ANTICIPATORY GRIEF AND DEMENTIA

by

SUSAN JOAN HIGGINbotham

B.A., Dalhousie University, 1975
B.S.W., University of British Columbia, 1984

A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF
THE REQUIREMENTS FOR THE DEGREE OF
MASTER OF SOCIAL WORK

in

THE FACULTY OF GRADUATE STUDIES

(School of Social Work)

We accept this thesis as conforming
to the required standard

THE UNIVERSITY OF BRITISH COLUMBIA

June 1994

© Susan Joan Higginbotham, 1994
In presenting this thesis in partial fulfilment of the requirements for an advanced degree at the University of British Columbia, I agree that the Library shall make it freely available for reference and study. I further agree that permission for extensive copying of this thesis for scholarly purposes may be granted by the head of my department or by his or her representatives. It is understood that copying or publication of this thesis for financial gain shall not be allowed without my written permission.

(Signature)

Department of [Department Name]

The University of British Columbia

Vancouver, Canada

Date June 30, 1944
ABSTRACT

This paper explores anticipatory grief as the experience of adult children caring for parents with Alzheimer's, multi-infarct, and Parkinson's dementias. Interviews were conducted with 10 daughters and two sons whose parents had been institutionalized in a special care unit of a long-term care facility. The age of the adult children ranged from 35 to 55. Forty percent of the adult children had no partner, 35 percent had no partner or sibling. All but one worked outside the home. Since onset and throughout the illness of the parent the adult children expressed a wide range of grief responses. Feelings of loss, uncertainty, and sadness predominated their experience. Their greatest loss was loss of relationship with the parent. The adult children's grief did not subside at the time of facility placement. The grief intensified as feelings of helplessness and hopelessness were experienced as the adult children continue to watch the physical and mental deterioration of the parent. Society neither recognizes nor supports anticipatory grief associated with the dementing illnesses. The study calls for more research of family caregivers and anticipatory grief in response to the irreversible dementias. Loss of quality of life and human dignity was expressed by the adult children as violation of the parent. Quality of life for aged people with Alzheimer's and related dementing disorders is becoming an ethical issue of our time.
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>ABSTRACT</th>
<th>ii</th>
</tr>
</thead>
<tbody>
<tr>
<td>TABLE OF CONTENTS</td>
<td>iii</td>
</tr>
<tr>
<td>ACKNOWLEDGEMENTS</td>
<td>v</td>
</tr>
<tr>
<td>DEDICATION</td>
<td>vi</td>
</tr>
</tbody>
</table>

## CHAPTER I: INTRODUCTION
- Confusion ........................................... 1
- Demographics ....................................... 2
- Effects on Family .................................... 3
- Assessment and Care ................................. 4
- Special Care Unit .................................... 5

## CHAPTER II: LITERATURE REVIEW
- The Shift from Acute to Chronic care .............. 9
- Women as Caregivers ................................. 10
- Caregiver Stress ..................................... 11
- Grief Theory ......................................... 13
- Attachment Theory ................................... 15
- The Process of Grief .................................. 17
- Attachment in Adults ................................. 18
- The Effects of Dementia on Close Relationships .. 19
- Concept of Anticipatory Grief ....................... 20
- Multidimensional Nature of Anticipatory Grief .. 23
- The Family’s Anticipatory Grief .................... 24
- Notion of an Optimum Amount of Anticipatory Grief 24
- Anticipatory Grief and Dementia .................... 25

## CHAPTER III: METHODOLOGY
- Introduction ......................................... 28
- Interviews ........................................... 29
  - Rationale ........................................ 29
  - Orientation ...................................... 31
  - Participant Selection ............................. 32
  - Participant Demographics ....................... 33
  - Data Collection and Analysis .................... 34
- Conclusion .......................................... 42
# TABLE OF CONTENTS, Continued:

<table>
<thead>
<tr>
<th>Chapter</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>IV:</td>
<td>FINDINGS</td>
<td>44</td>
</tr>
<tr>
<td></td>
<td>Introduction</td>
<td>44</td>
</tr>
<tr>
<td></td>
<td>Uncertainty</td>
<td>44</td>
</tr>
<tr>
<td></td>
<td>Loss</td>
<td>47</td>
</tr>
<tr>
<td></td>
<td>Adaptation</td>
<td>51</td>
</tr>
<tr>
<td></td>
<td>- Awareness and Gradual Accommodation</td>
<td>51</td>
</tr>
<tr>
<td></td>
<td>- Emotional Adaptation</td>
<td>54</td>
</tr>
<tr>
<td></td>
<td>- Cognitive Adaptation</td>
<td>59</td>
</tr>
<tr>
<td></td>
<td>- Behavioural Adaptation</td>
<td>61</td>
</tr>
<tr>
<td></td>
<td>Family Relationships</td>
<td>64</td>
</tr>
<tr>
<td></td>
<td>Conclusion</td>
<td>67</td>
</tr>
<tr>
<td>V:</td>
<td>SUMMARY</td>
<td>69</td>
</tr>
<tr>
<td></td>
<td>Implications for social work</td>
<td>73</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>BIBLIOGRAPHY</td>
<td>78</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>APPENDIX A: INTERVIEW GUIDE</td>
<td>87</td>
</tr>
</tbody>
</table>
ACKNOWLEDGEMENTS

This study is in recognition of adult children whose parent suffers with a severe, irreversible dementia.

Thank you for a learning experience that was both positive and challenging to:

Dr. Glenn Drover, my advisor, for your academic discipline, for your flexibility and vision, for your encouragement.

Mary Hill, Associate Professor Ex Emeritus, my committee member, for your astuteness, perseverance, and gentleness.

Sheila Armour-Godbolt, M.S.W., for your valuable insights from the practice perspective.

