different approaches to answering this question are presented. Although each of these approaches is drawn from a large body of literature, only selected elements are described here. The manner of presentation is congruent with the assumptions of the UBC Model (1980).

Marital Disruption as a Loss

Research on loss and its related concept, grief, has centred mainly on the study of bereavement. Although there have been attempts to integrate elements of loss theory with stress research (Parkes, 1971; Falek & Britton, 1974), the perspective used here is psychoanalytical.

Loss is defined as "being without that which has or could have had meaning for the individual" (UBC Model, 1980, p. 9). The lost object is usually a significant person, but it can also be a material possession or a symbolic value such as one's reputation (Averill, 1968).
Object loss also "entails the disintegration of social relationships, with a consequent alteration in the living pattern and social condition of the bereaved" (Averill, 1968, p. 724). Averill (1968) called the disruption of these social relationships role loss.

Parkes (1971) and Marris (1975) viewed the disruption following a loss as reflecting the extent to which the individual's sense of the continuity of life had been shaken. Individuals construct their realities on the basis of assumptions that they have about themselves and about their world (Parkes, 1971). These assumptions or what Marris (1975) called the structures of meaning, are created and tested through experience. Their effectiveness rests on the belief that there is continuity in life. An attachment relationship is a critical component of these structures of meaning. When the loved person is lost, the individual's sense of continuity is shattered and his or her assumptions are no longer valid. He or she can no longer make sense of reality and the past, present, and future have no meaning. Marris (1975) called this situation a crisis of discontinuity, while Parkes (1971) called it a psycho-social transition.

On a deeper level, the impact of a loss can also be seen as reflecting the disruption of an attachment bond. Bowlby (1961) believed that attachment relationships
arise from a strong, instinctual disposition to maintain proximity to a few other valued and/or loved individuals. As a child, one forms an attachment to a mother-figure, a source of protection, well-being, and security. As an adult, one forms relationships based on the earlier experience of attachment. Children and adults protest and fear the disruption of an attachment bond, for in its absence they are isolated, without a sense of place. In the absence of an attachment relationship, individuals feel the loneliness of emotional isolation (Weiss, 1973).

A number of writers on grief have viewed it essentially as the struggle between two conflicting impulses—to recover the loss-object or to recognize the loss and reorganize one's life (Bowlby, 1961; Freud, 1917/1957; Marris, 1975; Parkes, 1971; Peretz, 1970). Grief is commonly viewed as a process consisting of three phases—shock, despair, and recovery (Averill, 1968). In normal grief, the necessity to face reality conquers the seductive but, ultimately, self-destructive urge to maintain the past. Failure to work through grief has negative implications for the individual's future mental health (Lindemann, 1944/1965). Marris (1975) summarized the typical signs of grief as

physical distress and worse health; an inability to surrender the past—expressed, for instance, by brooding over memories, sensing the presence of the dead, clinging to possessions, being unable to comprehend the loss, feelings of unreality; withdrawal into apathy; and hostility against
Marital Disruption as a Major Life Change

Research on major life changes has been primarily concerned with establishing a relationship between certain events and subsequent mental and physical disorders (Dohrenwend & Dohrenwend, 1974). More recently, investigators have tried to clarify the nature and strength of that relationship (Dohrenwend & Dohrenwend, 1978) and to identify the variables affecting that relationship (Hyman & Woog, 1982). The following discussion focuses on the basic issue of what aspects of major life changes explain their impact on individuals' lives.

One group of researchers emphasize the importance of the magnitude or the quantitative aspects of the change (Holmes & Masuda, 1974; Holmes & Rahe, 1967; Ruch, 1977). Holmes and Rahe (1967) devised a social readjustment scale which rates various life events according to the amount of change or adjustment they entail. The scale contains socially desirable and undesirable events. The death of a spouse, divorce and marital separations are assigned the greatest number of life change units because they require the greatest amount of adjustment. Another aspect of this approach is that life change units are additive. That is, the greater the number of life change
units and the larger the life change score, the greater the individual's susceptibility to disorders (Holmes & Masuda, 1974).

The social readjustment rating scale has been criticized on methodological and conceptual grounds (Brown, 1974; Dohrenwend & Dohrenwend, 1978). Other researchers feel that the individual's perceptions or the qualitative aspects of the change should take precedence in explaining the impact.

It has been proposed that situations perceived as entailing loss are more associated with problems than are situations of gain (Mechanic, 1974; Paykel, 1974). The undesirability and the long term threat of the change also negatively affect adjustment (Fenwick & Barresi, 1981; Brown, 1974). Changes with ambiguous meanings and uncertain consequences for the individual may be particularly unsettling (Chiriboga, 1982a). As McCall and Simmons (1966) observed, man is a planning animal but "until we have made out the identity and meaning of a thing vis-a-vis our plans, we have no bearings; we cannot proceed" (p. 61).

Another factor suggested by Dohrenwend and Dohrenwend (1978) is the degree to which the individual perceives that he or she can control the course and the outcome of the change. Perceived lack of control reflects negatively on one's sense of efficacy or
competency and, ultimately, on one's sense of self-esteem and identity (Kuypers & Bengtson, 1973).

Some writers believe that an individual's adjustment to disruptive life change is determined by the society in which he/she lives (Pearlin, 1980). In Lopata's (1973) study of widows, higher levels of education and social status characterized subjects who lived in better circumstances and were more socially engaged. But, whether a change is seen as desirable or undesirable may depend on its consequences, the enduring social conditions with which individuals have to live as a result of the change (Pearlin, 1980).

The discussion to this point has viewed major life changes as discrete events disconnected from the individual's life course. Theories such as Erikson's eight stages of personality development (1959) "seek to explain the nature of growth and the patterns of change in individuals from birth to death" (Kimmel, 1980, p. 7). Losses, life changes, and other events are all viewed as part of the sequence of growth and change.

Neugarten (1970) believes that an individual "passes through a socially regulated cycle from birth to death as inexorably as he passes through the biological cycle: a succession of socially delineated age-statuses, each with its recognized rights, duties and obligations "(p. 71). A normative pattern exists, a "socially prescribed
timetable" of which individuals are well aware and which allows them to anticipate and prepare for the normal turning points in their lives. Neugarten feels that these turning points or markers such as marriage or retirement "are not, for the vast group of normal persons, traumatic events or crises that trigger mental illness or destroy the continuity of the self" (p. 79). Rather, it is the off-time, unpredictable events which are likely to be traumatic because they "upset the sequence and rhythm of the life cycle" (p. 86).

Other writers share Neugarten's concern with off-time or unpredictable events and their effects (George, 1984b; Pearlin, 1980). Recently, researchers have questioned the value of assuming a clear-cut relationship between events and subsequent problems (Chiriboga, 1982b; Levinson, 1980). Using Neugarten's terminology, Levinson (1980) proposed that these events be regarded as "marker events" that serve to punctuate and dramatize a relatively extended, complex sequence of change. If we focus too narrowly on the event itself, we lose sight of the deeper process. Other aspects of this sequence, though less dramatic or less accessible to investigation than the marker event, may yet be of fateful importance in the life course (p. 275).

Summary

From the review of the literature, it is evident that having a spouse in an institution does significantly
affect the lives of visiting spouses. Some elements of their situation are experienced by family members in general, but other elements, such as loneliness and identity problems, are unique to visiting spouses. Although the literature exhorts health care professionals to form a partnership with family members, there is a dearth of information to guide nurses in their interactions with family members and, specifically, with visiting spouses. The literature that does exist is based primarily on interpretations and opinions rather than being grounded in research. Because of the paucity of research studies, the nature of their experience can only be speculated upon. It is evident that there is a need for the present study.

The literature on loss and major life changes suggests ways of understanding the nature of the forces influencing a visiting spouse's life. Loss theory directs attention to attachment bonds and their importance to how individuals view the world and to their well-being. The institutionalization of a spouse may be expected to interrupt the visiting spouse's sense of the continuity of life and to be associated with grief reactions and loneliness.
The institutionalization of a spouse as a major life change is comparable to other changes involving the marital relationship. Its impact may be explained by: the amount of change it sets in motion and the presence or absence of other life changes occurring around the same time; whether it is seen as a loss or a gain; its desirability, ambiguity, and uncertainty; and, its potential to be controlled. Society and the conditions with which a visiting spouse has to live as a result of the change may also be important to his or her adjustment. Finally, the significance of the change to the visiting spouse's mental timetable is a vital consideration in assessing the impact.
CHAPTER THREE

Methodology

The purpose of this study was to explore and describe the visiting spouse's experience. Because little is known about having an elderly spouse in a long-term care institution an exploratory descriptive research design was appropriate. Such a design allows the researcher the flexibility and intensity of study required to characterize a relatively unresearched phenomenon (Selltiz, Wrightsman, & Cook, 1976). This chapter describes the congruence of this research design with the UBC Model (1980), the setting, the selection of the sample, the data collection, the data analysis, and ethical considerations.

The Research Design and the UBC Model for Nursing (1980)

A conceptual model provides a researcher with a simplified representation of the focus of inquiry. A model indicates the key elements of the phenomenon under study and the relationships between these elements (Hardy, 1974). It does not, however, constitute reality and can only "give us a sense of what is going on and why" (Hardy, 1974, p. 104). In this study the UBC Model (1980) provided the perspective on the focus of
inquiry—the visiting spouse. The Model was appropriate because it allowed for a broad assessment of the visiting spouse's experience, an assessment which can then be used in nursing practice.

Qualitative research methods are uniquely suited to obtaining the kind of in-depth knowledge of human behaviours that can enrich and guide nursing practice (Swanson & Chenitz, 1982). They allow the researcher to "get close to the data" rather than being constrained by "preconceived, rigidly structured, and highly quantified techniques" (Filstead, 1970, p. 7). They also allow the researcher to gain an understanding of individuals' perceptions of their experience and to inductively develop an interpretation that is true to their experience (Rist, 1979). The UBC Model (1980) simplified and systematized the researcher's exploration of the complexities of the visiting spouse's experience and directed the researcher to elicit the individual's perceptions and to validate the researcher's interpretations with the individual.

**Setting**

The setting was a 300-bed extended care unit (ECU) associated with a university and located on the periphery of a metropolitan area. Parking is available and the ECU is accessible by bus. Visiting is unrestricted from
8 a.m. to 8 p.m. The ECU has four floors, each of which is home to 75 residents. In addition to four- and five-bed rooms, every floor has three private and three semi-private rooms. At the time of this study, there were no private visiting areas for residents and their families. Each of the four floors is similar in terms of the residents' characteristics and their required level of care and of the mix of physically and cognitively impaired residents. At the time of this study, there were about 40 married residents. The ratio of professional (registered nurses) to non-professional (patient care aides and unit clerks) nursing staff was 20:80.

The researcher had worked in the ECU and thus was familiar with the setting and with the residents.

**Selection of the Sample**

**Sampling Criteria**

The sampling criteria in this study required that participants:

1. were the spouses of those residents who had lived in the ECU for at least six months.
2. visited their disabled spouses at least once every two weeks.
3. lived in private dwellings.
4. spoke English.
5. lived in the metropolitan area.

The first two criteria established that the sample could provide the richness of data required in an exploratory study—spouses who were frequent visitors to the ECU and who, it was assumed, had grown accustomed to having their husbands or wives in the ECU. The third criterion was based on the assumption that the experiences of spouses living in non-private or collective dwellings may be significantly different from the experiences of those living in private dwellings. The last two criteria made interviewing possible and feasible for the researcher.

Sample Size

Ideally, sampling in an exploratory study continues until no additional significant data can be found (Diers, 1979). In this study, theoretical sampling, as it was called by Glaser and Strauss (1967), was not possible because of time constraints on the researcher. A decision was made to seek a sample of eight to twelve visiting spouses to obtain the necessary richness of data and to meet the purpose of the study.
Selection Procedure

Two methods were used to introduce potential participants to the study. First, the researcher gave the unit clerk on each floor information letters describing the study (see Appendix B) and asked that they be given to visiting spouses. Second, information letters were made publicly available on the bulletin board on each floor. In reality, all the participants were obtained by the first method.

