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UNIVERSITY OF ALBERTA

CARING FOR THE DISORIENTED OLDER ADULT: THE FAMILY CAREGIVER'S PERSPECTIVE

BY

MOLLIE COLE

A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND RESEARCH IN PARTIAL

FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF MASTER IN NURSING

FACULTY OF NURSING

EDMONTON, ALBERTA

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FACULTY OF GRADUATE STUDIES AND RESEARCH

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled "Care of the Disoriented Older Adult: The Family Caregiver's Perspective" submitted by Mollie Cole in partial fulfillment of the requirements for the degree of Master of Nursing.

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Dr. Ronna Jevne

Date March 6, 1990

Dedication

To

Jennie Eleanor McAllister Atkinson who taught me that Reality Orientation is not always the best way,

and to

Sheila Mary Seddon Cole who showed me how to care for, and about, family.

Abstract

The experience of providing care to a disoriented family member is examined in this qualitative study. Eight women were interviewed to collect data on the behavioural, cognitive and affective responses of caregivers toward a disoriented older person during episodes of disorientation. Information was also collected on: the impact of the whole experience on caregivers' lives; what motivated them to care, and descriptions of episodes of disorientation.

Analysis of the data revealed that these caregivers strove to maintain a sense of dignity for the older person. The women viewed the disoriented older adult as a whole person requiring social, emotional and mental stimulation and care as well as physical care. They were distressed by others who did not share this view of the older person.

Caregivers revealed that they spent considerable time thinking of the reasons for the variation in the level of orientation of the older person. They determined that there were factors affecting the level of orientation that they could control, such as keeping their emotions hidden from the older person. They also found that some factors, such as the time of day, were not under their control. As a result of their reflections, many of the caregivers' actions involved maintaining a calm environment for the older person.

Caregivers explained that they experienced a wide range of feelings such as frustration, anger, sadness and isolation as a

result of their caregiving role. Supportive individuals allowed the caregiver an opportunity to express these feelings.

Data were also collected on the impact the caregiving experience had on the caregivers' lives. The role affected many aspects of the their lives, such as their energy level and resulted in changes in relationships with others. The caregivers used terms such as "my life is on hold" and "I feel as though I am on a roller coaster" to describe the overall experience of providing care.

The informants also provided some information concerning the health care system and how they felt about admitting the older person to a long term care institution. The need for health care professionals to listen to the caregivers' story was stressed.

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Caring for the Disoriented Older Adult:
The Family Caregiver's Perspective

The present demographic trends in Canada indicate that the population of those over 65 is growing rapidly. It is estimated that by the year 2035, 20% of the population will be over 65 years of age (Marshall, 1987). With advanced age, there is an increased likelihood of developing disease entities that result in cognitive impairment (Brody, 1982). Organic brain syndrome and cerebralvascular accidents are two such conditions that may result in disorientation. A large number of older adults with cognitive impairments are cared for by family members.

To provide effective nursing care to the family caregivers of these individuals, nurses must have an understanding of what it is like, from the caregiver's perspective, to provide care to the older adult who is disoriented. This understanding is required in order to develop nursing interventions which support family caregivers and improve their ability to provide effective care to the disoriented older adult.

Problem

Previous research concerning family caregivers has addressed caregiving in a global manner. Because of its global focus, this research has not identified specific strategies used by caregivers as they provide care to the disoriented older adult. Most of the research that has been carried out in this area employed quantitative methods. The use of qualitative methods in this study permitted the researcher to focus on the unique experience of individual caregivers. This study focused on the caregivers' interactions with the older person especially while they were disoriented.

Purpose

The purpose of this study was to examine the experience of providing care to a disoriented family member from the perspective of the family caregiver. The qualitative research design of this project included the use of interactive interviews which permitted the researcher to focus on the unique experience of individual caregivers.

There is strong evidence to indicate that families of older adults do not abandon their aging relatives but continue to be involved with their care throughout their lives (Brody, 1985). Two surveys, one carried out in Ontario and one in British Columbia, reveal that families provide a large portion of the total care needs of older adults residing in the community (Stolar, Hill & Tomblin, 1986; Kraus, 1984). Although it is recognized that the family caregivers of all older adults experience stress in their caregiving role, this is especially true of the caregiver who provides care to the cognitively impaired older adult (Brody, 1985; Haley, Levine, Brown, Berry & Hughes, 1987; Kraus, 1984; Rabins, Mace & Lucas, 1982; Sheldon, 1982; Williams, 1987).

Support for caregivers of frail older adults has traditionally been provided by nurses in the community. Today there is a need to formalize the nursing care that is given to these family caregivers. Such nursing care may enable the caregivers to maintain the frail older adult in the community, and possibly avoid or delay institutionalization. It is in the public's best interest to find ways of supporting family caregivers as institutionalization is an expensive method of caring for the older adult (Mirosh, 1988).

The decision to institutionalize a family member usually occurs when the stresses of providing care have reached an unbearable point. Although a review of the literature reveals that the factors which cause caregivers to experience stress are often unique to that caregiver, one factor that has been identified as causing caregivers stress is the disorientation of the older adult.

Potential nursing interventions may assist the caregiver by supporting them in (a) interacting with the disorientated person with effective behavioral responses, (b) addressing the feelings they experience, (c) altering the environment to reduce the episodes of disorientation experienced by the frail older adult, and (d) establishing sources of relief and support.

Research questions

The research questions which guided this study were: (a) What are the characteristics of episodes of disorientation? (b) What behaviors do caregivers use to respond to the person who is disoriented? (c) What are the caregivers' affective responses to the disoriented person? (d) What cognitive processes do caregivers use when the person they care for is disoriented? (e) What is the context surrounding episodes of disorientation? (f) How does the disorientation impact on the lives of the caregivers? One additional question arose during the study: What motivates caregivers to provide care to a disoriented older person?

Glossary of Terms Used

In this document, family caregivers are those women who provide support and care to older adults. In most instances, these family caregivers will be referred to simply as caregivers. When reference is made to professional caregivers, the term health care professional will be used. Dementing illness, or dementia, is the generic term used to describe the diseases that result in cognitive impairment in the older adult. Examples of these diseases are Alzheimer's disease; multi-infarct dementias and cerebralvascular accidents or strokes (Pimental, 1986; Toseland, Derico & Owen, 1984).

Disorientation refers to the lack of awareness of a common reality of current time (time of day, day of week, month or year), of place, and about people in the environment. Rarely do people suffering from senile dementia lose their orientation to their self identity (Brady, 1987). They do seem to become unable to recognize familiar people in their environment. The term disorientation will be used to refer to the situation where the person with dementia does not recognize the following: the current time; the present place; or familiar people in his or her environment.

Literature Review

The amount of literature related to informal caregivers of older adults has increased dramatically in the last ten years. The literature for this review reflects this, as a majority of the studies located are dated within this recent time period. The Cumulative Index for Nursing and Allied Health was searched manually from the years 1962 to the 1989. The Inter-national Nursing Index was searched manually from 1967 to the 1989. These sources are nursing data bases. Two other related data bases were also searched, by computer, for the years 1975 to 1989: Medline and Psychological Abstracts. The following is a summary of the relevant literature that has been collected from these sources. This literature review has been limited to the family caregivers of those suffering a dementing illness. Most studies included both male and female caregivers, but the largest proportion of the samples was female.

A majority of the articles collected for this review came from non-nursing journals. A selective review of the literature on informal caregivers (Goodman, 1986) revealed that there were few reports of studies about caregivers from a nursing perspective. This suggests a need for more research to be done on caregivers from a nursing perspective.

The literature review is divided into five major sections: (a) caregiving situations that are stressful to caregivers, (b) factors that are associated with negative impact on caregivers, (c) the emotional reactions of caregivers to stressful situations, (d) coping strategies used by caregivers in stressful situations, and (e) the nature of the responses of caregivers.

Caregiving Situations that are Stressful to Caregivers

A number of studies have been conducted to determine which of the behaviours or characteristics of the cognitively impaired person the caregivers find stressful. The following studies indicate that memory disturbances and disorientation are stressful for caregivers.

To determine the impact of dementia on the family, Rabins, Mace and Lucas (1982) used a structured interview format to survey 55 caregivers of persons suffering from irreversible dementia. The study results indicated that all caregivers described memory disturbances in their dependent relative as a problem and that 68% of the caregivers reported these memory disturbances to be a serious problem.

In a survey of 413 families on the mailing list of a large city's Alzheimer's Disease and Related Disorders Association it was found that memory problems were the first symptoms that caregivers noticed and for which they sought professional help (Chenoweth & Spencer, 1986). The caregivers of 289 people suffering from a dementing illness responded to the mailed questionnaire. The researchers found that in this study the problems that caused the families the most difficulty were: the need for constant supervision; strain on the caregiver; caregivers unable to get away from home; financial concerns; wandering; incontinence; and eating and sleeping difficulties. Although this report describes problems faced by caregivers from the early stages of diagnosis to the later stages, when institutionalization was considered, this report did not provide details of the personal experience of caring for someone suffering from dementia.

While conducting a study of the behaviours displayed by Alzheimer's patients. Shomaker (1989) identified that some people with Alzheimer's disease suffer from age disorientation. Age disorientation is a specific type of time disorientation characterized by the individual stating or indicating their age as much younger than their chronological age. In conducting an ethnography with six disoriented individuals and their caregivers, Shomaker also found that it was distressing to the caregivers when the person they cared for did not recognize them. In response to this disorientation, some of the caregivers argued with the disoriented person in an attempt to correct the disorientation. Other caregivers responded by ignoring the disorientation. Feelings of frustration and confusion were reported by these caregivers, in response to the disorientation displayed by the person with Alzheimer's disease.

Two problems that have been found to be frequently reported, but well tolerated by caregivers, are being tied down and being asked repetitive questions (Robertson & Reisner, 1982). These findings came from a study where interviews were conducted with 26 caregivers of patients with moderate to severe dementia who had been discharged from a geriatric assessment unit to live in the community. Wandering, incontinence, and lack of cooperation on the part of the person suffering from dementia were other problems that were cited by the caregivers. Incontinence was the problem least tolerated by these caregivers. Not recognizing the caregiver was a problem that was identified as occurring, but with less frequency compared to other problems.

In another study regarding the type and frequency of problems caregivers experienced while caring for an older adult with cognitive disabilities, it was found that the problems least tolerated by the caregivers were: limitations associated with activities of daily living; behavioural problems (such as being unco-operative, restless, and physically and verbally abusive); and inappropriate behaviours (such as fecal smearing) (Arglye, Jestice & Brook, 1985). These data were collected from interviews with 62 caregivers of patients who had recently been admitted to a psychogeriatric ward.

The Memory and Behaviour Problem Checklist is a measure of the problems caregivers experienced in caring for a person with a dementing illness (Zarit & Zarit, 1982). The checklist was developed to identify the occurrence and frequency of everyday problems associated with senile dementia. Behaviors that are on the checklist include wandering, hiding things, being suspicious or accusative. Some of the behaviours on the checklist refer to the care-receivers' inability to complete activities of daily living, such as dressing and washing. Others are related to behaviours associated with memory loss, such as forgetting the date. Not recognizing familiar people and reliving situations from the past are problems that are also on the checklist. When administered, caregivers are asked to rate the frequency with which these situations occur. A total score for the checklist is obtained by summing the scores associated with the number of times the problem occurs. This checklist is reviewed in this section because, according to its developers, it identifies common behaviours associated with senile dementia that caregivers find stressful. Detail regarding how the common problems on the checklist were identified is not provided in this article.

In summary, the reports of these studies indicate that caregivers do perceive memory loss and disorientation as problems which are difficult for some caregivers to tolerate. One limitation of these studies is the lack of description of how the researchers developed the questionnaires they used for data collection. The reports of these studies did not explicitly indicate how the problems and situations were chosen for inclusion in the interview studies. Another limitation in some of the studies is the lack of specific description of the problems the caregivers were asked to score for frequency and tolerance. There is potential for overlap in the labelling of some of the problems listed in the reports. The vagueness of the terms used in these reports leaves the reader without a clear understanding of the specific types of situations that caregivers find difficult to tolerate.

Factors Associated with Negative Impact on Caregivers

This section of the literature review identifies factors that relate to the impact of caring for an elderly person suffering from a dementing illness. 'Caregiver burden' is a term used frequently in this literature to describe the physical, psychological or emotional, social and financial problems that may be experienced by the caregivers of frail older adults (George & Gwyther, 1986). Although many researchers use the term burden to conceptualize the effects of caring on the caregiver, others have used alternate terms to describe this concept: caregiver stress; emotional distress; caregiving satisfaction; effects on caregivers; caregiver problems; and caregiver well-being. In this section of the literature review, the term 'impact' will be used to describe the effects of the stress that is experienced by caregivers who care for a cognitively impaired older adult.

Many of the studies that examine caregiver impact have been correlational studies. An integrated literature review of these studies is difficult to present as each study operationalized the dependent variable of caregiver impact in a different manner. The studies also included a variety of independent variables to measure the factors associated with the stress experienced by caregiver. The studies are presented here according to the significant independent variables related to dependent variable of caregiver impact. In addition to the correlation studies, this section of the review presents the results of studies that examined the impact of caring in a qualitative manner. These studies are also presented according to the factors related to the stress experienced by the caregivers.

Cognitive impairment. Three studies found that the severity of the cognitive impairment suffered by the person with dementia, as measured by the person's mental status, was correlated positively with the measures of caregiver impact. In one of the studies, a scale was developed to measure the caregiver stress and caregiver satisfaction with caring in two groups of caregivers: 19 current caregivers and 29 caregivers who had institutionalized their dependent relative (Worcester & Quayhagen, 1983). The gender, age and income of the caregivers were obtained. Using a path analysis of the variables the researchers found a strong negative relationship between psychological problems of the client and the satisfaction of the caregiver. This study also found that the older a caregiver was, the greater the level of satisfaction expressed. Overall, caregiver satisfaction was lower for caregivers who had given up providing care than for caregivers who were still providing care.

In the second study, the psychological well-being of the supporters of 40 demented elderly compared to the same well-being measures in caregivers of 40 non-demented elderly was examined (Eagles et al., 1987). The researchers used three measures of caregiver impact in their study: the General Health Questionnaire (measures psychiatric morbidity); the relatives mood scale (measures caregivers for depression, irritability, tiredness, tension, and worriedness); and Relatives Stress Scale (measures caregivers' functioning, family relations and standard of living). The results of this study indicated that the measures of cognitive impairment and behavioural disturbance were positively correlated to caregiver stress and that all caregivers of those suffering from dementia had higher stress levels than those who cared for individuals who did not have dementia.

In the third study, multiple measures of the independent variable mental impairment were used to assess the effects of caregiving on family members (Deimling & Bass, 1986). Not only were measures of cognitive incapacity used as the independent variables, but also social functioning and disruptive behaviours. Caregiver stress effects were measured with four scales, two of which were developed earlier by the researchers. These scales measured (a) the caregivers' perceptions of negative relationships between the elderly person, the caregiver and the family; (b) the caregivers' activity restrictions; (c) the caregivers' physical health changes; and (d) the caregivers' level of depression. The study included 614 caregivers (randomly drawn from a pool of 2000) who lived with the impaired elderly person. The results indicated that the level of social functioning and the presence of disruptive behaviours had a greater direct relationship on caregiver stress than cognitive impairments alone. The results also indicated that poor social functioning and disruptive behaviours that were related to cognitive impairments had a greater impact on caregiver stress than the social function and disruptive behaviours that stemmed from the elderly persons' limitations in activities of daily living.

Activities of daily living. There were two studies that found cognitive impairment was not correlated to caregiver impact but found a positive correlation between caregiver impact and the inability of the demented elderly person to carry out activities of daily living (e.g. dressing, feeding, elimination). In the first of these studies, a convenience sample of caregivers of psychogeriatric patients were used to measure caregiver perceptions of their burden (Pearson, Verma & Nellett, 1988). It was found that caregiver distress was positively correlated with the inability of the care-receiver to perform activities of daily living. Disruptive behaviours were positively correlated with both measures of caregiver burden and distress. Mental impairment was not correlated significantly to caregiver burden or distress. There is a possibility that Type I error occurred in this study because of the small sample size of the sub-set of those with dementia (20 out of the total 46 pairs of caregivers and care-recipients).

In the second study, a sample of 129 caregivers, whose dependent relative had been accepted by a local day hospital, was surveyed to examine the effects of caring for a mentally infirm elderly person (Gilleard, Gilleard, Gledhill & Whittick, 1984). The variables that were associated most strongly with caregiver strain and burden were the total number of problems identified by the caregiver, and the presence of a poor pre-disease relationship with the dependent relative. The problems that were the most difficult for the caregivers were feeling tied down, incontinence and providing proper hygiene for the dependent relative. Forgetfulness and behavioural problems were not major concerns for these caregivers. There was no correlation between caregiver burden or strain and the duration of caregiving, nor with the level of informal support the caregiver received. The greatest level of strain was found to be with caregivers who lived with and cared for male elderly people.

Social support. The studies presented in this section found that social support (either formal or informal) was a significant independent variable correlated with the impact of caregiving on caregivers. In the first study presented here, the Burden Interview was used to assess the impact of caring for a person with dementia (Zarit, Reever & Bach-Peterson, 1980). This interview schedule, developed by the researchers based on their clinical experience and prior research, contains questions regarding the health and psychological well-being of the caregiver as well as questions regarding their finances and social lives. The independent variables in this study were, the elderly person's mental status, their ability to perform activities of daily living and a check list of memory and behaviour problems displayed by the elderly person. The number of family visits was also measured. The sample included 29 caregivers. The results of this study indicated that none of the measures related to the dementia were correlated with caregiver burden. The only variable that correlated significantly (and negatively) with caregiver burden was frequency of family visits. This indicates that as the number of visits from people other than the caregiver increased, the caregiver's score on the burden scale decreased.

The Burden Interview (Zarit, Reever & Bach-Peterson, 1980) has also been used by other researchers. This tool was used in the second study presented in this section to measure the impact of caring on 120 caregivers of people with Alzheimer's disease (Jenkins, Parham & Jenkins, 1985). In this study, the following measures were correlated with caregiver burden: (a) two measures of the level of dementia (cognitive and behavioural) of the elderly person; (b) caregiver stress responses; (c) caregiver help orientation; (d) social support; and (e) pre-disease relationship between caregiver and dependent relative. The results indicated that the correlations between caregiver burden and measures of severity of dementia were not significant. There was a significant positive correlation between stress responses of the caregivers (avoiding thoughts about the event and intrusion of the event into thoughts) and caregiver burden. Social support (as measured by attendance at a support group and reports of help from friends and family) was also positively, but weakly, correlated with caregiver burden. Further analysis of the data revealed that although this overall correlation was positive, the caregivers who had the highest burden scores also attended the most number of support group meetings. This indicated that the support groups did seem to relieve burden for these caregivers. Pre-disease relationships were negatively correlated with caregiver burden. This indicates that those caregivers who reported a close pre-disease relationship reported lowered levels of burden.

In the third study presented in this section, measures of well-being of caregivers of demented elderly were compared with the same measures in the general population (George & Gwyther, 1986). The measures of well-being were similar to those variables measured with the Burden Interview developed by Zarit et al. (1980) and included caregiver assessment of their physical health, mental health, social participation and financial resources. The results of the study of 510 caregivers of memory impaired older adults indicated that caregiver well-being was correlated to (a) the relationship between caregiver and elderly person, (b) the living arrangements of the dyad, (c) the caregiver's perceived need for more social support, and (d) the severity and length of the dementing illness. Spousal caregivers were found to have more stresses than adult-child caregivers or other relatives. Caregivers who lived with the person with dementia reported more stresses than caregivers who lived in another home. It was also determined that well-being was significantly correlated to caregiver's perceived need for more social support. The severity and length of time that care had been provided were the two measures that failed to reveal significant correlations with caregiver well-being. Compared to the general population, the caregivers in this study suffered more in each of the areas of mental stress and involvement in social activities. Specifically the caregivers spent less time relaxing and working on hobbies than the general population did.

In the last study to be presented in this section, the effects of family support to caregivers of Alzheimer's victims were studied (Scott, Roberto & Hutton, 1986). The sample included 23 caregivers and 19 family members who were not the primary care providers, but who were related to the caregivers in the study. The Burden Interview (Zarit et al., 1980) was used to measure the impact of giving care to the person suffering from Alzheimer's disease. The results of this study, like the ones previously reviewed in this section, found no correlation between the mental status of the Alzheimer's patient and caregiver burden. Interestingly, caregivers' perceptions of too much and too little family involvement were related to increased measures of caregiver burden.

It is interesting to note that all but one of the studies in this section of the literature review used the Burden Interview (Zarit et al., 1980) as a measure of the caregiver impact of caring for a dementia patient. As each of them failed to find correlations with the severity of the illness (cognitive impairment) and caregiver burden, one wonders if this tool has construct validity for use in studies which examine the relationship between the stress experienced by caregivers and the severity of the cognitive impairment suffered by the person with dementia. Only one of the research teams (Scott, Roberto & Hutton, 1986) reported tool measures of reliability or validity. Inter-item reliability was reported to be .79. The test's validity was determined by correlation with a subject's global evaluation of overall burden (r=.71) and correlation with the brief symptoms checklist (r=.5 to .6). These instrument tests do not address the construct validity of the tool.

Other significant variables. The following studies all examined the factors related to the impact of caregiving. The results were not similar to the studies previously presented.

In the first study, 127 caregivers of older adults were interviewed to test the hypothesis that caregiver depression is directly related to the symptoms of dementia suffered by the dependent relative (Drinka, Smith, & Drinka, 1987). Measures of depression were taken for both the caregivers and their dependent relatives. The Burden Interview (Zarit et al., 1980) was also used as an outcome measure of caregiver burden. The results of this study indicated that the only variables that were significantly correlated were caregiver burden and caregiver depression. Dependent relatives were assessed for ability to perform activities of daily living but this was not correlated with caregiver depression.

In the second study of this section, semi-structured interviews were used to carry out an exploratory study of factors affecting psychological well-being of caregivers of demented relatives in the community (Gilhooly, 1984). Of the 37 caregivers interviewed for this study, 20 of them lived with their dependent relative and 17 of them did not. Morale and mental health were the caregiver impact measures. The results of this study indicated that of all the independent variables measured, the ones found to be significantly correlated with caregiver morale and mental health were: the sex of the dependent and the sex of the caregiver (male caregivers had higher morale scores than female caregivers and all caregivers of female dependents had higher morale scores than those caring for male dependents); satisfaction with help from relatives; blood/role relationships (closer relationships are associated with poorer caregiver mental health); duration of care (longer caregiving duration was related to higher caregiver morale and mental health); and frequency of professional support. Family visits and the measures of cognitive impairment for the older person with dementia were not significantly correlated with caregivers' mental health or morale.

In the third of the studies reviewed here, caregivers of Alzheimer's disease victims were used to study the effects of chronic stress on immunity (Kiegolt-Glaser et al., 1987). Immunosuppressive measures of the caregivers as well as measures of depression, life satisfaction, and mental health were used to assess the effects of caring on the caregiver. The caregivers of Alzheimer's victims were matched to controls who were not caregivers. The results indicated that the caregivers had increased measures of depression, decreased measures of life satisfaction, and decreased mental health. The severity of the dementia was correlated with decreased social contact of the caregivers and increased loneliness. The results of the immunosuppressive data revealed that the caregivers of Alzheimer's patients had poorer immune functions than the matched controls.

In the next study, two scales, developed by the researchers, were used to measure the behavioural disturbances of elderly demented patients in the community and the effects of these disturbances on caregivers (Greene, Smith, Gardiner & Timbury, 1982). The first scale measured the behaviours and mood disturbances of the dementing person, the second measured the impact of caring for the dementing person. The researchers requested that the primary caregivers of 38 patients at a geriatric day hospital complete the scales. Factor analysis was used to analyze the collected data. The results of this study indicated that caregiver distress was significantly correlated to apathetic behaviour and mood disturbances of the dementing person. Caregiver distress was not related to measures of the dementing persons' cognitive impairment or inability to carry out activities of daily living.

In the next study, the emotional distress of three groups of caregivers who were either attending or were on a waiting list to attend psychogeriatric day centers in Britain were studied (Gilleard, Bleford, Gilleard, Whittick & Gledhill, 1984). The size of the groups was 60, 129 and 45 respectfully. The General Health Questionnaire, for psychiatric disorders, was used to measure caregiver emotional distress. Distress was found in the caregivers of all three groups. Distress was associated with demanding or disruptive behaviours of the dependent relative, poor caregiver health, and poor pre-disease relationship between caregiver and dependent relative. Mental status was not measured directly in this study.

The next study made use of a structured schedule to interview 119 caregivers of elderly persons with dementia (Kraus, 1984). The caregivers were divided into two groups: 78 whose elderly relative was institutionalized; and 41 whose elderly relative lived with them in the community. The focus of the interviews was on the history and course of the dementing illness and the caregivers' state of mind and health status. The older adults who had been admitted to an institution had higher levels of cognitive impairment than those living in the community. The caregivers reported that the mental deterioration of the elderly relative was more difficult for them to cope with than the physical limitations of person suffering from dementia. Nearly 30% of the caregivers indicated that disorientation and confusion was a major problem and 13% had problems related to the elderly person losing articles and not recognizing individuals.

The last study to be presented in this section of the literature review is a qualitative study that identified a unique form of caregiver stress. A grounded theory approach was used to examine the intergenerational experience of middle aged women providing care to their aging parents (Bowers, 1987). It was found that by distinguishing types of care by purpose rather than by task a number of previously unmentioned roles that caregivers fill were identified. The five categories of caring that were provided by the caregivers in the study were: anticipatory, preventive, supervisory, protective and instrumental. Of these, only the last involved the tasks usually associated with caregiving, such as assisting with activities of daily living. The concept of invisible caregiving was identified from this data. Invisible caregiving referred to the effort that caregivers took to ensure that the care-receiver was not aware that they were being cared for. Much of the stress identified by the caregivers, related to providing care in an invisible way, was the constant need to reconstruct for the older adult the meanings of situations. This study was able to identify a number of facets of caring for older adults that had not previously been discussed in the literature.

Emotional Reactions of Caregivers to Stressful Situations

There is very little research that deals specifically with the emotional responses of caregivers to their role of providing care to older adults suffering from a dementing illness. The case studies that are reported in the literature on Alzheimer's disease reveal that caregivers often experience shame, embarrassment, denial, frustration, anger, depression, self-pity and guilt as they care for people suffering from a dementing illness (Oliver & Bock 1985; Powell, 1985).

There have been a number of self-help books written for caregivers of people with cognitive impairments. One of the best known is The 36-Hour Day by Mace and Rabins (1981). In this book, the authors reported many of the emotional reactions the families in their practice had to the role of providing care to a person with dementia. Among the feelings described were, anger, frustration, guilt and hopelessness.