Thank you to:

Shirley, my partner for tireless support in every way.

Family, friends and colleagues, for assisting me over the difficult times and sharing with me the joyful times.
DEDICATION

to GERT

who drew the picture

to Carol, Cliff, Phyllis, Rosalynn, Joanne, Joan

who painted the colors

and

all the adult children in this study

whose shared experiences

provided richness and texture and depth to meaning

of this painted canvas of their grief.
CHAPTER I: INTRODUCTION

Confusion

While you ponder your choices
Mother continues to slip.
She thinks she will go to jail
for being a dope addict
She thinks there is a conspiracy
Against the family.
She worries about the poison
in the drinking water.
Though people call her lady
She isn’t sure if she’s a woman or a man.
(Selzer, 1987, p. 61).

In our western world, death of an individual means the physical death of that person. Society provides grieving norms and bereavement rituals to help remaining family and friends adjust to and accept the death of a loved one.

There is another kind of death in our society and that is the psychological death of the individual suffering with the most devastating and ruthless of illnesses, the Alzheimer’s and related dementing illnesses. For these, there is no societal recognition nor is there sanction for the family’s grief. As well, family and professional caregivers may fail to realize that grief is an appropriate response when a family member is cognitively impaired.

The word dementia comes from Latin and means ‘away’ and ‘mind’. Dementia from the Alzheimer’s and related dementing illnesses involves a progressive deterioration and eventual loss of all intellectual, social and physical functioning. Loss of human dignity of the affected individual and prolonged suffering of family is evident in the final phases of the illness. In the final stages
of a progressive dementing illness, much of a person’s brain has been affected. The individual recognizes no one and cannot speak in any intelligible way. Eventually, the individual is confined to bed, totally dependent on others for care.

**Demographics**

Dementia affects five percent of the population over 65 years of age and 20 percent of the population over 85 years of age (Alzheimer’s Society of B.C., 1992). Alzheimer’s disease appears to be the most frequent cause of severe irreversible dementia in adults. The demographics are staggering. At present, an estimated 300,000 Canadians (34,000 British Columbians) are affected by the Alzheimer type dementia. It is predicted that as many as 700,000 Canadians (80,000 British Columbians) will be affected by the year 2020 (Alzheimer’s Society of B.C., 1992).

Multi-infarct dementia is believed to be the second most common cause of dementia and can progress to a severe dementia (Mace & Rabins, 1991). According to Mace and Rabins, 50 percent of the cases of dementia are caused by Alzheimer’s disease and 20 percent of the cases of dementia are caused by multi infarct disease and 20% are caused by a combination of Alzheimer’s and multi-infarct disease. The remaining 10 percent of the cases of dementia are caused by other illnesses such as Parkinson’s disease (Mace & Rabins, 1991, p. 365).

Canadians spend 4 billion dollars a year to keep persons with Alzheimer’s, and related dementing disorders in institutions (Alzheimer’s
Society of B.C, 1992). The duration of these illnesses from onset is anywhere from five to fifteen years.

**Effects on Family**

As a social worker on a geriatric assessment unit, and now as a social worker in a long term care facility, I became acutely aware of the ravaging effects of these illnesses and the toll they take on families. The struggle to accommodate loss reflects our humanity, and yet for the family of the severely cognitively impaired, the task is almost impossible. What has occurred is a psychological death of the relative. The physical being remains. There is very slow closure. The family experience an ‘endless funeral’, trying to integrate the loss while the relative lives on. I have had to deal with this painful reality myself as well as with family. Families ask what quality of life there is for the severely demented individual who can no longer speak, or walk unassisted, who is confined to a wheelchair or bed, who can no longer attend to any of his or her own personal needs or recognize loved ones, who can no longer understand the simplest of language with any degree of consistency, and who seems to have lost all human dignity forever. The degree of suffering I have observed in families is immense. In some ways these dementias impact more on the family than any other disease, but the degree of grief and the cumulative degree of grief in our communities and care homes goes largely unrecognized.

My professional experience as a social worker in a care facility lead me to believe that what I was observing and hearing in the thoughts, feelings and behaviours of families with relatives with dementia was anticipatory grief. I
developed a keen interest in exploring that notion. I also wanted to hear families' own perceptions of the illness and how it affected them. The purpose of this study became the exploration of the phenomenon of anticipatory grief in families whose relatives had cognitive impairment; to determine the family’s perception of quality of life for the individual in the final stages of the illness; and, to seek from the family their own thoughts regarding direction for their own life should they develop a profound type of dementia. For the purpose of this study, family is defined as adult children. Relative is defined as a parent with dementia. Anticipatory grief is defined as the grief of the adult children in response to the nature of losses and the multidimensional nature of the grief that occurs with the dementing illnesses.

Assessment and Care

In B.C., the cognitively impaired individual can be cared for in the community for a number of years. Home and community support is available to the individual and family through the Continuing Care program of the Ministry of Health. Functional assessments are completed by the long term care case manager. This person determines the appropriate level of care, which in turn determines the hours of support available. There are several levels, including personal care, intermediate (1, 2, and 3), and extended care. The individual assessed at the personal care level requires the least amount of care. Generally, the individual in the early stages of the Alzheimer and related dementing illnesses is assessed at the first level of intermediate care. An individual generally becomes ready for the second level of intermediate care when his or
her mental functioning has diminished to the point that community management and care are no longer feasible. This individual will be admitted to the general care area of a long term care facility. In the general care area there is no confinement, and the nursing and other facility staff can accommodate the care needs of the new resident. Some of the facilities have both a general care area and a special care area. The special care area is located in what is called a special care unit.