Interested visiting spouses were directed to fill in the reply section on the letters if they wished to participate and then to place the letters in boxes attached to the bulletin boards on each floor. The researcher contacted interested visiting spouses by telephone, explained the study again, and arranged for a first interview time. Ten potential participants indicated their interest; nine agreed to participate. Before each interview began, the researcher explained the study once more and obtained the participant's written consent (see Appendix C).

Data Collection

The researcher used focused interviews to collect the data. This relatively unstructured interview approach is appropriate when little is known about a
research area (Selltiz et al., 1976). The function of the interviewer "is to focus attention upon a given experience and its effects" (Selltiz et al., 1976, p. 188).

The data collection guide used to explore the visiting spouse's experience listed the nine basic human needs and indicated specific areas of inquiry associated with each need (see Appendix D). Three basic questions corresponding to the three aspects of the purpose of the study were asked in each need area. For example, participants were asked, "Has having your spouse in the ECU affected the way you feel about yourself?", "What do you do to feel good about yourself?", and, "What helps you feel good about yourself?".

Demographic data and background information added to the depiction of participants and their spouses. Thus, the participant's age, perceived health status, and length of time married; and the disabled spouse's age and duration of residence in the ECU were included as areas covered by the guide.

Although the data collection guide provided some structure to interviewing, the wording and sequence of questions was not predetermined. In keeping with the study's approach, participants were free to recount their experiences in as much detail as they wished. In addition to the three basic questions associated with
each need area, other questions were asked in order to explore the participants' responses fully and to develop the recurring themes.

Data Collection Procedure

Different "slices of data" (Glaser & Strauss, 1967, p. 65) enrich a researcher's understanding of the phenomenon under study. In this study, audio-tape recorded interviews and written impressions of the participants and their living situations were the slices of data. When participants continued talking after closure of the interview, the researcher/interviewer recorded their remarks from memory as soon as possible. Written impressions, as Diers (1979) cautioned, were only used as data and not as the researcher's definitive interpretations of the situation.

The process of interviewing was similar for all participants. Participants had a choice of where they wanted to be interviewed; all chose to be interviewed in their own homes. For the purpose of this study, it was anticipated that two interviews with each participant would provide a sufficient richness of data. All participants were interviewed twice except for one woman whose husband died in the interval between the first and second interview. About one month's time separated all first and second interviews. As Glaser & Strauss (1967)
suggest, the researcher needed this time for the practical aspects of transcribing the data and noting categories and for the contemplation necessary to gain insights into the data. The researcher had originally anticipated that each interview would last about one and one-half hours but, in fact, interviews varied in length from 45 minutes to three hours.

The purposes and content of the first and second interviews differed. The first interview served to assess the visiting spouse's experience using the data collection guide. In accordance with the model's assumption of interdependency and interaction between subsystems, different areas of inquiry were recognized to be interrelated.

The second interview served primarily to develop themes, categories, and concepts evoked by the data and to clarify the meaning of statements made by participants in first interviews. For example, one participant stressed that getting to know other residents had helped her feel more comfortable. Subsequently, other participants were asked if they had gotten to know other residents and whether they had found it helpful.

**Data Analysis**

Data analysis in this study was modelled after the constant comparative method developed by Glaser and
Strauss (1967). This method is characterized by the joint collection, processing, and analysis of data. It is used to generate descriptions of "what the situation is, in as full as way as possible so that the reader has a picture of the event or situation he can relate to" (Diers, 1979, p. 37).

In an exploratory study, data analysis ultimately depends "on the integrative powers of investigators, on their ability to draw together many diverse bits of data into a unified interpretation" (Selltiz et al., 1976, p. 98). The researcher's interpretation is valid since it is drawn from the data (Stern, 1985). It is reliable if "a reader, adopting the same viewpoint as articulated by the researcher, can also see what the researcher saw, whether or not he agrees with it" (Giorgi, 1975, p. 96). Verification of categories with participants also ensures the fidelity of the researcher's interpretation to their experience (Stern, 1985).

Data processing and analysis began in the interview situation. The researcher initially sorted data as they were received according to the pertinent basic human needs. This served to alert the researcher to areas not yet covered in the interview.

The audio-tape of an interview was transcribed as soon as possible after the interview and before subsequent interviews. During the transcription, the
researcher noted the demographic characteristics of the participant. Brief biographies were composed for each participant in order to indicate the context in which the institutionalization of the spouse occurred.

The completed transcript was studied in more depth. Beginning themes or clusters of similar information were noted, contrasted, and compared and then were verified or disproved with participants. Because data analysis occurred simultaneously with data collection, the information gained from an interview with one participant was used to help direct data collection in subsequent interviews with other participants and to develop tentative categories of themes.

The themes, expressed in the participants' own words, were then coded according to the purpose of the study—that is, the impact of having a spouse in the ECU on their lives, the coping behaviours they used, and the factors influencing or determining these coping behaviours. The formal coding was not done according to the nine basic human needs because the purpose of this study directed analysis toward viewing the visiting spouse primarily as a behavioural system rather than as nine subsytems.

The themes within each of the three main coding categories were then further analyzed into concepts, categories, and their properties. These were, in turn,
synthesized and integrated into a meaningful description of the visiting spouse's experience.

**Ethical Considerations**

The rights of the participants were protected in a number of ways. The rights to refuse to participate, to withdraw from the study, or to terminate an interview were guaranteed. In addition, participants were assured verbally and in writing that their participation or non-participation would in no way affect the care of their spouses in the ECU. No risks were anticipated.

Participants were assured that the staff of the ECU would not be informed of their involvement and that all the data obtained would be kept confidential. No names were used on the tapes, transcripts, and other written records. Participants were informed that the tapes would be erased following the final analysis and interpretation of the data. Arrangements were made to send participants a summary of the study on its completion.

One ethical consideration was unanticipated. The participants were well known in the ECU. Many of them had been visiting almost daily for years. Thus, their accounts contain information that makes them readily identifiable to ECU staff. The researcher eliminated the more obvious identifying information from the presentation of the accounts without detracting from the import of the data.
Summary

This chapter has described the methodology used in this study. The congruencies between the UBC Model (1980) and the research design were presented. The setting, the sample, and the data collection and analysis were described. Finally, ethical considerations were noted.
CHAPTER FOUR

Findings and Interpretation

This chapter is organized into four major sections. The first section describes the sample; the second details the process of becoming a visiting spouse; a third, much larger section, describes what it is like to be a visiting spouse; and, the fourth presents the core concepts. The third section corresponds to the purpose of the study by describing the impact of having a spouse in an ECU on the visiting spouses' lives, the coping behaviours used, and the factors influencing or determining coping behaviours. Because of the interdependency of coping behaviours and factors, these two aspects of the purpose are combined into one subsection describing clusters of coping behaviours and influencing factors. The fourth section presents the three core concepts—the concepts having the most power to explain variations in the data (Maxwell & Maxwell, 1980).

Throughout this chapter the findings and their interpretation are interwoven. The interpretation cites literature that was included in the second chapter and introduces additional literature to enrich the discussion of concepts, categories, and themes drawn from the data.
The Sample

The sample was relatively homogeneous (N=9). The participants were elderly, ranging in age from 65 to 80 years (median=73 years). Most had been married to their disabled spouses for many years (mode=43 years) although one had been married for only three years. All of the participants lived alone; five lived in houses, four in apartments. Only one lived more than five miles away from the ECU. Seven participants were retired, one had never worked outside the home during her marriage, and one was still working. Of the seven who were retired, one had retired during the period she had cared for her husband at home, one had retired two years after his wife entered the ECU, and the remainder had retired before the onset of their spouses' disability.

Six participants were male and three were female. Their disabled spouses had lived in the ECU one to seven years (median=3 years). Five required institutional care because of the effects of cerebrovascular accidents, three because of chronic neurological diseases such as Parkinson's Disease, and one because of organic brain syndrome. All disabled spouses were physically disabled and seven of the nine were cognitively impaired.

The literature suggests that a significant proportion of residents of long-term care institutions are admitted directly from home (Smallegan, 1985). In
the present study, all of the participants' spouses were admitted to the ECU from other institutions—six from general hospitals, two from other ECU's, and one from a rehabilitation hospital.

The ages of the disabled spouses ranged from 62 to 84 years (median=73 years). In contrast, the average age of residents of long-term care institutions is 80 years (Atchley, 1980) and in the ECU used in the present study the average age was about 82 years. Thus, most of the disabled spouses were younger than the average resident.

There are a number of possible explanations for the preponderance of men in the sample and of visiting spouses whose disabled partners were "young" residents. The sampling criteria biased selection toward visiting spouses who were physically able to visit and therefore they and their disabled spouses were likely to be among the young elderly. In addition, focusing on the married elderly biased the sample toward men since the greater proportion of the married elderly in the general population are male (Statistics Canada, 1984).

The main intent of this study was to describe what it is like to have a spouse in an institution but it became apparent in the first interview that participants viewed their experience as having both ongoing and static elements. There was the process of becoming a visiting spouse as well as the state of being a visiting spouse.
The next section describes the process of becoming a visiting spouse.

Becoming a Visiting Spouse

The participants' descriptions of their lives prior to the institutionalization assumed the quality of stories--personally significant narratives whose plots located being a visiting spouse within the context of time. Although each story was unique in its details, four phases were common to most or all of them. These were: married life; the onset of the disability; the caregiving period; and, the decision to institutionalize.

Married Life

Most of the participants stated that their married lives prior to the onset of their spouses' disability had been happy. One woman stressed that she and her husband had done everything together.

Visiting Spouse (VS): He helped me with everything I did. We were always together. We...went out together, we came home together, we sat together, we worked together.

Others described a more traditional division of labour within the marital relationship but still emphasized the happiness of their married lives.
VS: We had a terrific life, I think. She was a heck of a good cook, and a good housekeeper. She was a good wife and a good mother.

That most of their descriptions of married life were so positive may be due to an idealization of the past like that observed by Lopata (1973) and Glick et al. (1974) among the bereaved. Regardless of whether their memories were accurate, the visiting spouses' portrayal of married life prior to the onset of their spouses' disability reflected their perceptions of it as a relatively happier time.

Onset of the Disability

Five participants described how they became gradually aware that something was wrong with their husband or wife.

VS: Well, he was diabetic and he'd always been a very active person, golfed 18 holes practically every day of the week and then he got so that instead of playing 18 holes he would just play nine. This is when I noticed first, and then just one thing, just like that, and then it got so that he, well, he'd have to get up so many times at night and one thing and another and just generally like that until finally he took a stroke.

The four other participants told of the sudden onset of the condition that eventually necessitated their spouses' admission to the ECU. One man described the worsening of his wife's longstanding disability and a sudden exacerbation.
VS: She began, oh, ten years ago, she began to get worse. Her lower limbs were in such a state that finally she went into the wheelchair...She could stand up as long as she had something to hang onto and she gradually got worse and worse until she couldn't stand at all really...and then in September...I think she'd been holding back a bit, that she was having problems, and she got so sick we got the doctor in one morning and she was off to [the hospital] by ambulance that morning diagnosed as a blockage of the bowel.

Another described a sequence of events, unbroken by a caregiving period, preceding his wife's institutionalization.

VS: She had a massive stroke I understand. It was five years ago. She...just left home for a few hours and I had a phone call that she keeled over. I went down to where this happened and called an ambulance and took her to the [hospital]. She was there for weeks, several weeks. I didn't know whether she'd make it or not. Quite a trying spell. But she hung on and was semiconscious for several weeks. She was about two months at [the hospital]. Then they took her to a rehabilitation hospital...She was there for a few months but they didn't figure...they could do anything for her...so [she] had to go over to an extended care hospital...She's been there ever since.