Adams (1987) found that much of the literature on caregiving did not describe the experience of caregivers. This researcher conducted a qualitative study to learn about caregivers' emotional experiences of caring for a person who suffers from dementia. The researcher reports that grief counselling is an appropriate intervention to use with some caregivers. This recommendation stemmed from comments his informants made regarding their feelings of grief over the loss of their spouse as the person they married.

Coping Strategies used by Caregivers in Stressful Situations

One study which examined the coping strategies of caregivers was a qualitative study which explored the factors which influence a caregiver to continue living with and caring for an older adult with dementia versus those factors which lead the caregiver to consider placing the person in an institution (Hirschfeld, 1983). In-depth interviews and participant observation were used to collect the data from 30 caregivers and their dependent elderly relatives. The informants were found through service agencies in a large urban setting. 'Mutuality' between the caregiver and the person suffering from dementia was found to influence the families' ability to manage to provide care to an older adult with dementia. Mutuality grew out of the caregiver's ability to find gratification in the relationship with the impaired person and to find meaning in the situation. Another important component to mutuality was the care-recipient's ability to reciprocate the care by virtue of their existence. Those caregivers with high mutuality were found to be less likely to consider institutionalization for their dependent relative.

Another study which examined the coping strategies of caregivers was conducted using a questionnaire survey which was completed by 240 caregivers of Alzheimer's patients (Pratt, Schmall, Wright & Clevland, 1985). The coping strategies were measured using the Family Coping Strategies instrument (Olson, et al., 1983). The internal coping strategies found to be negatively correlated with caregiver burden were reframing (redefine experience to make it meaningful), and confidence in problem solving. The coping strategy of passivity (avoidance of problem) was correlated positively with measures of burden. The external coping skills (use of social supports) that were found to be negatively correlated with caregiver burden were spiritual support and extended family. These measures indicate only that there are different methods of coping that might be related to types of caring and ability to care without experiencing great feelings of burden. These measures do not describe in detail the methods of the coping the caregivers use.

In another study that examined caregivers' coping strategies, two different methods of adapting to the stress of caring for a dependent elderly relative were described (Johnson & Catalane, 1983). Both structured and unstructured data collection methods were used to interview 115 older adults and their caregivers. The first group of adaptive methods were found to be distancing techniques. These techniques were used predominantly by children of the older adult. Distancing was created by establishing greater physical or psychological distance and by enlarging the family network of caregivers. The second method of adapting to the caregiving role was through enmeshing techniques, used by both spousal and child caregivers. These techniques were used primarily in two situations. The first, when the relationship between the caregiver and dependent relative intensified: the caregiver and care-receiver turned to one another for satisfaction of both instrumental and emotional needs and often excluded other social supports. The second situation where enmeshing techniques were used was when the caregiver chose to make the caregiving role the most important role in his or her life: the caregiver redefined the relationship and was able to find altruistic rewards which enhanced his or her self-esteem and sense of competence.

Nature of the Responses of Caregivers

The research that has been presented previously in this literature review supports the concept that caregivers react differently, and individually, to the impact of caring for a person with a dementing illness. Poulshock and Deimling (1984) based the analytic model of analysis of their study on the assumption that the burdens caregivers experience are the result of their highly personal and individualized responses to specific caregiving contexts. Jenkins, Parham and Jenkins (1985) concluded the report of their study by arguing strongly that "burden truly lies in the eye of the beholder" (p. 54). When the researchers Rabins, Mace and Lucas (1982) asked their sample of 55 caregivers what was the biggest problem in caring for the person with dementia, they received 22 different answers. This, they claim, stresses the importance of assessing each family individually.

Other studies have found similar results. Individual tolerance to the caregiving situation was the basis of the different reactions of caregivers to problem behaviours in one study (Zarit, Todd & Zarit, 1986). In this study the difference between subjective burden of husbands and wives as caregivers was examined. A sample of caregivers consisting of 33 wives and 31 husbands was used. Husbands reported less burden than wives. This appeared to be related to husbands' greater tolerance of memory and behaviour problems. The researchers found that caregivers reacted differently to problem behaviours and not all caregivers found the same problems difficult.

Other authors, in discussion articles not based on research, support the concept that caregivers find different aspects of their role stressful. The need to be aware of the variety of responses of caregivers to various situation is stressed when health care professionals assess these family caregivers (Woods, Niederche & Fruge, 1985). Other authors suggest that caregivers interpret symptoms of dementia differently and place different meanings on these behaviours, and view the tasks of caregiving differently (Given, Collins & Given, 1988). And Zarit and Zarit (1982) state that the tolerance of caregivers to the common problems found on their memory and behaviour checklist is idiosyncratic.

One review of the literature on the family dynamics of caring for an older suffering from dementia suggests that there is very little known about the impact of dementia on the family or how the family deals with this disorder (Niederche & Fruge, 1984). This review of the literature identified that many general concepts have been identified under the general heading of caregiver 'burden' but that there is little known about the specific reactions of caregivers to specific aspects of dementia. It is suggested that as this knowledge becomes more specific, health care professionals will be able to utilize this information in the clinical setting. The current study examines the specific situation of disorientation in relation to the caregivers' experience in caring for the cognitively impaired older adult. This specific aspect of care was focused on to begin the process of developing more detailed knowledge of the caregiving experience.

Summary of Literature Review

The literature review supports the view that memory loss and disorientation in the dependent relative are perceived as caregiving situations that are stressful to caregivers. Although the severity of the cognitive impairment alone was not found by all researchers to be associated with a negative impact on the caregivers, this factor has been demonstrated by some to have an influence on the impact experienced by the caregiver. The emotional reactions of caregivers to stressful situations have thus far been described in relation to the entire experience of providing care to an older adult suffering from dementia. There is little information available to describe caregivers' emotional reactions to specific situations of providing care. The coping strategies used by caregivers in stressful situations are varied. Some strategies, such as perceiving mutuality in the relationship with the care-recipient, have been associated with greater levels of caregiver satisfaction. Overall, the literature review revealed that the nature of the responses of caregivers is individual and unique to each caregiver.

Most of the research that has been done in this area used quantitative methods. The use of qualitative methods in this study facilitated collection of data that will help nurses understand caregivers' perspectives of what it is like to care for a disoriented person. A clearer understanding of their perspectives was obtained by focusing the study on: (a) the descriptions of the characteristics of episodes of disorientation; (b) the behaviours that caregivers use to respond to the person who is disoriented; (c) the caregivers' affective responses to the disoriented person; (d) the cognitive processes used by the caregivers when the person they care for is disoriented; (e) the context of the episodes; (f) the impact on the lives of the caregivers resulting from this symptom of dementia; and (g) the factors which motivate caregivers to provide care to a disoriented older person. With this understanding, nurses will be better equipped to develop interventions to support caregivers of older adults with dementia.

Methods

Study Design

A qualitative research design was chosen for this study. Open ended semi-structured interactive interviews were the predominant method of data collection and generation.

Sample

Selection criteria. The informants in this study were women, who lived in a large urban centre in Western Canada and who were able to communicate clearly in English. It was decided that women informants would be the most available sample and would be representative of the present population reality. A 1982 study conducted in Ontario by Kraus (cited by McDaniel, 1988) indicates that wives and daughters make up 64% of the caregivers of older adults in that area of the country. As no clear, consistent evidence was found indicating that there were differences in the impact of caring between daughters and wives, the sample for this study included both.

Eligibility for this study was also determined by asking the caregiver, over the telephone, questions regarding the dependent older adult's orientation to time, place and person. If the caregiver did not perceive that the person they cared for was disoriented to any of the three spheres, then no interviews were conducted. If the caregiver did perceive that the person they cared for was disoriented, and if they met the previously stated criteria regarding language and place of residence, a initial meeting was set up. During this initial meeting, the consent form (Appendix A) was explained and the informant's consent to participate in the study was obtained. Although caregivers who provided care to older adults in the community were the focus of the study, one woman who defined herself as a caregiver was interviewed even though the person she cared for was in an institution. During the study, two other caregivers admitted the older person for whom they cared to a long term care facility.

The sample was not limited to people who had been assessed and diagnosed as having one of the dementing illness such as Alzheimer's disease or multi-infarct dementia. Caregivers were asked for permission to complete the Mini-Mental Status Exam (Folstien, Folstien, & McHugh, 1975) (Appendix B) with the older person so that a description of the sample of older adults could be collected. Only two of the caregivers consented to this. The scores for these two older adults were one and two correct answers, respectively, out of nine possible questions on the orientation portion of the exam.

Selection method. As is common in qualitative research (Morse, 1986), the sample was a volunteer one. The primary method of finding informants was though advertisements (Appendix C) in local community newspapers and specialized newspapers such as "News for Seniors" (published by the Society for the Retired and Semi-retired), through newsletters and posters associated with churches and the Society for Alzheimer's and Related Disorders. Caregivers in the community were invited to contact the investigator if they were interested in being interviewed.

By obtaining the sample through public advertisement, caregivers who had not necessarily sought help from health care professionals were included in the sample. It was considered important to have access to these caregivers as it was believed they might have developed unique methods and strategies to use in caring for the demented person. Caregivers who had no contact with the health care system would be missed if advertising were limited to agencies and organizations such as the Alzheimer's Society.

Sample size. Eight women were interviewed for the study, all but one were interviewed at least twice. The study was limited to eight informants because data was well validated after these interviews and because of limited resources available to conduct this study.

Setting

The interviews were conducted at locations that were identified by caregivers. Most were conducted in the homes of the caregivers. Three informants suggested locations away from the home where conversations could be carried out privately. Interviews were all held during times that the informant was not required to supervise the older adult.

Data Collection and Generation

Open-ended and semi-structured interactive interviews (Appendix D) were used as the major data collection method in the study. Open-ended portions of the interviews allowed the informants to describe their experience without being biased by specific questions regarding the burden or stresses of caring for the disoriented person. All but one of the informants were interviewed more than once to ensure clarity and completeness of the data. A series of interviews presented the researcher with an opportunity to verify with the informant the information that had been collected and to verify the researcher's preliminary analysis of the data (Robertson & Boyle, 1987). As well, by interviewing over time, the stability and variability of the phenomena under study was assessed (LeCompte & Goetz, 1982).

The informants all signed a consent form (Appendix A) indicating that they were aware of the purpose and procedures of the study. Informants were reminded at the beginning of each interview about the use of the tape-recorder.

To pretest the procedures and methods of data collection, two preliminary interviews were conducted with a caregiver who was not included in the study. This provided the researcher with an opportunity to practice obtaining consent, asking questions and using the tape-recorder. As the recording of the first interview was technically not adequate for transcribing, a second interview was conducted. This interview allowed the researcher the opportunity to develop questions based on the first interview. The informant was asked for feedback concerning the researcher's manner during these interviews. She indicated that the researcher's explanation of the consent form and general approach to the interview were appropriate.

A member of the thesis committee reviewed the transcript of the second pilot interview and provided feedback on the researcher's interviewing techniques. This review allowed the researcher to incorporate the suggestions for the subsequent interviews.

Time was spent establishing rapport and developing trusting relationships with the informants early in the data collection phase. Informants were given the opportunity to "tell their story from the beginning" which was found to be an effective method of building a positive relationship with the informants. The researcher also emphasized that she was present to learn from the caregivers. Occasionally caregivers asked for the researcher's opinion regarding the care of the older person. One example of such a question was whether the caregiver should try to use humour with the disoriented person. It was determined that none of these questions required referral to another health care professional as the health and/or welfare of either the caregivers or older person was not assessed to be threatened. If this had been so, a referral would have been made.

The literature indicates that elder abuse might have been a problem occurring in situations where the care-receiver is cognitively impaired (Beck & Phillips, 1983). No evidence of abuse within the caregiver-older adult relationship was found during the study. The provision in the consent form, regarding contacting appropriate health care professionals if either party were in danger of harm, was not required to be used during the course of the study.

Copies of the transcripts, before coding, were sent to the informants so that, if necessary, corrections could be made to the data. There was a serendipitous result of this practice with one daughter-caregiver who shared the transcript with her husband. After reading the transcript she found that he was more supportive of her position as he indicated that he had not previously understood what she was going through in caring for her mother.

In addition to the interviews, field notes were kept by the researcher. There were three sections to the field notes. One section contained notes on any observations made during the interviews, such as the body language of the informant and the interviewer. These notes were tape-recorded immediately after the interview and were transcribed for analysis.

The second type of field notes were theoretical notes. These notes contained the beginning stages of analysis of the data. They recorded the researcher's hypotheses about the meanings of the data collected. Theoretical notes allowed the researcher to begin to develop code categories. These notes helped trace the growth of the analysis of the data and helped form the basis of writing the findings of the study.

The third type of field notes were methodological notes. These notes contained information about the research approach. For example, when caregivers indicated their unwillingness to allow the researcher to complete the Mini-Mental Status Exam (Folstein et al., 1975) with the older adult, the need to re-evaluate the use of this exam was recorded as a methodological field note.

Data triangulation refers to collecting data about the same phenomena from a number of different sources within the same study. Data triangulation allows the researcher to examine the similarities and differences of the phenomena under a variety of conditions. The conditions may be different groups of people, different time periods, or different places (Mitchell, 1986). In this study, one form of data triangulation was interviewing more than one person a number of times. Collecting the data in this way provided data that was collected over time and from a variety of people. Another method of collecting data was asking the informants to keep a diary, for a couple of days, describing how they reacted to the episodes of disorientation that occurred during that time. The diary entries proved to be another method of data collection that was not a success. Caregivers found that they had little time to make many entries. The entries that were made by the informants were discussed and explained verbally during their second and third interviews.

The final focus of data collection and verification was a group discussion with informants who were willing and available to participate in this forum. Some of the major preliminary results of analysis of the data from the interviews were shared with informants for their feedback and their perception of the accuracy of this information. Although all eight informants were asked if they would like to participate in the group discussion, only four were able to do so. A number of the caregivers mentioned during the course of the interviews how excited they were to have an opportunity to meet other caregivers and to learn how others felt about the caregiving role. To protect the anonymity of the caregivers, each was asked how they would like to be introduced to the others in the group. All chose to use their first name for introductions. This group session was tape-recorded. The transcribed tape was then analyzed in the same manner as the individual interviews.

The researcher met with a member of the thesis committee to discuss techniques that would be appropriate for conducting such a group. The importance of placing the informants at ease, for example, by creating a relaxed environment was discussed with the committee member and carried out during the group.

During the first portion of the group time, the researcher presented some categories of codes and read a few quotations from the transcripts that seemed to best characterize the category. Before the group met, the group members were contacted to clarify that they were aware that quotations from the interviews were to be read in the group. Informants were assured that all quotations would be edited to ensure that informant anonymity was protected. During the group, caregivers were asked to comment on the code categories but were not "put on the spot" to respond. The data collected from this method proved to be very valuable in validating and expanding code categories that had been developed through data analysis to that time.

Data Analysis

Analysis of data provided a method of describing, summarizing and interpreting the data that was collected. The themes or categories identified from the informants were summarized and are presented in the findings chapter.

Key words used by the informants were identified in the first level of coding the data. In the next level of coding, similar thoughts were grouped into more general themes. These codes were then entered into the Ethnograph computer program (Seidel, Kjolseth & Clark, 1985) and sorted using this software package. Appendix E contains an example of the code map used in this process. The themes were then organized according to the research questions to facilitate the presentation of the findings for both the group session and the final report of the study. The Ethnograph form of data management allowed the researcher to try different approaches to "putting the data together".

The coded transcriptions were all reviewed with a member of the thesis committee. Suggestions for alternate ways of considering some passages from the interviews were made. Verification of these categories was provided, in part, by the informants who, either in the group or individually, responded to the accuracy of the categories. When data from informants who did not agree with the categories were found, reasons for the discrepancies were identified. For example, when discussing one of the categories that indicated that it was troublesome to caregivers when others did not view the older person with great dignity, one caregiver found she could not relate to the code. During the ensuing discussion, she indicated that that her husband and children interacted with her mother with great dignity and that this was why she could not relate to the code.

In the group discussions, individual informants were sometimes reminded by other caregivers of incidences they had not mentioned in their individual interviews. In the group a "free flow" of conversation allowed caregivers to share these new thoughts. For instance, when the category of codes was discussed regarding the reasons caregivers had for why the disoriented person was more or less oriented on certain occasions, one caregiver remembered that her husband was more oriented when visiting with members of the opposite sex. This code was immediately verified by the other caregivers.

Trustworthiness of Data: Measures of Reliability and Validity

Trustworthiness of the data were considered within the framework developed by Guba (1981). The framework includes the following sections; credibility, transferability, dependability, and confirmability of the study. Each section will be addressed separately.

Credibility refers to truth value of the data. This is the testing of the credibility of the research findings and interpretations, with various audiences or groups. In this study, credibility of the data was addressed in the following ways. The data were collected over a period of time so that the researcher was able to verify the data and the analysis with informants, both individually and in the group. Consultation with a member of the thesis committee during the coding of the data encouraged the researcher to step back from the data and examine the growing insights in alternate ways. Data triangulation permitted data to be verified by different sources. The use of a tape-recorder during the interviews preserved the data and thereby enhanced credibility. Together, these measures addressed the credibility of the study.

Transferability is the term that refers to the applicability of the results of the study. If the results of a study are transferable, this means that they may be transferred from one context to another. Transferability relies on the fit, or similarities between two contexts. Appendix F contains the demographic data of the informants which provides others with information to compare the informants of the study with their own situations. The Mini-Mental Status Exam was not well received by caregivers so this objective form of assessment of the level of disorientation could not be used to facilitate transferability of the data. The anecdotes of the informants did verify the informant's perception that the person they cared for was disoriented.

Dependability refers to the consistency of the results of a study. The consistency of naturalistic studies refers to the provision of sufficient evidence to allow others to trace the progress of the research. This is described as leaving an "audit trail" (Guba, 1981, p. 87). Through working closely with a member of the thesis committee, the researcher received ongoing feedback regarding the data analysis. These discussions were all tape recorded and formed the basis of an audit trail. These notes would provide others with a way of understanding how the study developed.

The final criterion for establishing trustworthiness of a naturalistic study is confirmability. This criterion reflects the neutrality of the study. Neutrality places emphasis on the confirmability of the data and the interpretation of the data. Confirmability is accomplished by providing evidence that the findings of the research, are supported by the data. The extensive use of quotations in the presentation of the findings assists in establishing the trustworthiness of the codes presented.

The methods of the study have been presented here. In the following chapter, the findings of the study will be presented.

Findings

The findings of the study are presented in this chapter. Quotations have been included where the informants words best captured the sense of the theme being presented. In sections where no quotation is included the ideas of the informants have been summarized by the researcher. All names that appear in the quotations of the caregivers have been changed. In quotations taken from the group interview, the informant's code letter has been used to indicate speaker. The findings presented were derived from analysis of data collected from all sources: interview transcripts; theoretical field notes; observational field notes and the few diary notes made by the caregivers. The methodological field notes assisted in keeping track of the progress of the research project.

The data regarding the theme which was determined to be most central to the experience of the caregivers will be presented first. This theme of data involves the caregivers' perception that the older adult for whom they provided care was a valued individual despite their cognitive impairments which often resulted in disorientation. This perception of the older adult influenced how the caregivers described the episodes of disorientation, the caregivers' feelings, thoughts, actions and the impact this experience had on the caregivers' lives. This theme was determined to be most central to the experience of these women caregivers because it influenced how they perceived other aspects of their role. Major themes were identified by the following criteria: there were large volumes of data to support the theme; most of the informants mentioned the theme; and the data were rich in describing the theme.

The findings which addressed the specific research questions will be presented in subsequent sections of the chapter. The data that did not address specific research questions, but were considered to be of significance to the overall research question concerning the caregivers' experiences, are presented in a separate section of the chapter. Each section begins with an outline which provides the headings for the parts of that section.

Figure 1. Section outline: Perceiving the disoriented older adult as a person.

- Family View the Older Person Differently
- Caregivers see the Older Adult as Worthy of Dignity
- Special Bond
  - Interpreting Actions
  - Thinking for Two
- Treating the Older Person with Dignity
  - Overlook cognitive impairments
  - Reassure
  - Stimulate
  - Be truthful
  - No humour

Perceiving the Disoriented Older Adult as a Person

Throughout the study there was an important theme that emerged from the analysis of the data. In many ways, in many different instances, the caregivers told of a difference they perceived between the way they viewed the older person and the way they felt that others viewed the older person. Caregivers seemed to view the older adult as a person, with feelings, special needs and an identity. Others in the environment such as family members, friends and health care professionals did not always give the caregiver the impression that they saw the older person in this way. These others all seemed concerned about providing adequate physical care for the older person, but, from the caregivers' perspective, did not seem to have the same desire to provide for the older person's emotional and intellectual needs. The changes in the older person's mental status seemed to influence the way these others interacted with and viewed the older adult. Caregivers, on the other hand, developed ways of either maintaining a previously well established relationship with the older person, or developing such a relationship for the first time in their caregiving role. Despite the episodes of disorientation, bizarre behaviours, or memory loss, the caregivers seemed able to view older adult as a person.

The caregivers treatment of the older person reflected this sense of personhood. The manner in which they thought about the person, about their situation and about their feelings all were based on a premise that the person they cared for maintained a sense of individuality despite their cognitive losses.

Family View the Older Person Differently

People who indicated to the caregiver that they did not view the older adult in this way were considered unsupportive. Caregivers felt that the difference in the way others viewed the older person was one reason why these others could not understand the caregivers' experience of providing care to the older person. The following excerpts are from the group session held after the individual interviews:

> H: No one understands what we go through. I have a hard time explaining to people what I'm doing.
>
> G: I have to defend myself: "Why don't you just leave her? Why do you keep seeing her? Just let her rot away there [in the nursing home]." That's really frustrating. You shouldn't have to explain yourself. If you're not going to get support from people, you shouldn't have to explain why you're doing this.
>
> H: No, you need positive reinforcement, not negative reinforcement. [group:1918-1938]
>
> G: It's dealing with those emotions that's hard to describe to other relatives or family members because it really drains you as a caregiver to try to keep supporting [the one you care for] during those times [of disorientation]. Other people choose to deal with it by not dealing with it at all.
>
> B: It's the same in my family too.
>
> G: "Oh, just let her go." And you're saying, "well this is fine but they've been saying this for six years!" [group:378-395]

Some caregivers were fortunate enough to have family members who viewed the older person in the same manner as they did. One caregiver said of her husband:

> He treats [my mother] as an adult, like an equal because he teases her and things like that and when he comes home

> he'll make sure he goes in to the sitting room to see her and say "Hi mom, how was your day?" and she'll just beam.

Some family members though, seemed to have difficulty altering their relationship with the older person to account for the cognitive impairment and resulting special needs. In one instance, a caregiver felt that others in her family expected the older person to continue living alone when, in the caregiver's mind, this was clearly no longer possible.

Disagreements about the interpretation of situations occurred between caregivers and other family members. One caregiver felt that her grandmother's mental status slipped considerably when she was unable to visit the older woman on a regular basis. This caregiver indicated that the other family members thought that she was "reading too much into" the decline in the older person's ability. These disagreements contributed to the caregiver's feeling of lack of support from family members.

Caregivers see the Older Adult as Worthy of Dignity

Caregivers' efforts to maintain a sense of dignity for the older person seemed motivated by the underlying sense that he or she was still a person. The following is a collage of quotations that describe the importance caregivers placed on maintaining the older persons' dignity. These quotations also exemplify the friction that could occur between the caregiver and other family members when there were disagreements regarding the value of the older person.

> Interviewer: So even in their disorientation in your minds they are people. They have maintained their individuality?

> G: Their dignity.
>
> H: Ya. Right on. They're not meant to be put away. They should have every chance for a normal life.
>
> [My family] see that when you hit eighty you should just -- "she's lived a good life and don't worry about it and let her be confused. That's why she's in a place to be confused." [g2:485-492]
>
> So my father's attitude, when she hit that nursing home, was like, "Okay, that's it. That's the end of her life." I don't think they mean any malice by it but they really saw that their hands were totally washed of responsibility in that sense. "Her life is over." I don't see it like that and that's been, probably, the conflict....I guess that's the difference. [g2:787-799]
>
> I see Dad differently than the other three [siblings].... [After his stroke] they didn't see Dad as alive. They saw him as gone and it was a body left. They found it almost impossible to visit him. They couldn't relate to him and they certainly didn't look at him as Dad. Whereas, he's Dad to me. When he fights illness and he's not prepared to die he shows me that, and he shows me the spunk and he shows me the conviction.... I just get so much reinforcement that the old guts are there.... For me, Dad is "alive and well." ... He is there and he is a person. [a1:713-758]
>
> Interviewer: How do you think your sister sees your grandmother?
>
> Informant: I often wonder that myself. See, I sort of see Grandma as someone needing some help... I think my sister's attitude is "let the nursing home [take care of it], they're getting paid for a job and that's their total responsibility and what we [the family] do is extra, pluses. It's not really necessary."

Special Bond

There were other ways that caregivers indicated they had a special relationship with the older person. For some, this bond was the result of years of closeness that continued despite the disorientation. Caregivers indicated that they continued with this special closeness by trying to "get inside the older person's head" to determine what it was that the older person was thinking when communication was impaired.

> You know often he'll say something like... "I just want to get in the boat too," and I instantly, without thinking, know he means "I want to be one of the gang." So if the family are all here and just, not thinking, the children have gravitated to the living room, and Dad is still in the family room and he needs to be wheeled up the ramp, I don't even think. Whereas the others don't understand. I know. I'll say, "Oh dad, you want to be with the gang." And the light goes on.... And the family just say, "Oh, mom, you're so amazing.... you understand Gramps metaphorical talk." So I like to think that I'm right and that because he's left sided stroke, his speech and what is in his mind to say doesn't necessarily come out. The words that tumble out aren't necessarily what he's thinking. And I believe he is thinking. So I just do the interpretation of what does tumble out.

<u>Interpreting actions</u>. Although other caregivers indicated they were not always able to understand the speech of the disoriented person, they were able to interpret the older adult's actions and meet their needs to the best of their ability. One caregiver watched how her husband put on a shirt and was able to determine that he did not like wearing that piece of clothing. At another time she was able to eventually determine that he was looking for his keys when he came to her and picked up a piece of bread, put it against the loaf of bread and said, "It fits. It fits and we've had it around here for forty years." Another caregiver spoke of how she was able to determine that her husband was looking for his glasses or his lighter by the way he moved around the room.

Some caregivers spoke of how they believed that their understanding of the older person's disorientation was due to knowing and living with the disoriented person for a long time. As one caregiver said:

> Maybe it's because when you live with a person that long you get to know them pretty well and especially if they're habitual people, like they're not constantly doing different things, you kind of come in tune with their pattern and I don't think I've ever had the problem where I haven't in some way, understood what he was trying to get across because he's never become frustrated about what he's trying to tell me. [b2:1341-1354]

In addition to interpreting the disoriented person's words, and actions, caregivers also interpreted their moods and unspoken requests. One instance where caregivers commented on the need to do this type of interpretation concerned the rest and sleep needs of the older adult.