**Special Care Unit**

On average, the special care unit accommodates 20 residents. The unit is set somewhat apart from the rest of the facility, with its own eating and activity areas. When appropriate, special care residents will join in facility special events. It is recommended that special care units have access to the outside where there is a garden and walking area. All special care units are secured and most are accessed through electronic computer. The staff/resident ratio is much higher in the special care unit due to the special needs of the individuals in care. A resident must meet criteria to be eligible for admission to the unit. The person’s physical and medical health status must be stable. They must, on a continuous or intermittent basis, exhibit behaviours which are either unsafe for themselves or disruptive to general care residents. Examples include wandering behaviours, either within the general care part of the facility or outside; misappropriation of others belongings; socially unacceptable behaviour such as continued resistance to physical care; aggressiveness towards other residents; and, requiring constant supervision and assistance in all aspects of daily care. A
resident is generally assessed at Intermediate level 3 when he or she meets the special care criteria. Those admitted to the special care unit can include those transferred from general care whose degree of dementia now requires special care, or those directly admitted to the unit from the community. A resident can be transferred from the unit if there is some improvement in his or her status. Individuals are also moved from the unit when they can no longer walk or transfer unassisted and require extended care, or when they need to be placed in a non-voluntary psychiatric geriatric institution.

In summary the study examines the experience of adult children who have a parent with dementia in a special care unit of a long term care facility. Loss, and that grief which is the emotional response to loss, must be understood from the perspective of the affected family. Given the extent of the loss that family of the cognitively impaired experience, grief would seem to be a natural progression. The study addresses the unique nature and duration of the anticipatory grief of the adult child. Traditionally, anticipatory grief is grief associated with physical terminal illness where death of the individual occurs within a time period of five years or less (Rando, 1984).

Chapter II reviews the literature on grief and anticipatory grief. Grief theory is used to explain loss of attachment and the manifestations of loss through grief behaviour. This review reveals that mainstream contemporary thinking has not yet recognized or supported anticipatory grief for the family of the cognitively impaired, even though the individual as they were known and loved is gradually lost forever. Existing caregiver research focuses, in large part,
on the burden of caregiving and deals with day-to-day issues of caring for the individual. There is very little discussion on the subject of caregiver anticipatory grief throughout the dementing illness (Shadday-Haarhoff, 1992). The studies by Austrom and Hendrie (1990) and Theut, Jordan, Ross and Deutsch (1991) break ground in this area, providing results that indicate the presence of anticipatory grief in the family of the relative with Alzheimer's disease and related dementing disorders.

Chapter III explains the choice of methodology used in the study. It is a qualitative study that takes a phenomenological approach to exploring the notion of anticipatory grief. The inquiry approaches the study from the theoretical perspective of grief, and the concept of anticipatory grief. I used the general interview guide to interview twelve adult children whose parents were in a special care unit of a long term care facility. Anticipatory grief was seen and heard in its own unique way as each adult child shared a painful journey. From the data analysis, anticipatory grief emerged as the over-arching theme of the study.

Chapter IV discusses the findings of the study and examines the relationship of the findings to the literature. Anticipatory grief and its component parts were well reflected in the findings according to its traditional definition. In addition, the duration of the Alzheimer and related dementing disorders, combined with the loss of parental and human dignity, sets apart the nature of the anticipatory grief of these families from the anticipatory grief of families of individuals with palliative physical illnesses. The grief of the adult
children is protracted and does not subside. These findings concur with the Austrom and Hendrie study.

The final chapter summarizes the exploratory study of the phenomenon of anticipatory grief. To date, there is little acknowledgement of and therefore little support for anticipatory grief with this population. Suggestions are made for recognition and support for family members grieving throughout the endless course of the Alzheimer and related dementia disorders. Suggestions for continuing care policy and for social policy are made to facilitate the 'best care' possible for the relative. The position of the professional social worker in long term care facilities is seen as key in working with family members of the cognitively impaired. The losses voiced by the adult children are bleak reminders of the devastation that occurs with these illnesses.
CHAPTER II: LITERATURE REVIEW

The Shift from Acute to Chronic care

Prolonged dying is a relatively new phenomenon, resulting from progress in medical science and the cause of death shifting from infectious disease to chronic illness. The context in which dying and death are experienced has changed dramatically. The overwhelming majority of deaths now take place either in hospital or care homes (Fulton, 1986). As a consequence of these developments, dying and death are primarily an experience of the aged and their families. Logue (1991) points out that aged women, the main consumers of long term care, are mostly affected. Legal, moral and medical experts have yet to resolve what the most humane treatment is for growing numbers "who cannot express opinions, implement a plan for their own survival, or even recognize where or who they are" (Kane, Kane, Reinardy & Arnold, 1987, p. 371). Others have argued that the quality of life and the individual’s perspective have been sadly neglected (Plough, 1986).

The powers of medicine cannot restore all frail elders to a reasonable quality of life either, so families and their dying relatives are left to cope as best they can within a system ill-prepared to deal with the problems it has created (Logue, 1991). Volkart (1957) states that death, and by implication disease leading to death, causes greater psychosocial impact on the family in North America than in other cultures. The emotional involvement is unusually intense due to the absence of the extended family. This loss of the extended family
increases the vulnerability of families because there is no way for emotional involvement to be dispersed.