The Caregiving Period

Most (N=8) of the participants had cared for their disabled spouses at home before hospitalization. The main source of help for the married disabled elderly living at home are their spouses (Shanas, 1979) and, indeed, the participants in this study were the primary caregivers.
VS: Well he took a stroke in July...and he was on the critical list for six weeks and then he recovered enough in November to come home. After that we took several trips. He was in a wheelchair but he was active, alert, conversational, and we had alot of fun after he came home.

The caregiving period varied in length from three weeks to 13 years (mode=3 years). As the preceding quote indicates, caregiving had positive aspects but it was also a time of physical and mental hardship for participants.

VS: It was two or three weeks. It was a very tough three weeks on me.
Researcher (R): What was tough about those three weeks?
VS: Well, cleaning her up, just like a baby. Putting diapers on her and up during the night. She'd call out and trying to turn her over. I'm not a young man. It was really quite a strain.
R: Even with help [a homemaker] coming in, it wasn't 24 hours.
VS: Well, help was four hours in the morning....I had 20 hours a day to look after her.

Others considered the mental strain of caregiving harder to bear. A male participant stated that "as far as the physical end of it, I don't think it bothered me that much. It was the mental that really bothered me."

As studies of caregiving suggest (Sanford, 1975), several (N=4) of the past caregivers in the sample identified the loss of sleep as a problematic aspect of the caregiving period.

VS: The hardest on me was that he was incontinent and I was up all night with wet beds and such and I think I got very tired. That was the
hardest...I didn't get much sleep. I couldn't rest in the day time because he would want something.

Studies often comment on the social and emotional isolation experienced by people caring for the disabled elderly at home (Crossman, London, & Barry, 1981; Golodetz, Evans, Heinritz, & Gibson, 1969). In the present study, seven past caregivers described a gradual reduction in social participation during the caregiving period. In some situations, friends initially rallied around but then gradually withdrew their attentions as the acute period ended. The bereaved experience a similar phenomenon (Glick et al., 1974).

VS: Well, you know we ran into the same thing as most families do. When you have a sickness like that, your friends and your neighbours rally around and give you help with various things and, ah, bring in little goodies that they have made and that. But, as time goes on those little visits get fewer and farther apart, until after a period of time...that has stopped completely. Ah, as far as your friends and neighbours are concerned, you've been written off. Yeah, you're sick, that's fine, that's your problem.

The demands of the caregiving period necessitated less social contact outside the home.

R: You were quite social and active?
VS: Yes very. It dwindled because of all this time that [my husband] needed...I haven't enlarged my horizons gradually like I maybe should have.

One participant, though, deliberately did not decrease her social participation during the caregiving period.

R: So you didn't cut down?
VS: No, I didn't think it was good to.
R: Can you say a little more about that?
VS: You have to keep well yourself and you're not much company if you don't get out and know a little of what's going on in the world. So you have to do that as long as you don't overdo it, you know.

The Decision to Institutionalize

In discussing the decision to admit their disabled spouses to the ECU, the participants detailed the reasons for the decision and their feelings about the institutionalization.

The sense of burden experienced by caregivers is often described as the impetus for the institutionalization of an elderly disabled relative (Zarit, Reever, & Bach-Peterson, 1980). In the present study, the majority (N=5) of the past caregivers ascribed the decision more to the actual or threatened deterioration of their own health. This probably reflects the older age of the participants in this study, since most studies on caregiving at home have younger subjects in their samples. Most of the participants described their disabled spouses during the period before institutionalization as requiring total assistance in most or all of the activities of daily living. Even so, some delayed the decision to institutionalize for as long as two years.

VS: It got to the point where we [vs and homemaker] just weren't able to cope with her at home. It
was just a bit too much and the doctor advised me that we would both end up in the hospital unless I did something about it...and I carried on for another couple of years or more and it ended up that I just couldn't cope.

The institutionalization of one participant's wife was forced by his own acute illness.

VS: I was able to look after her here for almost five years with a little help from homemakers...but I wasn't feeling too well. I went to the doctor, he sent me to a specialist. They found that I had cancer of the bowel...But, before they put me in hospital, they had to put my wife in hospital, because there was no other way of taking care of her.

In his case, as in three others, the decision to institutionalize was influenced or, indeed, determined by a doctor's concern for the caregiving spouse's health.

R: Did you have any input into the decision?
VS: The doctor knew that I wasn't going to be able to take care of her, and, he kept her in the hospital until a bed became available, in the ECU, and he just told me, well, she's been moved to the ECU now, where she'll be taken care of—you just relax.

One other participant would have continued caring for her husband at home if her doctor had not expressed concern for the disabled spouse's quality of life.

VS: So he was put in in nothing flat...not over my protests but not with my active consent...The only way I could take him home was to keep him in bed. I suggested that to the doctor and he said that that would be an awful thing to do to him. He said that he's still got a life ahead of him. He can't just lie in bed for the rest of it.

The participants associated feelings of relief and regret with the institutionalization of their disabled
spouses. George (1984a) suggested that the burden of caregiving continues since institutionalization may only substitute one set of anxieties for another. The past caregivers in the present study saw the institutionalization of their spouses more positively because it relieved them of the ongoing strain of caregiving at home. In one participant's story, it was perceived as resulting in an improvement in his wife's condition.

VS: I think that she's better off there than she would be here anyway because there she gets better attention and she's more relaxed and I'm physically better off because I'm not up in the night two or three times to care for her and I get a little outside activity. I know what it was like when she finally went there. It was getting a little rough.

The participants recognized the impossibility of caring for their disabled spouses at home.

VS: I knew I couldn't possibly have taken care of her at home. I realized that very quickly. I wished I could.

"I wished I could" was a common theme that tempered any relief they may have felt. Although the literature suggests that family members feel guilty about institutionalizing their elderly relatives, the participants expressed regret rather than guilt over their spouses' institutionalization. When asked directly whether they felt any guilt, the initial response of some participants was particularly interesting.
VS: I've thought back since during the last five years trying to figure out if I should have known or... what I could have done to prevent such a thing anyway.

These responses suggest that participants had sought explanations for their spouses' disability, as the bereaved do for the death of a spouse, through an obsessional review of the past (Glick et al., 1974). When the researcher clarified the intent of the question, the participants referred to the impossibility of caring for their disabled spouses at home and to the affective bond between spouses.

VS: I can understand younger people having guilt feelings if it is their mother or father, having a bit of a guilt feeling that, well, they didn't want to place them there but they didn't have room for him at home or whatever so they might have....But when it's a spouse up around my age bracket I don't think that you'll find anybody with guilt feeling....'cause older people don't want to get rid of their spouses.

And as another participant stated, "the ECU was the only alternative."

An underlying assumption of this study was that the institutionalization of a spouse is a discrete event ending one way of life and introducing another for the visiting spouse. Instead, the participants indicated that their way of life had changed before the institutionalization and, for some, many years before. One man stated that "the biggest change is when we
stopped going anywhere, and she was confined to the house."

Their descriptions of when their lives changed support Parkes's (1971) and Marris's (1975) conceptualization of major life changes. The participants' "crises of discontinuity" or "psycho-social transitions" occurred when they realized their lives were irrevocably changed. Institutionalization of a spouse then assumes the status of a marker event indicating that a process of change is taking place.

In summary, the participants' stories began with their remembrances of married life and described the process that resulted in their being visiting spouses. For most, this process consisted of the onset of their spouses' disability, a caregiving period which exacted a toll on their mental or physical health or both, and ended with the disabled spouses' hospitalization and the decision to institutionalize. The participants ascribed their lack of guilt to their knowledge of the impossibility of caring for their disabled spouses at home.

The institutionalization of a spouse was not the crisis the literature portrayed it to be. Rather, it was part of a process of change which began with the participants' realization that their spouses'
disabilities required a change in the way they viewed the world and themselves.

**Being a Visiting Spouse**

**Impact on Their Lives**

During the interviews, one could sense the distress of some participants and the relative contentment of others. Regardless of these variations, all participants experienced the impact of being a visiting spouse as chronic loneliness and preoccupation with the disabled spouse. These two concepts represent the enduring conditions with which they had to live as a result of having a spouse in an ECU and were indicators of behavioural system imbalance.

**Loneliness.** One participant referred to himself and other visiting spouses as "us poor old lonely people." As he suggested, all the participants described themselves as lonely. Loneliness was a continual source of anguish for some and, for others, it was an accepted, albeit undesirable, part of their lives.

**VS:** You get pretty lonesome. I think this is the hardest part. I really do.

**VS:** I'm always lonely.

Being old is often equated with being lonely (Peplau, Bikson, Rook, & Goodchilds, 1982). But the
literature suggests that only a small proportion of the elderly, about 25%, report feelings of loneliness (Townsend, 1973; Wenger, 1982). Indeed, compared to other age groups, "self-reported loneliness is less common among old persons" (Peplau et al., p. 332). Thus, the reporting of loneliness by all the participants in the present study was unanticipated. Their descriptions of loneliness, of the forms it took, and of its associated feelings comprise the rest of the discussion of this concept.

Participants described their loneliness in a number of ways.

VS: But it is a lonely sort of a life now. It really is. It's pretty empty.

VS: There's quite a void there you know.

VS: Your life is not exactly the same. You're breaking off half of your life really.

VS: [My life] is a vacuum. We spent 30 years together. It sort of becomes part of your life.

The sensation of there being a "hole in the self" (Rubenstein & Shaver, p. 221, 1982) is a common metaphor for loneliness. Taken together, the words "empty," "void," "breaking off," and "vacuum" also imply being deprived of something that was once part of one's self.

The loneliness of widows is often experienced as a relative deprivation, "not in comparison to other people, but to one's own past, when the husband was well and life
was moving along in an established way" (Lopata, Heinemann, & Baum, p. 323, 1982). The forms of loneliness identified by the visiting spouses reflected their sense of relative deprivation.

The visiting spouses reported seven forms of loneliness, six of which bore some similarity to those identified by Lopata (1969). In the present study, participants were lonely for: companionship; the disabled spouses' performance of certain tasks; someone to discuss problems or decisions with; the presence of another person in the house; a confidante; and being part of a couple. Lopata (1969) had also observed that one can feel lonely for the past, present or future. The seventh form of loneliness expressed by the visiting spouses was a longing for what could have been or what should have been.

First, visiting spouses (N=7) were lonely for the companionship of their disabled spouses.

VS: You know if the wife was sitting down talking, even if we don't converse very much, the company, that we've been married now going on 44 years.

Or even just someone to share experiences with.

VS: You know, you go to a show by yourself...you come out; there's no one to share it with. You go on a trip. No one to share it with, you see.

This companionship could not be provided by others.

VS: Even if you travelled with any of your relatives. I got a brother,...he likes to
travel also, and his wife couldn't care less if she travels or not and I took a couple of trips with him too, but, ah, it's not the same. It's not the same as going with your husband or wife.

Second, participants (N=6) missed their disabled spouses as someone to discuss problems or decisions with.

VS: That becomes the difficult part of it. Nobody to even talk over with—you may not always get along that well, on different subjects—you may not want to go somewhere that I'd like to go, but you can compromise, you can talk things over, nobody to talk things over now.

Third, participants (N=5) were lonely for the disabled spouses' performance of certain tasks.

VS: I missed him. It was horrible. I missed him helping with the dishes....When I was cooking or baking he used to chop the nuts or grate the cheese or whatever was going to be needed to be done for my baking....By the time I got it in the oven he'd have it all washed up. I was spoiled rotten you know, but we were happy together. So, that's the way it was and I still miss him. When I go to do something I think, yikes, I've got to do this all myself.

VS: She was a good housekeeper and a very good cook, that's something I miss.

Fourth, a few (N=4) just missed the presence of another person in the house.

VS: You go to bed at night, there's nobody to say goodnight to. You get up in the morning and there's nobody to say goodmorning to and, unless you go out, you can spend the entire day in and around the house and never speak a word because there's nobody to speak to.