> I don't think mother realizes that she's tired and you sort of see this mood coming on, you have to try the straws -- figure out what on earth is the matter. [group/d:700-704]

Thinking for Two. The heavy emphasis on the need to spend so much time thinking about the needs of the disoriented older person led one caregiver to use the term "thinking for two." This expression was extensively validated by the others. "Thinking for two" was similar to the caregiver's interpreting the older person's actions but went further to describe how the caregivers had to keep thinking about all the needs of the older adult, especially those that could not be identified by them. The following quote explains what types of concerns the caregivers had to keep in mind:

> It's terribly frustrating thinking for two people. You have to remember when to go and get their eyes tested to make sure their glasses are right. You have to know when it's time that, maybe his teeth are not fitting quite properly, and maybe you should take him in and get his teeth relined. You have to know if there's something wrong

> with his socks and if that's why he keeps taking his shoe off his foot. Or to make sure that he's comfortable all the time because these people have a really hard time describing to you what is bothering them. [f1:563-579]
>
> You have to think of what he is going to wear and decide what shoes he should have on today and decide whether he needs a raincoat. You have to know when to send his clothes to the dry cleaners. He'd never know when to do it. Absolutely everything that they're beyond knowing: when to have a bath or when to clean their teeth or whatever. You're always, always doing their thinking for them. So yes, you are thinking for two and sometimes it's, you don't know if you're doing a good job thinking for two. But that's the way it has to be. [f2]

Another caregiver realized how tiring this type of thinking was when her mother had been admitted to a long term care facility and she realized she felt relieved that she was no longer responsible for worrying about "her bowels and bladder and all that stuff" [h3:43-49].

The special bond between the caregiver and the disoriented older person was important to understanding the dignified manner in which the caregiver viewed the older person. The special bond involved not only a past closeness with the older person, but a continuation of this despite the disorientation.

Treating the Older Person with Dignity

Maintaining the older person's sense of dignity was a very prevalent approach taken by the caregivers in the study. Predominately this approach allowed the older adults to "save face," especially during episodes of disorientation. The specific ways in which dignity was maintained are detailed in the following paragraphs.

Overlook cognitive impairments. One approach caregivers used, which considered the older person's feelings and resulted in treating the older person with dignity, involved not reminding the older person that they had forgotten something. In situations where the older person initiated the same conversation many times in a row, caregivers would continue to respond with the same interested response each time rather than remind the older person they were repeating themselves. Ignoring the episode of bizarre behaviour, the blaming comments and the times that the disoriented person was "fixed" on one train of thought, was another technique used by the caregivers to not draw attention to the older person's cognitive impairments.

Reassure. When the older person indicated they were discouraged with their situation or about their memory loss, caregivers were gentle and reassuring. They would say things like: "It's okay that you've forgotten" [e2:892-905]; "Don't worry about it" [b2:127-132]; "Aw come on mom now, it's not really that bad" [c2:370-373]; and "no, it's okay" [g1:515-520]; "Oh, it's alright" [f1:383-389].

Stimulate. Not only did caregivers fail to draw attention to the cognitive impairments, they also found that providing stimulation to the older person could alleviate the disorientation and result, in their minds, in an improved sense of dignity, or pride, for the older person. All of the caregivers spoke of the need to stimulate the older adult to help keep them oriented and functioning at their maximum capacity. One caregiver spoke of how she would repeat simple directions for her husband and resist carrying out the task herself in an effort to help him feel independent and to maintain his dignity.

Stimulation was also provided in an effort to alleviate the older person's depression and thereby avoid disorientation. During the times that the older adult appeared to withdraw inward caregivers tried to encourage the older person to come out of themselves:

> She'll be talking to you and then mid-sentence she's kind of drifting off so you sort of -- and sometimes I'll say, "Grandma, come one, I'm visiting. Try to keep your eyes open" and then she does, actually she will try then. But I think a lot of it is that she has to consciously force herself to be aware. [g2:196-208].

Sometimes the stimulation was in the form of physically touching the older adult. One caregiver indicated that after a bed bath her mother was far more alert and seemed to recognize people more easily.

Be truthful. Another way that dignity of the older person was considered was in the truthful answers given the older person. Caregivers did not report ever lying to the person they cared for. Although they might decide not to share some information with the older person, they took every measure possible to maintain the trust between themselves and the older adults. One caregiver described a situation in which her husband was to have had a chest X-ray but a test of the lower gastrointestinal system was actually conducted. The caregiver relayed that she was very upset with this change and was especially upset that the health care professionals involved in the examination did not seem to be concerned that a different test had been completed. The following quote was her recount of what she told the health care professional when he seemed unconcerned about the change:

> I told him, "It does matter because I told my husband that you were going to look at his chest and I want him to keep on believing what I tell him and that's going to break his trust in me if people do something other than what I had tried to explain to him." [f2:1048-1054]

Caregivers were [illegible] about avoiding situations where the older person might [illegible] to mistrust them.

<u>No humour</u>. During interactions with the disoriented person, caregivers did not often use humour as they were concerned that this would be interpreted as laughing at the disoriented person and would result in upsetting him or her rather than pacifying them. Not using humour was another way in which the caregivers considered the dignity of the older person. "I tried [to use humour] but it doesn't work... She just thinks I'm making fun of her" [c2:362-370]. Caregivers made moment by moment assessments of how appropriate it would be to use humour with the older person. Generally, although caregivers did not feel that using humour during episodes of disorientation was effective, they did use this technique sometimes for episodes of memory loss not associated with disorientation.

> I give her a lot of support, a lot of, you know. Her biggest thing to say is "I have this big hole in my head." Well it's humour again and I say "well Grandma, if you've got one there then I got one there, it's probably not as big but it's getting there because a lot of things I forget too" and then she laughs and it's enough to, as an acceptance thing I guess. But a lot of support because she does get down about it. [g1:1229-1245]

In addition to making a joke out of the memory loss, caregivers would turn the attention from the disoriented person to themselves to allow the older person to "save face." This technique is described in the following quote:

> But sometimes when he's saying things he gets the words so mixed up and I find myself saying, "well, I can't understand you" or "tell me again." I laugh a little bit and say "I'm really stupid today." Try to make a joke of it. [e2:1254-1266]

Caregivers felt that the older adults they cared for were still people and deserved respect, dignity and special considerations. As can be seen in the following sections, this approach was a common thread that influenced the caregivers' response to the caregiving role.

Figure 2. Section outline: Descriptions of episodes of disorientation.

Time disorientation

Disorientation to age

Disorientation to place

Disorientation to person

Dream world

Panic

Bizarre actions

Paranoia

Relationship of these findings to the literature

Descriptions of Episodes of Disorientation

Although each caregiver was screened over the phone to ensure that the person they cared for had at least episodic periods of disorientation to time, place or about people in the environment, a single, clear definition of the term disorientation was difficult to determine from the interviews of the caregivers. The data revealed that caregivers had different interpretations of what constituted an episode of disorientation. Many choose not to use this term, but referred instead to the older adult as: "out of sorts"; "moody"; "overwhelmed"; "out of it"; or "glazed over". "Bizarre behaviours", "confusion", "memory loss" and "periods of time when the older adult withdrew into themselves and lost touch with the surrounding environment" were also expressions used by the caregivers to describe instances when the older person was not fully oriented. One of the caregivers felt that her mother's "panic attacks," her inability to make decisions and her inability to follow through with an action, were indicators of confusion, not disorientation, but she was unable to further articulate the difference in her mind between the two terms.

Clear definitions of disorientation were difficult to obtain for two reasons: a) not all caregivers tested the older adult with questions such as those found on the Mini-Mental Status Exam (Folstien et al., 1975); and b) there was variability in the level of disorientation experienced by each of the older adults in the study as well as the variability of disorientation experienced by each.

Caregivers used informal interactions to assess the level of orientation of the person they cared for and thus their definitions of "disorientation" were drawn from anecdotes given during the interviews. Caregivers were not always certain how the older adult would respond to the standard questions used by health professionals to assess for orientation: "Where are you?"; "What day/month/year is it?"; "What is your name/Who is that person?" Only two of the caregivers consented to testing the older person with the Mini-Mental Status Exam. These older adults scored 1 and 2 out of a possible 9 questions on the orientation portion of the test. It is unlikely that the use of this test would have altered the difficulty of determining a clear definition of the term disorientation.

When defining characteristics of disorientation were searched for in the transcripts of the interviews, one of the most outstanding features of the reported episodes of disorientation was the variability of the phenomena. Disorientation was not static. It varied not only from moment to moment, but from interaction to interaction. This variability in itself was an important factor in how the caregiver responded to the older person and how the caregiving experience impacted on the life of the caregiver.

Although the phenomena of disorientation proved difficult to define in specific terms, the following sections will present some of the caregivers' descriptions of episodes of the older adults' disorientation to time, to place and to person, as well as reports of other unusual behaviour that were the result of the cognitive impairment suffered by the older person.

Time disorientation. One caregiver spoke of how her mother seemed to have lost her general perception of time. She told how the older woman would talk to young people about things that were meaningless to the younger people:

> I noticed that her perception of time is changing. She'll talk about something that the younger people just can't associate with, you know. She will have gone back. I know what she is talking about, but they don't know. They weren't even born. Her perception of time is disappearing to a certain extent. [cl:470-483]

One caregiver indicated that although days of the week and dates of the month did not have meaning to her father anymore, family members and the activities they carried out together did have meaning to him. For this caregiver there was great tolerance of her father's disorientation to usual measures of time because there was accurate orientation to family activities. This caregiver's tolerance to some episodes of disorientation is supported in reports of other studies. As indicated in the review of the literature, Pearson, Verma and Nellett (1988) and Gilleard, Gilleard, Gledhill and Whittick (1984) both found that the cognitive impairments of the older person were not significantly correlated with measures of negative impact on the caregiver. Rabins, Mace and Lucas (1982) found that although 100% of their sample reported that memory disturbances occurred, only 68% of the sample reported them to be a serious problem.

Other caregivers spoke of the older adults' lack of interest in time or inability to perceive the concept of day, week, month or year. One caregiver indicated that when asked the date the older person she cared for indicated that she thought the year was twenty or thirty years ago. Another caregiver found that her mother was losing track of the passage of time and would think in the morning that a visitor who had arranged to visit in the afternoon was late. One caregiver felt that her husband might think she had been gone for a month when she was away at work for one day.

One caregiver felt that her mother had lost the concept of all numbers and might, if asked, give her age as the inverse of the numbers; 57 instead of 75 years old. But the caregiver did not feel that this would always be consistent, that her mother might indicate that she was 49. In the same way this woman might think that a blouse costs the same amount as a house. This anecdote is one example of the difficulty in labeling this type of disorientation. It is unclear if this is an example of time disorientation or expressive dysphasia resulting from the woman's stroke.

Disorientation to age. Age disorientation is a subcategory of disorientation to time where the older adult appears to believe that they are much younger than their chronological years. One of the caregivers in the study spoke of how her mother did not recognize herself in the mirror and would not use the toilet because she felt that was someone else in the room watching her. This "mirror sign" is one indication of disorientation to person (the older person does not recognize themselves in the mirror reflection) and disorientation to the present time (the older person does not recognize that they have grown older). Another caregiver explained how her husband was still able to tie his shoes but could not manage to do his zippers up. This may be another instance of age disorientation where the older technology, tying a bow, is more familiar because of the time period the older adult may believe himself to be living in.

Disorientation to place. Caregivers spoke of disorientation that would occur if the older person broke a regular pattern that appeared important to keep the older person from becoming disoriented to place. One caregiver spoke of how her mother was able to walk to the grocery store and do some shopping if she entered the store from the same door each time. Another caregiver spoke of how disoriented her mother became when she was admitted to an active treatment hospital which was an environment with which she was unfamiliar. Losing one's way on a walk or in a shopping mall was another typical example of disorientation to place. According to the caregivers, this need to stay within a known environment resulted in a number of the older adults not venturing out of their familiar territory for fear of becoming lost.

For one caregiver it was an episode of disorientation to place that convinced her that her husband had a cognitive difficulty and prompted her to have him examined by the physician. In that case, the husband was unable to drive home because he lost his way and she also had to take the car keys away from him. Another caregiver recalled also that episodes of disorientation to place were her first clues that her husband had a cognitive problem.

Disorientation to person. Although some of the older adults had periods of being disoriented to some people in the environment, there were very few instances of a failure to recognize the caregiver. In most cases the older person would indicate disorientation about other family members, especially those who were not seen on a regular basis. As one caregiver commented:

> I don't think there has ever been a time where she hasn't really known who I am. But I know my cousin... well, apparently she didn't know him... I think [she always knows me] because I see her more often. [gl:395-404]

Some caregivers indicated that the older adult might not be able to call family members by name but might know their faces. Other caregivers identified that the older person might know that they ought to know the name of an individual but be unable to remember that name.

There were few instances discussed by the caregivers of the older person being certain that one person was someone else. In one of the few such incidences, the caregiver was mistaken for the older person's son and in another case the caregiver was mistaken for a health professional. More frequently, though, the older person would have fleeting moments of not knowing who someone was. One caregiver relayed this story:

> This morning, as a matter of fact, I took his coffee in to him; he looked over on my side of the bed and said "Oh, is Nancy gone already?" So he obviously did not know that his wife was serving him coffee this morning and Nancy is the name of our daughter and he never ever has called her by name for many years. So I don't know just what made him this morning -- that's the first time that's happened, that he called our daughter's name and my name is Gina so I don't really know what happened this morning but he seemed as though he did not recognize his wife was bringing him his coffee. [fl:213-232]

Dream world. In addition to the episodes of disorientation, some caregivers spoke of the dream world that they felt the person they cared for went into. They spoke of how the eyes of the older person would get foggy or glazed over "like a cloud has come over [them]" and their voice would change and they would turn inward. This change could occur in the middle of a sentence. When the older person was in the "dream world" they didn't seem able to focus on issues outside of themselves and might begin to talk about things that affected only themselves, such as the number of clean socks they had in their drawer. Although one caregiver felt that her husband was happy in his own little world, another caregiver had a sense that her grandmother really didn't like being in this dream world:

> The dream world isn't all that great. There's the feeling that "I don't know where I'm at in this world." At least that's the sense that I get from her. I don't know. [group/g:351-356]

Memory loss. Simple loss of memory was a source of concern for caregivers in some situations. Many of these episodes of memory loss were similar to time disorientation and the caregivers used the same interventions with the older person as they did with disorientation to time. In some cases the memory loss was over a short period of time and would result in the older person repeating the same questions over and over. In other cases the memory loss resulted in forgetting an entire event such as an afternoon birthday party that the caregiver spent considerable time on, or forgetting a familiar place such as a shopping mall.

> His favourite expression if we go someplace is, "Oh, I've never been here before" or "never seen this before" and probably he's seen it every week of his life or dozens of times but that's a familiar expression with these people. [f1:265-274]

Panic. Some caregivers spoke of the panic attacks that the older person would have. Many of these episodes would have elements of disorientation connected to them. For instance, in one case the caregiver told how her mother panicked when she was asked to make sandwiches for a bridge party. The caregiver got the impression that her mother thought that she was responsible for organizing the whole party when in fact there were other women who were ultimately responsible. Panic attacks seemed to be characterized by the older person's inability to think clearly, to take in new information or to be reassured. Some found that it was fear of the unknown or the older person's inability to make a decisions that stimulated panic attacks.

Bizarre actions. Another category of behaviours described by the caregivers have been labeled "bizarre actions." One example of a bizarre behaviour was one older adult's removal of all the food in the caregiver's deep-freeze when the caregiver was at work. Another example was described by one caregiver who came into a room to find her husband putting her blouse on over his own clothes. Waving to people on television was another example of bizarre behaviour described by the caregivers. Although these bizarre behaviours did not have specific elements of disorientation, the caregivers' reactions to them proved to be very similar to the actions taken to more clearly defined episodes of disorientation.

Paranoia. Some of the caregivers described episodes of paranoia, or delusions that the person they cared for had. These episodes seemed to be focused on thoughts that the caregiver was going to murder the older adult or that someone was going to steal things from them. One of the older adults thought that his wife was seeing another man and another thought that her daughter was out enjoying herself whenever she would have to work late. This type of disorientation was very distressing for the caregivers as they found it difficult to reassure the older person, especially when the older adult thought the caregiver was trying to murder him or her.

Relationship of these findings to the literature. Most general categories of disorientation or cognitive impairment mentioned by the caregivers in this study have also been reported by others. Although questionnaires such as the Memory and Behavior Problem Checklist (Zarit & Zarit, 1982) list problems such as wandering, being accusative, and forgetting the date, the rich description of these situations by the caregivers in this study add to the general understanding of the experience of providing care to a disoriented person.

In this study, it proved difficult to categorize some of the caregiver's anecdotes into distinct episodes of disorientation to time, place and person. Often a situation described by the caregiver could fit into more than one category of disorientation. In light of this, a question is raised regarding how questionnaires such as the Memory and Behavior Problem Checklist (Zarit & Zarit, 1982) are administered.

Caregivers reacted intensely to these episodes which have all been labelled disorientation for purposes of this study. Their emotional responses were often the most immediate reaction and because of this, these reactions will be presented first in the following sections. When caregivers did not respond to the older person based on these feelings, they would modify their actions based on thoughts they had regarding the situation. In light of this, caregivers cognitive responses will be presented after their emotional responses. Following these sections will be details of the actions taken by the caregivers in response to the older persons' disorientation.

Figure 3. Section outline: Caregivers' emotional reactions to the disoriented person.

Anger

Frustration

Lack of control

Guilt

Resentment

Hurt

Disappointment

Sadness

Alone

Unsure

Responsible

Tired and unhappy

Upset

Variability of feelings

Relationship of these findings to the literature

Caregivers' Emotional Reactions to the Disoriented Person

Caregivers told about a wide variety of feelings that they experienced as a result of their caregiving role. The feelings ranged from anger and frustration toward the person they cared for to feeling guilty when they responded to the the older adult in an angry manner. They also reported feelings of resentment at being in the caregiving role. These feelings will be detailed in the following paragraphs.

Anger. Caregivers reported that they may become angry at some times and not at others. As one caregiver said, it depends on what else is going on in your life. Another caregiver said:

> Sometimes I just can't hold it back. I just, I consider myself as a person who has a lot of patience, but sometimes it just too much for me. I really try and think about it. When I go to my mom's place I really try and confront that, the possible anger or crankiness that might be inside me and I try and control it but sometimes it's just something, the lid pops open and all this anger just [comes out]. [el:728-741]

Caregivers revealed during the interviews that they became angry at the disoriented person, at family members and at the health care system and at "fate" for their circumstances. Anger toward the disoriented person occurred under a number of circumstances such as when they wandered, when they blamed the caregiver for their present circumstances, when they refused help that was set up by the caregiver, such as homecare services, and when the disoriented person was not happy despite much effort on the caregiver's part. Memory loss on the part of the disoriented person and their failure to understand explanations was another source of anger for the caregiver. Caregivers also used the words "annoyed", "irate", and "mad" to describe their emotional reactions to these situations such as when the older person lost objects or spoiled food during meal preparations.

Caregivers indicated that they felt angry that the person they cared for was ill and required their care. As one caregiver said:

> I think a lot of where my anger came from at first was, well, like at first it's not that you want to feel self pity, but you -- maybe it's part of the female gender - but you say, "Well, whose going to look after me? I have needs, I have wants. What about me?" That's what you feel like shouting but, I mean, but you don't shout it. At least I didn't. [b1:432-449]

> At times I still get very angry and I think why did [this] happen to us? [b2:987-990]

Although it was a common feeling, caregivers identified that it was a negative experience to become angry at the older adult. "It's not a good thing inside me" [e1:832-844] one caregiver said.

<u>Frustration</u>. Similar to the anger described by the caregivers was a feeling of frustration. Again the frustration was caused not only by the disoriented person but also by external conditions such as the health care system.

The long term nature of the problems suffered by the older adult and their general deterioration was a source of frustration for caregivers. One caregiver indicated that there never seemed to be an end to the arrangements she made for her mother.

> It's never ending. It's one problem that you think you've solved, but no, it's not because it keeps coming up, the same thing keeps coming up because of her confused state...it's frustrating, very frustrating when you don't see one thing completed, finished with. You don't see an

> end point, you don't see accomplishment, not tangible accomplishment anyway. [e1:519-541]

As well, it was frustrating for the caregivers when they realized that there was nothing else they could do to help the older adult stay in touch with reality and that they, the caregivers, had no control over the episodes of disorientation. This feeling was especially strong when no explanation for why the older person became suddenly disoriented could be found by the caregiver. Frustration also occurred when the caregiver had been making a special effort for the older adult and the disorientation occurred suddenly and seemed to ruin the good time that preceded it.

The memory loss of the older adult was a very major source of frustration for the caregivers. One caregiver told how her mother threw out the notes she had written to remind her mother not to prepare an evening meal. When the caregiver arrived home and found a poorly cooked meal, the older woman would claim that she had not been told not to prepare a meal. Other caregivers reported that it was frustrating for them when the older person asked the same question repeatedly or when they would lose objects that the caregiver would have to spend considerable time looking for.

Caregivers also identified that the invisible nature of the disease process also contributed to their feelings of frustration.

> ...it was like I was fighting something invisible. Like if it could show itself then I could deal with it but you know it's not like someone with arthritis or some other disease that you can see and that's what I found, well I thought to myself well if it would show itself in some form then maybe it would become easier for me to accept it too.

Caregivers found the variability of the disorientation very frustrating. They never felt that they knew when the older person was going to lose touch with reality and become disoriented.

Caregivers also reported that they found it frustrating that the older person would show them negative feelings that were hidden from others in the older person's environment. They found it frustrating that they were the ones to hear the older adults' complaints and suffer through their mood swings.

Frustrated feelings were also identified with interactions with family members who seemed not to understand why the caregiver had assumed the role of caregiver and were not able to support them in ways that the caregiver found helpful. Other feelings of frustration were directed toward health care professionals for reasons surrounding difficulty in obtaining appropriate physical assessments of the older adult and lack of flexibility in finding suitable placement for the older adult. The caregivers' interpretations of support from family, friends and the health care system will be discussed in greater detail in the section of the chapter entitled Supportive and Unsupportive Situations (p. 139).

Lack of control. Another emotion that was detailed by the caregivers was lack of control over the situation with the older person and over the caregiver's own emotions. This feeling was related to: 1) the sense that the caregiver had no apparent control over the mental status of the older adult; and 2) the caregiver's sense that the disability was a long term one with improvements unlikely. As one caregiver said:

> You have no control over it and that's the hard part to accept. You think, well I don't understand that. Yesterday they knew me and they talked to me. How come today it's like that? [gl:391-396]

One caregiver indicated that she felt a lack of control over her emotions and would sometimes become angry at her mother even though she knew cognitively that it was her mother's illness that was causing her to act in a bizarre manner. This caregiver was uncomfortable with her lack of control and consequently felt very guilty when she did become angry with her mother.

Guilt. Feelings of guilt were discussed often by the caregivers for a variety of reasons. One caregiver said that there was a time when she felt very guilty about leaving her husband, who suffered from Alzheimer's disease, at home when she would go out to visit a friend or go to a movie. Eventually she indicated that she worked through that feeling and realized that she needed some time to herself on occasion and she comforted herself by knowing that she never left him without appropriate supervision. In her words:

> You feel really guilty cause you've gone out and you've left him at home. And you've gone out on your own. It's almost like you were cheating on your husband when you're not. It's really a difficult situation to be in, but I know it has to be done.

Other caregivers spoke of the guilt surrounding the possibility of placing the older adult in a long term care facility. Most felt that they wanted not to feel guilty about such a move, but anticipated that they would wonder if there was anything else they could have done to avoid placement. One caregiver, who admitted her mother to an auxiliary hospital during the time of the study, indicated that she felt guilty because she was a little relieved that her mother was no longer living with her. Caregivers, who had already been responsible for moving the older adult out of his or her home, expressed feeling guilty for taking way the older adult's independence. One caregiver who did not live with the person she cared for felt guilty that she had not arranged to have the older person live with her.

Resentment. One caregiver said that she sometimes felt resentful of the time she spent caring for her grandmother and then felt guilty for feeling resentful. Some felt resentful for being the person within a family left to assume the caregiving role. Others felt resentful that the older person did not demonstrate appreciation for the care they received. Others felt resentful that their lives had been put "on hold" because of the demands of their caregiving role. As one caregiver said:

> I feel quite upset sometimes, resentful that my life is on hold right now and I'm not able to pursue my goals, my dreams and I'm not sure why that is that I feel I can't pursue my dreams. I feel quite upset about that. [el:909-917]

One caregiver also indicated that she felt resentment that the disease that afflicted her husband had robbed them of their dreams of travelling during their retirement. Although the caregivers tried not to feel self pity, some admitted that it was easy to let yourself "get into a self-pity thing" [g2:1252-1253].

Feelings of resentment were also expressed toward family and friends who the caregiver felt had deserted her and toward health care professionals who promised support and help but who failed to provide these things.

At least two caregivers indicated that feelings of resentment were usually more prevalent when they felt tired and run down. As one of them expressed it:

> You get the feeling sometimes you're imposed on depending on how tired you are today. There are mornings when you just don't feel like getting out of bed but you have to because this man has to be fed or you have to do something because this has to be done and I suppose if a person were really tired or really imposed on it would be very easy for them to think "oh he's just doing that to me." [f2:1596-1612]

Hurt. Some caregivers explained how they could be hurt very badly by the older person for whom they cared. As two caregivers said:

> Because you're giving so much and not getting much back, it hurts and then you have to remind yourself that they wouldn't do that if they were all there. [group/h:131-1135]

> Well, emotionally you feel like you've been betrayed. Like you're trying to do your best, and this is sort of what happens and yet you know logically they don't have any control over what's happening to them. [gl:92-99]

Disappointment. The variability of the disorientation caused the caregivers to experience a type of disappointment when the older adult suddenly became disoriented.

> Sometimes you really feel that she's normal and then all of a sudden she does something and you know she's not. And then it's such a let down. It's such a sinking feeling. [hl:903-909]

Sadness. Often the caregivers spoke of how sad it was for them to watch the person they loved and cared for deteriorate, lose their independence and become helpless.

> This is a very sad disease because a man who is well educated and who's always held down a responsible job all of a sudden, doesn't even know how to sign a greeting card; he can't write a letter or write a cheque. He's not in control of anything anymore. [f1:966-975]

Some found it sad to watch the older person withdraw into themselves, failing to find interests in their environment. Vitality, interest, enthusiasm, enjoyment waned and interest in themselves increased.

Some caregivers recognized that some of the sadness related to caring for the older adult revolved around the realization that the person they cared for was growing older and would eventually die. For some, the caregiving role forced them to anticipate this death and they mourned for the anticipated loss of their family member.

A number of the caregivers identified that they felt that a person with a cognitive impairment suffered from a slow death.