**Women as Caregivers**

Research studies on the effects of caregiving for the elderly dependent in the community are numerous (Malonebeach, 1991). Studies that were firstly directed to the principal caregiver identified the physical and emotional burdens of caregiving. To a lesser extent, research has identified the effects of caregiving on the family unit. Brody (1986) states that while filial care has become normative, it too is stressful. The entire family is affected. Family stability is weakened by the added stress of caring for the elderly parent. Gottlieb (1988) makes the point that the term 'family' may well be an euphemism for 'women in the family' as it is the 'woman as caregiver' who mostly provides the day-to-day care to the frail elderly. The literature on caregiving cites the commonly referred to 'sandwich generation' as the fast growing group of adult children providing elder care. By far, daughters provide most of the daily care and support to the elderly parents. Daughters are more likely to assume caregiving responsibilities to elderly parents than are sons (Shanas, 1979). States Gottlieb "... In fact, middle-aged married women are the group of women who are most frequently in the work force (Bengston & DeTerre, 1980). The 'sandwich generation', or 'women in the middle' (Brody, 1981) are apt terms, although i believe a more realistic description would be a 20th century rack, since women are being pulled from the direction of their children, both young and adult, as well from their parents and grandparents, while they are also working outside
the home. The intensity of those pressures come not only from the practical realities of their home and work responsibilities, but from the life-long messages they have incorporated about these responsibilities" (Gottlieb, 1987, p. 4).

**Caregiver Stress**

Research has shown that caregiver stress is the most reliable predictor for admission of the dependent elder to a care home (Neundorfer, 1991). It was believed that institutionalization of the dependent relative would abate the stress of caregiving. The documented experiences of family members of institutionalized dependent elders reveals that one set of stressors is replaced by another set of stressors associated with institutionalization. Brody (1977) states that regardless of the need for institutionalized care for the relative, many caregivers experience tremendous guilt and perceive placement as a personal failure. George (1984) investigated the experiences of the families of institutionalized dementia relatives and found family members often feel a strong sense of continued responsibility after placement. She also suggests that continuing to watch the progressive deterioration of the relative allows no relief from emotional distress. Further, families face great difficulty in maintaining any sense of relationship with the individual who is so demented that he or she no longer recognizes family members (York & Calysnm, 1977).

Pratt, Schmall, Wright, and Hare (1987) reviewed studies by Wright (1986), and Zarit, Gatz, and S.H. Zarit (1981), that compared the well-being of community caregivers with facility caregivers. Wright's study revealed that caregivers to institutionalized patients had significantly higher mean scores for
chance control orientations reflecting beliefs that the world is unpredictable and uncontrollable. The study by Zarit et al compared the well-being of community caregivers with facility caregivers using Zarit’s Caregiver Burden Scale. Facility caregivers gave significantly high ratings to burden items that assessed concerns about not being able to provide continuing care and feeling they should do more. Significantly, these same caregivers related their own health as poor or fair and were more likely to report that caregiving had a greater negative effect upon their health status. Pratt et al conclude that both studies reviewed show how the stress of caregiving is not abated with institutionalization. As well, a study by Stephen (1991) that compared the stress of in-home caregivers and facility caregivers found there was no difference in emotional distress between the two groups. To date, there are no studies that investigate caregiver burden of family caregivers to patients with dementia in special care units.

According to Neundorfer (1991), there are few explanations for depression among caregivers. Levinsohn’s social model of depression found daily hassles and less social activity were related to greater depression. However, the caregivers of the institutionalized elderly experienced no lessening of depression when daily frustrations were removed and social activity increased (Stephens, 1991). In a 1985 developmental study, Pagel, Becker and Coppel did not find that caregivers perceived loss of control over life changes to be significantly correlated with depression. They speculated that knowledge of the continued deterioration of the Alzheimer spouse had greater impact on caregivers than life changes. Hence, it is possible that the loss (and the nature of the loss) of a
relationship with a loved one with a severely dementing illness elicits the universal human response of grief. Caught in a paradox of a living death, family are faced not only with physical deterioration of the loved one, but with the even more significant experience of a slow and painful loss of a close relationship.

Grief Theory

The earliest theoretical formulation explaining loss is generally credited to Freud, whose psychoanalytical perspective suggested that grief was a state where the ego of the individual survivor withdrew libidinal attachment from the lost object, but only with great pain. The ego after many attempts to recover the lost object eventually abandoned the effort, accepting the reality of the finality of death. However, the struggle to do so could be both prolonged and intense (Freud, 1917). Rosenblatt stated that "any theory that deals with human emotion, behaviour, interaction, or cognitive process can be a theory of grief."

He sees the major theory of grief as the theory of grief work, originating in Freud's work on grief (Rosenblatt, 1983, p. 32). It is 'work' in the sense that the process of grieving involves working through the pain of grief and coming to eventual resolution. According to the theory of grief work, losses are greater when there are more memories, hopes, and behaviour patterns to be disconnected from the lost person. States Rosenblatt, the theory implies that the most difficult losses are of people one has known for a long time and of people with whom one has had a complex rather than a simple relationship. Yet diarist data that Rosenblatt studied ran counter to the notion that the closeness of a
relationship (such as parent) is associated with greater grief over death. He found that when people no longer live together they begin to disconnect behaviour patterns and memories from one another.

Grief theory and the rate of grief work has been somewhat examined in the literature. The idea of reminders of grief originated with Freud. New memories or hopes suddenly come to the individual, creating a washing-over of grief. It is suggested that grief work is slower if one is out of contact with important reminders. On the other hand, grief work may not even be necessary in some instances if one stays out of contact with reminders of them. Gorer (1967) suggests that the process of grief work is slower when there are no mourning rituals to stimulate grief work. This was reinforced by the study that found that ritual facilitates grief work (Rosenblatt, Walsh, & Jackson, 1976).

There is evidence that all human beings grieve a loss to one degree or another. Psychiatrist George Engel sees mourning as similar to a state of healing. He asserted that the loss of a loved one is just as psychologically traumatic as severe physical injury. He argued that grief is a departure from well-being, and just as time is required for physical healing, so too is time needed for the mourner to return to a state of equilibrium (Engel, 1961).