Fifth, only one participant expressed missing his wife as a confidante although this form of loneliness was implied by other participants.
R: Is there no one that you talk about these things to?
VS: Well you talk to your family. But even then I don't know how much you tell your sisters or brothers. You know there are certain things that you only talk to your wife about. Like you [the researcher] probably talk to your husband.

Sixth, some participants (N=3) missed being part of a couple.

VS: Myself with the wife in the hospital now,... most people if there's couples, they don't wish to ask me around. I'm by myself. They just don't ask you because they feel you might be uncomfortable, sometimes, maybe for them too. So, it's quite a change.

One woman, while recognizing the change in how people viewed her, felt that her "single" status had worked to her advantage.

VS: I have more friends....I have grown happily more friendly with them because I can identify with them. They're all widows and I think they like me better since I was alone. Well, you know, widows find it difficult coming into a house with a couple and I found that over and over again and now I know why.

Seventh, several (N=4) of the visiting spouses expressed loneliness for what could have been or what should have been. The longing for what could have been was often the disappointment that travelling had ceased. The longing for what should have been was congruent with Neugarten's (1970) concept of off-time events. Two participants, in particular, saw their wives' disability and institutionalization as inconsistent with their mental "timetables."
VS: I mean we both worked hard and we got to the point where we could sort of start enjoying life—the kids were raised and obligations were far less. After you work for a while you feel you can start to take off and if you can't you sort of feel cheated.

R: When you say cheated, you were really cheated of your future together?

VS: That's right. Right now, I mean, you really should be enjoying life. You should be free to take off if we wanted to take off.

To varying degrees, the participants expressed feelings of depression, of purposelessness and boredom, and of low self-esteem.

Rubenstein and Shaver (1982) observed that there is a "well-worn path from loneliness to depression" (p. 219). Several (N=4) of the participants stated they felt depressed some or most of the time.

Weiss (1973), in his influential book on loneliness, observed that when no one is present to witness or affirm the importance of our daily lives, tasks lose their meaning. He noted the "the day's duties then are a burdensome ritual which one can hardly persuade oneself to observe" (p. 22). The statements of four participants, all expressing feelings of purposelessness or boredom, confirm the wisdom of Weiss's observation.

VS: I can tell I'm getting awfully stale right now. The office is a drudgery. I know right now I'm not producing what I should because I just can't seem to get into it. I've got lots to do. I just don't like to get at it. And I know I should get away from it and take another run at it. I don't.
Another participant referred repeatedly to his "pointless existence."

VS: I mean I'm not, ah, taking much interest in anything. Just get up and struggle through each day..., put every day behind me and every day is as same as the day before.

Loneliness and lowered self-esteem "are intimately and reciprocally related" (Peplau, Miceli, & Morasch, 1982, p. 146). Most participants (N=6) expressed feelings of dissatisfaction with themselves or of lowered self-esteem. One participant explained, "I guess you kind of get to...not think that much of yourself." Another stated, "I'm not much good to anybody in this world."

The reason for the relationship between loneliness and low self-esteem lies with how we form and maintain our identities. Other people, especially a significant other, confirm and support an individual's identity (McCall & Simmons, 1966). When the significant other is lost or absent, one's sense of identity and self-esteem suffers. It is not surprising then to find that the participants in this study expressed feelings of low self-esteem. The existence of cognitive impairments in most of the disabled spouses limited their ability to confirm and support the participants' identities. In addition, the participants had lost the continuing presence at home of the person who had served as an
"audience" (McCall & Simmons, 1966) for their identity for many years.

**Preoccupation with the disabled spouse.** A visiting spouse expressed the meaning of this concept as, "My whole life revolves around her." The daily lives and thoughts of most participants were dominated by the continuing presence of their disabled spouses in the ECU. The extreme of this preoccupation was obsession.

VS: Yeah, I think about it too much. I don't know how you get it out of your mind. How can you just shut it [out] and think of something else?

Preoccupation with the disabled spouse took two main forms in the present study. First, participants explained that their daily lives were dictated by their disabled spouses' presence in the ECU. Second, they revealed that their disabled spouses were constantly in their thoughts.

The first form, dictated lives, was indicated by their visiting patterns, the displacement of other valued activities, and the avoidance of vacations.

All of the participants visited their disabled spouses at least twice a week and six visited almost daily. Visiting also included taking the disabled spouse on outings.

All the participants intended to continue their visiting patterns. They gave a number of reasons for
doing so—obligation or duty, avoidance of guilt, pity, reciprocity, and affection.

R: Why do you go every day?
VS: Why? Because it's my duty to go every day, or six days of every week. I think it's sad for the person in the hospital that has no visitors...Even though I don't stay too long, she looks forward to my visits.

VS: I guess this for better or worse applies in time of trouble.

VS: If I quit going or if I only went once or twice a week, if I started that, I don't know, I'd feel so bloody guilty, I guess.

VS: I just can't do that [stop visiting], for after all she was a very, very good wife to me...and you can't just leave her after 30, 40 years or so.

One woman described how 20 years before her husband had helped her to recover from a stroke and implied that she was in some way repaying him for his care. Although all participants said they still cared for their disabled spouses, only three participants cited affection as the major reason for visiting.

Participants reported that there were certain bad times associated with visiting. Most found leaving or getting ready to leave their spouses after visiting difficult.

R: When you leave the ECU, is that a difficult time for you?
VS: Well, it's not pleasant but I guess you sort of grow accustomed to it. When she first went in it's very difficult. I would say the hardest part is when I have her home, to get her ready to take her back up there, that's the hard part. Much harder than saying goodbye when she's in there.
One woman felt anxious anticipating visiting.

VS: I get a little bit apprehensive or concerned if I don't go (visiting) and when it comes nearly time to go I get a bit uptight.

For a few (N=5), their spouses' presence in the ECU meant that they were unable to participate in other activities that gave them a sense of accomplishment.

VS: I don't even help out my daughter-in-law with my grand-daughter anything like I'd like to. I'd love to have her more and, no, in lots of ways the way I would fulfill myself to think I was important or to feel that today I had been important are things that I refuse now to do.

One man said, "I pay with my life" and have given up "everything that I gained the greatest satisfaction [from]."

Although most participants stated they did not have financial worries, two men had to limit their spending in order to pay their wives' ECU bills. Anticipating their own illness or death, the two men also wished to have enough money saved to provide for their wives in the future. One man had to move from a large two bedroom apartment to a small studio because of financial limitations.

Most (N=6) participants denied themselves vacations because of the their disabled spouses' presence in the ECU.

R: Have you thought about taking any kind of vacation?
VS: No, I make my own life around the visits out there...I don't feel I should be away from him.
The reasons for allowing their lives to be dictated by their disabled spouses' presence were not totally altruistic. For two men in particular, their wives were something to organize their lives around.

VS: It takes me about 7 hours to take a bus, go out to [the ECU], spend three hours there and take a bus back here. It's about my day...most days. So I don't have to worry about what to do.

When asked what he would do if he did not visit his wife every day, he was unable to name any alternative activities. He and two other participants were extreme examples of dictated lives. Although they were exhausted and anguished by their preoccupation, they were unable to alter the organization of their daily lives.

A writer on caregiving has commented, "caring...is experienced as a labour of love in which the labour must continue even where the love falters" (Graham, 1983, p. 16). The visiting spouses cared but had no one to care for or about them, that is, no one to say, "Don't care so much." One participant reported that his children had tried to convince him not to visit so frequently and to develop new interests, to no avail. For most of the participants, the one person they might have heeded was the person least able to care for them—the disabled spouse.

The second form of preoccupation was having their disabled spouses constantly in their thoughts. Their
disabled spouses were a source of anxiety for most of the participants. Some of the participants worried about the care that their spouses received in the ECU.

R: When you're at home, do you worry about the care she's receiving?
VS: Oh, I suppose....I mean, it's sort of a constant thing that's sort of with you all the time, you're concerned about it.

This was not the main source of this form of preoccupation. Rather, most of the participants expressed feelings of sorrow associated with seeing the deterioration of their spouses. These expressions were congruent with Berezin's (1970) concept of partial grief. The participants were constantly aware and reminded of the losses suffered by themselves and their disabled spouses.

VS: Well, the worst thing was just to see him the way he was after being such a big healthy man, you know....That bothered me, it still does.

There were certain times when their sorrow was more intense, such as, family gatherings and special occasions (birthdays, anniversaries, holidays).

VS: And I can see that she's slowly going down which is the saddest part. Especially times like this [Christmas]. You know, you go around and see the rest of the family, you might be able to enjoy yourself but just in the back of your mind is always the same thing, that she cannot partake in this. That's the bad part.

Although most participants found their constant awareness of their disabled spouses painful, one participant drew great comfort from it. Like a widow
described in Parkes's (1972a) study of grief, this participant had a reassuring sense of her spouse being with or part of her even when they were not together. Another participant described having symptoms similar to those of her husband.

VS: I woke up one morning and my right hand was all tingly and kind of not my arm and immediately I think, oh, stroke...that's all I could think of was stroke...and I feel like a bowl of jelly at times but there was nothing wrong.

These two extreme examples of this form of preoccupation indicated that the visiting spouses were identifying with their disabled spouses. Parkes (1972a) felt that the identification of widows with their husbands represented an attempt to recover their husbands, that is, by not fully recognizing the loss the widows could retain the past. It was evidence of a continuing attachment to the lost person. As time went on, though, most widows were able to detach themselves from the lost person as they recovered from their loss. Glick et al. (1974) observed that "this did not mean the husband was forgotten, but rather that he was no longer felt by widows still to be a present influence on their decisions and behaviour" (p. 155). Divorced people also reported a continuing attachment to their ex-spouses even if no affection remained (Marsden, 1969; Weiss, 1979). The visiting spouses were unable to detach themselves
because they were faced with the disabled spouses' continuing existence.

It can be seen from the two major concepts of loneliness and preoccupation that the participants were living a paradox. They suffered because of their spouses' absence from home and because of their spouses' continuing presence in the ECU. As one spouse said, "You miss him terribly and you see him going downhill." Each side of the paradox affected the other side. One visiting spouse fell further and further into social isolation because he felt that people were depressed by his preoccupation with his situation. As Weiss (1973) noted, the desperation felt by the lonely for companionship can ostracize them even more.

Weiss (1973) proposed that loneliness is the response to the absence of a relationship providing attachment or of one providing social integration. Yet, the participants in the present study described a continuing attachment to their disabled spouses and several of them were satisfied with their social relationships. Therefore, their loneliness reflected the absence of some other aspect of the marital relationship.

Rubin's (1974) discussion of the components of love sheds some light on the visiting spouses' paradoxical situation. He proposed that there are three components of love—attachment, caring, and intimacy. He defined
caring as the giving aspect of love and felt that "as a couple's relationship becomes increasingly close, it will be associated with both increased attachment and increased caring" (p. 165). The long duration of most of the participants' marriages would suggest that caring and attachment were well established components.

VS: [Visiting] does mean alot to him and this is why I feel it is important to him to have my company as much as possible. A little stimulation.

VS: She is...she is a part of me. Not that she was a wonderful wife. But it is something, let's see, like a kid, you know, you get used to and became a part of.

Instead of reflecting the absence of attachment, the visiting spouses' loneliness can be viewed as their response to being deprived of an aspect of the marital relationship that depends on the close proximity of the two partners--intimacy. As one visiting spouse explained, "I miss him, I miss him at home." Intimacy is "a relationship between loving people whose lives are deeply entwined" (Traupmann & Hatfield, 1979, p. 254). An intimate relationship is characterized "most clearly by close and confidential communication between two people, through nonverbal as well as verbal channels (Rubin, 1974, p. 166). An intimate relationship is beneficial and may even be critical to maintaining physical and mental health (Traupmann & Hatfield, 1979). Its importance to the visiting spouses was evident in the
variety of forms their loneliness took and the intensity of the feelings associated with the absence of their spouses from home.