> I feel my mother is dying -- slowly. I'm losing her every day, a little bit every day. [e2:1001-1006]
>
> Interviewer: Somebody said it was like a slow death.
>
> Informant: Yes. Agonizingly so. Yeah. And maybe that sounds unfeeling on my part too but often I have wished that he had been run over by a car or had a heart attack. It's because when you love someone and you know that there's no cure and there's no future, maybe that's being selfish on my part but instead of seeing it drawn out agonizingly slow you wish that it would come to an end and you could deal with it. [b2:1738-1798]

For one caregiver, the older person for whom she cared was her only other family member. This meant that the older woman's deterioration and impending death was particularly sad and isolating as there were no other family for the caregiver to turn to.

<u>Alone</u>. Other caregivers expressed feelings of isolation and feeling like they were "in this alone." While some felt that friends

and family had deserted them, other caregivers felt the additional loss of the friendship of the person they cared for.

Unsure. Caregivers indicated that they sometimes feel unsure of their ability to make the correct judgement concerning the care of the older adult. This feeling unsure was related to feeling alone in the caregiving role because the women felt they did not have an opportunity to discuss their concerns with other family members who might share in the decision making role. Decisions surrounding when to admit the older adult to an institution were the ones that caused the caregivers to feel most unsure.

Responsible. Caregivers expressed a great sense of responsibility for the person they cared for. They felt responsible to ensure that the places they sent the older adult, such as day care programs, were safe. They felt responsible when the older adult wandered off. And, although they recognized that it was not realistic, they felt responsible for the older person's happiness.

> I suppose I lie awake at night in bed and wonder what I could have done better or what I should have done differently. I probably have been inclined to take too much responsibility myself, but what else can you do? You can't blame him because he's not in control of his own thought or his actions or whatever. [f1:661-670]

For some the responsibility was similar to that of caring for a child. As one caregiver said of her grandmother:

> Basically it was like adopting an 88 year old adult. I had no idea how much when I took it on. I wouldn't not do it now just out of love and respect but I don't know if other people have a grasp of what a responsibility it is, or at least that I feel it is.

Tired and unhappy. The caregiver role caused all the women in the study to feel tired and stressed out and unhappy at least occasionally.

> Oh, I just get really tired of looking after mom. Like my brain gets all foggy and I don't feel like doing anything, where I know there's lots I can do around the house and I don't feel like entertaining her. [hl:10-23]

> I used to be such a happy person and now, strapped down with all these responsibilities, I'm just feeling unhappy. [el:954-957]

Upset. Upset was a feeling word that came up frequently during the interviews. The disoriented person might make the caregiver upset by being angry at the caregiver and blaming her for things. Caregivers also felt upset when they could not understand what the older adult was trying to say. They felt upset when the older person was "down." They also felt upset when the older adult failed to recognize them. They felt upset when they have caused the older adult to be upset and when the older adult did bizarre things.

Variability of feelings. The caregivers discussed how variable their own feelings were over time and how this variability depended on many things. One of the variables that affected caregiver feelings was their level of energy and the other events in their lives. The length of time in the caregiving role also seemed to affect the emotions of the caregiver. The caregivers who had been in the role for a considerable amount of time were able to speak about how their feelings had changed over time.

> Before I understood what was happening with her I was upset, angry. Why is this? What's the matter with you, how come you're doing this? I don't understand. Just on and on, just up and down. Turmoil with emotions with hers

> and mine and just didn't know what was going on. Confused. Come on mom snap out of it, are you crazy or what's going on. [el:1039-1049]

In one case, the caregiver said that with time she had come to be feel less guilty about the possibility of having to place her husband. Another caregiver said that in the beginning she was angry but now did not feel the same way and this affected how she was able to interact with her husband without yelling at him. Other caregivers discussed how they anticipated that their feelings would change over time and even commented during the second round of interviews how differently they felt even after this interval.

Although caregivers spent a considerable amount of time thinking about their emotional reactions to their situation, they were not always able to describe these emotions during the interviews. One caregiver spoke of how difficult it was to label her feelings:

> Sometimes it is difficult to put to words how you feel because sometimes you really don't know how you feel. You feel very confused about -- for example, to give you a specific example: When I get angry at my mom, I look at that, I come home and I think why is that? Like I'm confused. Why do I react that way? Why does she react that way? What is it that's going on within me? Why, period. Why? And how can I put that into words what it is that's happening? Sometimes I can't. I just got upset. Everybody gets upset. And maybe through talking to people or friends or the social worker that came to see me a few times, you're able to put it into perspective and see it and say, "oh, yes. I'll put a label on it. That is this particular feeling." [el:1130-1164]

Caregivers spent a considerable amount of time thinking about their feelings and their reactions to situations. They were not always able to find explanations for their feelings, but they did try to understand themselves better from this experience:

> I think we do go through a process of examining and looking back. We can, at some point -- maybe in a few days, a few weeks, a month or whatever, when you detach from the feeling, from the emotion and you look at the situation and say, " oh, well, that's clear. You were reacting to this particular situation so it had to be this particular emotion that you're feeling" and sometimes that can be quite accurate. [el:1175-1187]

Relationship of these findings to the literature. As identified in the literature review chapter, few researchers have focused on the feelings experienced by caregivers in their roles. There are a number of anecdotal and case study reports, however, which support the findings of this study. Mace and Rabins (1981) present a section in their guide book on the feelings caregivers might experience. They identified the following emotions which they found to be commonly experienced by caregivers of demented older adults: anger, helplessness, embarrassment, guilt, laughter, love and joy, grief, depression, isolation and worry. Flitterman and Fulmer (1986) also report in their guidebook for caregivers of Alzheimer's patients, that the following feelings are common: grief, anger, guilt, loneliness, sadness and embarrassment. With the exception of the emotion of embarrassment, the caregivers in this study provided evidence that they too experience emotions related to the older adults' episodes of disorientation that are similar to the emotions reported in the two guide books.

Figure 4. Section outline: Caregivers' cognitive reactions to the disoriented older person.

- Finding Reasons for Worsening Orientation
    - Time of day
    - Phases of the moon
    - Diet
    - Medications, alcohol, illness
    - Winter housebound
    - Young children
    - Sleep patterns
    - Sensory limitations
    - New situations
    - Lack of stimulation
    - Boredom and depression
    - Caregivers' emotions
    - Rushed

- Finding Reasons for Improving Orientation
    - Mental, social and physical stimulation
    - Family members help orient
    - One-on-one visits, opposite sex, doctors' visits

- Questions without Answers

- General Thoughts
    - Just accept it
    - It's a disease
    - Pretending
    - Mental preparation

- Caregivers' Expectation of Themselves

- Learning about the Disease

- Caregivers' Reactions to Diagnosis
    - Delay diagnosing
    - Relief
    - Changes in approach based on diagnosis
    - Relationship of These Findings to the Literature

Caregivers' Cognitive Reactions to the Disoriented Older Person

During the interviews, the caregivers spoke of the thoughts they had about their experiences as caregivers. The caregivers provided evidence that despite the sometimes negative feelings they had toward the older person and about the situation they found themselves in, they spent considerable amounts of time thinking about ways they could improve the care they provided the older person. Determining reasons for why the disorientation improved or worsened provided caregivers with data to use in altering their care and in helping them cope with the experience by making the disorientation seem less abstract. By thinking about the reasons why they provided care for the older person, some of the caregivers found they were able to keep in perspective the sometimes negative feelings they had associated with the role. Some of the thought patterns of the caregivers will be described in this section of the chapter.

Finding Reasons for Worsening Orientation

The caregivers all spent a considerable amount of time trying to find reasons to explain why the person they cared for was disoriented and, on good days, why they were not disoriented. They tried very hard to assess situations for clues that they could use to affect other situations in the future and to prepare themselves for future episodes of disorientation. These explanations seemed to be sought because the variability in the disorientation led the caregiver to believe that there were things that affected the older person's level of orientation. They acknowledged that although the physical changes in the older person's brain were the reason for much of the disorientation, there were other, external reasons that affected their level of orientation.

During the group discussion caregivers spoke of how difficult it was not to have a tangible reason for the variability in the disorientation. For instance, one caregiver spoke of how she used the explanation of "mini-strokes" to help her explain why the confusion was worse one day. Other caregivers agreed:

> caregiver G: At least [strokes are] tangible. It's concrete, that maybe that is the reason that whole day was gone. There was so much confusion. There's no medical basis for it but, I don't know. It's something to sort of grasp on to.
>
> caregiver B: Well it's like she said, it's a tangible thing. Like it kind of gives you something to grasp on to and help you through that situation.
>
> caregiver G: To say no matter what I'm doing, I'm not going to make any [difference]. Or there's nothing going to be any different with whatever we try here. And it's okay. [group]

Some of the specific variables caregivers identified as affecting the level of orientation of the older person will be described in the following sections. These variables were also how the caregivers described the context of the episodes of disorientation.

<u>Time of day</u>. The time of day seemed to affect the orientation of the older adults. Some caregivers found that in the morning the older person was more alert, so they would use this time to explain things to the older adult. Some found that the older person was more alert later in the day. Others found that time of day had no impact on the orientation of the person they cared for. The literature

describes a phenomenon called sundowning which labels the increased confusion that has been associated with the onset of evening (Volicer, Fabiszewski, Rheaume & Lasch, 1988).

Phases of the moon. A few of the caregivers made a connection between the phases of the moon and periods of disorientation experienced by the older adult. The older adults seemed worse during a full moon.

Diet. Others wondered about the connection between the older person's diet and his or her level of orientation. One caregiver felt that her mother seemed far more alert after a complete meal and had concerns about how much her mother cooked for herself when she was on her own.

Medications, alcohol and illness. One caregiver felt that her mother's alcohol intake might affect her orientation. Other factors that were noticed by caregivers as affecting the older person's orientation were their medications and other acute episodes of physical illnesses such as anoxia because of a heart condition, surgery for a broken hip, mini stokes, or even constipation.

> I think, "well is the medication doing this to her? Would she be better off all the medication?" [h1:890-897]

> If he gets sick... if he has a flu or if he has a temp at all, he gets disoriented. And he gets sick very fast and it gets very scary. [a1:611-613]

Winter housebound. Caregivers identified that there were environmental factors that affected the orientation level of the person they cared for. Some felt that the limitations of winter, concerning getting outside for a walk, affected the older persons' orientation.

Young children. Another factor that affected the older person was the presence of young children. Some caregivers wondered if this was related to the older person being jealous of the attention received by the young children. One caregiver spoke of how difficult visits from her grandchildren were on her husband:

> If we were going to give Jesse, my grandson, a new toy, my daughter and I had to make sure we had two of those toys otherwise Jesse couldn't play with it until my husband had a turn first. And if Jesse knew he was going to have a cookie, he had to have two cookies, one to give to Grandpa. It was just like having two children in the house -- very, very childish. [f1:867-877]

Sleep patterns. Some caregivers noticed a connection between the level of tiredness of the older adult and their orientation.

> She sometime thinks I'm her son that passed away. But it's mostly when she's tired... like she really needs a lot of rest. [h1:80-83]

Some caregivers also found that the person they cared for was more disoriented when they woke up.

> You see he may have had a dream, and uh, can't get to reality again and is still with it. And he may have dreamt that uh, someone was interfering with his affairs, or uh, his cheque didn't come in, pension cheque. He may be somewhere else totally. [a1:583-594]

Sensory limitations. The older persons' decreasing sensory abilities were also seen by the caregivers as a reason for their disorientation. One caregiver felt that her mother mistook her for someone else because she had short hair like the other person. Another caregiver felt that in the evening, especially when her mother was tired, that she was more disoriented because she could not hear as well as earlier in the day.

<u>New situations</u>. A strange environment or the presence of strange people were two situations that were also identified as increasing the older adults' disorientation.

> Strangers really throw her. She really, just throws her whole day off or she clams up. She withdraws. She's just not happy. She's okay if it's just the immediate family but if there's one friend or a stranger in the bunch, well just forget it. [gl:1326-1335]
>
> In a new environment, like in the hospital, she doesn't do very well at all. There, she totally withdrew and there was total confusion then. She had no idea what was. Whereas in the nursing home it's a little more middle area. I think this is why she gets so upset at just to come to my place and yet she's been here many times. She says, "Where am I? What am I doing here?" [g2:282-294]

<u>Lack of stimulation</u>. Some felt that it was an environment of little stimulation that resulted in disorientation:

> I don't know. I think that's part the nursing home too. I think that the surroundings -- it's just very easy to sort of withdraw in you own little world. Hard to tell what's old age and what's surrounding. It's hard to tell. [g3:208-215]

The conviction that the appropriate amount of stimulation was required to maintain the older person's level of orientation has been reviewed in the section of this chapter entitled, <u>Perceiving the older adult as a person</u> (p. 43).

<u>Boredom and depression</u>. Caregivers felt that when the older person was bored or did not make an effort to stay in touch with their surroundings, the disorientation increased. Depression was also mentioned as a reason for this lack of interest in the person's surroundings and resulting disorientation. Some caregivers mentioned

how difficult it was for them to distinguish between depression and disorientation in the person they cared for:

> There again, I think it's depression rather than disorientation, well, disorientation I guess because of the depression.

The literature supports that distinguishing between the two can be very difficult for health care professionals who assess the disoriented older person. Pseudodementia is the term that describes conditions when dementia is suspected without physical pathology to support such a diagnosis. As the symptoms of depression may mimic many of the symptoms of a dementing disease process such as Alzheimer's disease, depression is regarded as one of the pseudodementias (Lishman, 1978). The caregivers in this study alluded to a very real diagnostic problem facing health care professionals.

Caregivers' emotions. Caregivers also identified that if they showed that they were upset over something, the older adult would pick up on that emotion and become upset themselves. For some this lead to an increase in disorientation, or paranoid thoughts. One caregiver told of a time that she became very upset because another family member was very ill. Because of her mother's cognitive impairments, she was unable to leave her alone while she visited the other family member. In the tension of the moment, her mother became convinced that the family was plotting to murder her. The caregiver identified that her mother was frightened because she could not understand the strong emotions of the situation and this contributed to her increased disorientation.

Rushed. When the older adult felt rushed there was a greater tendency for him or her to become disoriented. One caregiver spoke of the time she had to move her grandmother to a new location:

> Literally we just put her in the car and gave her a Gravol and hoped she did okay on the road up there but that was a lot of it... there was no preparation for her either. You know, you sympathize. You put yourself in that position and you can see why you would be a little mixed up and a little turned around. [gl:653-661]

There were a wide variety of reasons caregivers found for the worsening of the level of orientation of the person they cared for. Some were under the control of the caregiver, some were not. Caregivers actions were often impacted by the experiential knowledge they gained from their reflections.

Finding Reasons for Improving Orientation

In addition to identifying factors which seemed to result in a worsening of the older person's orientation, caregivers spoke of situations which seemed to result in an improvement of their orientation, however temporary this improvement might be. Some conditions seemed to prevent disorientation. These situations will now be presented.

Mental, social and physical stimulation. Caregivers found that some mental and social stimulation resulted in the older adult being more oriented and brighter. One caregiver felt her regular visits with her grandmother resulted in maintaining the older woman's level of orientation. Another caregiver felt that her mother was more alert after a bed bath. Spending time talking to the older person seemed to have a positive effect on the older person.

Family members help orient. For some older adults contact with family members was more effective in preventing disorientation than social contact with people outside of the family, such as nurses in the long term care settings. The importance of family contact was also demonstrated by the content of the recent memory retained by the older person. Even when many memories of current events were lost, the older adults' recent memory for events concerning close family members was very accurate. There seemed to be a connection between the closeness of the past relationship with a person and the events remembered in the confused state. One caregiver spoke of how amazed she was that her disoriented father remembered that his favourite grandchild was about to have a baby. Another caregiver said that her husband would consistently remember telephone messages from only one person: a daughter who was very close to him. Some caregivers believed that the person they cared for would never become disoriented to the caregivers' identity because of the closeness of the bond between the two.

One-on-one visits, opposite sex, doctors' visits. In addition to family members, caregivers noticed that the older person was much brighter during one to one interactions than in group situations. This occurred especially when the other person was a member of the opposite sex. This apparent ability to be more oriented for some interactions resulted in frustration for the caregiver. A number of caregivers mentioned that this often occurred during visits to the doctor's office or during assessments by other members of the health care team. They spoke of how the increased effort the older person put into these interactions resulted in them appearing more oriented and aware than the caregivers felt they were under more normal circumstances. Understandably, this added to the caregivers feelings of frustration as they sometimes wondered whether the older person had control over their mental abilities as it seemed they were able to "rise to the occasion" at times and act as if they did not have a cognitive disability.

Caregivers determined many reasons for the improved orientation of the person for whom they cared. Their actions toward the older person also reflected these revelations.

Questions without Answers

There were times when the caregivers failed to determine the reason why the older person had a specific episode of disorientation or displayed some strange behaviour. It was particularly frustrating for the caregivers when they were not able to find any explanation for the suddenness of the change in the person they cared for.

> The trip back wasn't very good because she sort of withdrew and said, "I shouldn't be out, you know. Something's going to happen." She gets panicky, which is kind of sad and it's frustrating in that she really is totally enjoying herself and then she gets into this, turns inwards and she gets herself all worked up and there's really no real reason for it. [g2:380-390]

Caregivers also wondered why the older person seemed to be trying so hard to hurt the family members who love them the most. For some, the blaming and anger of the older adult was enough to make them wonder why they were trying so hard in their role as caregiver. They asked rhetorical questions regarding why the older person suffered from a cognitive disease process. The caregivers spent a great amount of time thinking about possible explanations for why events occurred as they did.

General Thoughts

Caregivers indicated that they thought very much about the various possible causes of the variation in the orientation level of the person they cared for. In the following sections some of the caregiver's general thoughts regarding care of the older person will be described.

Just accept it. Although caregivers spent a considerable amount of time trying to determine what might have caused a fluctuation in the older person's cognitive ability they did have periods of convincing themselves that they had to accept the older person's decline and the inevitableness of the periods of disorientation. Their lack of control over the presence and course of these periods was usually recognized at some point by the caregivers.

It's a disease. There were times that the caregivers had to remind themselves that the older adult's cognitive problems were not caused by the older person and that a disease process was responsible for their disorientation and strange behaviour. Often when the caregivers felt angry or frustrated they reminded themselves that the older person could not control his or her actions. One caregiver said:

> Because you're giving so much and not getting much back, that [failure to recognize caregiver] hurts and then you have to remind yourself that they wouldn't do that if they were all there. [group/h:1131-1135] It's the disease, that's not her doing that. [h3:755]

> You have to accept it as a disease. If that person fell down and broke their arm and had a cast right down to their fingertips you wouldn't expect him to carry two suitcases for you. Or if he was lying in bed with cancer and was screaming with pain you wouldn't say, "well, I'm not going to give him a pill. He's just pretending." So when they're saying things when they have a brain disease, they're not capable of knowing what they're saying and I think you have to tell yourself, "he's sick but I'm not." [f2:1541-1555]

<u>Pretending</u>. Some caregivers spoke of how the thought that the older person might be pretending regarding their memory loss, or bizarre behaviour caused them to feel confused about the whole situation. For some, it was as though the older person was trying to make them crazy.

> It's as though, and I've said this to her I think, "Mom, what is it? Are you trying to really drive me 'round the bend or something?" [c2:1237-1244]

> I thought for sure, "she's got to be kidding me. I just told her five minutes ago this -- and now this is happening and she's asking me again. She's got to be just playing around with me....She's just getting at my nerves and I don't know why." [e]

Caregiver handbooks, such as the ones written by Mace and Rabins (1981) and Flitterman and Fulmer (1986), refer to other caregivers who have experienced this feeling of wondering if the disoriented person is pretending when they experience acute episodes of disorientation.

<u>Mental preparation</u>. Caregivers spoke of preparing themselves mentally before seeing the older adult. They would think of topics

that would be of interest to the older person such as news about family members. They would coach themselves and say things like "Stay calm, don't worry about it", "Ignore it. Roll with the punches." One caregiver spoke of how she tried to "confront the possible anger or crankiness that might be inside [her] and try and control it" before she met with her mother [e1:733-741]. Other caregivers coached themselves to slow down before they met the older person so that they would not negatively affect the older person's level of orientation by appearing rushed or "keyed up."

The variability of the mood of the older person affected how the caregiver prepared for a contact. One caregiver said that she would "psyche herself up" before a visit as there was a chance that her grandmother would be feeling depressed and require a lot of energy to reassure the older woman and build her up. Another method of preparing themselves before contact with the older person was anticipating what could possibly be wrong so that they were prepared for such things. For example, one caregiver told herself that she expected her mother's medication would not have been administered correctly so that she would not be surprised when they weren't. This mental preparation helped the caregivers approach the older person with the greatest amount of calm and dignity.

These general thoughts of the caregivers provided an indication of the variety of ways the caregivers thought about the disorientation. Their mental preparation helped the caregivers react to the older adult in the most optimal way for the situations. These actions will be described in a following section.

Caregivers' Expectations of Themselves

Caregivers spoke of how they spent time thinking about ways they could improve the care they gave the older person. They strove to do the best for the older person. For some that meant providing a high level of quality of life: of providing happiness and making sure that the older person was not lonely.

> I suppose I lie awake at night in bed and wonder what I could have done better or what I should have done differently. [f1:661-664]

> You just can't give up. You have to keep trying to find -- out maybe this way will work better or this way will work better. [group/h:1532-1537]

The caregivers' expectations of themselves were discussed in this section as they revealed more about the thoughts caregivers had regarding their experiences. The caregivers often reflected on their experiences.

Learning about the Disease

In addition to thinking about why events occurred, and how they could have improved the care they provided the older person, many caregivers read and learned a considerable amount about the disease that affected their family member. This knowledge was used to determine if the older adult they cared for was following the normal, or usual progression of the disease. In a number of cases, the caregivers found discrepancies between the symptoms or behaviours of the older adult and the "normal" course of illness. One caregiver determined that her husband did not have the impatience and agitation and aggressiveness that the books had lead her to understand was normal for a person with Alzheimer's disease. She reported that her husband would try to do something many times without becoming agitated. Another caregiver found it unusual that her husband would mention his poor memory as she believed it was very unusual for people with Alzheimer's to recognize their memory loss. This woman also was amazed that her husband seemed to be sleeping more as the disease progressed and not less, again as she believed decreased sleep was the normal course for the disease. These examples are presented as further evidence of the amount of time and energy caregivers spent thinking about their situation and trying to understand it.

Caregiver's Reactions to Diagnosis

The caregivers' reactions to the diagnosis were predominately cognitive reactions. These reactions are discussed in this section on the caregivers' cognitive reactions for this reason.

Delay diagnosing. The caregivers' reactions to the diagnosis of a mentally debilitating disease were varied. Some caregivers seemed to encourage a delay in obtaining a diagnosis while others indicated distress at not having a diagnosis soon after noticing that the older person's mental capacities were slipping.

> I sheltered him for a long time before I took him [to the doctor] because I thought "oh, we'll look away and I don't want anyone to know." And even after I had the diagnosis, I didn't tell anybody, not anybody, for at least six months afterwards and then I started telling one or two friends... It's just something that's hard to accept at first and I suppose there's been that stigma of a person with a brain problem. I don't really feel that stigma now, I don't think I did then, it's just that you don't want people to

> know that your husband is no longer the same person he used to be or no longer capable of doing the things that he used to do. You try some how to protect or shelter him. [f1:993-1017]

In the study, only one caregiver indicated that she felt that her mother's cognitive difficulties were related to normal changes of aging. This older woman had not had a medical investigation completed of the changes to her memory and ability to make judgements. At the time of the interviews, this caregiver had decided not to seek medical intervention for her mother's condition. Some sources (Mace & Rabins, 1981; Flitterman & Fulmer, 1986) recognize this approach as a type of denial.

Relief. For some caregivers and family members there was relief when the diagnosis was finally made. One caregiver said that her son was relieved because he felt that his father didn't care about him because he didn't seem to listen when he talked and the son had to repeat things over and over. Knowing the older person had a cognitive impairment made him feel relieved. The family found that they lowered their expectations of what the older person was capable of after a diagnosis was made. This helped everyone feel less frustrated with the older person.

Changes in approach based on diagnosis. For some of the caregivers, there was a difference in the approach they took with the older person before a diagnosis of cognitive impairment was made compared to the approach taken after a diagnosis. Before a diagnosis was made the caregivers had more difficulty maintaining a calm, gentle, reassuring attitude with the older person. After diagnosis they seemed better able to use their cognitive processes to help them develop more effective actions to take with the disoriented person.

> Oh, before it was diagnosed, he used to maybe take out the garbage and then immediately come right back into the kitchen and say, "Where is it?" and I would maybe give some smart aleck answer "Well you just carried it out" or be a little bit snippy with him. But then, once it was diagnosed, if he did something like that I would say, "Oh, it's alright" or I'd say, "Oh, I already carried it out" or "it's already there" or just sort of pass it off. Once the diagnosis was made I just made a point of learning about the disease and knew that if you argued or made him upset, you just made him worse. [f1:376-393]

These cognitive reactions indicate another aspect of the thoughts caregivers had regarding their experiences. The knowledge that accompanied the diagnosis of a cognitively impairing disease process influenced how the caregivers thought about the older person's disorientation.

Relationship of These Findings to the Literature

No research was located which reported the detailed thoughts of caregivers regarding the causes of disorientation in the person they cared for. Resource books for caregivers including The 36-Hour Day (Mace & Rabins, 1981) suggest interventions such as keeping calm to reduce the likelihood of making worse the disorientation of the older person. Many of the factors that influenced the level of orientation of the older adults in this study have been described by others. The relationship of increased disorientation to lunar phases was one factor that was not discovered in any of the research reports reviewed. Future research projects might be developed which evaluate the generalization of some of the factors that the caregivers in this study found to influence the disorientation of the person they cared for.

The thoughts of the caregivers had impact on the actions they chose to use when interacting with the disoriented person. These actions will be described in the next section.

Figure 5. Section outline: Caregivers' actions toward the disoriented person.

- Maintaining a Calm Atmosphere
    - Suggestions
    - Be patient and use a quiet tone of voice
    - Answer concerns
    - Physical contact
    - Limiting stimuli
    - Flexible
    - Take a break
    - Ignore
    - Guarded emotions
    - Not sharing plans
    - Staying one step ahead
    - Remove things
    - Being careful in approach

- Situations where Dignity was not Given Priority
    - Safety
    - Older person's daily needs
    - Yelling

- Specific Actions
    - Continual assessment
    - Reorient
    - Change the subject
    - Change the environment
    - Use mother tongue
    - Use reason
    - Use repetition
    - Explain things
    - Modify the content

- Relationship of These Findings to the Literature

Caregivers' Actions toward the Disoriented Person

Although the focus of this thesis was the reactions of caregivers to the disoriented person during episodes of disorientation, the caregivers shared many of their reactions to things that the disoriented person did that could not be defined specifically as disorientation to any of the usual spheres of person, place or time. As the caregivers' responses to both these stimuli were generally similar, they will be presented together.