With the Alzheimer and related dementing disorders, families psychologically lose their loved one. However, there is no recognized mourning as the relative lives on. Fresh grief surges with another loss of whom the parent was. The adult child may visit the failing parent more than if the parent were
well, and past memories can become constant reminders of what was. There is no communication with the parent. There is no future.

**Attachment Theory**

John Bowlby developed his attachment theory over a number of years. In 1958 and 1959 he presented theoretical papers on attachment, separation and loss that were eventually published in three volumes. His first volume, entitled, "Attachment" drew heavily on ethological concepts in describing the attachment behaviour of the young child to the mother figure (Bowlby, 1969). Bowlby stated that "Attachment behaviour is conceived as any form of behaviour that results in a person attaining or retaining proximity to some other differentiated and preferred individual, who is usually conceived as stronger and/or wiser. Whilst especially evident during early childhood, attachment behaviour is held to characterize human beings from the cradle to the grave" (Bowlby, 1979, p. 129).

Bowlby stated that attachment behaviour is directed towards one or a few specific individuals, usually in clear order of preference, and that the goal of attachment behaviour is to maintain closeness with the preferred other(s). These early attachments are not easily abandoned and readily persist. Even though Bowlby's central framework for his work was psychoanalytical, he broke from the psychoanalytical theories of dependency and orality that explained attachment as immature and pathological.

Bowlby defines caregiving as "Behaviour complementary to attachment behaviour and serving a complementary function, that of protecting the individual. This protective behaviour can be shown by one adult towards
another, especially in times of ill health, stress or old age. The sick parent/adult child dyad is an example of such complementary behaviour (Bowlby, 1980, p. 40).

His second volume, entitled, "Separation" discusses the young child's intense attachment to the mother-figure, and the child's dramatic response to separation from the mother. In this volume he describes his collaborative work with Robertson (Robertson & Bowlby, 1952) in which they identified three phases of separation response: protest (related to separation anxiety), despair (related to grief and mourning), and denial or detachment (related to defense), (Bowlby, 1973).

The third and final volume explored ways in which young children respond to a temporary or permanent loss of the mother-figure. While still remaining in the initial framework of psychoanalytic theory in his dissertation on loss Bowlby draws on cognitive psychology and human information processing (Bowlby, 1980).

Bowlby extended his work on loss to adults and brought the experience of loss into a forum of healthy grieving as opposed to the psychoanalytical belief that responses to loss were pathological in nature. He applies the term grief to the condition of the person who is experiencing distress at loss and experiencing it in a more or less overt way. Bowlby revoked the idea that loss is not intensely distressing and disabling.

Bowlby acknowledged that empirical data regarding how individuals of different ages respond to losses of different kinds under differing circumstances
are still scare. To date, caregiver studies have mostly been concerned with the caregiving spouse. The association of grief and dementia in the literature is almost nonexistent.

In summary, Bowlby developed a theory of attachment from the central concepts of attachment behaviour, separation anxiety, grief and mourning. He describes attachment theory as "a way of conceptualizing the propensity of human beings to make strong affectional bonds to particular others and of explaining the many forms of emotional distress and personality disturbance, including anxiety, anger, depressions, and emotional detachment, to which unwilling separation and loss give rise" (Bowlby, 1979, p. 127). His theory encompassed the whole life span with affectional bonds being developed first between parent and child and later between adult and child. "Bowlby’s attachment theory provides a way for us to conceptualize the tendency in human beings to make strong affectional bonds with others and a way to understand the strong emotional reaction that occurs when those bonds are threatened or broken" (Worden, 1991, p.7).

The Process of Grief

Colin Murray Parkes is well known for his research on bereavement. While working with psychiatric patients he came to realize how little was known about normal grief. Parkes studied a large group of widows in London, England, and charted the course of normal grief. He described grief as a process rather than as a set of medical symptoms, and developed the four stages of grieving. The first stage, numbness gives way to yearning. This is followed by
disorganization and despair, and, the final stage becomes recovery (Parkes, 1972). At any one time an individual can seem to be moving back and forth from one stage to another. Parkes who was involved in the founding of the modern hospice movement, uses attachment theory in developing programs for the emotional care of the dying and bereaved (Bretherton, 1991).

**Attachment in Adults**

The expression of some of our most intense emotions occurs with the beginnings and endings of our attached relationships. We form a bond as we fall in love, and grieve when we lose our partner. Attachment theory helps us to conceptualize our ability to make affectional ties. It also explains the anxiety aroused by threat of loss and the anger and sadness brought about by actual loss. However, there is little in the literature assessing attachment in adults.

The first efforts to test life-span implications of attachment theory were made by Parkes (1972) and Weiss (1975). They argued that the parent child relationship is normally complementary, with the parent giving, but not receiving, care. In adulthood relationships are usually more reciprocal. "The prototypical adult attachment relationship is structurally more complex, involving at least three behavioral systems: attachment, caregiving and sexual mating" (Shaver, Hazan & Bradshaw, 1988, p. 92). Love is a relationship referring to all three — love of parent is attachment, love of offspring is care-giving and being in love (intimacy and sexual relationships) is love of partner.

The impact of the severely dementing illnesses on personal relationships with family members has largely been ignored to date. In the 1980's, scientists
began work on issues of loss in a close relationship, defining a close relationship as one which is highly interdependent or nurturing. This earlier work focused only on divorce, but since then, research has expanded to include relationship loss through death and disease.