The participants' caring for and attachment to their disabled spouses meant that they were unable to address the absence of intimacy. One man noted that "you're by yourself, in other words, you can't get...interested in anybody else, because you're still married, you know, and still you're by yourself." One woman explained,

VS: I am really beginning to think that a lack of a sex life is--not that I want somebody in bed with me, not that idea, just to hop in and hop out, but some kind of a relationship and yet the more I think about it, the less it would work out because I cannot let myself go.

R: So with [your husband]...in the ECU you wouldn't really be able to think about forming a relationship with another man?

VS: No....As long as [my husband] is like this, I can't. No entertaining.

Feelings of helplessness and anger arose from knowing that there was nothing that they could do to alter their own or their spouses' situations.

VS: So you get kind of crushed with yourself or you get crushed with life, I don't know. I get angry at times.

R: At yourself?

VS: At myself, at the whole thing...what's the use, what's the purpose of it.

Most participants were well aware of their paradoxical situation, a situation made harder to bear by not knowing when it would end. One participant voiced what perhaps others were unable to say.
VS: I would think that in some ways, I shouldn't say this--that it's worse [than if she had died]. I shouldn't say that but in some ways it is because, you know, a death--all right you've got grief and you're stricken and then the survivor sort of picks up and goes on from there and carries on. This way, neither of you can go anywhere. That's the way I look at it.

His statement captures the essence of Berezin's (1970) concept of partial grief. This participant's grief was unresolvable for it stemmed from a loss that he perceived as incomplete and ongoing.

In summary, all participants experienced loneliness and preoccupation with their disabled spouses. These two concepts indicated that the participants experienced behavioural system imbalance. Their loneliness took seven forms and was associated with feelings of depression, purposelessness, boredom, and low self-esteem. Their preoccupation took two forms and was, for some, an obsession. Most participants found this preoccupation painful although some gained pleasure and reassurance from it. Two distinct dimensions of their experience formed a paradoxical situation. They suffered from their spouses' absence from home but were faced with their continuing presence in the ECU. It was suggested that the participants' loneliness arose from being deprived of intimacy and their preoccupation, from their continuing attachment and caring for their disabled spouses.
Clusters of Coping Behaviours and Influencing Factors

The experience of being a visiting spouse has two dimensions— not having one's spouse at home but having him or her in the ECU. The coping behaviours discussed here were those used by the participants in response to the impact on their lives of these two dimensions. Factors (forces and abilities) influencing or determining coping behaviours are incorporated into the discussion but are summarized separately. In this subsection, the four clusters of coping behaviours and influencing factors were associated with: a) the disabled spouse; b) painful emotions; c) the roles formerly performed by the disabled spouse at home; and d) social participation.

The disabled spouse. The coping behaviours related to the disabled spouse were: tending to the needs of the disabled spouse; sharing experiences with the disabled spouse; and, acting as an advocate for the disabled spouse.

Tending to the needs of their disabled spouses included such activities as reading, grooming, exercising, transferring, feeding and bringing food, and bringing cards and gifts on special occasions. Participants felt that these activities were important to their disabled spouses' lives in the ECU.

R: In your visits to the hospital do you feel that you are playing an important role?
VS: Oh, I think she looks forward to it all the
time, yes, you can ask the nurses. They notice, they tell me that they notice quite a change if I'm around. She's more alert and she perks up and she'll do things that she'll just ignore without [me].

Some participants also saw these activities as important to their own lives and provided them with a sense of satisfaction.

VS: To go and look after him. I shave him and fix his nails and see that he's clean and nice. Not that [he] needs it, they do a lovely job, but I like to do it.

Perceiving that they were appreciated by their disabled spouses helped these coping behaviours. One man described his wife's reaction when he visited after being away for two weeks.

VS: She had a big smile on her face for just a few minutes. You know, that helps. She knows me and she recognized me. She likes the attentions that she gets.

Some participants felt that these activities were necessary because of a perceived inadequacy in institutional care. As Linn and Gurel (1969) suggested, the quality of institutional food was a focus of concerns.

VS: I take her food quite often. That's one of the things, the food in that hospital. I...think somebody from the government or in the hospital owns a macaroni plant or something.

Although most participants gained satisfaction from tending to their disabled spouses' needs, two participants felt ambivalent about these coping behaviours.
VS: Of course, her literature, her religious literature that she seems to want to read, it kind of annoys me but it seems to pacify her.

Seven of the nine participants had family members—daughters, sons, and daughters-in-law—who assumed some of the responsibility for tending to the needs of their disabled spouses. One participant's two daughters visited their mother in the ECU three times a week. One man's son took his disabled mother home every weekend. But, as Locker (1981) noted, adult children sometimes cannot deal with their own painful emotions.

VS: He never sees her, the older son.....I don't know what it is with him. He hates going to the hospital....Maybe he just can't, looking at this, seeing his mother in those conditions.

The importance of family was dramatized by its absence. One participant, who had no children and who seemed to be meeting his needs successfully, felt that visiting spouses with adult children would have fewer problems.

Sharing experiences with the disabled spouse included such activities as going to concerts or other forms of entertainment together, taking the disabled spouses swimming, talking and sharing news with the disabled spouse, sitting silently but companionably with each other, participating in family gatherings and other outings together, and going on walks with the disabled spouse. One woman described their Christmas with great delight.
VS: We had a Christmas party on the floor and...there's a Christmas dinner at the ECU at noon....That's what we did on Christmas day and then we're downstairs and open his presents and he gave presents to everyone that he had chosen. I made him choose his own presents from the gift shop and that was lovely because it took us about three weeks of our spare days.

Another man explained,

VS: We're not that great conversationalists. I think we enjoy one another's company, just saying nothing as a matter of fact. Once I've told what the news is or who I was speaking to, I got nothing more to say and she's got nothing more to say about up there so we can sit there and watch the world go by and not say much.

These kinds of activities, though less frequently mentioned, seemed to bring the participants more pleasure than the activities associated with tending to their disabled spouses' needs.

There were three visiting spouses, two of whom were women, who gained an intrinsic pleasure from interacting with their disabled spouses. These participants looked forward to their visits and stated that if they could not visit they missed the interaction with their disabled spouses.

Some participants were not able to describe any sharing activities. As the literature suggests (Moss & Kurland, 1979), their disabled spouses' disturbing behaviours had a negative effect on the quality of their interactions. One man stated, "When something physically bothers her she gets all flustered and that's, when she gets flustered, I get flustered too." Their spouses'
cognitive and physical impairments also influenced the sharing of experiences. One man described his interaction with his wife.

VS: She can't discuss things. She starts to tell me something and she forgets half way through really what she's telling me. So you really can't discuss. She gets annoyed with herself but this just makes it worse for her so it's a miserable thing for both parties.

Another man described, with great sadness, his inability to take his wife out for an anniversary dinner. She was too difficult to transfer from the car to her wheelchair.

Two women, though, did not allow their spouses' disabilities to restrict their sharing activities.

VS: When I go out to see him, I tell him, I just ramble on about all this.
R: Do you tell him all the things you've been doing?
VS: Yes, yes.

Another woman described how she chatted with her husband as she pushed his wheelchair even though she knew he did not understand most of her conversation.

Three participants had difficulty in sharing experiences with their disabled spouses because of unrealistic perceptions of those spouses. One participant felt his wife could recover if she wanted to and another said, "I can't help thinking of her the way she used to be." McCall and Simmons (1966) wrote that in interacting with another "we are really acting toward our images....We impute to the real him all those characteristics, goals, and motives that constitute our
image of him, and then we act toward him in terms of those imputed features" (p. 121). These participants had not revised their image of their disabled spouses and thus were constantly discomfitted by their disabled spouses' failure to conform to their image.

Acting as an advocate for the disabled spouse included such behaviours as protecting him or her from the hostility of other residents, intervening on his or her behalf with the staff, and reporting observations to the staff. In Dobrof's (1976) study of the family members of the institutionalized elderly, acting as an advocate was a major coping behaviour. In the present study, it did not assume such importance. Dobrof's sample consisted primarily of the adult children. They may have experienced more guilt and ambivalence about institutionalizing their elderly parents and thus were more critical of institutional care than the participants in this study. As was shown earlier, the participants felt little or no guilt and their concerns about care and their suggestions to improve it seemed entirely justified.

One woman described her interactions with the staff.

VS: I ask them sometimes how he's doing. Is he drinking enough. I've been worried about him not drinking enough. Sometimes they come to me and say [your husband] didn't eat his lunch today. And then I'll take him downstairs and find him something.
Another participant had intervened in his wife's medication regime.

VS: So I asked him [the doctor] if he couldn't cut the quantity down and give it a little bit more regular. And this seemed to have helped a little bit, you know.

Viewing the staff as caring and competent influenced the use of this coping behaviour. Four participants saw the staff positively and described very few occasions when they felt the staff unreceptive or incompetent. Four were more ambivalent and one was hostile toward the staff. Most of the participants mentioned they found the professional staff more caring and competent than the nonprofessional staff. One participant stated that staff tended to "pigeon-hole" those residents who could not speak for themselves and who had no relatives to act as advocates. Although his wife was cognitively unimpaired and could communicate her needs, he wished to have reassurance that staff treated all residents as individuals.

One man had made his participation in the study conditional on being able to air his complaints. He did not bring his concerns to the attention of the nursing care manager because he was afraid of negative repercussions on his wife's care. His and some of the other participants' advocating activities had ended in anger, outrage, and frustration. One man no longer brought concerns to the attention of the staff.
VS: What's the point in saying it. They don't pay attention. They hear you, I guess, but that's it.

Painful emotions. The coping behaviours associated with painful emotions were escaping and decreasing painful emotions. These coping behaviours were seen as particularly effective by participants and were not, in the words of Folkman and Lazarus (1980), problem-focused, that is they did not function to change a situation. Emotion-focused coping responses are used more in situations that the individual perceives as unlikely to change regardless of his or her actions (Folkman & Lazarus, 1980). George (1984b) suggested that this kind of coping response may be crucially important to well-being and to the maintenance of the self. In her study of individuals caring for elderly relatives, instrumental (problem-focused) coping decreased and palliative (emotion-focused) coping increased over time as caregivers realized that little could be done to change their situations. Thus, it is not surprising in the present study that coping behaviours reducing the impact of painful emotions were seen as particularly effective.

Coping behaviours intended to escape painful emotions included keeping busy and drinking. Keeping busy was very effective.

VS: When you get busy these other thoughts go out of your mind to point. You got to be thinking
of what you're doing so it does help I think and whereas if you have alot of time to yourself naturally you'll be thinking about her...I think it would get to you.

Keeping busy included such activities as working, volunteering, going out, housekeeping, chores, gardening, and hobbies. Participants said that it helped them to stay sane and kept them from feeling depressed or sorry for themselves and dissatisfied with life. Four participants explained their use of this coping behaviour as part of their life-long repertoire of coping behaviours. They had always kept busy. The importance of keeping busy was evident by its absence in one participant's repertoire of coping behaviours. He explained, "I never had a hobby. I think it's one of my faults. I probably need a hobby to fall back on....My hobbies are worrying about friend wife....It doesn't pay off." Having an interest other than their disabled spouses determined the use of this coping behaviour. Keeping busy contributed to recovery among the bereaved in the studies by Glick et al. (1974) and Lopata (1973).

Some participants drank alcohol in order to escape painful emotions. As one said, "it kind of takes your mind off, distracts you. I enjoy it, I just sip away at it....I get by I guess." One participant drank to lessen his anger about the care his wife was receiving and about the cuts to the ECU's budget.
VS: I know there's nothing that I can do about it except go over to Victoria and strangle Bennett and strangle that so called minister of health. I'd like to see him face to face.

Decreasing painful emotions was achieved in a number of ways--accepting the situation, the use of humour, positive comparisons, self-admonishments, confiding in others, not thinking about the future, and getting to know the staff, other residents and their family members. Most participants to varying degrees stressed the importance of actively accepting the situation. Its importance was derived from their recognition of the uncertainty of their situations and their lack of control over the outcome. As one participant said, "What can you do? You can't do anything," and another, "It's never going to change. It's just an ongoing thing."