The caregivers' actions can be divided into a number of categories of approach. Maintaining the older person's dignity was an important approach taken by the caregivers which has been discussed in the first section of this chapter. Maintaining a calm environment was identified by all caregivers as an important approach to caring for a disoriented older person. Details of how caregivers accomplished this will be described first followed by some of the specific ways caregivers approached the disoriented person.

Maintaining a Calm Atmosphere

Remaining calm was one of the most important techniques used by the caregivers to interact with the disoriented person. The following quotation from one of the caregivers expressed this well:

> You can't have a short fuse around an Alzheimer's patient. It's better just to go out in the yard and walk around or go to the washroom and close the door and sit quietly for five minutes rather than to turn around and scream at them. Because they have no idea why you're screaming and you're just upsetting yourself more because they're perfectly calm. They pick up their emotional vibes from you, so the calmer you can keep yourself, the better it is. [bl:829-843]

Suggestions. Caregivers maintained a calm environment in many ways. In situations where the disoriented person was behaving in a bizarre manner, they made suggestions that helped keep a peaceful environment. The caregiver in the following quotation is responding to her husband who tried to put on one of her blouses over his own:

> Like the event with the blouse, I just said to him, "I wouldn't put that on if I were you. I think that it's going to be too small." And he said, "oh" and he just dropped it then. But I find if I can keep myself calm then he doesn't get as upset either. [b1:326-333]

Suggesting seemed to be a way to maintaining peace in the environment by not further upsetting the disoriented person.

Be patient and use a quiet tone of voice. Caregivers mentioned other effective methods of maintaining a calm environment. They found that speaking quietly to the disoriented older person, especially after disagreements, was a useful method of maintaining a calm environment. The caregivers spoke of the amount of patience this required, but emphasized the benefits of not losing their patience. Some caregivers prepared themselves to be calm for the older person. One woman reported that when her husband came home from the day program she had to slow herself down so that she could be in "low key" when he arrived. The Alzheimer's disease had impaired this man's communication abilities and he took a very long time to explain things to her. By slowing herself down before he arrived, she was able to sit still and be patient when he'd tried to tell her what he'd done that day [f2:1339-1342].

Answer concerns. Another way one caregiver kept a calm environment for the disoriented person was by answering the disoriented person's concerns and not trying to stimulate them to think of other things.

> It's almost like they slip into another dimension or a world. They're in a world all their own and it's hard to break into that world. You're trying to bring them back and sometimes you can't. Sometimes you just have to accept that and just say, "yes, [your socks] are in the drawer." [gl:757-766]

Physical contact. If the disoriented person were feeling frustrated or upset, one caregiver relayed that she would hug her mother until she could feel her settling in her arms. "It calms her somehow," she said [hl:305-309]. Sitting quietly with the older adult also had a calming effect.

Limiting stimuli. Limiting the amount of stimuli the older person received was a technique caregivers used in maintaining an equilibrium in the person they care for and thereby maintaining their calmness. One caregiver said:

> I'm in the habit of knowing I have two hours with Dad if I'm in a crowd. If you take him to [the mall], he's oriented for two hours and then flooding, as it is with strokes, he just gets over stimulated and then you may lose him. He may get agitated and just say, "have to go home, have to go home" and then he may be disoriented by the time you get home. He may even say, "This isn't where we live"... So I always look at two hours. [al:452-467]

Flexible. Caregivers agreed that being flexible and being able to alter plans to keep the older person from becoming upset and consequently disoriented was constantly on the minds of the caregivers. Caregivers recognized that when they failed to be flexible, they would find themselves with difficult situations to manage.

Take a break. When the caregiver did not feel she was able to remain calm, she would leave the situation, if possible, to allow herself a chance to recompose herself and to avoid responding in a negative fashion to the disoriented person.

> From the information that I've got they strongly urge you not to raise your voice or for you not to act upset which is the hardest thing ever to do all of the time. Like sometimes I just have to walk out of the room in case -- and take four or five deep breaths and get a hold of myself before I can go back in and handle the situation. [b1:313-322]

Ignore. Letting it go and ignoring the disoriented comments were techniques used by the caregivers to keep the person they care for from becoming upset. One caregiver spoke of how her husband mistook her for someone else she let it pass over and didn't make an issue of it.

> It was just something that I'd been expecting and it was just a momentary thing. It passed over and I didn't make any issue out of it. I don't ever argue with him. If he says "It's raining" or "It's not raining" I don't tell him otherwise. We live a very quiet style of life so that I don't agitate him or aggravate him and he's much easier to live with then. [f1:337-357]

At other times though, if the caregiver felt she didn't have the energy to put into explaining reality to the disoriented person, she would let it go:

> ...sometimes if I'm tired I really can't be bothered. I let it go. ...There's no way that I'm going to pick it up every time. No way. I mean she's forgetful enough. I really don't need to push them so many times every day. [c2: 222-237]

Guarded emotions. To keep the older person from becoming upset, some caregivers found they were guarded in what they told the older person and in hiding their emotions from the older person. In their efforts to remain calm in front of the older adult, caregivers reported that they tried very hard to keep their emotions hidden from the person they cared for. The following quotes illustrate this technique:

> I used to go in to my moms and one day I was so upset I just went in and I said, mom don't say anything, I just came to have a good cry. Cause if you cry around my husband, he gets upset. [b1:454-458]

> I still get angry when I'm here at home making all these phone calls for all these services so that she can be comfortable and yet she's refusing them. Then I still get angry but at least I get angry on my own here. I don't take it out on her. So I know that she's not being upset by me being upset and it's not a positive emotion. It's not a good thing inside me. [e1:832-844]

In the same way that caregivers hide their feelings from the older adult, the caregivers also refrained from talking if they felt they would not be able to respond calmly or when the disoriented person was not receptive to them.

> It's very difficult not to argue. It's very, very difficult not to argue. You have to just sort of let her go on and say very little. I find that I don't talk to her very much because I know she is always going to argue so I just don't say very much. [d1:311-332]

Not sharing plans. Another way in which caregivers avoided upset was by not preparing the older adult too soon before an event was to occur. For instance one caregiver said:

> Sometimes I know a month or two ahead that we're going to do something on a certain date but there's no use in telling him because he'll forget and also when he does remember, he's stewing and fussing about it. [f1:1512-1518]

Keeping details of such outings away from the older person helped maintain the atmosphere of calmness. Caregivers also did not share plans of activities they had made for themselves for the same reason of trying to keep a calmness.

Some caregivers determined that they needed to keep some part of their lives secret from the older adult to avoid upsetting them. One caregiver kept two calendars, one by the phone with appointments that she felt were suitable for her husband to see and another calendar in her desk for appointments that she is "counting on her own" [f1:1492-1503]. Another caregiver stated:

> Respondent: It just amounts that you don't tell her always where you're going.
> Interviewer: So you are having to keep part of your life a secret?
> Respondent: Yes, yes that's exactly what we [the caregiver and her sister] are doing. You have to or she's, you know, because she is jealous. [d1:363-373]

<u>Staying one step ahead</u>. Caregivers spoke about staying one step ahead of the older adult. They would try to anticipate possible problem situations and work out solutions to these problems in advance. Caregivers also planned activities for the older adult, another example of thinking for the older adult.

> Well you sort of have to plan the next move or try to analyze what's going to happen in this situation before it happens so that maybe you can avoid it. [d2:1239-1243]

<u>Remove things</u>. Another way in which caregivers avoided confrontations with the older adult was by removing or hiding objects that the older person used which caused problems for the caregiver. For instance, one caregiver reported hiding a piece of clothing which she felt was inappropriate for her mother to wear, hoping that she would forget about it. Another caregiver indicated that her husband regularly put his wallet and his keys in unusual places and she found

she was spending a considerable amount of time searching for them. Eventually she simply failed to mention the wallet or the keys to him after she had found them one day and he stopped carrying them and stopped asking about them.

Being careful in approach. Caregivers were careful in their interactions with the older adult so that they avoided difficult situations:

> I think it is one of my little fears in the back of my mind that I have to be awfully careful not to do something that might aggravate him... and I would feel badly if I thought I had done something to aggravate him when if I had been more patient we could have avoided it. [f2:1925-1938]

Unfortunately, remaining calm was not always possible for the caregivers. There were times caregivers caught themselves reacting with panic to the disoriented person's panic. In one instance, one caregiver said that when, during a drive in the country, her grandmother became suddenly agitated and wanted to go home, the caregiver found that it was hard not to "sort of hit the gas and get home faster" [group & gl:751-755].

Maintaining a calm environment was a general type of action taken by caregivers to help the disoriented person stay as oriented as possible. A calm environment avoided upsetting the older person and resulted in a more easily managed situation for the caregiver. In addition to keeping the environment calm, caregivers used other actions in their interactions with the older person.

Situations where Dignity was not Given Priority

Maintaining the dignity of the older person has been described previously in the section of the chapter entitled Perceiving the Older Adult as a Person (p.43). There were occasions though where caregivers indicated they did not treat the older person with as much calmness and dignity as they did at most times.

Safety. Issues that concerned the safety of the older person were assessed to be of sufficient importance to warrant confrontation with the older person. Safety concerns fell around the following: fire resulting from the stove being left on; wandering away and getting lost; falling and breaking a hip or hurting themselves in some way; choking on food; and getting into an accident while driving. It seemed that safety issues were ones that usually prompted the caregivers to risk the anger of the older person so that measures could be taken that would ensure that they remained safe. For instance, taking keys away form a driver, insisting that food be cut into small pieces and placing the older adult in a long term care institution to avoid the hazards of fire.

Older person's daily needs. Sometimes caregivers found themselves in a power struggle with the person they cared for regarding their need for rest and exercise. Caregivers reported that when gentle suggestions failed to convince the older person to carry out a direction, such as lying down for a rest, they would become "rather cross" with the older person to ensure the older person would comply.

In addition to becoming cross, there were two other ways caregivers would try to get the older adult to do something: by trying to get the older adult to imitate them and by almost tricking them into doing it. In the first instance, if the caregiver wanted the older adult to lie down, she might say:

> I feel kind of tired. I'm going to take a magazine and lie down a bit on the bed and have a rest. Why don't you lie down and have a rest too? [b2:241-248]

In the second instance the caregiver might find an excuse, like needing a loaf of bread, to "trick" the older adult into going for a walk [f1:1503-1512].

Yelling. Although caregivers tried hard to maintain a sense of dignity for the older person there were times that the caregiver found it difficult to be gentle with them. Their feelings of frustration and anger sometimes led them to respond to the older adult by yelling or becoming upset with them. One caregiver said:

> I was so upset because her medications that day were all screwed up and for the last week and something else went wrong and she was complaining about home care and that sort of thing and this thing was just, I couldn't handle anymore. I just felt hopeless and useless and like I'm spinning my wheels and I'm not getting anywhere and I got upset. I got angry at her and I yelled at her but I just, I knew what I was doing, this is wrong, this is wrong to do this because she's sick. She can't help what she does and sometimes she doesn't know what she does but why am I getting mad? I just got mad and I yelled at her, so that's what happened. [e1:698-718]

Caregivers recognized that this was not an effective response and admitted that sometimes they could not stop these emotional outbursts. They reported apologizing to the older person afterward.

Specific Actions

In addition to the general approaches of caregivers of maintaining a sense of calmness and protecting the dignity of the older person, there were other more specific approaches taken by the caregivers as they cared for the older person. These approaches will be presented next.

Continual assessment. Caregivers assessed situations constantly to determine the best response to make to the disoriented person. They assessed, for example, whether or not the time was right to reorient their family member or whether they should let the disorientation go without notice.

> It's like you almost have to feel them out. Take each moment and grab the good moments when you can to stimulate them but when they are really confused or agitated there really is no point -- where it's worse for them. [group/h:292-298]

Reorient. During episodes of disorientation to person, place or time, caregivers used a variety of responses. One approach used by caregivers was reorientation; presenting reality to the disoriented person. The decision to reorient was based on many things. If the disoriented person asked for information or if the caregiver felt that the disoriented person would benefit from having the information, then they reoriented or explained the situation to the disoriented person:

> ...every time I went up I would spend a lot of effort on that and it really was not effective so I eventually just, I let it ride. If she asks, I try and reorient her. [gl: 1178-1182]

> ...she'll look at pictures of the family... and you know she's getting upset because she knows she should know and that's when I [say], "yes, that's your son Bill." Then, quite often, she'll go through sort of our little repertoire and it stimulates enough that she feels like she belongs, that there's a connection. [group/g:338-356]

The decision to reorient was also related to how easily the disoriented person accepted the presented reality and if the end result would make the caregiving role easier. For example, one caregiver said, about keeping her husband in bed at night when she heard him get up:

> ...sometimes he's dressed or half dressed before I get in there but as soon as I say, "this is 10:00 at night. I'm just getting ready for bed," he says "okay" and gets back in [to bed] again. [f1:470-479]

Caregivers tended not to try to use reorientation when the disoriented older adults were disoriented to the caregivers' identity or to their own self identity, such as when they failed to recognize him or her self in a mirror. In these cases, actions such as changing the environment were used. For instance, one caregiver put a blind over the mirror when her mother would not use the toilet because she thought her reflection in the mirror was someone else watching her.

Change the subject. When the older adult seemed to be getting particularly upset during an episode of disorientation, caregivers would try to change the subject. For instance:

> I try to change the subject as quickly as I can and that particular evening out there I even resorted to bringing out the Sears catalogue and trying to look at dresses or blouses or anything but it just didn't work. Nothing seemed to work. [d2:475-482]

Change the environment. Caregivers would also change the environment by taking the disoriented person someplace else to try and alter a mood or train of thought that is disturbing to the caregiver. Another example of changing the environment was described by one caregiver who set up her husband's routine activities in a more familiar location when he was no longer able to find his way to one part of the house.

Use mother tongue. When the disoriented person was disoriented to people in the environment and was very withdrawn the caregiver sometimes tried speaking in the mother tongue of the disoriented person. This technique was successful in getting a reaction from a withdrawn individual, but not necessarily in helping him or her to recognize caregivers or become more in tune with surroundings.

Use reason. Some caregivers used forms of logical reasoning to explain things to the older person. One caregiver used the calendar to reorient the time disoriented person. This method was not consistently successful in altering the older person's perception of situations.

Sometimes caregivers try to prove to the disoriented person that the idea they seem to be stuck on is not true. For instance, the husband of one of the caregivers felt that when she was away from home, she was not at work but was someplace else. The woman who cared for her husband while she was away told her that he felt that she was having an affair. In an effort to prove that that the caregiver was truly at work the hired caregiver brought the older adult to the family caregiver's place of employment to show him that she was where she said she would be.

Use repetition. Caregivers found that they needed to repeat themselves over and over to help the older adult understand the message. Coming to the realization that repetition was unavoidable was challenging for some caregivers.

> I should just let some of these incidences just sort of roll off my back. Just think oh she forgot, I'll just remind her and I'll have to do that every day. It's just something you have to accept. You've got to do it every day. [el:566-573]

Explain things. Caregivers explained things to the older person at times when they anticipated that the older person seemed more likely to remember the discussion. One caregiver explained to her mother every morning that there was no need for her to prepare a meal for that evening as the caregiver was either not going to be home or would prepare the meal herself when she got home from work. She anticipated that her mother would ruin the food if she cooked it because of her "poor judgement" around the proper way to prepare food. This explaining helped her avoid discussing her mothers inability to cook properly and allowed her the vehicle of being gentle with her mother.

Modify the content. Information was presented in a way that would allow the older adult the best possible means of understanding and comprehending the message. Often this entailed presenting the message in a very simple manner. Sometimes, the caregiver would edit what they would normally talk about in conversations to assist the older adult's involvement in the conversation. As one caregiver said:

> You're not consciously aware of that [editing what you say]... but I wouldn't go into great detail... I try and actually stick more to topics of like what I've heard from my parents or if they they've written me... I try to stick to family members that she knows. I don't bring in a lot of

> stuff from the outside because it really mixes her up. It's easier just to talk about immediate family.

Although there were a number of specific actions taken by the caregivers as they interacted with the disoriented older person, these actions can be generally grouped into two categories: those actions that maintain a calm environment and thus avoid upsetting the disoriented person, and those actions which emphasize the dignity of the older person. The later of these two general categories was discussed in the first section of the chapter. The former has been discussed here.

Relationship of These Findings to the Literature

Again, no studies were found that provided details of the actions taken by caregivers toward the disoriented person. Mace and Rabins (1981) make recommendations regarding maintaining a calm environment based on their experience and interviews with other caregivers. Some of the specific techniques used by these caregivers to change the environment are also found in Mace and Rabins' The 36-Hour Day and Flitterman and Fulmer's Understanding Alzheimer's Disease: A specific guide for families (1986).

Quayhagen and Quayhagen (1988) found in their correlational study of coping with the role of providing care to an Alzheimer's patient, that mental stimulation of the Alzheimer's patient was not correlated to measures of caregiver well-being. The researchers hypothesized that there might be such a relationship as caregivers had indicated a desire to do something to help the person with dementia and mental stimulation was seen by the researchers to be such a method. The daughter caregivers and husband caregivers in their study reported feeling that such efforts were futile. The efforts of the caregivers in this study to provide mentally stimulating activities for the older adults were not compared to the caregivers' well-being but nevertheless these caregivers found it important to provide such stimulation at least on occasion. The perceived benefits to the older person were the motivation to provide this stimulation.

Figure 6. Section outline: Reasons why caregivers provided care.

Motivation from Within

Motivation from the Older Person

Motivation from Others

Relationship of These Findings to the Literature

Reasons why Caregivers Provided Care

Caregivers' reasons for caring for the older person were important to explore in this study as their motivation to provide care shed light on the impact this caregiving experience had on the their lives and was related to their individual methods of coping. The caregivers' motivation to care seemed to be a key component needed to describe how the caregivers made their sometimes intolerable situations tolerable. This topic also provided a link to understanding how the caregivers dealt with their negative feelings toward the older person.

The reasons for caring provided by the caregivers were varied and can be divided into three major categories: a) motivation originating from within the caregiver; b) motivation stimulated by the older person; c) and motivation stimulated by others, such as family. Although explanations given by individual caregivers overlapped these categories, each will be presented separately.

Motivation from Within

For some caregivers, the motivation to provide care for the disoriented person came from within themselves. One caregiver said:

> I don't feel it's an obligation. It's something that I have a drive, a need to do. I feel it's the only thing to do. The right thing to do and anything else -- I couldn't live with. So it's an internal drive more than just an obligation... I do it because it can't be any other way. [e2:774-784]

A number of caregivers spoke of how they felt they had to provide care to the older person so that they would avoid feelings of guilt or remorse in the future.

> It's just that I project into the future and it would really bother me to look back once Grandma passes away to say, I had the opportunity to make a difference or to make her last years as familiar and family oriented as I could and I didn't. And that part would bother me, the guilt. [g2:583-591]

For some caregivers, it just felt right to be providing this care. There was a sense of moral obligation for some, but others denied this feeling and emphasized that the desire to care was motivated by a sense of feeling that caring was the right thing to do.

> I get a really good warm feeling inside that I'm doing something right and that it -- to see her content and happy, clean, her daily needs met. That makes me feel really good inside. [h2:1217-1222]

Motivation from the Older Person

Another category of reasons why caregivers were motivated to provide care centred around a stimulus provided by the older person. Concern, love and respect for the older person as well as a desire to see him or her happy, and thriving, with a high quality of life was the motivation for caring provided by some caregivers.

> There's a real genuine feeling of accomplishing something or of mattering. Doing what really matters. Like doing something worthwhile to her because it really is. It is important to her. [g2:1275-1280]

For some caregivers, the motivation to care evolved from a feeling of reciprocity for the love and caring that had been provided to the caregiver from the older adult.

> I know that the person that I love, which is my mother, who's taken care of me and been a wonderful mother most of my life, I know she's going to be taken care of, that she's being looked after, that she's living the best life she can at this point. Those are the benefits. That I'm happy and I'm contented with the fact that I'm doing the best I can to keep her happy.... and because she's family. [e2:740-751]

Maintaining the family unit was a strong motivating force for some caregivers: "I'm holding my family together and doing what I think is right" [f2:622]. The feeling that family is worth maintaining, for these caregivers, was also tied to the feeling that the caregiver and older adult had shared a good relationship before the older adult became cognitively impaired. The wives of the older adults indicated that they cared for their husbands because they knew that if it had been they who had been affected with the disease, their husbands would have looked after them.

> If I were the one that was sick, Jack would do his best to look after me and it just never occurred to me to do anything else except to keep on living with him, looking after him. [f1:582-587]

For some caregivers, it was important to provide care so that the older person would not have to be placed in a long term care facility. Some felt that placement would decrease both the quality of life and life expectancy of the older person. Despite feeling that placement was not the best alternative, caregivers indicated that they recognized that placement was likely an option they would one day have to consider. In the meantime, they indicated that they felt they were doing their best at the time and this sense of doing one's best was motivation in itself to continue caring.

Receiving thanks from the older adult for the care provided was a motivating experience for caregivers. Although few of the caregivers received verbal thanks from the older adult for their care, the women were able to identify ways in which the older people expressed their thanks. Caregivers interpreted the older adults' tender looks and touches as the thanks that they were no longer able to express verbally.

Receiving thanks helped the caregivers view the older person as part of the caregiving/receiving team. Some caregivers felt that they were working with the older adult to develop the best method of providing care. As one caregiver said:

> I feel more comfortable with the role. I don't feel like I'm imposing my will on her as much as I was at the beginning... I feel like now it's more a team thing, that I'm part of helping her. And she looks upon it, I think, as that too. [gl:1470-1482].

Tied to the feeling that caregivers had about feeling that they were part of a team with the older person was the sense the caregivers had that there was great trust between them and the person they cared for. This trust was exemplified when caregivers felt that the older adult was not suspicious of them over the way they dealt with financial arrangements, or other legal activities. Trust was identified as one reason why the older person would display anger or depression in front of the caregiver and not when in front of others. Although caregivers felt it was difficult to be the recipient of these feelings, at least one caregiver found pleasure in the fact that the person she cared for trusted her enough to display such emotions. Perceived trust in the relationship added to the caregivers' motivation to provide care. Actions that caused the caregiver to question the amount of trust the older person had for her strained the caregiver's motivation to provide care. For instance, when the older person would hide articles, one caregiver commented that she wished her husband would trust her more. Although she recognized that these actions were part of the disease process, they led to an increase in the caregiver's feelings of frustration. When the caregiver perceived that there was a sense of trust between older person and caregiver, motivation to care appeared to be high.

Another instance of how the older person motivated the caregiver to continue providing care occurred when the older person seemed to be able to "come through" and comfort the caregiver. These times were considered positive experiences and in a way helped the caregiver see the older person as they used to be; as caring, loving family members. Some caregivers felt that the older person developed even better inner sense concerning the caregiver's mood than they had before they developed the cognitive disorder. They seemed able to pick up whether the caregiver was feeling down or upset and sometimes would respond to them by saying something to the caregiver such as: "you'd better go have a rest" [group/h:1803-1807].

Caregivers spoke also, though, of how the older person seemed unable to consider that the caregiver needed breaks and rest from their role. It seemed to be more of the norm for the older adults not to recognize the needs of the caregiver than to recognize them. Caregivers spoke of constantly giving to the older person without receiving much in return. They described how the older person seemed to become more and more focused on themselves, on their needs and less on the people around them. When this occurred, caregivers felt increased resentment toward the older person with no reaffirmation of their motivation to provide care.

Motivation from Others

There were some instances where the motivation to care was stimulated by individuals other than the caregiver or the care recipient. For one caregiver, who provided care to her grandmother, the motivation to care was partially stimulated by her father's inability to provide this care himself. This caregiver also felt she was fulfilling a commitment she had made to her grandfather before his death that she would care for his wife when he died.

Relationship of These Findings to the Literature

A number of articles have examined the factors that influence a person to provide care for an older adult family member. Silliman, Earp, Fletcher and Wagner (1987) found in their exploratory study of 89 caregivers of individuals who had suffered a stroke that there were three main reasons why they took on the responsibility of providing care for their disabled relatives: 1) spouses saw this role as part of the spouse role; 2) it was a natural response; and 3) there was no one else to provide the care and without their care, the disabled individual would have had to go into an institution. These reasons are all validated in the responses given by the caregivers in this study.

Baldwin (1988) found that daughter caregivers of dementia patients provided care because of factors such as affirmation of close parent-child ties, the caregivers' perception of being needed, and as an opportunity to repay parents for providing them with care as children. These reasons were also identified by the caregivers of this study.

Finley, Roberts and Banahan (1988) have studied the motivators and inhibitors of attitudes of filial obligation toward aging parents. In their study, the researchers found that there was a greater emotional component to the filial obligations felt by daughters when compared to sons' filial obligations. Two caregivers in this study identified that there were differences in the way they, as women, felt obliged to provide care to the older family member compared to how the males in their family felt. These women felt that the males believed they had discharged their filial obligations if services were being provided for the older adults. The women felt obligated to make an effort to provide for the happiness of the older person as part of their filial obligation. The studies that describe the motivators of obligation to provide care for an aging relative validate the responses given by the women caregivers in this study.

Figure 7. Section outline: Impact of providing care on the caregivers' lives.

- Overall Impact on Caregivers
    - Life on hold
    - Roller-coaster

- Specific Impact on Caregivers
    - Energy level
    - Number of illnesses
    - Employment
    - Financial
    - Legal
    - Privacy
    - Information provider

- Changes to the Caregivers' Lives
    - Changes in other relationships
    - Changes in the caregivers' roles
    - Change in the relationship with the older person
    - Change in socialization
    - Change in focus, interests

- Positive Influences on Caregivers
    - Benefits
    - Increases knowledge
    - Personal growth

- Maintaining the Caregivers' Well-Being
    - Daily coping strategies
    - Taking holidays
    - Taking breaks
    - Forget about it
    - Day by day
    - Letting go
    - Others are worse off

- Relationship of These Findings to the Literature

The Impact of Providing Care on the Caregivers' Lives

Caregivers reported that many areas of their lives had been affected by the caregiving role they had assumed. In addition to some general ways the role impacted on the caregivers, there were specific ways the role impacted on them. These areas will be presented in this section. Some of the strategies used by the caregivers to address their concerns will be presented.

Overall Impact on Caregivers

Life on hold. Caregivers spoke often about the feeling they had that their lives had been put on hold by their caregiving role. This feeling arose for two reasons; one reason was the caregiver's inability to plan for the future because of the uncertainty surrounding the older person's future needs and the other reason was the caregiver's lack of energy to put toward moving on with areas of their lives which were unrelated to the caregiving role. It was as if caring for the older person became an "all consuming" role for these women.