The Effects of Dementia on Close Relationships

The symptoms of the severe dementias gradually prohibit family member intimacy and or interaction. Rusbult (1987) developed a model to explain possible reactions to an unsatisfying relationship. The model included four coping strategies: exit meant ending or threatening to end the relationship; voice meant actively and constructively expressing problems; loyalty meant waiting for the relationship to improve; and neglect was allowing the relationship to wither. Blieszner and Shifflett (1990) ponder whether these concepts are applicable to the situation of the Alzheimer disease families. In their study, "The Effects of Alzheimer Disease on Close Relationships between Patients and Caregivers" the authors found that "Caregivers were saddened at the loss of reciprocal aspects of the close relationship. They were unable to complete the grieving process and focus on other primary relationships in place of the lost one because the relationship continued, though in a drastically altered form" (Blieszner & Shifflett, 1990, p. 57). They conclude that none of the models of close personal relationship pertain to the situation of non-voluntary relationship decline inherent in families with Alzheimer’s disease present.

In summary, the meaning of attachment in adults and relationship loss due to dementia has yet to be further researched.
Concept of Anticipatory Grief

Grief is the emotional response to loss of an attachment figure. The concept of 'anticipatory grief' may be described as the underlying phenomenon experienced by family members of the cognitively impaired individual. The term anticipatory grief was first used by Lindemann (1944) when he cited a case of the soldier returning from war. The soldier experienced a lack of love and intimacy from his wife. Lindemann concluded that the wife had so worked through her grief over his separation and possible death that she had completely emancipated herself emotionally. Since the 1950's, there has been an effort to study anticipatory grief systematically. Research has been divided between studies involving children and studies involving adults, and the balance between the two has shifted over the years.

Studies of children saw anticipatory grief as a way for parents to cope with prospective loss, whereas studies of adults concerned themselves with the value of anticipatory grief in the after-death grieving process. At first, anticipatory grief was thought to be harmful as well as benign, and that view, too, has shifted over time (Fulton & Fulton, 1971). According to Fulton and Gottesman, anticipatory grief has been confused with 'forewarning of loss', a perception that a death is likely to take place, but says nothing about the presence of anticipatory grief. According to the authors, anticipatory grief and adjustment to loss are complex subjective experiences not particularly amenable to quantification, where anticipatory grief has been defined according to the length of time of the patient's terminal illness (Fulton & Gottesman, 1980).
Glick, Parkes and Weiss, (1974) argue that anticipatory grief is not grief begun in advance. It differs from post-death grief in duration and form.

Aldrich (1974) noted that while some dynamics of anticipatory grief parallel conventional grief, there are dissimilarities. One difference is the end points of the two griefs. Conventional grief can continue for a long time, depending on the psychology of the mourner. Anticipatory grief is finite. The two also differ in terms of acceleration of grief. In conventional grief following death, bereavement decreases with time. The opposite is true for anticipatory grief, where loss becomes imminent. Ambivalence impacts differently on anticipatory grief than on conventional grief, too. In the latter, grieving can be prolonged because unacceptable feelings about the deceased inhibit conscious resolution. In anticipatory grief, the dying individual is alive and vulnerable, rendering ambivalent feelings (hostility) unacceptable. As a result, anticipatory grief can be denied.

Fulton and Gottesman (1980) state that anticipatory grief can be analyzed on three levels. On the first, or psychological level, feelings of guilt, anger, and despondency can be felt and expressed differently. On the second, or interpersonal level, the way in which family members deny or deal with the grief amongst themselves will affect their grieving. On the third, or socio-cultural level, the trend in modern society is to shy away from traditional mourning (Owen & Fulton, 1978). The role of the anticipatory griever is even more confused and problematic. It has never been institutionalized, so lacks norms for appropriate behaviour.
Through a review of the literature and her own clinical findings, Rando (1986) established what is and what is not anticipatory grief. She sees anticipatory grief as a complex and multidimensional set of processes, and she defines anticipatory grief in the following way: "Anticipatory grief is the phenomenon encompassing the processes of mourning, coping, interaction, planning and psychosocial reorganization that are stimulated and begun in part in response to the awareness of the impending loss of a loved one and the recognition of associated losses in the past, present, and future. It is seldom explicitly recognized ... The experience of anticipatory grief mandates a delicate balance among the mutually conflicting demands of simultaneously holding onto, letting go of, and drawing closer to the dying patient" (Rando, 1986, p. 24).

Rando's studies mostly concentrate on the terminally ill child dying with cancer, but she does shed light upon generic other adult terminal illnesses: "... the uncertainty ... or its relentless and persistent consistency; the steady debilitation ... the wish that the end would come. The period of time of anticipatory grief has become longer and more complex. The 'extra time is often filled with the painful witnessing of progressive debilitation over which there is no control" (Rando, 1986, p. 6).

She states that it is not valid to say that the process of anticipatory grief cannot begin because death has not taken place. Rando argues that the views of Parkes and Weiss (1983) and Silverman (1974) have put too much emphasis on the ultimate loss of death, with no regard for the many, many losses leading to
death. Rando gives as examples the loss of function and abilities, as well as the loss of sharing today and planning for a future which is now so unpredictable. Whatever involvement is possible is a goal of anticipatory grief, and she refutes the views of Parkes and Weiss, and Silverman who claim the phenomenon is impossible.

**Multidimensional Nature of Anticipatory Grief**

Rando defines anticipatory grief across the two perspectives of the dying individual and the family, three time focii of past, present, future and three interrelated classes of variables, the psychological, social and physiological. Only in understanding the perspective of the individual and the family, and the interaction between each person’s unique psychological, social and physiological situations set against the backdrop of time, can we truly understand the anticipatory grief experience.