It is not surprising, then, that accepting the situation required ongoing effort from the participants. As one man said, "there are times that I think, this is ridiculous, if I take [wife] home, we'll manage somehow. Then I think well, let's be realistic, it's not going to work." Another participant recognized changes in herself during the month and one-half separating her first and second interviews.

VS: It has taken me a long time to face up to the real fact that he will never be out of there.
R: Has it?
VS: I knew within myself that he wouldn't be but you know there was always that little hope that there'd be some improvement.
The importance of accepting the situation was evident from its absence among the coping behaviours used by some participants.

VS: I can't understand it. She had a faith in a God that wouldn't look after her, I don't know....I can't understand it.

The use of this coping behaviour also was influenced by the participants' approach to problems and their philosophies of life. The participants who stated they used a problem-solving approach to life admitted to frustration with their present situation.

VS: I think that I've got a problem right now....the wife...and it's not going to go away.

The participants who had personal philosophies that were more congruent with acceptance expressed less frustration. As Mechanic (1974) wrote, "people who accept their environment, and who do not struggle against it, experience greater physical comfort and less psychological symptomatology" (p. 95). One woman described the philosophy that had guided her through many years.

VS: I found a little text...to the effect that you thank God for putting...[you] in so large a room. And that stuck because a room has walls, and you're inside the room and it depends on those walls how much you can do but if you can look in on what's possible, not out on what's denied you can make quite a life out of very little. There are alot of things that are possible and with [my husband] this is what's happened and what I'm looking at now is the room I'm in and what's possible to do with it.
The participants' use of humour to decrease painful emotions was evident throughout the interviews. Two participants specifically mentioned humour as an important coping behaviour. One man explained, "You have to look on the funny side of it or you'd go crazy. Humour is the only salvation for a lot of these things." Humour was not so effective for another participant because it was humour turned against himself, a kind of self-deprecating black humour that only increased his feelings of alienation and grief.

Positively comparing themselves or their spouses to others also served to decrease painful emotions. Mechanic (1977) viewed comparison with others as an important dimension of individuals' adaptive responses to serious and chronic conditions for it allows them to evaluate their skills and coping capacities. Pearlin and Schooler (1978) cited the phrase "misery loves company" to explain the value of positive comparison. He added, "conditions appearing to an outside observer as very difficult may be experienced by people as relatively benign when they judge the conditions to be less severe--or no more severe--than those faced by their significant others" (p. 6). In the present study, participants seemed to be reassured by positive comparisons. One participant felt that going to the ECU had "mellowed" him because of seeing people less
fortunate. Interestingly, participants seemed to gain a perverse sense of satisfaction from observing that other residents had no visitors. Another form of positive comparison was favourably comparing their spouses with other residents. One woman felt that the staff liked her husband and said, "I'm as proud as punch of him. Just like having a child. He doesn't let me down....I feel very sorry for some of them who come and...their patients act so objectionably." One participant, however, revealed the inherent weakness of positive comparisons.

VS: There's lots of people that are worse off than I am. I realize that. But when you have to deal with it, you kind of feel cheated. So far, at least, I've got my health so I should be grateful for that.

But where positive comparisons were not used, participants felt miserable. One man negatively compared his situation to that of a brother whose spouse had died and who had subsequently remarried.

VS: So he got over the horrors of bereavement in a couple of years I guess. It don't seem fair. They're happy as a couple of pigs. They've solved the problem by starting a new life. In this situation there's no way you could do it.

Self-admonishment was another way of decreasing painful emotions and took the form of "pep talks." This kind of positive inner dialogue was viewed by Meichenbaum (1977) as a means of "stress innoculation." One woman said, "I pretty well keep assessing my feelings daily. I
almost literally give myself a kick on the butt to get going and not feel sorry for myself."

Another coping behaviour associated with decreasing painful emotions was confiding in others. One woman described how after leaving the ECU she talked with the parking lot attendant and then would come home and telephone good friends. She had also formed a friendship with a lottery ticket vendor who knew about her husband and she could "unload on him." She was the only participant who described such a network of people she could confide in. One man said during the interview that he had never spoken about his thoughts and feelings to anyone else and explained, "I know that you won't talk about it to other people. It'll be all confidential ...but it is good to talk about it once in a while."

One participant tried to ease his terrible loneliness by talking to a picture of his sister-in-law and hoping that it would talk back to him.

VS: That's it because I was under the impression it was lonely--feeling that maybe, maybe to take her off the wall, when [she] came into the rooms and maybe she will start and say a word or two. It didn't work out.

R: You must have really wanted her to talk?
VS: Oh, no doubt about it. But I was foolish.

He admitted that loneliness "affects, you see, my thinking to quite an extent...not being able...to have anybody to talk [to]." He found his delusional thinking distressing for, not only did the picture not talk back
to him, he was sufficiently lucid to feel that this coping behaviour was unsuitable.

Four of the participants still viewed their spouses as their confidantes and did not feel the need to find others. One man noted that his male friends were not confidantes. Rather, they were friends to do things with. It may well be that these visiting spouses saw the role of confidante as inextricably linked to their disabled spouses.

Brandwein, Postoff, and Steinberg (1979) viewed the visiting spouses' inability to think about the future as a matter of concern. Other writers have concluded that a future orientation among the aged "may be a sign of physical and psychological adjustment" (Lowenthal, Thurnher, Chiriboga, & Associates, 1975). In the present study, the participants who tried not to think about the future saw this as a suitable coping behaviour. As one participant observed, "There's no sense planning for what isn't, what might never come. I think about the future but it's a total blank. He could live for years."

Others said that they tried to take one day at time. The participants who did think about the future expressed feelings of hopelessness and despair, "there's no future. If the situation goes on what can you do?"
The final coping behaviour associated with decreasing painful emotions was getting to know the staff, other residents and their family members.

VS: When I went there first it [bothered me] a little bit seeing the other patients but one of the nurses said to me,...she said, you get to know them and you'll think differently and that's true as can be and...I don't know whether they...know [me] of course, but I always speak to them and you feel differently about them and that's true as can be.

One woman described her delight in seeing her husband's friendship with another resident. Another participant indicated how getting to know others helped her.

VS: The interchange with residents and the interchange with visitors is a tremendous help. We spend our life there gossiping [laughs]. Oh, yes, the people are definitely part of the entertainment. I guess we're part of it [laughs].

Viewing the ECU as a benign environment influenced the use of this coping behaviour.

VS: The ECU is really a terrific place. It's not one of those places where everybody's in bed in the morning and unchanged and unwashed. They're well cared for.

Conversely, the participants who viewed the ECU primarily as a hostile environment did not use this coping behaviour. One man, though recognizing the value of institutions, said, "These institutions, you're thankful for them, but they're an awful place to be."

Several of the participants had attended a support group held in the ECU for the spouses of residents. Most of them found the support group interesting and helpful.
Killilea (1982) listed the benefits of mutual help groups as providing

identification and reciprocity, access to a body of specialized information, an opportunity to share coping techniques based on realistic expectations for optimal functioning, an increased sense of worth by focusing on how like the members are to others in the same situation, reinforcement for change and maintenance of effort...and an arena for advocacy and social change empowerment (p. 185).

Similarly, one participant noted three positive features of the support group. They were: knowing what to do with herself when she returned to an empty house; knowing how other people felt; and knowing about the economic restraints on care. Another participant added that the people in the group were able to make useful suggestions to the social worker regarding new programs. One participant made an interesting comment. She said that the group was very nice but "I didn't seem to have the problems that they [the group leaders] were looking for." Her comment illustrates that support groups may not be appropriate for all visiting spouses.

It is significant, although not surprising, that it was primarily the women in the sample who stressed the importance of getting to know the staff, other residents and their family members. Women are likely to have more experience and ability in establishing social relationships than men (Kohen, 1983) and interaction with others may be more important to mediating stress for women than for men (Elwell & Maltbie-Crannell, 1981).
Most of the men in the sample viewed the residents as non-human or non-aware beings. One man stated, "They [the other residents] don't take an interest, they don't care what's going on. They're not interested in their own well-being or in food, they're just there." Another wondered, "I don't know how she stays there without frothing at the mouth. It's terrorizing to think that day after day to know that you'd never be a human being again." Contributing to their lack of desire to get to know the residents was the integration of cognitively impaired, disturbing residents with those who did not evince disturbing behaviours.

VS: I mean, there's a lot of people out there that I don't think they should have there. These other people that are just causing upsets and some of the weird noises, I mean, after a while, you get a little peculiar yourself living in this. It's bad enough being in an institution to begin with...and then you get all these other things going with it. I really think it's too bad to have to do it this way. I really don't know why they can't segregate them, I really don't.

The roles formerly performed by the disabled spouse. This cluster reflected the visiting spouses' ability to compensate for the instrumental functions formerly filled by their disabled spouses. Most of the sample used coping behaviours associated with compensating such as learning new skills and assuming the primary responsibility for tasks. Contrary to popular opinion, most of the men in the sample were able to learn cooking
and housekeeping skills without much difficulty. One man stated, "I didn't use to cook but I learned to. It was a case of having to--you either cook or you starve. You got no choice. So you start cooking....It turned out great, no problem at all." Another man had employed housekeepers but then decided to do the cleaning himself.

VS: I found out how these girls did it. Boy, brother, I can do that. I can do it quicker.
R: And now you do it all yourself?
VS: Yeah...Well It doesn't take very long but then I don't do it as often, probably. Once a week is enough to vacuum the house. There's no problem there.

Past caregiving experience positively influenced the ability to compensate among the men in the sample. They described a kind of apprenticeship in housewifely tasks during the caregiving period.

VS: Well, after the stroke and she was unable to do the cooking or the shopping, she would tell me pretty well what to buy...and if it was ground meat to make a meat loaf, she'd tell me what to put in the meat loaf, how to make it, what pan to put it in, and what temperature to put it in the oven at, and the rest of it. So, she was really doing the cooking by remote control.

Other coping behaviours included taking on gardening responsibilities, keeping track of correspondence, remembering special occasions, and, in one participant's case, talking more. Three of the men were experiencing some difficulty in compensating for their spouses' absence. Two men had been doing most of their cooking and cleaning but were experiencing increasing difficulty because of deteriorating health.
VS: It's nearly four years, you know. It has become really tough going. I'm not getting any younger....One of these days I will have to have some people to do things for me, I guess.

One man had never tried to learn new skills. He managed by eating most of his meals in restaurants.

Social participation. Participating in social activities and interactions with family and friends were viewed as important coping behaviours by all of the participants. Two women felt that it was important to keep themselves interesting for their husbands. They and others also saw social participation as a coping behaviour related to reducing the impact of loneliness and painful emotions. Even so, there were differences among the participants in their use of this coping behaviour. Three participants increased their social participation as a result of their spouses' institutionalization. They attended senior citizens' groups, went bowling, joined community interest groups, took part in the ECU's activities, and visited or went out with friends and family. One participant talked more with people.

VS: I also talk to people that I maybe wouldn't have made conversation with previously, when I'm shopping. Somebody ahead of me or behind me in the check out counter, I'll, depending on the type, I'll either joke with them or something more down to earth. And the girls, the clerks, the cashiers.
Two of these visiting spouses increased their participation in response to the withdrawal of their major source of human contact--their spouses.

VS: If my wife was home then I would have had to cut down on the social contacts on the outside because there'd be really no need for them and I wouldn't want them because I'd rather be here.

Troll (1982) asserted that married people are more likely to have non-family friends than are single, widowed, or divorced people. But, this participant's comment is more congruent with Kohen's (1983) finding that the widowed had more social contacts than married people.

Another three participants, though engaging in the same kind of activities as the above group, chose to maintain their level of social participation at what it was before the institutionalization of their spouses. This was either because they had never decreased their levels of participation during the caregiving period or because they did not have the energy or desire to have more social contact.