> It's a terrible thought for me that when I haven't yet hit 70, that my life is sort of on hold. There's nothing I can do now. I can't plan to go anywhere, I can't plan to do anything. The house needs some new repairs because it is 23 years old but you don't feel like putting a lot of money in repairs on an old house if you're not going to be living here much longer. So there are a lot of things you that you sort of just keep, you don't do, but you wish you could do... I sure would like a new chesterfield but if I buy a new chesterfield, maybe by next year I'll be moving into a suite and it will be too big for that suite or whatever. [f1:685-711]

> I really feel that I don't have the energy. I can't even come up with ideas. I can't even come up with goals. It's almost like everything stopped. [el:993-998]

> I do have the odd evening when I'm feeling a little bit down and I think geez, these are my retirement years. I should be able to enjoy my grandchildren, I should be able to do some travelling. I should be able to visit some relatives in other places but life is on hold. I'm not free to do anything whether it be this afternoon at 2:00 or whether it's next week for two days or next year for a month's holiday. I can't plan anything ahead at this point. Life is definitely on hold. [f2:2177-2190]

<u>Roller-coaster</u>. Caregivers talked about how much they felt that their caregiving experience could be equated to being on a roller-coaster. The variableness of the disease process resulted in caregivers never knowing if the day, or even the specific interaction with the older adult was going to be a positive, effective, good, or bad one. Not being able to predict what would come next made the caregivers feel that they were on a roller-coaster. The woman who first mentioned the term "roller-coaster" referred it to her feelings as she suffered through the disappointments of various approaches to her mother's care not working out. In another section of the interview she indicated that she felt that she and her mother were on a roller coaster together: when her mother had a good day, she had a good day and when she was not feeling good, then the caregiver felt upset and uptight. [hl:820-831]

> H: When things are good, I don't think I'm frustrated. It's like a roller coaster (group agreement). When things are going smoothly then boy it's the best thing in the world, caregiving. But when things get rough, then you start being really frustrated. It really is a roller-coaster.
>
> G: The roller-coaster was great. That described it perfectly. [group:1542-1550 & 2274-2275]

One caregiver, who had been in her role for a number of years, could not identify with the ups and downs of the role that others saw in the term "roller-coaster." She said that their lives were very routine and she tried hard not to allow any variation as this helped her husband maintain his level of calm and therefore his care was easier. In a later interview this caregiver said that after much reflection she felt she understood the expression "roller-coaster" from a different perspective. For her, the caregiving experience was like being on a roller-coaster because she couldn't get off it; she saw the disease as "going on and on and you wonder when it is ever [going] to stop." [f3:189-217]

The caregivers' expressions, used to describe the impact the role had on their lives, were very rich. "Life on hold" and "roller-coaster" described for many of the caregivers two overall aspects of how their caregiving role impacted their lives. The following sections describes more specific details of how the role impacted the caregivers lives.

Specific Impact on Caregivers

Energy level. Caregivers mentioned frequently that this role impacted significantly on their energy level and on the amount of time they had. The drain of their energy level took two different forms. One form was the mental energy required to orient and lift the spirits of the person they cared for:

> It's a lot of energy when someone's confused or disoriented to keep trying to keep them with you and not sort of slip [g2:456-459]

The other form of energy draining was the physical demands of caring such as shopping or cleaning the older person's home as well as caring for finances and making appointments for him or her. These energy demands resulted in the caregiver feeling she didn't have energy or time left over for her own life tasks. One caregiver felt that she did not have the energy to dream of new goals for herself and she certainly did not have the energy to move toward accomplishing these goals. This lack of energy was also described by caregivers as they mentioned frequently how tired they were. For one caregiver, nightmares about losing her husband on an outing interrupted her rest. She said these nightmares were how her frustrations and fears came out.

Number of illnesses. A few caregivers spoke of the stress-induced illness they had suffered since assuming the caregiving role. One caregiver said that she rarely had time to eat her own meals she was so busy between working full-time and providing care to her mother. Another caregiver found that she had gained weight since beginning this role.

Employment. For the caregivers who were employed, their caregiving role impacted on them in a variety of ways. In one instance, a caregiver decided that she could not take a new job because it would entail moving to another city and would leave her mother without family support. Other caregivers felt that they did not have the usual amount of energy to give to their jobs.

> I'm finding that I don't work as hard at work as I used to because I need to have some energy when I come home and

> have to deal with the situations at mom's place. [el:581-587]

Some caregivers stopped working to provide full time care. One caregiver was planning to take early retirement, and although this was not solely to provide more supervision to her mother, she indicated that this would be easier to do when she was not working. Other caregivers continued to work although they found it difficult to combine their work and caregiving duties. One caregiver said that in order to have her days off work all to herself she would visit her grandmother on the way home from work. This proved to be an unsatisfactory arrangement as the caregiver had little energy to put toward trying to stimulate her grandmother after a day of work.

The impact of having to give up a job to care for an older family member introduced financial consequences for some caregivers. The solutions to these problems were unique to each situation. In one case, the money that had been spent by the older person's family on lodge fees was turned into an allowance for the caregiver to partially compensate her for having to give up her job to care for her mother. In another case, the pension of the older person paid for a nurse to care for him while his wife was at work. Without these arrangements, the caregivers indicated that the financial impact of caring for the older person would have been significant.

<u>Financial</u>. For most caregivers there were some cases where money had to be spent as a direct result of the caregiving role. For example, money was needed to pay for a taxi to take the older person to a day program, or to pay for relief personnel to provide respite

care. In another case, a caregiver did not receive regular sums of money from her mother for room and board because the older person failed to remember to pay her. The caregiver did not remind her mother in an effort not to embarrass her.

Legal. There were legal responsibilities that impacted on the caregivers' lives as a result of their role. Many assumed power of attorney for their relative. For one caregiver assuming this role put her in an awkward situation with other family members who resented her control of the older person's finances.

Privacy. Caregiving impacted on the caregiver in the amount of privacy she had. Making phone calls and taking showers were some of the activities mentioned by caregivers as being difficult to do at a leisurely pace because of the need to supervise the older adult. The need to share living space, including negotiating with the older person the amount of television that they watch was irritating for one caregiver. Having privacy to entertain friends without the older person present was difficult for caregivers as the older person would often end up being the centre of attention, leaving the caregiver unable to focus on the guests.

Information provider. For some caregivers being closest to the older person resulted in their also having to assume the role as "go between" for the rest of the family. This role included keeping family members informed about the older persons' condition through letter writing and phone calls. One caregiver identified another aspect of this role which she called "running interference" for the older person. This aspect of the role included trying "to protect the older person from family members." For instance, when the older person said something offensive to a family member, the caregiver spent time trying to explain to the offended family member that the older person did not say such things on purpose, thus saving the older person from the anger of the family member.

Some of the specific ways the caregiving role impacted on the women's lives have been discussed in this section. In the next section, changes described by the informants will be presented.

Changes to the Caregivers' Lives

Changes in other relationships. The caregiving experience resulted in alterations being made to other relationships in the caregivers' lives. Married caregivers who provided care for a parent indicated that their husbands often "received the short end of the stick." One caregiver was amazed that her father's sleeping pattern had changed since his stroke from being a night owl to going to bed early:

> The thing that is good about salvaging something for Jim is that Dad always wants to go to bed at 7:30. That's the thing that has changed. It's amazing -- it's almost as if God said, "hey, you need a marriage and a father too." [a1:1010-1017]

Caring for both teenage children and an older person with a cognitive impairment resulted in many stresses for one caregiver. The arguments between grandmother and son were very difficult for the caregiver to take.

Changes in the caregivers' roles. Caregivers spoke too of the need to alter roles previously assumed by the older person. As mental abilities declined, caregivers found themselves assuming more and more responsibilities for tasks that had previously been shared, such as shopping, banking, decision making, and household security. One caregiver spoke of the hardest day in her life as being the day she had to take away the car keys from her husband because he was unsafe to drive.

Caregivers spoke of feeling that the roles between them and the older adults had been changed; for example, daughters were now acting as parents. For one caregiver this role change resulted in her feeling sometimes that she disciplined the older adult, a situation she tried not to have occur. There was sadness in the caregivers' voices as they described losing the relationship that had once been between them and the person they cared for.

> She has endearment terms that she used to say a long time ago. She doesn't say them much anymore... I'm not her child anymore, but her caregiver now. A different role. [e2:850-858]

For the wife of a previously strong, independent man the change in their roles was especially hard as she had to assume more and more responsibility for the running of their lives. The increased responsibly of being in a caregiving role resulted in caregivers having to consider even things like when to take holidays as they now had to contemplate how the older person would survive without them.

Change in the relationship with the older person. The sense that the caregiver had lost a close friend in the older person resulted in acute feelings of loneliness for some caregivers:

> We always did everything together and he could almost read my mind without me having to verbally say anything -- and

> you just kind of lose that togetherness.... You lose the companionship, you lose your best buddy. [b1:243-256]

> What I felt when she had her stroke last year, and what I felt since then, was that she has always been my solid foundation to my life. When this all happened, I felt like my foundation for living had just suddenly crumbled and it's slowly disappearing and I'm wondering if I can survive without it. [e2:914-923]

Some caregivers spoke of feeling that the cognitive changes in the older person made them feel that this was a stranger they were caring for and as a consequences they felt they had already lost the person they knew before the disease affected the older person's cognitive abilities.

> This person that I'm living with is not really my husband. It's a stranger I'm living with most of the time... Each day he's getting a little worse. He's certainly not getting ant better. So each day he's becoming less and less like my husband, more and more like a stranger, so at some point you really have lost your husband, but you can't bury him. It really is like a never-ending funeral... It's hard to say when it is you've completely lost them because some days out of the pure blue sky there's a halfway decent conversation or you're glad to be with that person again but it's such a fleeting thing that it really is a never-ending funeral. [e2:2022-2051]

<u>Change in socialization</u>. For some caregivers, their situation necessitated a change in previous social contacts resulting in a feeling of isolation. Not being able to leave the older person unattended meant that caregivers could not attend as many social functions. For spousal caregivers, this was sometimes exacerbated by feeling they did not want to attend social functions alone. Many of the caregivers commented on the feeling they had that the friends that had been part of their lives before the older person became ill,

had stopped making contact with them which resulted in great feelings of isolation.

> I mean it's a terminal disease and it's also a mental disease and I think those two things your friends can't stand. They don't know how to handle it so... people just stop coming. ... Your friends just drop off and people do not drop in and they don't phone. [f1:1630-1650]

Change in focus, interests. One caregiver found that since she started caring for her grandmother, her focus of life had shifted considerably. She felt that her friends did not relate to her new role. She felt uncomfortable discussing with her friends the anecdotes of her grandmother that she found amusing. Socializing with her peers was difficult as she was not able to maintain the same interests as they did. Common ground for discussions were few. This lead to a sense of isolation for her. Other caregivers commented on this difficulty as well. One woman said that although she does like to hear about her friends grandchildren over lunch, she really appreciates being able to talk about her husband for a few minutes because he is all that she is living for right now.

These changes described by the caregivers provide additional insight as to the impact the role had on their lives. The caregiving role did also have positive aspects for the caregivers. These will be detailed in the following section.

Positive Influences on Caregivers

The caregivers identified some benefits for themselves as a result of their role. They also indicated that they had to learn in order to fulfill their role as caregiver. This learning, and the personal growth that occurred as a result of their caregiving experience, have been categorized as additional ways in which the role of caregiver impacted on the women in the study.

Benefits. There were some benefits of caring for the older person identified by the caregivers. Some caregivers found that the older person was company for the caregiver. In one case the older person was filling a void in the caregiver's life that resulted from waiting to adopt her own child. Another benefit for one caregiver was the opportunity to stay at home and not work outside of the home. She felt that she had missed this opportunity by marrying a man with grown children. This was her chance to be "Susie Homemaker." For another caregiver, her caregiving role included spending a considerable amount of time encouraging the older person to discuss memories of the past. This allowed her to learn more about the family history that she otherwise felt she would not have spent time investigating.

Increased knowledge. Caregivers who provided care for a person who had been given a diagnostic label, for instance Alzheimer's disease or stroke, spent time learning about that disease process. Caregivers learned from books, other caregivers and from experience. The caregivers in the study who had nursing backgrounds spoke of relying and building on this knowledge to provide better care for the older adult. Examples of how nursing knowledge was used were found in the measures taken by the caregivers to ensure adequate skin care or methods of communication appropriate for the sensory changes of the older person, or appropriate for their disease process. Appendix

G includes more data from these informants regarding how their experiences of providing care for a family member influenced their current nursing practice and how their nursing backgrounds influenced the manner in which they approached their roles as family caregivers.

Personal growth. Caregivers spoke of the amount of personal growth they had experienced as a direct result of their caregiving role. Learning patience and control of anger were two examples of how caregivers felt they had grown as individuals. Discovering that they had more strength to deal with the stresses of caregiving, than they previously suspected they had, was another example of their increased self awareness. This increased awareness of abilities was described by one caregiver as one of the benefits of being in this role.

Maintaining the Caregivers' Well-being

There were various ways in which caregivers maintained their well-being as a result of the impact the role had on their lives. These strategies will be detailed in this section.

Daily coping strategies. Caregivers spoke of the variety of ways in which they dealt with the stresses of providing care. Maintaining other interests, such as gardening, helped one caregiver ensure that her life did not become completely focused on the older person she cared for. One caregiver realized that writing some of her thoughts in the diary supplied for the research project helped clarify her thoughts and resulted in helping her cope better with her feelings. Sewing, knitting and listening to music were other forms of diversion that helped the caregiver maintain a sense of balance in her life. Prayer and a strong religious faith were the major sources of support and coping for some caregivers.

> I pray. That helps me a lot. Prayer and I guess just do something that I like to do. My sewing is a big help as well because I can just get my mind on my sewing and music is my thing too. [h2:1260-1265]

> I sew and I like to sew but because of work I don't have the time. When I do sew I feel, I think, a lot about my problems, my triumphs or my goals and a lack of goals and lack of the opportunity to or what I should do about it. So I think about life in general and sometimes that makes me feel peaceful inside, that I'm actually trying to do something about it. Thinking effectively about it. [e1: 1201-1211]

Exercise was used by one of the caregivers as a means of losing some of the weight gained during the time the older person was living with her. This caregiver, and another, mentioned the stress reduction benefits of exercise. One caregiver found golf to be a form of relaxation for her. One caregiver realized that when she did not have other outside interests she was not able to give as much emotionally to the person she cared for.

Taking holidays. Ensuring that holidays were planned and taken away from the responsibilities of providing care helped some caregivers renew their energy and help with the ongoing task of providing care on their return. Other caregivers indicated that they too came to realize that they needed breaks from their role if they were to continue to provide quality care. One woman occasionally booked a week long respite bed when she realized that she was becoming "burned out." By using this service every couple of months she felt better able to continue providing care to her mother with patience and enthusiasm. She indicated that it took her quite a while to learn the signs of burn out in herself, but that now when she recognized the signs she was able to book her mother into the respite bed before she became over tired. Extreme tiredness, lack of patience and enthusiasm were the most obvious sign of her impending need for a break. Not all caregivers felt comfortable using long term care facilities though, for these breaks, so had to make complicated and often expensive arrangements to have private coverage so that they could get away.

One caregiver identified that it was during a holiday that she realized that she could delegate some of the tasks she was presently doing for her mother to other sources and thus reduce the overall burden on herself. She negotiated for the homecare nurse to prepare her mother's medication dosett and for the grocery store to deliver weekly supplies. The time away from her role seemed to provide some distance to allow her to reassess it.

Taking breaks. One caregiver identified that she needed a "little space" every once in a while. To get this space she arranged to have the hired caregiver stay later in the day so that she could shop on the way home from work. Going for a drive, a walk or finding someplace like the park that is quiet was found to be relaxing for one caregiver. Recognizing their need to do this helped the caregivers find time for themselves away from their caregiving tasks.

> I'm going to become very stagnant if I never have anybody else to talk to or never have any other noise around him. Then I'm going to be like he is. I won't be able to stand

> noise and confusion. And even now I found we live such a quiet lifestyle that if we get out in a crowd or to be in a noisy restaurant or whatever, I really do notice the noise. [f2:382-492]

Taking breaks was difficult for some caregivers to arrange even when they did have other family members they could ask to help. Some caregivers indicated that they needed to feel independent in their role, especially when it came to asking their children to help with the care of the older person. They did not feel it was fair to expect this of the children.

Forget about it. One caregiver found that she consciously tried to forget about the problems she had with her mother. She had a very busy life in addition to the role of caregiver and found that she did not have time to sit and dwell on these problems. For her, forgetting about the situation from time to time helped her continue in the role.

Day by day. Caregivers spoke of needing to take this role on a day by day basis to help them cope. They recognized that decisions regarding, for example, possible admission to a long term care facility would have to be made eventually, but felt that they coped best living each day as it came.

Letting go. At other times the caregivers felt they had to, at some point, just let go of that feeling of responsibility.

> I have to fight the feeling that I'm totally responsible for her happiness, for one thing. I mean if she chooses to be miserable and I've met every need that I could see, then that's her choice. That's helped. I've been able to kind of walk away a bit from that. [g1:633-644]

Others are worse off. Caregivers found that by remembering that there were other situations where people had troubles worse than theirs, they were able to find solace. For instance, one caregiver indicated that her small irritations with her mother seemed insignificant compared to the problems in families where drinking and abuse were common occurrences. Another caregiver felt that parents of handicapped children had a far worse situation than she was in caring for her mother because for those families a child was involved. For other caregivers, benefits in their situations were found by pointing out that the cognitively impaired older person did not suffer the pain of diseases such as cancer. For them, watching their family member in pain would be worse than the stresses associated with the cognitive disability.

Caregivers were also able to find relief in knowing that the symptoms of the person they cared for were not as bad as they had read about or knew of other cases. One woman felt lucky that her husband did not wander and another felt pleased that her husband did not use any electrical appliances so she did not have this safety concern. The fact that the older person was not belligerent or did not make accusations to the caregiver was seen as a positive situation for some caregivers.

Relationship of These Findings to the Literature

Many of the self help books written for caregivers of people with Alzheimer's disease have identified many of the same areas of impact that the caregivers in this study identified (Mace & Rabins, 1981; Flitterman & Fulmer, 1986). Some of these areas are the overwhelming feelings of tiredness, the financial implications, changes in roles and great sense of isolation from the rest of world. Further support of the data collected regarding many of the areas of impact on the caregivers' lives can be found in the self help books mentioned. Suggestions found in these self help books, on how caregivers might maintain their well-being, are similar to the techniques identified by the caregivers in this study. Arranging for respite care is one suggestion made frequently in this literature.

Figure 8. Section outline: Supportive and unsupportive situations.

- Categories of Support
    - Tangible support
    - Affective support
    - Informational support

- Health Care System
    - Supportive/unsupportive interactions
    - Respite care
    - Obtaining information
    - Identifying resources

- Admission to Long Term Care Facility
    - Preparing for placement
    - Reasons to admit
    - Ways of avoiding admission
    - Changing roles after admission

- Caregivers' Needs
    - Need for information
    - Need for instrumental help
    - Need for acceptance, respect and understanding

- Relationship of These Findings to the Literature

Supportive and Unsupportive Situations

The caregivers' interpretation of actions by friends, other family members and health care professionals that were considered both supportive and unsupportive will be discussed in this section of the chapter. The caregivers also provided valuable data concerning how the health care system impacted on them in their caregiving role, especially for the caregivers who had had to place the person they cared for in a long term care facility. Finally, the areas the caregivers identified as their "needs" will be explored as these identified needs summarize other aspects of support for the women.

Categories of Support

Support, as described by the caregivers, could be divided into three categories: tangible support such as supervising the older person so that the caregiver could go out; emotional support such as listening to the caregiver; and informational support such as providing advice to the caregiver. Examples of these are presented in the following sub-sections.

Tangible support. Tangible support like offering to care for the older person was seen as very supportive by caregivers. Hairdressers, neighbours, friends and family members were all identified as offering to supervise, and actually supervising at one time or another. Health care professionals provided supervision, as well, in the form of day programs, respite beds and permanent placement. It was seen as especially supportive when the health care system offered the services that were identified by the caregiver as being needed. For instance, for one caregiver this meant obtaining a permanent part time placement on the weekends for her mother. For another, this meant a physiotherapist coming to the home on a regular basis.

Two of the caregivers employed staff to care for the older person when they were out working themselves. The availability of this supervision was seen as very supportive by these caregivers. One caregiver employed women for both a night shift and a day shift. The night shift was added so that she could sleep without concern that her father would require her help during the night. For the other caregiver, the hired person provided not only supervision during the time she was at work, but was available to talk with the caregiver in the evenings and thus decreased her sense of social isolation. Having another person to discuss approaches to care was also advantageous for this caregiver.

Offers from friends to be available for supervision of the older person, to spend time with the caregiver or run errands for them were also perceived as supportive by the caregivers, especially when the offers were reinforced by giving the offered service.

> Another thing that's been a big help is having a friend telling me that "I will do 'something' for you regarding your mom. I will make the phone call for such and such a person. Tell me about what's bothering you" ... or "Can I get something for your mom today while you're at work?" That sort of thing is a big help. [e2:1077-1093]

Family members were considered supportive if they interacted with the older person and provided some supervision so that caregivers felt less alone in their role. Offers from health care professionals to take the caregiver on a tour of a long term care facility made one woman feel supported and cared for.

Offers that were not carried out were not seen as supportive, especially if the offer came from a family member or close friend whom the caregiver felt ought to be more available to help. Caregivers without family members to share the responsibilities of caring for the older person mentioned they missed having the availability of backup supports. Family members who did not involve themselves in the care of the older person were also generally considered unsupportive and caused frustration for the caregivers. The following quote illustrates this point:

> There are a few people that I know that I can call on if I'm desperate or if I'm really stuck but I also find that I sometimes can be down my complete list of seven or eight names and every one will have some excuse and after I finish my list I think, "Now I wonder if that was the legitimate excuse or if they just made it up?" Maybe I shouldn't doubt people, but you can't help but feel that way.

When help was received though, caregivers often ensured that the person offering to help was rewarded in some way so that they would continue to offer. One caregiver tried to arrange appointments for shopping trips with a widowed friend around a mealtime so that he could eat with them after the outing. She also tried to have some special treat prepared for this gentleman when he stayed with her husband on the evenings she went out. Another caregiver, who was actively sharing the role of caregiver with her sister, talked about how she protected her sister from her mother's anger as she knew that she needed to keep her sister available to help with her mother's care. These were examples of how caregivers took care of their supporters to ensure they continued offering support.

When the older person was institutionalized and family members visited the older person in hospital caregivers considered those visits supportive as they felt the burden of caring was shared and they could be relieved of the need to spend some time with the older person. It was considered unsupportive if family members did not visit the older person in hospital.

Affective support. It was important for the caregiver to not feel alone in her role as caregiver. Any one who made her feel that the responsibilities were shared in some way was identified as being supportive. Situations where the caregiver could see that others were in the same position as she was were also considered supportive. This was so because these group situations decreased her sense of isolation and feelings of being the only one in the world in this predicament. The Alzheimer's meetings were an example of this type of support.

Family members who showed appreciation for the care provided by the caregiver and respected their decision to provide the care were considered supportive by the caregivers. This was especially true of family members who did not, or could not, provide tangible support to the caregiver, for example in the form of visiting the older person. Unfortunately, in some cases it took the caregiver a considerable amount of time to believe the appreciative words of the other family members.

Caregivers also spoke frequently of the battles they had with family members who felt that the older person should be institutionalized while the caregivers felt a great need to continue to provide care at home. It was not seen as supportive when these family members would constantly indicate that the older person ought to be admitted to an institution.

For one caregiver, there was a feeling that not all family members trusted her to administer the finances of the older person. This caused the caregiver to feel angry. She felt that the rest of the family thought that she could do all the care but that they were not willing to put down on paper, in the form of granting her power of attorney, that they trusted her.

Respecting the caregiver for her decision to care for the older person at home and respecting her ability to make decisions about the care was considered very supportive.

> My brother was up last weekend and he encouraged me this time a lot. He didn't talk about putting [Mom] in [a nursing home] or anything. He said, "Sis, you've got to do what you've got to do." And he said, "I know when the time comes you'll know when Mom has to go in." He was very encouraging that way. And that helped me a lot.

Unfortunately the respect shown for the caregivers' judgment in making decisions had some aspects of a double edged sword. There was potential for the caregiver to feel abandoned in this role and feel very unsure of her ability to choose correct alternatives. In one case, the caregiver worried that she would not be able to distinguish between acute, curable illnesses that her father might suffer and illnesses that were an indication of his impending death. In the former case, she wanted to be able to take the appropriate steps to cure the short term problems, and in the latter case, she wanted to be able to provide a peaceful death without aggressive medical intervention. Caregivers responded well to situations where someone would reassure them that they were doing the right thing by providing care at home and when the situation arose that the older person had to be admitted to an institution, that this move was also the right thing to do. When family members ignored situations and failed to be involved in the decision making process regarding aspects of care of the older adult, caregivers felt unsupported.

> When I place [my husband] in a nursing home it will be my decision and [his children] will be quite happy to let me deal with it and that above everything else hurts the most because I know he was a good father and he did everything for his kids and it's like now they're kind of saying "oh well, you deal with it. I haven't got time." [b2:857-868]

There were other ways, though, that individuals were able to show support to the caregivers. Providing a diversion to the caregiver was important. One young caregiver indicated that she needed her friends to "help me get back into my world, my young world, rather than this old world" [e2:268-271]. Having lunch with a friend offered a diversion for some caregivers. One caregiver said that even if she is lunching with someone who was also in a caregiving role, they tried not to spend their whole lunchtime talking about spouses. "There'd be no pleasure if we didn't talk about something else" [f2:543-548].

It was considered supportive when family members would phone or visit just to see how the caregiver was doing. Indications that the person cared about the caregiver and wanted to know how they were doing, or wanted to give them a hug were perceived as supportive. Telling the caregiver that they were worried about them was also supportive if there was also respect for the caregiver's decision to care and tangible help for correcting the situation.

Talking and listening to the caregiver were the most often mentioned means of finding support in the caregivers' social network. They indicated that it was important to find somebody to talk to who understood the situation at home. Just having an opportunity to express thoughts and feelings was very important to the caregivers.

> The talks I've had with Mark and with my other friends, I was able to -- see I constantly seek understanding. I want to understand why I feel this way and what is happening because I feel confused when it's just me and my mom. I sort of need the opportunity to be able to talk to somebody so that I can clarify it in my mind. They can maybe help me clarify it. They can maybe help me see something I don't see. So through that process I've been able to identify what's going on. [el:1081-1096]

Talking allowed the caregivers an opportunity to get their emotions out. Unfortunately, some caregivers had family members who did not encourage this expression of emotion, leaving the caregiver with little opportunity to express their concerns and feelings of frustration.

> I'm sure if I lost it for a while and just couldn't handle [caring for dad], [my husband] would encourage that. So I can never let go. I can never show insecurity or just sound off. [al:1043-1047]

For the caregivers who did have a support system that encouraged self expression, the person listening to the caregiver was sometimes able to help the caregiver see her situation from another perspective.