A number of factors influence a person’s anticipatory grief. Psychological factors fall into three categories: the meaning of the relationship and the person to be lost; the personal characteristics of the griever; and the type of illness with which the griever must contend. Social factors also fall into three categories: the impact that the attitude and behaviours of the dying person have on the griever; the characteristics of the family and the family’s response to illness; and socioeconomic and environmental factors. Physiological factors, including the griever’s health, also have an impact (Rando, 1986).
The Family's Anticipatory Grief

Rando argues that family members experience three interrelated grief processes which she defines as follows: the first or psychological process that encompasses awareness and gradual accommodation to the illness, as well as the affective and cognitive states of grief; the second involves the interaction between the dying individual and the family members; and, the third includes family and social processes that take place as a result of the illness.

Notion of an Optimum Amount of Anticipatory Grief

Rando's empirical study of 1983 investigated grief and adaptation of parents whose children had died of cancer. The findings revealed further support for an optimum amount of time for anticipatory grief. Illnesses that were too sudden, too short, or too long, predisposed survivors to a poor bereavement outcome. Rando and Sanders (1982) found that where survivors were concerned, there appeared to be optimum lengths of time for a terminal illness. They discovered that survivors of death from short term chronic illness (less than six months in duration) fared better afterward than those surviving a sudden death or long-term illness (more than 18 months). The Alzheimer and related dementia disorders run a course of six to 12 years. Rosenblatt (1983) suggests long-term anticipation of loss may appear to result in less grief because the emotional exhaustion contributes to temporary numbness, suppression of grief, or even to relief that the long and painful struggle is over.
Anticipatory Grief and Dementia

Research investigating the anticipatory grief response of families of the cognitively impaired has been almost non-existent, but two pieces of work which look at anticipatory grief and family of the memory impaired individual are available. Austrom and Hendrie (1990) conducted a study comparing responses of caregivers looking after an individual with a terminal illness with responses of caregivers looking after an individual with Alzheimer’s disease. They found that the responses of caregivers looking after an individual with Alzheimer’s caregiver’s responses were similar to bereavement and anticipatory grieving related to other terminal illnesses. However, the intensity and duration of their responses were qualitatively different.

They concluded that even while grief associated with chronic illnesses is generally misunderstood by family, and that society offers no rituals to sustain the individual, it is even more difficult to understand the grief associated with the Alzheimer’s victim. What has died is the personality. The death of the personality is similar to Kamerman’s quasi-death experience which involves some combination of separation, termination and loss. Kamerman points out that the major difference between quasi-death and the real death experience is that in quasi-death one cannot count on as much social and ritual support (Kamerman, 1988). Both authors report that in cases of Alzheimer’s disease and related dementing disorders, anticipatory grieving has not yet been recognized or encouraged.
A second study done by Theut, Jordan, Russ and Deutsch (1991), was a first attempt at constructing an instrument to quantify anticipatory grief. In this pilot study Theut defined anticipatory grief as "a multi-dimensional construct consisting of anger, guilt, anxiety, irritability, sadness, feelings of loss, and decreased ability to function at usual tasks" (p. 114). The Anticipatory Grief Scale assessed the bereavement of wives whose spouses had been diagnosed with dementia. The wives completed the questionnaire that consisted of 27 items that would measure grief. The study provided quantitative data supporting the reports of caregiving spouses who experienced elements of anticipatory grief. The study concluded that anticipatory grief could well be the underlying construct of the spouse's response to a very tragic illness.

The review has addressed grief theory and how individuals are affected by loss through death of a primary attachment. It recognized that grief is a normal and healthy response to loss and that the grief of the individual unfolds through a process. Grief is described in stages. How and when an individual passes through each of those stages is unique to each individual.

The evolution of attachment behaviour and its lasting (although inactive) adult state provides a framework for analyzing an adult child's involvement with an ill parent. To date, there is no model that explains the affects of loss of attachment through non-voluntary decline (dementia) in close relationships. As a concept, anticipatory grief is put forth as the phenomenon experienced by adult children whose parents have dementia. Rando provides a framework for the adult children interviewed.
Grieving in response to loss is central to both grief theory and the concept of anticipatory grief. Yet, grief frequently goes unrecognized, except in extreme cases of death, war and disaster (Schneider, 1984). The loss felt by the adult children of individuals with dementia was painful. Rando has recognized the many losses that family endure over the time of these very lengthy illnesses. To date the literature does not recognize the companions of grief and dementia.
CHAPTER III: METHODOLOGY

Introduction

The inquiry into the phenomenon of anticipatory grief was pursued through an exploratory study. The term exploratory implies a field of study where little work has been done and little is known about the nature of the phenomenon (Patton, 1990).

While a considerable amount is known about anticipatory grief and palliative conditions of patients and family there is little in the literature regarding anticipatory grief and dementia. I was able to find only one study (quantitative) done by Theut et al that studied bereavement issues of spouses of patients with dementia. This study used a new instrument to measure anticipatory grief and suggested that anticipatory grief may be the unifying underlying construct of the spouse’s response.

I was able to find only one qualitative study that described the grief response of the Alzheimer’s disease family caregiver. This study used respondent questionnaires and accompanying letters and concluded that while many of the family caregiver responses were similar to bereavement reactions and anticipatory grieving of other terminal illnesses, the intensity and duration of the responses make them qualitatively different (Austrom & Hendrie, 1990).

I was unable to find any further data that addressed the association of anticipatory grief in the caregiver of family with dementia and this finding was reinforced by Austrom and Hendrie. I have been particularly interested in the response of adult children with parents with dementia since being a social
worker in a long term care facility and observing and working with adult children with parents in special care. Qualitative methods are particularly oriented towards trying to make sense of phenomenon observed, but little studied. Through the interview, exploration is made possible with the collection of descriptive information (Patton, 1990).

The following pages discuss the methodology of the study in terms of rationale, orientation, participant selection, data collection and analysis, and conclusion.