R: Do you feel you are getting the right amount of social contact?
VS: Yes, because if I wanted any more, I could quite easily go out and get more....I think I don't try hard enough. I don't want to get involved with that any more.

Three men withdrew from social participation. One man had noticed his withdrawal over a number of years.

R: What kind of things have you done to get some of that contact with friends?
VS: Really, I guess not very much, I suppose
...because there's really not much fun going somewhere by yourself and so this is basically you kind of go into a shell and once you do it, it's awful hard to get out of it, it's awful easy to drop into it, sort of get to be a stick in the mud.

Their withdrawal was source of concern to them but they felt helpless to reverse it. One man did not have enough energy to maintain his social participation but as the above quote indicates, a negative attitude to being alone also had an influence. An aversion to being alone may be especially pronounced in the elderly (Chiriboga, 1982a) and overcoming it is the first step in alleviating loneliness (Young, 1982). Being single in a society that stresses couple-compäniate activities can also increase one's sense of alienation (Lopata, 1969). Participants who "enjoyed their own company," as one woman said, and who were comfortable in doing things alone tended to participate in social life more.

Family and friends were also important to the visiting spouses' social participation. One participant noted that his family asked him to dinner more since his wife's institutionalization and others described their interactions with friends. One participant had no family and no caring friends. The pain of his loneliness was intense.

VS: First of all there is nobody left [meaning none of his friends are alive].
R: No one is left.
VS: Only two people and they can't even...telephone me.
In summary, coping behaviours and influencing factors clustered around four aspects of the visiting spouse's experience--the disabled spouse, painful emotions, the roles formerly performed by the disabled spouse, and social participation. The first category pertained to the disabled spouse's continuing presence in the ECU and the last two categories pertained more to the disabled spouse's absence from home. The second category, painful emotions, was associated with both aspects of the visiting spouse's experience.

Suitable coping behaviours used by the participants reduced the negative impact of not having their spouses at home and of having their spouses in the ECU. These included: tending to the needs of, sharing experiences with, and acting as an advocate for the disabled spouse; keeping busy; accepting the situation; using humour in a positive way; not thinking about the future; making positive comparisons; getting to know other residents and their family members; self-admonishments; compensating for the instrumental functions once filled by the disabled spouse; and, increasing or maintaining social participation. Unsuitable coping behaviours did not reduce the negative impact, and, indeed, often heightened it. Delusional thinking and responding to an inaccurate image of the disabled spouse were unsuitable coping
behaviours. Others were, in general, the opposites of suitable coping behaviours.

The factors influencing or determining the use of the participants' coping behaviours were: previous caregiving experience for male participants; social support; health; the quality of the interaction with and the physical and mental state of the disabled spouse; the institutional environment including staff, residents, and other visitors; their characteristic approach to problems and philosophy of life; and, the uncertain, uncontrollable, and ongoing nature of their experience.

Core Concepts

Three core concepts emerged from the data and had the greatest explanatory power. These were: perceiving mutuality in the interaction with the disabled spouse; humanizing the institution; and integrating being a visiting spouse into the continuity of life. The first two concepts were necessary to, but subsumed, by the third core concept. This last concept touched all aspects of the visiting spouses' lives.

Perceiving Mutuality in the Interaction

Hirschfeld (1983) studied the factors influencing the satisfaction of individuals caring for elderly relatives
at home. She found that the core variable was mutuality in the interaction. This mutuality "grew out of the caregiver's ability to find gratification in the relationship...and meaning from the caregiving situation" (p.26). It also included the "caregiver's ability to perceive the impaired person as reciprocating by virtue of his/her existence" (p.26). It was evident that mutuality also helped the visiting spouses. The participants who were able to share experiences with and to receive an intrinsic pleasure from interacting with their spouses were more at ease with their situation than those who derived no pleasure from the interaction and felt no affinity with their disabled spouses. Those who perceived mutuality gained a sense of intimacy from their interactions with their disabled spouses and felt less troubled by their preoccupation.

Humanizing the Institution

A central issue for participants was whether or not they saw the ECU as an environment for human beings and, therefore, a fitting environment for their disabled spouses. The participants humanized the environment by forming relationships with other residents and their family members and with the staff. Participants who did not humanize the environment tended to see the staff as uncaring and incompetent and the other residents as
non-humans. They were more distressed by seeing their spouses in what they perceived to be a hostile environment. This is not meant to imply that their concerns regarding care were merely the product of slanted perceptions. As noted earlier, their concerns seemed entirely justified and not unrealistic. Rather, certain participants expressed more negative feelings about the institution than others even though their spouses were being cared for in the same ECU and, in some instances, by the same staff.

Part of the explanation for participants' negative image of the ECU may lie with the negative image of long-term care institutions in general. Brody (1973) attributed this image to the historical development of institutions from being refuges for the poor and to ageism. Dimond and Jones's (1983) discussion of the concept of stigma also helps to explain the participants' reactions. They noted that structure decreases anxiety and that people develop typifications of the perceptual and experiential world in order to structure their orientation to the world. There are individuals who are "so disparate that they are not normative, yet they are still human beings; they are ambiguous or stigmatized human beings" (p. 174). Their ambiguity arouses anxiety and fear in other people. The participants who viewed the ECU as an environment for non-humans may have been
reacting to the ambiguity or stigma of residents who, though still human beings were perceived as non-human in their behaviour or appearance. The participants who got to know residents were able to see them as unambiguous, human, beings.

Integrating Their Experience into the Continuity of Their Lives

The institutionalization of a spouse in the ECU was seen as part of a process of change by the participants. Their stories describing the events leading up to their spouses' admission to the ECU suggested that the actual admission was not a crisis but, rather, a marker event. For many participants, their psycho-social transitions or crises of discontinuity had occurred long before. Their adjustment to the process of change left them with enduring and, at times, painful conditions—loneliness and a preoccupation with their disabled spouses.

About one-half of the participants saw having a spouse in the ECU as an interruption in their lives. For some, the interruption began with the onset of their spouses' disability and, for others, it began with their spouses' hospitalization. Marris (1975) believed that after a major loss the sense of continuity of life can only be restored through grief. The participants had not resolved the basic challenge of grief—to restore the
past or to adjust to a new situation and incorporate the loss.

VS: I mean what can you do. I can't try to open up a new life. I'm tied to the old one. But then the old one is essentially collapsed. So in between there's a vacuum.

Unable to explain the loss of a spouse as she or he had once been, they were unable to reconcile the two sides of their paradoxical situation.

There was a sense that these participants were waiting to be released from a limbo state. They were unlikely to perceive mutuality in interactions with their disabled spouses and, thus, were unable to obtain any feeling of intimacy. They saw the ECU as an environment for non-humans and this perspective only increased painful emotions associated with preoccupation. Being a visiting spouse had little connection with married life or with the world outside the ECU.

Other participants were able to integrate having a spouse in an institution into the continuity of their lives in both time and space. As one woman said, "His life has been cut short. Mine has changed direction." These participants viewed their own and their spouses' situations as part of their lives together. Having a spouse in the ECU was not a separate part of their day-to-day lives and also, it was not the sole focus of their lives. Although they experienced loneliness and preoccupation, they tended to lead rich lives. They
perceived mutuality in interactions with their disabled spouses but also benefitted from social participation. Humanizing the ECU reduced the dissonance between the institutional environment and the outside world. By integrating their experience into the continuity of their lives, they were able, in part, to reconcile the absence of an intimate relationship in their lives with their continuing attachment to and caring for their disabled spouses.
CHAPTER FIVE

Summary, Conclusions, and Implications

Summary

Few people could deny the pathos of elderly people faithfully visiting their institutionalized spouses, day after day, year after year. Our society attaches great significance to marriage and the family. The existence of longstanding marriages in which spouses have sustained and supported each other through the joys and troubles of a long life together reconfirms our faith in the family and the inherent strength and value of human relationships.

It was partly this emotional response to the sight of visiting spouses in an ECU that stimulated the researcher's interest in their experiences. An additional impetus was the belief that only by working in concert with family members rather than in opposition or isolation can nurses ensure that residents retain individuality and connectedness with society. A related belief was that, in long-term care settings, the family rather than the individual resident should be the unit of care.

The paucity of literature specific to the visiting spouse's experience only emphasized the need for further
research. Their frequent visiting was ascribed to guilt and their conflict with staff was viewed as an expression of internal conflict. Institutionalization was implicitly or explicitly regarded as a crisis. There was also the implicit assumption that the visiting spouse's experience was similar to that of other family members such as the adult children of the institutionalized elderly. Yet, the literature on bereavement and divorce illustrated the traumatic effects of disrupting the marital bond and lent credence to the belief that the visiting spouse's experience was unique.

This study explored the visiting spouse's experience using the UBC Model for Nursing (1980). The Model facilitated a broad assessment as well as allowing the researcher the flexibility necessary for intense study. Relatively unstructured interviews were conducted with nine visiting spouses. The data were initially coded into three categories corresponding to the purpose of the study, that is, the impact of having a spouse in an ECU on their lives, the coping behaviours they used, and the factors influencing or determining coping behaviours.

During the process of constant comparative analysis, themes, categories, concepts, and their properties emerged. Rather than viewing the institutionalization of a spouse as a crisis, participants saw it as part of a process of change. Their stories of how they became
visiting spouses contained certain common elements. Other categories and concepts described what it is like to be a visiting spouse.

All the participants saw the impact of being visiting spouses as leaving them with two enduring conditions: chronic loneliness and preoccupation with their disabled spouses. These two concepts were interpreted as reflections of behavioural system imbalance resulting from the absence of intimacy in their lives and their continuing caring for and attachment to their disabled spouses. They attributed their visiting to the existence of the marital bond. No participant expressed guilt. Instead, their feelings were a mix of regret and sorrow, purposelessness, depression, and lowered self-esteem.

The intensity of the impact varied from one participant to another. Some were relatively at peace with themselves and their lives and others were more troubled by their situation. Within and between each visiting spouse, a wide variety of coping behaviours existed which were, in turn, influenced or determined by a variety of factors. These clusters of coping behaviours and influencing factors centred on four aspects of their experience--their relationship with their disabled spouse, painful emotions, the roles
formerly filled by the disabled spouse, and social participation.

The core concepts of perceiving mutuality in interactions with the disabled spouse, humanizing the institution, and integrating the experience into the continuity of life pervaded all aspects of their day-to-day lives.

The sample was easily divided according to the core concepts: visiting spouses who gained an intrinsic pleasure from interactions with their disabled spouses and those who found interactions a source of pain; those who viewed the ECU as an environment for human beings and those who saw it as a hostile, non-human environment; and, those who integrated having a spouse in the ECU into the continuity of their lives and those who saw it as an interruption in their lives. This last core concept subsumed the other two. Being able to integrate their experience allowed visiting spouses to make sense of and reconcile the basic paradox of their situation—the absence of their spouse at home and his or her continuing presence in the ECU.

Conclusions

1. The institutionalization of a spouse assumes the status of a marker event dramatizing and punctuating a process of change. The participants' major losses, their
crises of discontinuity, happened long before their disabled spouses' actual admission. Having a spouse in an ECU is like the chronic strains of life described by Pearlin (1980), not a discrete critical period but an ongoing situation characterized by uncertainty and uncontrollability. Thus, we cannot assume that, because an individual has been a visiting spouse for many years, he or she has adjusted to the situation.

2. There were commonalities in the participants' description of their experience but there were just as many variations. The individuality of their accounts emphasizes the danger of assuming that, for example, all family members are plagued by guilt or that conflict with staff is a projection of internal conflicts. Such assumptions contribute to negative stereotypes of family members of the institutionalized elderly and could possibly inhibit nurses and other health care professionals from interacting with family members in an unbiased, helping manner.

3. The literature indicated that frequent visiting by spouses should be a matter of concern to health care professionals. In the researcher's clinical experience, many nurses share the same interpretation. Many participants were exhausted by having their lives dictated by their spouses' presence in the ECU. Visiting was a source of anguish for some, but for others, it
offered a purpose in life and a focal point to their days. For still others, it allowed them to obtain a degree of intimacy. Thus, the same behaviour, visiting, has different meanings for different individuals. Generalizations based on one interpretation ignore these different meanings.