Some were able to help the caregivers focus on more positive aspects of their lives. Some just acted as a sounding board for the caregivers, giving them an opportunity to hear aloud what they have been thinking. One caregiver said:

> My sister's been a pretty big help even though she may not get in [to town] often. She's a sounding board and the one to say, "Now, now. Just walk away from it. You've done the best you can. You're not responsible for her confusion." [g1:1597-1604]

Caregivers spoke of using humour in describing incidences of unusual behaviour to friends and family which helped them cope with the stresses associated with these behaviours.

> It isn't that I display much humour in front of him, but sometimes when I'm telling somebody else something he's done I have to make a joke out of it. If I didn't make a joke out of some of the stupid things he does then I could be pulling my hair out. So I think you have to have a sense of humour in this caregiving job. [f2:1266-1281]

One caregiver used humour to gain access to support from friends that she felt would not be receptive hearing her complaining.

> If somebody's been hurt, or is frustrated they will take it out with humour. I will tell funny stories about my mother and they, my friends, take that. I mean, it's not good me coming along and complaining. You soon get tired of complainers. So I say, "You never know what my mother's done now." "Oh, goodness, what?" So I tell them and they all burst into laughter. You see and it gets it out of my system too a little bit, otherwise I get frustrated. [c1:337-351]

At times, caregivers also appreciate having friends to ask advice about situations.

> It relaxes me to talk to my friends about the whole thing and get concrete advice too. Like what can I do about this situation. Or help me to think this through. So that's what I try and do to help myself. [e1:1216-1223]

Participation in the study provided some caregivers with the opportunity to talk about their situation. As one caregiver said in a second interview:

> I think it [the first interview] was a chance for me to sort of get a lot of things off my chest or to sort of express how I was feeling about the role to someone that wasn't family. [g2:39-43]

Most of the caregivers indicated that they had never spoken of their experiences, their feelings and reactions to this role in such detail. Some of the caregivers indicated that they were relieved to have the opportunity to talk at such length about the experience. One caregiver shared a copy of the transcript of her interview with her husband with the result that she felt that her husband had a greater understanding of her feelings regarding providing care for her mother. One caregiver contacted the researcher to request a third interview after she had had to unexpectedly relinquish care of her mother to a long term care institution. She stated, "I don't know if this is any help to you. It is for me. I needed to talk" [h3:418-421]. This data may be used by nurses to validate the need to provide time to listen to caregivers "tell their story."

Informational support. Advice given by some health care professionals and advice given at support groups such as the Alzheimer's society meetings, were appreciated by the caregivers. Providing sources of information, such as resource books, was also appreciated. Lecturing the caregiver was not appreciated. Lecturing usually meant telling the caregiver what to do when they did not agree with the advice or it was offered without being solicited.

Caregivers provided a considerable amount of information regarding both the supportive and unsupportive interactions they had with family, friends and health care professionals. Some of the most valuable support was affective. Empathic, non-judgmental listening was considered very supportive for these caregivers.

Health Care System

Caregivers initiated conversation about the health care system in many of the interviews. The researcher wondered if this topic was mentioned because the advertisement for informants included a section on one of the possible uses of this data being to improve the care offered caregivers by the health care system. This hypothesis was not reviewed with the informants.

Supportive/unsupportive interactions. Many of the supportive activities carried out by family and friends, were also found supportive when done by health care professionals. Indicating understanding of the caregivers' interpretation of the older person's needs, and showing concern for the caregiver's well-being were considered supportive measures. Not respecting the caregiver's decision to continue to provide care for the older person in the home was considered unsupportive. When health care professionals encouraged caregivers to consider placement for the older person, especially when the caregiver wanted to continue to provide care at home, the health care professionals were considered unsupportive.

Interactions with health care professionals who hugged the caregiver or spoke to them with concern were considered supportive.

Offers of help from health care professionals seemed not to require the same amount of commitment for follow through that was expected when family or friends made offers of help.

<u>Respite care</u>. When arrangements were made to provide appropriate respite se[illegible] the caregiver, then the health care system was seen as bein[illegible]ive. Appropriate care included things such as the prope[illegible]unt and types of medications and appropriate level of mental stimulation for the older person. When the arrangements seemed inflexible to the caregiver, then the system was interpreted as being unsupportive. For example, if a respite bed was made available in an institution very far way from the caregiver's home, the caregiver found the relief unsupportive of her individual concerns.

One caregiver found that using a respite bed involved considerable stress for her because of what she termed territory battles over her mother. When she first used a part-time respite bed, she felt that the staff did not regard her as the primary caregiver. She wrote in the diary given her for the research project:

> Three weeks at the nursing home. I feel like straightening them out by making it clear that I'm the caregiver -- they're helping me out. I feel threatened. [h2:1549-1553]

Caregivers found that the care received by the older person varied from acute care settings to rehabilitation hospitals to long term care facilities. In general, all who had had contact with acute care facilities found that the older person did not receive care that they felt would have been appropriate for the older person. The older patients were not stimulated mentally in acute care settings and the pace was too quick for them to cope with. In addition to this, the older person was seen not to be eating as well as they should have been. All caregivers who had made use of a rehabilitation hospital felt that the care there was appropriate and of a high quality. The older person was given treatments that would facilitate improvements. Long term care facilities were perceived by the caregivers as providing more appropriate care than the acute care facilities, but not necessarily as aggressively as the rehabilitation hospital. They felt that in some cases the potential for improvement in the older person was not being realized in the long term care setting. Caregivers also mentioned the fact that not all long term care settings were equal. They sought out the best one for their older person whenever possible. Staff to patient ratios were identified as one reason why care might not be optimum in the health care system in general. Some caregivers identified that there was a lack of coordination between services in the community resulting in overlapping services being provided for the person they cared for.

Obtaining information. Obtaining information from health care professionals was difficult for some caregivers. Access to physicians in hospitals seemed difficult and nurses were sometimes seen as not facilitating access to these personnel. Information regarding medication use, side effects and diagnosis and the older person's condition were two areas caregivers identified as requiring more feedback from the health care professionals. Continued assessment of the older person was also requested to investigate physical problems of the older person not necessarily related to the cognitive changes they were experiencing. Day hospital assessments were anticipated with enthusiasm as caregivers felt that these assessments were needed, even if the older person had been previously diagnosed with a cognitive disease process. Caregivers identified that because health care professionals spent very little time with the older adults, assessments were difficult to complete in any depth. This sometimes led to a failure to diagnose problems that the caregiver felt certain existed. The older adult's ability to put great effort into interactions with some people, like physicians, increased the likelihood of health care professionals "missing" the problem that caregivers lived with.

> G: I think because you spend more time with the person than maybe a nurse in the hospital would, you see that confusion and that disorientation. Other people come in and on the basis of five minutes say, "No, oh she's just fine -- hundred percent lucid" and that just really frustrates me.
>
> B: I can relate to that too because I've had people come in when he's having a good day and then they don't see anything wrong with him. He looks so normal. And I say, "Well of course he looks normal. You caught him on a good day." [group]

Identifying resources. Health care professionals provided support to caregivers in the form of advice on how to act toward the older person in specific circumstances, and in the form of providing additional resources for the caregiver to utilize and by providing some counselling services to help the caregiver cope with their feelings. The Alzheimer's meetings were considered supportive because they were a source of information and a chance to socialize with others who understood their situations.

The caregivers provided a considerable amount of information regarding the supportive role the health care system played. The supportive interactions were exemplified by congruence with the caregivers' expectations of the system: appropriate respite, appropriate care while in the system, appropriate information, appropriate affective support. Unsupportive interactions occurred when caregiver and health care professional did not have similar views on the situation.

Admission to Long Term Care Facility

Admission to a long term care facility was an issue for the family caregivers as many of them anticipated such a move eventually. This issue is discussed in this section of the chapter because the caregivers who admitted the older adult to a long term care facility during the study provided information on how difficult this transition was for them. One caregiver's description of how unsupported she felt during this transition will be presented.

Preparing for placement. Caregivers generally approached admission to long term care facilities in a gentle manner with the older person. Although they did not lie to the older person about the possibility of this occurring, they did try to "pass it off" by saying they would look after the older person as long as they could. They anticipated that they would feel guilty in the future when they had to place the older person, but tried to temper these feelings by doing their "best" at the present time in their caregiving role. Most had prepared the necessary paper work needed for admission, but were holding back placing the older person on an active waiting list for the time being.

Reasons to admit. New behaviours, from the older person, that were considered unacceptable to the caregiver, such as aggression and incontinence, or a decline in the caregiver's health were identified as reasons why placement would have to be considered. A decline in the mental status of the older person to the point where they would no longer ever recognize the caregiver was another anticipated catalyst for admission. Safety of the older person was a factor that was taken into consideration when decisions regarding placement had to be made. Falling and leaving the stove on were examples of instances that forced the caregiver to consider placing the older person.

One caregiver who admitted her husband during the time of the study indicated that it was a difficult decision for her to make and she prayed that she had made the right decision for her husband. After visiting him in the institution, she felt that she was having a harder time adjusting than was her husband. She did indicate though, that had he given her any indication that he was not happy in this place she would have had a more difficult time adjusting to his admission.

Caregivers identified that admission to a facility resulted in taking away the older person's independence. This was difficult for caregivers to come to terms with as the older person's anger at this was often directed at them.

Caregivers also identified that the older person would likely have gone "down hill" quickly if they had been placed before they needed to be, especially if they had been placed on a floor with patients who where more cognitively impaired than they were. One caregiver indicated that she felt she would be signing her mother's death warrant if she placed her. Many caregivers worried about when the time was going to be right for them to consider admitting the older person. They wanted to be sure to balance their needs with the older person's needs: they wanted to admit the older person before they felt unable to cope themselves but not so early as to risk causing the older person to decline prematurely.

> That is what bothers me the most of this whole thing. How do I know when the time is right [to admit him]? Even going to the Alzheimer's meetings, everybody's interpretation of the right time seems to be different. [b2:416-421]

> I think I'm at the point now where it wouldn't take too much or very much to make me realize that the time has come and I can't cope with it any longer. But I'm hoping I can carry on a while longer. [f2:958-964]

Ways of avoiding admission. Caregivers often took measures to avoid the admission by their actions. Trying to avoid upsetting the older person to avoid the possibility that they might become aggressive, and taking measures to avoid incontinence such as offering to take the older person to the toilet on a regular basis were examples of such actions.

One caregiver had been advised by health care professions that she ought to place her husband immediately because they had assessed him to be aggressive. The caregiver felt that they needed to warn her of this, but she interpreted her husbands' actions in a completely different way and thus did not see the immediate need of placement that the health care professionals did. She interpreted his firm handshakes as a cover-up for not remember people's names and the shaking he did of others in wheelchairs as a life long continuation of playing jokes on people.

Integrating the health care professional's assessments of the older person and the caregiver's assessments of the older person and of themselves caused discomfort for many caregivers. They felt they were in the best position to know when they had had enough of this role and found it very difficult to justify this to professionals who felt that the caregiver ought to place the older person in a long term care facility immediately.

<u>Changing roles after admission</u>. Caregivers felt that people did not understand the difficulty they had admitting an older person to a long term care facility. One caregiver indicated that her friends and family seemed to assume that she was happy to have placed her mother when this was not at all the case. She really wanted them to call and offer condolences that her mother had had to go into the nursing home, but these had not been forthcoming. One health care professional indicated to her that she should not feel guilty about admitting her mother. Unfortunately, this also failed to capture her

feelings of sadness at not being able to continue to provide care for her mother at home.

This caregiver worried that other health professionals would think that she was guilty about something if she continued to be involved in her mother's care while in the long term care facility. She spoke of being perceived as a "sore loser" regarding the new role she felt she had to forge for herself in the institution. She was concerned about not treading on the territory of the health care system, but was unsure of how much authority she could have, or should have, in being involved in her mother's care. She felt uneasy about letting go of her role as primary caregiver but felt that she didn't have the same level of authority in the institution. She was concerned that the level of care provided for her mother was not as aggressive as she felt it should be and therefore did not feel comfortable about not being somewhat involved in the care. She identified that it would take a considerable amount of time to work out her new role.

"Letting go" was a code that seemed to capture part of the caregivers' process of changing their role from primary caregiver to family member who visited an older person in a long term care setting.

> Interviewer: And something's making you feel like you're supposed to step back. You're supposed to just let them take care of her now?
>
> Informant: Yeah, that's exactly how I feel. Should I be aggressive or shouldn't I? Just let them look after her and let nature take it's course or should I be aggressive? It's not that I want to hang on to her forever. I know she's going to go to heaven and I'm not

> worried about that in the least but it's just -- am I crazy? Why can't I let go the way everybody expects me to? [h3:970-1001]

> It's hard to shut it off, like to say okay, now they're looking after her. I don't have to worry about it. She's been a part of my life for so long that it's really hard to make the transition. [h3:91-97]

Caregivers often continued to provide some physical care, such as bathing and helping to feed the older adult during admission to hospital and to some extent after placement in a long term care facility. Sometimes this occurred because the caregiver felt that the care provided was not adequate and other times it was to feel like the primary caregiver again.

Some caregivers spoke of the need to have an "in between" level of institution that would allow both caregivers and the older person to grow accustomed to the idea of institutionalizing the older person while maintaining a small, home like atmosphere.

The caregivers provided much information on their views of the health care system. The supportive and unsupportive aspects of their interactions with the system have been presented here.

Caregivers' Needs

Caregivers identified areas where they felt that improvements could be made to make their role as caregiver easier to deal with. These needs can be classified into three broad categories: need for information; need for instrumental help such as respite relief; and affective needs such as acceptance and respect.

Need for information. Caregivers all felt that a diagnosis was very important for them to have. For those caregivers who had been told the older adult's medical diagnosis, learning about the disease and learning to accept it was made easier. For those caregivers who had not been given a diagnosis, these tasks could not be accomplished.

> This wishy-washy organic brain syndrome and stuff like that, really... once you know what it is, then you can face it. But it's not knowing that drives me crazy. [group/h:1170-1175]

Many caregivers spoke of how unprepared they felt to assume the role of caregiver. They felt isolated and alone when they first assumed the role.

> I don't think there was a lot -- I wish there was some literature, some place that I could have got a little bit of help from at the time as a caregiver for someone that's confused. I really felt isolated that there wasn't [any information]. "Here, you go and deal with it." And it was pretty overwhelming at first.

Caregivers needed information to help them. For some, information was needed about different methods of intervening. For example, when the older person was very angry and blaming the caregiver for their present situation caregivers wanted suggestions on ways of dealing with such scenarios.

> One thing I would like to say that I have found that has been very important in helping me deal with everything, especially with my mom, with her aging process, with her illness process and that is information. When I become informed as to her condition and what happens, what is the process that is going on, it makes a big difference on helping me deal with the situation. [e2:1029-1038]

Need for instrumental help. Because of the mental deterioration of the older adults, caregivers needed to provide almost constant supervision. This need for supervision resulted in constraints being placed on the caregiver when she wanted to get away for a weekend, for a holiday or even for a shopping trip. Institutional respite beds were not optimum for a number of the caregivers because of the difficulty they had convincing the older person that the move was temporary. One caregiver anticipated that her husband would deteriorate in a long term care facility and therefore it would be more difficult for her to care for him afterward In light of this, she made arrangements for him to be cared for in a private home during her holiday. This arrangement was expensive though, and required considerable organization on her part to arrange.

Although day programs were utilized by some, one caregiver spoke of how difficult it was for her to go out during that time because her husband did not leave the house early enough for her be able to get to any morning group activities that might be held in her community and he generally arrived home too early for her to stay out for afternoon activities. In addition to these concerns, the caregiver was in constant fear that she would not arrive home before her husband and she had no idea what he would do if she were not home.

Other caregivers spoke of not having anyone else they could call on in the evening to put the older person to bed so they did not feel they could go out at night. One caregiver said that when her siblings came to visit, they would never dream of offering to spend the evening with their father so that she and her husband could go out for dinner alone. Caregivers spoke of the need to have a service where people could be booked for short term relief. This was especially needed if there were no other family members around who could offer to provide temporary care for the older person. One caregiver recognized that she needed to have regular days off from her role as caregiver so arranged part time placement in a nearby nursing home for her mother on weekends. Caregivers identified too that there was a need for a service that could supply supervision on very short notice so that caregivers could respond to other emergency situations that might occur.

Caregivers felt uncomfortable about asking family members or friends for help. One caregiver felt that she would be much happier if her friends would offer to come and take her and her husband for coffee at their house, or even stop by for a visit. She felt that she would not feel as forgotten if this were to occur.

> If they would make the offer it would be so much nicer than me having to phone and say, "I'm really sorry to bother you but could you do me a favour?" I really hate to beg and it seems to me I'm begging when I have to ask somebody who hasn't responded on their own. [f2:1155-1166]

Need for acceptance, respect and understanding. During the interviews, caregivers often spoke of how unsure they were that they were doing the right thing providing care for the older person and that the care they were providing was good care. They indicated that it would be helpful to hear from family members or health professionals not only that they were doing a good job of caring, but that providing care at home or deciding to admit the person to a long term care facility was the right decision. They needed to feel respected for the decisions they had made.

Caregivers who had been involved in support groups, such as the Alzheimer's society, felt that these groups had been beneficial in helping them to learn and feel less alone in their role. Those who had placed the person they cared for in a long term care institution spoke of the need to belong to a support group during this time to help them deal with the wide range of feelings they had over this move. Caregivers expressed interest in knowing how other caregivers felt about the situations they all faced. The following is an excerpt from the closing minutes of the group interview held at the end of the study:

> H: Is it ever nice to be with other people who have the same problems.
>
> B: Yes, it doesn't make you feel as alone does it?
>
> G: I think that's why, when I saw [the study advertised] I thought gee this is finally an opportunity to see if other people have these same feelings. And they do.
>
> H: Ya, I can't believe it.
>
> Interviewer: So there's a need for a lot more talking, is there? A lot more...
>
> G: Support. [group: 2260-2283]
>
> I needed somebody to tell me that I'm not crazy because I felt like I just needed to know that. I just needed somebody to say, 'no, Sue, you're not crazy. You're just concerned.' [h2:1487-1504]

Relationship of These Findings to the Literature

Four of the caregivers indicated that they volunteered for the study to find out how other caregivers reacted to the experience of providing care to a disoriented family member. The need for caregiver support groups may be inferred from these comments. The use of support groups has received widespread support in the literature (Bishop, 1989; Barnes, Raskind, Scott & Murphy, 1981; Glosser & Wexler, 1985; Haley, Brown & Levine, 1987; Hartford & Parsons, 1982; Heagerty, Dunn & Watson, 1988; Steuer & Clark, 1982; Wasow, 1986; Wright, Lund, Pett & Caserta, 1987).

The caregivers identified that they would benefit from better support from friends, family and health care professionals. The need for information, for instrumental help and for acceptance, respect and understanding were clearly stated by the caregivers.

Conclusion

The findings of the study reveal that caregivers develop individual and unique ways of interacting with the older person. An underlying theme that seemed to direct the caregivers' thoughts, actions and words, was the assumption that the person they cared for maintained a dignity, a sense of worth, a personhood despite the cognitive changes that resulted in their memory loss and disorientation.

The episodes of disorientation proved difficult to isolate and examine apart from the whole caregiving experience. The caregivers' approaches to the older adults were similar in both instances of disorientation and in instances that seemed to be more accurately labelled memory loss or bizarre behaviours. The most characteristic attribute of the disorientation described by the caregivers was the vast variability of the phenomena.

The older adults level of orientation varied considerably depending on a number of factors, some which were identified by the caregivers, some which could not be identified. These factors were presented under the heading of cognitive responses to the caregiving role as they were evidence of the types of thoughts caregivers had as they provided care to the older person.

The emotional responses of the caregivers to their caregiving role were varied and strong. Frustration and anger were two frequently mentioned emotions, but sadness, guilt and feeling alone were other commonly expressed feelings. The ability of the caregivers to think about the causes of the disorientation and other bizarre behaviours allowed them to modify their actions so that their emotional responses were usually tempered. Actions involved predominately maintaining a calm environment for the older person and maintaining the older person's sense of dignity.

The caregiving experience impacted on the caregivers in a wide range of spheres of their lives. The caregivers' energy level was universally mentioned as being affected. Some caregivers spoke of feeling that their lives had been put on hold as a direct result of this experience. Others mentioned that they felt they were on a roller-coaster because of it. The role certainly affected many aspects of the caregivers' lives including changes to many of the relationships the caregiver had with others.

Caregivers revealed much regarding activities and interactions they considered supportive and those they did not feel were so. Congruency with the caregivers thoughts concerning care of the older person were perceived as most supportive to caregivers. Caregivers expressed a desire to be understood by other family members, by friends and by health care professionals. Family caregivers' experiences of caring for a older adult with a cognitive impairment have been found in this study to be both universal and unique. Consequently, those supporting caregivers need to assess the individual on an ongoing basis to determine the best approach for the individual caregiver.

In the next chapter, these study findings will be discussed in a more general fashion. The relationship of this study to others that have been completed will be explored as well as the implications of this study for nursing and suggestions for subsequent research.

Discussion

This chapter will focus on a general discussion of the findings of the study and their relationship to the literature. The implications of these findings for nursing and suggestions for further research will also be discussed. In the previous chapter, the specific findings of the study were related to pertinent selected literature. In this section, the findings will be discussed in a more global fashion.

Manner in which the Caregiver Viewed the Older Adult

In this study caregivers provided details about the type of relationship they had with the disoriented older person. The caregivers spoke of their ability to consider and interact with the older adult as a valued individual despite their cognitive impairments. Their ability to maintain a relationship with the older adult, based on respect and value as a person, influenced the caregivers' thoughts, feelings and actions. The caregivers' efforts to "get inside the heads" of the older adults, to empathize with them and to try so hard to think for them are testaments to the importance and value the older people had in the lives of the caregivers.

Although studies have been conducted which examine the variable of the relationship of the caregiver to the older person, none have been found which focus on the manner in which the caregiver viewed the older adult with respect and value despite the disorientation. Gilhooly (1984) found that "close" relationships between the caregiver and the disoriented person were correlated with a decrease in the mental health of the caregiver. Gilleard, Belford, Gilleard, Whittick and Gledhill (1984) found that a poor pre-disease relationship between caregiver and older adult was correlated with an increase in caregiver distress. Hirshfeld (1983) found that mutuality in the relationship between the caregiver and the disoriented older person grew out of the caregiver's ability to find gratification in the relationship with the impaired person. The caregivers in her study who were determined to have high mutuality in their relationship with the older person considered themselves to be managing well. These caregivers seemed to have similar characteristics to the caregivers in the current study, especially in recognizing that the older person they cared for was important in their lives. The reports of these studies, however, did not provide great detail regarding the characteristics of the relationships. The current study offers a contribution to this body of knowledge by supplying detail about the way the disoriented person is valued by the caregiver.

Manner in which Others Viewed the Older Person

The caregivers' perception that others did not view the older person in a valued manner was considered unsupportive by the caregivers. Other family members and health care professionals were identified as failing to support the caregivers by not sharing a "valuing" perception of the older person. Literature on family relationships during the caregiving experience provided direction for the discussion of this finding.

Hasselkus (1988) conducted an ethnographic study to examine meaning in family caregiving roles, especially in the relationship between the caregiver and the health care professional. She used Schon's (1983) model of reflection-in-action to describe how family caregivers conducted three stages of "invisible" caring before they carried out visible actions which were interpreted by health care professionals. These caregivers named the stimulus to which they would respond, framed the context in which they would act and judged their actions based on what they had named and framed. Hasselkus identified that the tensions expressed by the caregivers between themselves and health care professionals stemmed from the different perspectives that the health care professionals named and framed the stimulus which they would respond to. This tension was also felt between the caregivers and other family members.

The data from the current study supports this idea of tension between the caregivers and others. The caregivers in this study experienced tensions when they felt that health care professionals and other family members failed to respect and value the decision they had made to provide care to the older disoriented family member. The caregivers reported that health care professionals encouraged them to give the caregiving role over to an institution before the caregivers felt ready to do so. According to Hasselkus, this tension might be reduced if health care professionals were to make more detailed assessments of the family caregivers' perspective and share with the family caregiver the meaning of the situation from their perspective. In this way, the invisible processes of naming, framing and judging might become more visible and erroneous assumptions would be avoided. Caregivers in this study gave a clear message that they felt that health care professionals ought to spend more time listening and trying to understand and reinforce their decision to provide care to the older person.

The caregivers identified in many ways how important it was to them that people understood them. It was important to the caregivers that family and friends as well as health care professionals knew what they endured and supported their decisions to provide care. Baillie, Norbeck and Barnes (1988) have studied the buffering effects of social support on the psychological distress of caregivers of the elderly. These researchers tested three hypotheses: 1) perceived stress of caregiving will be positively related to psychological distress; 2) satisfaction with social support will be negatively related to psychological distress; and 3) social support will have a buffering effect on the relationship between perceived caregiver stress and psychological distress. They collected data from 87 caregivers using questionnaires that were completed by the caregivers. The questionnaires covered the following areas: demographic variables of the caregivers; characteristics of the caregiving situation such as the physical and mental condition of the older adult and the duration of caregiving; measures of perceived stress of caregiving; satisfaction with social support; and psychological distress of the caregiver. The researchers used multiple regression analysis to determine that satisfaction with social support was negatively related to psychological distress. To further describe the variable of satisfaction with social support the researchers examined the relationship between the demographic variables of the caregiver and the variables concerning the characteristics of the caregiving situation. In the resulting regression equation, only one variable, the number of hours of care required daily, was significant and it accounted for only 8% of the variance in satisfaction with support. From this result, the researchers concluded that there are many other unmeasured factors that account for caregivers satisfaction with their support.

From the current study, the data would suggest that a variable which might explain a greater amount of the variance for the variable "satisfaction with support" could be "the congruency between the caregivers' perception of the older person as someone deserving of respect and dignity and the perception of supportive individuals." The caregivers in the current study found it very distressing when other family members or friends did not recognize the special relationship the caregiver had built with the older person.

Scott, Roberto, Hutton and Slack (1985) found that caregivers' ability to adapt was enhanced when family members shared a similar meaning or perception of the older person's illness. In their study, caregivers and other family members were interviewed to determine the frequency and type of conflicts experienced between family members and caregivers. Like the other studies mentioned, this study did not describe the manner in which the family member or caregiver viewed the older person. Conflicts cited by these informants focused on tangible issues such as number of times the family members visited and expectations of the care the older person was to receive.

Implications for Nursing

Providing support to caregivers is an important nursing intervention. Nurses will be better able to understand the caregiver and offer her support if they recognize the way that many caregivers value the person they care for. Understanding and valuing this special relationship between caregiver and the older person is important in formulating supportive nursing interventions.

In the interests of providing support to caregivers, there is also an apparent need to help families of caregivers learn strategies that are considered supportive by the caregiver. Nursing might play a role in helping families gain increased insight into this by helping families understand that the caregiver sees the older adult with dignity. In order to be supportive of the caregiver, nurses must also examine their own manner of viewing and interacting with the disoriented person. The evidence from this study indicates that caregivers use the apparent view of others (families, friends, health care professions) toward the disoriented adult to help them determine whether or not the person is supportive of their situation.

Understanding the Caregivers' Situation

Bunting (1989) presented a conceptual model based on Orem's Self-Care Theory to describe the competing demands made on caregivers of older adults. The model indicates that as the needs of the older person increased, the caregiver was forced to choose between directing resources of time, energy, attention and money toward the older person or toward themselves in the form of prevention and health maintenance. Bunting's review of the literature led her to postulate that caregivers chose the older adult over themselves until resources were depleted and a crisis had occurred.

This model of competing demands is supported by the data collected in this study. The informants indicated in many cases that they knew they ought to be taking better care of themselves but had difficulty freeing up enough of their own resources to take care of themselves. Those caregivers who did schedule time for themselves felt that they had more energy to provide better care to the older person. Bunting suggested that nursing research concentrate on trying to determine, from caregivers, interventions that would best support them in their efforts to provide care to the older person. The informants in this study repeatedly suggested that health care professionals did not understand their situations and made erroneous decisions regarding the best type of care needed by the caregiver.

Implications for Nursing

The information provided by the caregivers regarding health care professionals has many implications for nursing. Premature suggestions that caregivers place the older adult in a long term care institution were not received favourably by the caregivers. Nurses must assess carefully the caregivers perception of the stresses they experience. In not all cases was the older person the primary source of stress for the caregivers in this study.

Caregivers indicated that they felt misunderstood when the person they cared for was admitted to a long term care facility. If nurses were to recognize that placing an older family member, for either part-time or full-time placement, resulted in a readjustment of roles for the the caregiver, then they might be able to adjust their approach to ease this transition for the caregiver.

Nurses might also alter their approach if they recognized that caregivers might be frustrated at not receiving information from health care professionals, at not being involved in the planning of the care of the institutionalized older person and at having their judgement and knowledge about the older person questioned by health care professionals.

Complete assessments of caregivers is paramount in assisting nurses to improve the care they give the family caregivers. Listening with empathy to caregivers as they tell their story would be one way of carrying out this assessment.

Overall Stages of Providing Care

The overall experience of providing care for a disoriented person described in this study can be related to the recently published work of Wilson (1989a, 1989b). Wilson completed a grounded theory study with caregivers of people with Alzheimer's disease. The findings of the current study support her research. She found that there were eight stages that the caregivers in her study experienced in their role. The first stages dealt with the initial reaction of the caregivers to their suspicions that the older person had a cognitive impairment. Stage one, called noticing, stage two, called discounting and normalizing and stage three, called suspecting, were all described by the caregivers in this current study as well. The caregivers in both Wilson's study and the current study spoke of how they could remember incidences in the past that they could attribute to the older person's cognitive changes in retrospect but that they s took conscious efforts to ignore the episodes of unusual iour displayed by the older person in the early stages of the disease process.

Wilson's stage four, searching for explanations, described the caregivers' efforts to obtain a satisfactory diagnosis for the older person. Many of the caregivers in the current study commented on their need to obtain a diagnosis. Even after a diagnosis had been made, the caregivers in this study did not stop searching for explanations for the changes in the orientation of the person they cared for. They continued to search for reasons why there was variability in the level of orientation of the older person.

The fifth stage detailed in Wilson's study describes the recasting that caregivers carry out. Wilson found that after a diagnosis had been made, caregivers reappraised, retrospectively, various experiences they had had with the older person in light of the diagnosis. This stage was not described in detail by the caregivers of the current study.

The last three stages described by Wilson (1989a) were: taking it on; going through it; and turning it over. These stages concerned the actual process of providing care to the older person. These stages are described in more detail in Wilson's second article (1989b) which described the basic social psychological problem as "coping with negative choices".

"Taking it on" occurred when the caregiver assumed the role of primary caregiver. The caregivers in both Wilson's study and the current study described their experience of taking the role on as having great uncertainty and unpredictability. The caregivers in the current study spoke of feeling very unprepared to assume the role. Some even questioned if they would have taken on the role had they known what it entailed.

Wilson found that caregivers assumed the role out of a sense of moral duty. Caregivers in the current study described a wider range of motivational forces beyond strict moral duty. Filial moral duty to care for parents has been described by a number of philosophical writers (Callahan, 1985, 1987, 1988; Daniels 1988). An examination of their work indicates a difficulty in describing the moral justification of such moral obligations. Some of these authors conclude that although there is no sound justification for such a moral duty, children are often the best sources of support for older people because of the importance of the sense of family. These writers also stress the need to foster this sense of family, not only for the good of the older person, but also for the good of society. The caregivers in the current study spoke of the importance they placed on the family unit. They reasoned that this was one of the reasons they provided care to the older family members. Wilson's description that caregivers assume the role out of a sense of moral duty warrants further defining in light of the data obtained in the current study.

Wilson found that caregivers in her study felt trapped by the role and experienced great life-style changes as a result of the role. The caregivers in the current study supported this feeling in the comments they made concerning the great impact their caregiving role had on their lives. Like Wilson's informants, these caregivers also indicated that they felt an enormous responsibility for the older family member. As well, like Wilson's caregivers, they also indicated a need for increased knowledge regarding the community services available to help them.

The coping strategies described for this "taking it on" stage involved self-dialogue, seeking solace and unburdening. All three strategies were described by the caregivers in the current study. In describing self dialogue, they detailed the mental preparation that they practiced before meeting the older person after an absence. Wilson's informants spoke of seeking spiritual solace to help them cope. Although some caregivers in the current study mentioned this, it was not validated by all. The final coping strategy for this stage, mentioned by Wilson, was unburdening. The caregivers in the current study supported this finding as they all mentioned the importance of talking with others who were non-judgmental. The support of friends and family who reinforced the caregiver's decision to care for the older person was highly valued by the caregivers in the current study.

Wilson found that as the unpredictability and uncertainty representative of this stage passed, caregivers moved on to the stage she called "going through it." This stage was characterized by a long list of problems such as family conflict, illness ambiguity, maintaining activities of daily living and breakdown of shared meanings (1989b, p. 96). Wilson found that the consequences of this stage of caregiving were exhaustion, and a sense that the caregiver's life had been put on hold. Both these consequences were supported by the caregivers in the current study.

The coping strategies used by caregivers in Wilson's study in the "going through it" stage were: taking care of business; selective resourcing; and protective governing. The first strategies involved not only setting up financial arrangements, but organizing the environment to best suit the older person. Caregivers in the current study reported completing both tasks. Selective resourcing involved the caregivers recognizing that they needed help and realizing that they did not have the necessary information about the help available. When services were found, the caregivers generally found them to be inadequate. Caregivers in the current study also found this to be the case. The last strategies of protective governing included the caregiver's awareness that they were putting themselves at risk by maintaining their caregiving role in the manner they had been. Some of the caregivers in the current study spoke of coming to this realization. Like Wilson's informants, they recognized that to continue in their role they had to take care of themselves by arranging respite services to allow them time by themselves, finding time to recharge their energy, and by avoiding stressful situations that involved the older person or others. Caregivers in both studies began to recognize their own breaking points and took steps to avoid reaching these points.

In the current study, a number of the caregivers might be assessed as being in the stage of "taking it on" while other caregivers who had been in the role longer, might be assessed as being in the next stage of "going through it". The caregiver's response to the term "roller-coaster" was one way the researcher found to distinguish which stage the caregiver was in. The caregiver who did not feel she was experiencing great fluctuations in her role had been a caregiver for the longest period of time. She interpreted this term to mean that her role was never ending. She said that like a roller-coaster ride that one could not get off, she was not able to stop the demands of her role. The caregivers who related to the roller-coaster term in the context of the highs and lows of their daily lives might best be described in the stage characterized by uncertainly and unpredictability which Wilson called "taking it on."

The final stage that Wilson described was termed "turning it over." Wilson found that this was a gradual process that followed the caregiver's recognition that they were no longer able to provide care to the older person and eventually the decision to place the older person in an institution was made. One caregiver in the current study, who placed her mother in an auxiliary hospital, found this move very stressful because she felt that she had not had the opportunity to make the decision to give up caring herself. She felt that this decision had been made for her because of her mother's unexpected increased physical needs resulting from a broken hip due to a fall. Not coming to this realization gradually was difficult for the this caregiver. Other caregivers in the current study did come to realize, over time, that they could not continue to provide care for the older person themselves. They seemed to have an easier time adjusting to the move of the older person into an institution.

Apart from Wilson's study (1989a;1989b), few studies have used the variable of length of time in the caregiving role to examine the differences in the experience of providing care to a cognitively impaired older person. One study on caregivers (George & Gwyther, 1986) was located which examined the relationship between caregiver well-being and the length of time the caregiver had spent in the role, however this study failed to find any significant correlation between these two variables.

The theory presented by Wilson (1989a; 1989b) concerning the stages that caregivers encounter in their caregiving role, was supported by the data collected in this current study. As Wilson states in her discussion, this theory highlights the shared features of the experience of caring for people with a cognitive impairment. The current study, having the objective to describe and understand experience rather than to find theory, was able to detail the unique ways in which this caregiving role was experienced by these women informants.

Implications for Nursing

Wilson's study (1989a;1989b), and the current one, have added to the body of knowledge of caregiver's experiences in providing care to disoriented older adults. A deeper understanding of the experiences of these caregivers can help nurses assess similar types of caregivers in their practice. The experience of providing care has been identified as being very isolating. Nurses can use the information collected in this study to help caregivers realize that there are others in similar positions who may have some common feelings and reactions to the experience. A number of the informants for this study stated that they volunteered to be interviewed to give them an opportunity to see if their experiences were similar to others in the same role. After the group session, a number of the caregivers stated that it was very good for them to know that others felt and reacted as they had. Knowledge of these benefits might assist nurses in encouraging caregivers to join existing support groups for caregivers, or in developing support groups themselves.

The nature of interactive interviews implies that the study itself will have an impact on the informants. This proved to be the case in this study. One caregiver requested a third interview from the researcher to provide her with an opportunity to discuss how she felt during the transition of placing her mother in a long term care facility on a permanent basis. She indicated that she felt this would be helpful information for the study, but also indicated that it was helpful to her to have someone listen to her talk about this experience. This information, though serendipitous to the primary goal of the study, is useful for nurses as it supports the need for nurses to provide time to listen to the caregiver's "story" for therapeutic reasons.

Suggestions for Further Research

The relationship between the caregiver and the older adult requires further investigation to make more explicit other characteristics of this special relationship. Increased understanding of this relationship would help nurses as they assessed the caregiver/care-recipient dyad and would provide a further basis for developing supportive interventions.

Based on the findings of the current study, it appears that it is important to the caregiver how others view and interact with the disoriented person. Further research is needed that would provide greater detail concerning this aspect of the caregivers' relationships with others.

There is a need to examine the process caregivers' under go as they admit the person they care for to a long term care facility. It seems that caregivers alter their roles from primary caregivers to a role of visitor of the older person. As primary caregiver, they were responsible for all aspects of the older adults' care, and as a visitor they seemed to feel they had no input into their care. A grounded theory approach to this issue might provide a low level theory to help explain how caregivers adapt to their new position after the older person has been institutionalized.

A number of general questions have been raised by this study. The caregivers in this study identified a number of factors they believed influenced the older adults' level of orientation. A number of these factors, such as the older person's diet, might prove valuable to investigate in order that we might gain knowledge regarding the etiology of the disease processes which result in disorientation. Correlations between the various factors identified by the caregivers and the variation in the older persons' level of orientation might potentially provide both family and professional caregivers with ways of preparing for periods of time when the older person might be expected to be more disoriented.

The informants in this study were all women. A similar study investigating the experiences of male family caregivers would shed light on this apparently growing body of caregivers. It was interesting to note that when informants were being sought for this study, a number of health care professionals were able to identify more male than female caregivers whom they felt would meet the study criteria. This fact in itself warrants further investigation: Do male caregivers utilize health care professionals in a greater proportion than female caregivers?

Conclusions

This research was guided by a number of questions. The major responses to these guiding research questions are provided here as summary.

Episodes of disorientation were described by the caregivers. The most universal characteristic of the episodes was the variability of the disorientation. Caregivers generally responded to the disoriented person with a calm affect and an approach which maintained the dignity of the older person. Although the caregivers felt angry and frustrated during episodes of disorientation, they tried not to show these emotions to the older person. Caregivers spent a considerable amount of time thinking about the factors which made the older person's disorientation better and which factors made it worse. These thoughts provided the context surrounding the episodes of disorientation. Caregivers also spent time trying to anticipate the needs of the disoriented person. As the episodes of disorientation were so variable, caregivers felt at times that they were riding a roller-coaster. They felt that in many cases their lives had been put on hold by this experience, as they had no energy left to plan their future or to maintain past activities. There were many underlying motives which explained why the caregivers provided this care. Love of the older person and the caregivers' ability to see them as valued people were the primary reasons.

Understanding the experience of providing care to a disoriented older person at home, is important for nurses who are in a position to support these caregivers. Listening to the caregiver's story may be one of the most beneficial interventions nursing can provide.

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Appendix A

Consent Form

Caring for the disoriented older adult:
The family caregiver's perspective

Person doing the research:	The supervisor of this research:
Mollie Cole, R.N.	Dr. Anne Neufeld,
Master of Nursing Student	Thesis Advisor
Faculty of Nursing	Faculty of Nursing
3rd floor, CSB	3rd floor, CSB
University of Alberta	University of Alberta
ph: 481-8228	ph: 432-6251

The purpose of this research project is find out what it is like to take care of an older adult who is confused, or disoriented. Examples of disorientation are when the person does not know where they are, or who the people around them are, or what day, month or year it is.

The researcher is interested in what the caregiver does and how she feels when the older person is disoriented. There are no known risks and no direct benefits to the caregiver for being involved in this research. The information that is collected during this study will be helpful to nurses. It will help them to understand what people at home go through when they take care of a disoriented older person. A summary of the final report will be sent to the caregiver if requested.

No names will appear in any reports of the study. As well, the names of the people involved in the study will be removed from all information that is collected for this study. The information will be kept by the researcher in a locked cupboard for no longer than 5 years. It will be kept this long so that the researcher may review the information again in a similar study of caregivers.

There are three parts to this study. Please cross out the parts of the study that you do not wish to be involved in.

The main part of the study involves you, the caregiver, talking with the researcher about what it is like to care for a person who is disoriented. There will be a maximum of three interviews lasting no longer than 1 hour and 15 minutes. A total of 4 hours of your time is needed for the interviews. The interviews will be done at a time and place that is good for you. In addition to the interviews, you may be asked to keep a diary for a couple of days about how you feel when the person you take care of is disoriented.

Second part. In addition to the interviews, you may also agree to be part of a discussion group with other caregivers who have been interviewed for this study. The group will be asked to discuss the main points of information that the researcher has collected from all the interviews. This information will be presented in such a way that the identity of the caregivers will remain unknown. There will be no more than two group discussions that will last no longer than 1 hour each. The discussion groups will be held near the end of the study, probably in the spring of 1989.

The interviews and the group discussions will be tape recorded. The information on the tapes will be typed. To help the researcher better understand the information in the interviews, she may discuss the interviews with her research advisors. No names will be used during these discussions. You do not have to answer any of the questions that the researcher asks during either the interviews or the discussion group. As well, you may withdraw from any part of the study at any time. If you do withdraw, the information from your earlier interviews will be destroyed.

Third part. In addition to talking with you, the researcher would also like to ask the older person you take care of some questions. These questions, from the Mini-Mental State questionnaire, are designed to measure the mental status of older adults. Examples of these questions are: 'What is the date?' and 'Where are you now?' The results of these questions will be used to describe the people in the study. These questions will take about 15 minutes to ask. If the older person does not want to answer these questions, they will not be pushed to. There are no known risks to the person related to answering these questions. If you wish, the researcher will explain the results of the questions that deal with disorientation.

If the researcher finds anything during the study that leads her to believe that your health or safety is in danger, or the health and safety of the person you take care of is in danger, she will discuss this with you then contact the appropriate health care workers for assistance.

If you have any questions or concerns you are encouraged to contact either the researcher, Mollie Cole or her supervisor, Dr. Anne Neufeld. Their phone numbers and addresses are on the top of this consent form.

....

I, ________________________________, agree to be involved in the study
(caregiver)

called "Caring for the disoriented older adult: The family caregiver's perspective." The study has been explained to me by the researcher Mollie Cole. I have read the information on this consent form. My questions have been answered to my satisfaction. I have received a copy of the consent form.

______________________________________ _________________
signature of caregiver date

If you would like a summary of the final report of this study, please write your mailing address here:

____

____

____

Appendix B

The Mini-Mental State Exam (Orientation section only)

(Folstien et al., 1975) questionnaire [As adapted for community use by VON Canada].

I am going to ask you some question that require you to remember some things. Some of these questions may seem silly to you and others may be difficult for you to answer. Your answers will help me figure out what areas cause you difficulty. Don't be concerned if you are not able to answer any of the questions.

ORIENTATION:
** What is your name? (what shall I call you?)

____

___ What is the date (day of month)?
___ What season is it?
___ What year is it?
___ What is the day (day of week)?
___ What is the month?

___/5

___ What province are we in?
___ What country is this?
___ What is the name of this city?
___ What is your street address?

___/4

* ___ How old are you?
* ___ When were you born?
** ___ (point to caregiver) WILL YOU PLEASE TELL ME WHO THIS IS?
___/9 orientation section sub-total

/ no answer
X wrong answer
correct answer

*questions on the Short Portable Mental Status Questionnaire (Pfeiffer, 1975) and are asked to detect age disorientation.
** QUESTIONS are from mental status questionnaire (Fishback, 1977) and are asked to detect disorientation to person and about people in the environment. Scores on these questions will not be included this MMS sub-total score, but will be used to assess overall disorientation.

Appendix C

Advertisement for Informants

This notice was placed on the computer as electronic mail at a large city hospital; placed in two community newspapers and three agency newspapers; and posted on church bulletin boards.

January-May 1989

Are you taking care of an older person?

A master of nursing student at the University of Alberta is carrying out a study on **WOMEN'S EXPERIENCES** in caring for a **CONFUSED OLDER PERSON**. The purpose of this project is to find out, from women, what it is like to take care of someone who is not always aware of the current time, or where they are, or who the people around them are. The information that will be collected during the study will help nurses improve the support they give to family members who take care of a confused older person. Please contact Mollie Cole, at 481-8228 if you are interested in being **INTERVIEWED** or if you would like more information about the study.

Please take a tab from below for yourself or for anyone you know of who might be interested in talking to the researcher.

Mollie Cole	Mollie Cole	Mollie Cole	Mollie Cole	Mollie Cole	Mollie Cole
(study)	(study)	(study)	(study)	(study)	(study)
481-8228	481-8228	481-8228	481-8228	481-8228	481-8228

Appendix D

Guiding Questions for Interviews

(a) tell me about some of the times your _____________ has been disoriented?

(b) What did you do when he/she was like this? What do you do in these situations?

(c) How do you feel when your __________ is disoriented? Do your feelings change for each episode of disorientation?

(d) What do you think to yourself when he/she is disoriented? Do your thoughts change with each episode of disorientation?

(d) What seems to affect his/her disorientation?

[What else is usually happening when your _______________ is disoriented? Is there anything that seems to make them more or less disoriented? Anything that you do? Anything in the environment?]

(e) What is it like for you to take care of the your ___________ when they are disoriented? Tell me how taking care of your _______________ effects the rest of your life.

and the additional question that arose during the study:

(f) Why do you take care of your _____________? What motivates you to provide his/her care?

Appendix E

Example of a Code Map for a Portion of an Interview

[interruption] But one thing I would	1029	
like to say that I have found that	1030	
has been very important in helping me	1031	caregiver needs
deal with everything, especially with	1032	information
my mom, with her aging process, with	1033	
her illness process and that is	1034	support:
information. When I become informed	1035	information
as to her condition and what happens,	1036	
what is the process that is going on,	1037	
it makes a big difference on helping	1038	
me deal with the situation. Before I	1039	
understood what was happening with	1040	
her I was upset, angry, Why is this?	1041	
what's the matter with you, how come	1042	feelings:
you're doing this, I don't	1043	upset
understand, just on and on, just up	1044	angry
and down. Turmoil with emotions with	1045	why
hers and mine and just didn't know	1046	confused
what was going on, confused, come on	1047	
mom snap out of it, are you crazy or	1048	
what's going on. That kind of thing	1049	
and then when I realize oh this is an	1050	
illness, this is very organic, this	1051	reason for
problem that's going on right now is	1052	disorientation:
because of something physical, then I	1053	physical
can deal with it much easier.	1054	illness
I: Did you ever wonder if she was	1056	
pretending?	1057	
R: Yes. Oh yeah. I thought for sure	1058	disoriented
she's got to be kidding me. I just	1059	person
told her five minutes ago this and	1060	pretending
this is happening and she's asking me	1061	
again. She's got to be just playing	1062	
around with me.	1063	
I: She's trying to get my goat?	1065	
R: Yeah, that's right. She's just	1067	
getting at my nerves and I don't know	1068	feelings:
why. That kind of thing.	1069	why

Appendix F

Caregiver Demographics

Demographic Questions Asked of Informants

-Age:
-Length of time in caregiving role:
-Caregivers' perception of income: (circle one)
    1) income more than sufficient to meet needs
    2) income sufficient to meet needs
    3) income barely sufficient to meet needs
    4) income less than sufficient to meet needs
-Level of education of caregiver:
-Caregiver's employment status:
-Relationship of disoriented older adult to caregiver:
-Living arrangements of caregiver/care-receiver:
-Marital status of caregiver:
-Household composition:
-Other family/friends available to help:
-Dependent older adults' score on MMSE:

Profile of Caregivers

Caregiver A: 55 years old. She has provided care for her father for 1 year. She works full time as a nurse, is married and lives with her husband and father. She has hired help for supplemental care of her father. There is minimal additional family help available. Her father suffered a stroke.

Caregiver B: 53 years old. She has provided care for her husband for approximately 3 years. She lives with her husband and one other grown son. She works full time in health care facility and has hired help for supplemental care of her husband. There is minimal additional family help available. Her husband has been diagnosed with Alzheimer's disease.

Caregiver C: 58 years old. She has provided care to her mother for 1.5 years. She is divorced and lives alone with her mother. She works full time as a nurse. There is minimal additional family help available. Her mother has no medical diagnosis indicating cognitive impairment.

Caregiver D: 48 years old. She has provided care to her mother for 2 years. She works part time as school teacher and lives with her husband and one grown daughter. Her mother lives in a seniors apartment. This caregiving role is shared with her sister. Her mother suffered a stroke.

Caregiver E: 31 years old. She has provided care to her mother for 1 year. She works full time as a nurse. Both daughter and mother live alone in their own homes. She is single and there is no other family available to help. Some homecare services are used. Her mother suffered a stroke.

Caregiver F: 67 years old. She has provided care to her husband for 4 years. She has retired from part time employment as secretary. The couple lives together alone in their own home. There is no other family available to help. Her husband attends community run day program twice weekly. Her husband has been diagnosed with Alzheimer's disease.

Caregiver G: 34 years old. She has provided care to her grandmother for 6 years. The older woman lives in a nursing home very close to the caregiver's home. The caregiver lives with her husband and works part-time as a nurse. There is minimal additional family help available. Her grandmother has had a tentative diagnosis of Organic Brain Syndrome.

Caregiver H: 41 years old. She has provided care to her mother for 2.5 years. Her mother lives in her home with her husband and one grown son. She left work as a nursing assistant to provide care for her mother. Family and friends provide her with emotional support. Her mother has Parkinson's disease.

All caregivers indicated their household incomes were sufficient to meet their needs, with only one caregiver indicating income as barely sufficient to meet needs. All caregivers were Caucasian.

Appendix G

Caregivers with a Nursing Background

A number of the caregivers in the study had a nursing background. They commented on how their experiences of providing care to an older adult influenced their nursing practice and how their knowledge base as nurses influenced their caregiving role. One caregiver felt that her nursing practice had improved since she began caring for her family member. She had been told that she worked well with older patients and she attributed this to her personal caregiving experiences.

A number of the informants felt that their nursing knowledge helped them to provide good physical care to their family members to avoid skin break down and to deal with incontinence. One caregiver was surprised that she, a nurse, had failed to realize what was going on with her mother cognitively after her stroke. Other nurse/informants spoke of how they were unable to view their family member as objectively as they felt they viewed their patients. One caregiver found that, at one point, she began to feel that there were no cognitively oriented older adults anywhere because in both her nursing work and her private caregiving she was dealing with cognitively impaired older people. This was a depressing experience for her. One informant found that her task-oriented work environment influenced how frustrated she was with her mother's long term needs that seemed to her never to be completed. Another caregiver felt that her nursing experience caused her to think of many things that could happen to her mother, especially regarding things like side effects of medications. Others found that they used their nursing experience to anticipate what would likely happen with the older person and to make changes to avoid problems. For instance, one caregiver watched her husband around young children as she knew from working in a nursing home that many older people become upset around small children. Another caregiver had seen patients "dumped" in nursing homes and wanted to avoid this impression with the staff of the facility where her family member was, so visited her frequently.

Epilogue

You must not have seen me looking at you
your face made me stop and a cry of pain went through me
What are you waiting for old woman? As you sit in the car in the parking lot -- waiting for some non-existent family to come and take you "home"
You fall asleep while I watch the television and my heart jumps as you continue to sleep when I shake you
Your face so pale
Is it now that you have slipped into the existence that holds your husband, and brothers and sisters?
No, not yet. For you waken and turn to me and give me one of your sweet smiles and sheepishly say, "I guess I was sleeping"
No, it's not time yet for you to go. And for that moment, I am glad. For though you sometimes say you wish God would take you home, you too must fear a little the unknown of death -- or is it only the young who fear such reliefs?
This time I was glad, but how often have you made me so angry that I have not been able to stop myself
from slapping your hand or yelling at you.
Your strong will shows through at last... the years of bringing up children through the depression, of watching one son go off to war and a daughter die in her prime, have left their toll on you. You cannot stop and enjoy your harvest time, for without your husband by your side you feel you have nothing to enjoy.
Sometimes though, I know you are not weeping for those gone before you.
You have escaped into the only thing that you feel secure about.... you look at me and I wonder what character I have assumed in your eyes. For with the mounting confusion of our home you slip further and further away until you wonder where your mother is and no amount of explaining will make you see that she cannot be found.
Grandma, I love you. I want you to know that. Somehow as a child we took great advantage of you for you were always there and I never stopped to find out who you were.
And now, great mounds of history lie buried deep within your foggy memory and I wonder when you come out with funny statements if you are trying to tell me something of the life before I remember.
And when we laugh at the way you hide the garbage with the towels, it's not because of you, but because we are scared. Terrified as we look at each other and know that some of us will surely be like you when we are eighty-seven.
How can we ease your mind old woman? How can we help you wait with patience for that time which you are near to?
Is the strength from within, or without? Or does it matter?
Thank you Grandma, for showing me what aging really is. God Bless you and take you soon. Please.

Mollie Cole
July, 1982