4. The quality of the interactions visiting spouses have with their disabled spouses and with people in the institutional environment are of great importance in determining whether visiting spouses are able to integrate their experience into the continuity of life.

Implications for Nursing Practice

Brody (1973) observed that "it is ironic that despite universal emphasis on the value of older people living in their own home, the only social institution that has not contributed significantly to the shape of long term care is the individual's own home" (p. 434). The present study illustrates the importance of her observation.

Many of the participants spent a great deal of time in the ECU and, in that respect, it had become their second home. Yet, some of them were alienated by the environment. They saw the ECU as a "horror." Nurses may not be able to change visiting spouses' basic attitudes but they can do much to make the ECU more homelike and
more human. In a home, people are treated as individuals with a past, present, and future. In long-term care settings, it is easy to "pigeon-hole" residents because many of them share common disabilities and have common nursing needs. The effect of this pigeon-holing is to deny the individuality and humanity of each resident. The participants who saw residents as non-aware beings were, in part, influenced by what they perceived to be the attitude of the staff. We must also attempt to avoid stereotyping visiting spouses or family members in general. Generalizations about their behaviour are misleading. This study highlights the importance of assessing visiting spouses as individuals. For example, we must ask what needs does this individual meet by visiting frequently or what is loneliness doing to this individual.

Participants humanized the ECU by getting to know the staff, other residents, and their families. This study indicated that nurses cannot assume visiting spouses, particularly male visiting spouses, will initiate this coping behaviour. Formal support groups are of benefit but the day-to-day interactions between nurses and visiting spouses can be equally effective and therapeutic. Nurses can get to know visiting spouses, introduce them to other visiting family members, and, like the nurse in one participant's account, reassure new
visiting spouses or other family members that by getting to know other residents they will feel more at ease in the institutional environment. These nursing interventions should start as soon as the elderly disabled person is admitted to the institution. When visiting spouses, or for that matter, other visiting family members, are welcomed and made to feel "at home" from the beginning much conflict and misunderstanding can be avoided.

It was important to the participants that they saw the nurses as caring and competent. Several felt their concerns were listened to, treated with respect, and were acted upon. Others were frustrated by trying to act as an advocate for their disabled spouses and not having their suggestions or concerns responded to. Staff often feel that long-term care institutions are understaffed and that they are over-worked but if we truly want to engage family members as partners in care we must make special efforts to respond to their suggestions and concerns. Substituting non-professional staff for professional staff in long-term care institutions is often justified by stating that staff can be "trained" to care for the elderly residents. The participants indicated the fallacy of such an argument for they perceived clear differences in the quality of care.
provided by professional versus non-professional nursing staff.

Influencing the degree of mutuality visiting spouses perceive in interactions with their disabled spouses may be beyond the nurses' control. But we can help create a more intimate environment by advocating the use of family visiting rooms. Nurses can also help visiting spouses solve logistical problems associated with taking their disabled spouses on outings or home. Encouraging them to participate in sharing activities such as gardening, going for walks, or playing games together may enhance mutuality. Where a disabled spouse's disturbing behaviours interfere with sharing activities, nurses can help a visiting spouse devise strategies for dealing with these behaviours and for lessening their harmful effect on him or her. It was important to the participants that their disabled spouses appreciated their efforts. Nurses also can provide this kind of feedback to visiting spouses, for example, by praising their efforts to prevent contractions in the spouses' hands. Perhaps most importantly, nurses can help visiting spouses attain and be comfortable with a realistic image of their disabled spouses, their capacities, and their disabilities.

Much of the work involved in integrating their experience into the continuity of their lives must be done by the visiting spouse, but nurses can offer some
assistance. Visiting spouses who focus their lives on their disabled spouses but who seem to feel no sense of purpose in their lives could be helped to combine their frequent visiting with fulfilling some other function in the ECU such as organizing social gatherings with other visiting spouses. Others who are struggling with resolving their paradoxical situation may need to be given permission to have interests other than their preoccupation. Still others who have successfully integrated having a spouse in an ECU could be used as consultants to those who have not.

Implications for Nursing Education

Nursing curricula should emphasize that each client is part of a community of people, whether it is his or her family, a network of friends, or the larger society. In orienting nursing students to the philosophy of long-term care, the family rather than the elderly client should be promoted as the unit of care.

Students should be made aware of the stereotypes associated with the elderly, long-term care institutions, and the family members of the institutionalized elderly. Just as the visiting spouses reduced the stigma attached to the ECU by getting to know other residents, nursing students need to get to know the elderly as a group, and as individuals with a past, present, and future.
Implications for Nursing Research

This study has focused on the experience of visiting spouses. Since it has emphasized the importance of viewing the family rather than the individual resident as the unit of care, further research needs to be done on the experience of the family of residents of long-term care institutions. The present study has explored only one facet of this experience without considering family dynamics.

There were indications that visiting spouses experienced a process of change after their spouses' admission to the ECU. A longitudinal study of their adjustment would yield much information that could be used to help visiting spouses anticipate changes and to help staff in interacting with visiting spouses.

The responsibility for the decision to institutionalize their disabled spouses was virtually taken away from the participants in this study. Further research could explore the effects of this surrendering of control on their subsequent adjustment and, in addition, could investigate how health care professionals justified their paternalistic behaviour.

The concept of humanizing the institution introduces many avenues of inquiry to nurse researchers. Quantitative studies should be conducted to isolate the factors that best humanize an institution. The effects
of humanizing on visiting spouses' or family members' perceptions of the institution and of their elderly relatives could then be measured.

This study dramatized the importance of intimacy to human beings. Residents of long-term care institutions are removed from their familiar environments and must live with people they have not known before. Are they starved of intimacy or has their "threshold" for intimacy changed in some way? Further investigation is needed to identify the nursing behaviours that help residents meet their need for intimacy.

The individuality of each visiting spouse ran through their accounts. Nursing assessments commonly focus on the resident and include the family only in terms of how many family members there are. Further research is needed to determine what family members want nursing staff to know about them and how they see themselves functioning in a partnership with the institution.

Differences between the responses of male participants and female participants were evident in the findings. Although the small sample makes generalizations difficult, the women seemed to have adjusted to their situation with a greater degree of equanimity. Further research, using a larger sample, is necessary to determine whether gender differences exist
and then to clarify and understand the factors responsible for these differences.

This study has emphasized the importance of understanding the meaning visiting spouses ascribe to being a visiting spouse. Further research should explore, in more depth, the factors that influence or determine how visiting spouses make sense of their experience and how that knowledge can be used to improve the quality of care provided to both spouses.
Footnotes

1 The term "elderly" refers to individuals 65 years of age and over.

2 These writers and others have called the spouses of the institutionalized elderly, "community spouses." For the sake of clarity and consistency, the term "visiting spouses" will be used.
Bibliography


### Appendix A

#### Subsystems, Needs, and Goals

<table>
<thead>
<tr>
<th>Subsystem</th>
<th>Need</th>
<th>Goal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Achieving</td>
<td>For mastery</td>
<td>Feelings of accomplishment; satisfaction with accomplishments</td>
</tr>
<tr>
<td>Affective</td>
<td>For love, belongingness, and dependence</td>
<td>Feelings of love, belongingness, and dependence</td>
</tr>
<tr>
<td>Ego-valuative</td>
<td>For respect of self by self and others</td>
<td>Self-esteem</td>
</tr>
<tr>
<td>Excretory</td>
<td>For collection and removal of accumulated wastes</td>
<td>Absence of accumulated wastes</td>
</tr>
<tr>
<td>Ingestive</td>
<td>For intake of food and fluid; nourishment</td>
<td>Nourishment; satisfaction of hunger and thirst</td>
</tr>
<tr>
<td>Protective</td>
<td>For safety and security</td>
<td>Integrity of the system</td>
</tr>
<tr>
<td>Reparative</td>
<td>For balance between production and utilization of energy</td>
<td>Capacity for activity</td>
</tr>
<tr>
<td>Respiratory</td>
<td>For intake of oxygen</td>
<td>Oxygenation; easy respirations</td>
</tr>
<tr>
<td>Satiative</td>
<td>For stimulation of the system's senses</td>
<td>Sensory satisfaction</td>
</tr>
</tbody>
</table>
Appendix B

Information Letter

My name is Kathleen Nunn. I am a Master of Science in Nursing student at the University of British Columbia. I am interested in learning more about what changes have occurred in your life because of the placement of your husband or wife in the ECU and how you have coped with these changes. I believe your description of your experience will help nurses understand more about how placement of a husband or wife in an ECU affects the lives of people like you. I also believe that this information will help nurses work in partnership with spouses of ECU residents in order to personalize the nursing care provided.

I am interested in talking with people whose husbands or wives have resided in the ECU for at least six months. I would like to interview you in your home, or wherever you would feel most comfortable, twice for about one and one-half hours each time. The interviews will be arranged at times convenient to you. These interviews will be tape recorded but will have any information removed from them that might identify you. Thus, the interviews will remain anonymous and confidential.

The tapes will be erased once I have finished analyzing and interpreting the interviews. The results of this study will form the basis of my Master's thesis and may be published. It will not contain any information that identifies you.

Your decision to participate in this study will in no way affect your spouse's care in the ECU. The staff of the ECU will not be told whether or not you participated. You should also understand that you will be free to withdraw from the study at any time or to terminate the interview.
If you are interested in participating, please write your name, address, and telephone number in the space below. Then drop this letter into the box marked "KN" on the floor's bulletin board. I will phone you and arrange to meet with you at a time convenient to you. In this interview, I will answer any questions you have and will ask for your written consent.

Thank you for your interest.

Yours truly,

Kathleen Nunn, R.N.

Name: ...........................................................
Address: ...........................................................
Telephone Number: ..............................................
Appendix C

Consent Form

Study Title: Coping With Having a Spouse in an Extended Care Unit: A Descriptive Study

I have read the information letter about this study and understand its nature.

I also understand that I may withdraw from the study at any time, and that the care given to my spouse in the Extended Care Unit will not be affected by my withdrawal.

I give my consent to participate.

Date: ..............

Signature: .....................

☐ If you wish to receive a brief summary of the study after it is completed, please check the box.
Appendix D

Guide to Data Collection

1. Demographic data
   (a) participant's age, (b) participant's general health status, (c) age of spouse in ECU, (d) years married, (e) length of time spouse has resided in ECU.

2. Information regarding need satisfaction

<table>
<thead>
<tr>
<th>Need</th>
<th>Areas of Inquiry</th>
</tr>
</thead>
<tbody>
<tr>
<td>For mastery</td>
<td>accomplishments and activities, e.g., hobbies, employment, and recreation</td>
</tr>
<tr>
<td>For love, belongingness, and dependence</td>
<td>relationships with family, friends, neighbours, membership in groups--frequency and quality of contact. relationship with spouse--frequency and quality of contact</td>
</tr>
<tr>
<td>For respect of self by self and others</td>
<td>personal grooming; feelings about self and others</td>
</tr>
<tr>
<td>For safety and security</td>
<td>finances; living arrangements; ability to care for self and home; transportation</td>
</tr>
<tr>
<td>For intake of food and fluid; nourishment</td>
<td>weight loss or gain; grocery shopping; meal preparation; eating patterns; appetite</td>
</tr>
<tr>
<td>For balance between production and utilization of energy</td>
<td>sleeping patterns; feeling of restedness; daily routine; tolerance of activity</td>
</tr>
<tr>
<td>For stimulation of the senses</td>
<td>pleasurable activities, e.g., reading, music, going for walks, etc.</td>
</tr>
<tr>
<td>For collection and removal of accumulated wastes</td>
<td>bowel patterns, e.g., constipation or diarrhea; perspiration</td>
</tr>
</tbody>
</table>
For intake of oxygen breathing patterns, e.g., episodes of shortness of breath