Interviews

Rationale

Life in a special care unit is often filled with the stillness of silence, the murmurings of memory or the agitation of anger and awareness. Memory and intellect have often been dismantled to a disarray of tangles and plaques, or become inept at the neural junction, or starved from little infarcts, or unforgivingly compromised from too much alcohol. There is no flow of language once rich in colour and texture. Families visit and so often say, "What do I say". Friends seldom visit. As the social worker of an intermediate care facility I observed the pain, the tears, and the hostility in some special care families. The outlook of family members did not seem to get better even months after their parent was admitted to the unit. This concurs with studies in the literature. George suggests that continuing to watch the progressive deterioration of the relative prevents relief from emotional distress (George, 1984). My own professional experience recognized grief of a protracted and
profound nature. I wanted to explore the notion of anticipatory grief. I wanted to hear from families' their own perceptions of the illness and how it affected them.

Qualitative inquiry provided a way to see if the phenomenon of anticipatory grief was evident in family of the relative with dementia. It provided a way to study in depth and in detail the experiences of the adult children whose parents were in special care. Qualitative inquiry is also appealing from a feminist perspective. The interview, consistent with feminist rejection of control over others, develops participant connection rather than imposing standardized tests and making participants responses' fit the predetermined responses of the researcher.

From the feminine perspective in qualitative inquiry, each participant's point of view is a valid source of knowledge for the researcher (Stanley & Wise, 1983). It is from material rich in the personal experience of these adult children that the findings, insights and understanding emerge. This is the essence of qualitative inquiry.

The environment was open to me to qualitatively interview the adult children. As social worker at the facility I was afforded the opportunity to get to know the family members and develop trust and rapport with them. The fact that I was able to interview all those adult children whom I approached I attribute to my being somewhat of a friend as well as an advocate for their relative. There is controversy in both mainstream and feminist thought regarding interviewing. At issue is whether the interviewer should be a friend or stranger to the people being interviewed. Denise Segura wrote about the
necessity of having a close relationship before the interview takes place. She found she had access to the people she wanted to interview, and that familiarity permitted her to do more focused interviews in a shorter period of time (Segura, 1989). The experience in this particular study supports her findings.

Orientation

The term phenomenology describes the type of inquiry carried out in this study. Phenomenology focuses on how we put together the phenomenon experienced so as to make sense of the experience (Husserl, 1913, 1962). "What is the structure and essence of experience of this phenomenon for these people" (Patton, 1990, p. 69). In this type of inquiry it is important to recognize the assumption that "There is an essence or essences to shared experiences" (Patton, 1990, p. 70).

The study also employs what Patton refers to as an orientational qualitative inquiry. "Orientational qualitative inquiry does not even attempt any pretence of open-mindedness in the search for grounded or emergent theory ... the inquiry begins with an explicit theoretical or ideological perspective that determines what variables and concepts are most important and how the findings will be interpreted" (Patton, 1990, p. 86). Thus, I have addressed those adult children sharing in common the experience of having a parent with dementia in a special care unit. Using a phenomenological point of inquiry, I have approached the study from the perspective of grief theory and the concept of anticipatory grief. I have assumed anticipatory grief to be the common human
experience shared by these adult children, and at the same time recognize that each person has their own set of experiences.

Participant Selection

The selection of the participants was purposive. Earlier in the university year, as part of a research project, I conducted a survey. An anticipatory grief questionnaire had been mailed to all spouses, adult children, and other family members with a relative in special care of the facility where I was working as social worker. At the time of the study, the adult children had the highest representation of family of relatives in the special care unit, and were the highest represented in returns of the questionnaire. Therefore, with this study, I purposively chose to interview only adult children. All those adult children who returned the questionnaire were contacted regarding an interview. I felt that the adult children could provide a richness and density of experience in this exploratory study that a random sample could not provide. "The logic and power of purposive sampling lies in selecting information-rich cases for study in depth. Information-rich cases are those from which one can learn a great deal about issues of central importance to the purpose of the research, thus the term purposive sampling" (Patton, 1990, p. 169).

While it is the cohort of women in their 50's and 60's who are providing most of the personal caregiving of the elderly, in this study gender was not the primary issue. I decided to include the token two male representatives to provide the best composite picture possible, while at the same time avoiding gender bias. Furthermore, feminist research is interested in rectifying research
biased by gynopia. Gynopia has been defined as the inability to perceive the existence of women or to perceive women in undistorted ways. I did not want to commit the same error by excluding the experience of the two adult sons (as small as the sample is).

Participant Demographics

Ten daughters and two sons were interviewed, all of whom had a parent in the special care unit. In the daughter category, there were two families of three daughters. Five of these daughters were married and one was divorced. Two other daughters were divorced and two other daughters were married. The two sons were single and had no children (see Figure i). All of the daughters but one had children. One son lived with his father. Fifty percent of the adult children had a partner and siblings (see Figure ii). The mean age of the daughters was 47 (range 37-54). The mean age of the sons was 46 (range 44-48). Seven of the daughters worked full time, two worked part-time (both married
with children) and one was a stay-at-home mother with young children. Both sons worked full time (see Figures iii a, b, & c). Over 50 percent of the adult children had university or other post secondary education (see Figure iv).

Data Collection and Analysis

The facility is governed by the Continuing Care Facilities Licensing Act. I initially contacted the Continuing Care Facilities Coordinator of the Vancouver Health Department for subject participation approval in the study. The Coordinator contacted the Director of Residential Care of Metropolitan
Vancouver and the Sunshine Coast, Continuing Care Division, Ministry of Health, Victoria. The Coordinator was informed that the Ministry’s position is that each facility is its own legal entity and therefore able to make its own decision regarding research involving facility residents and their families. I then met with the Administrator of the facility and discussed the proposed study as well as giving the Administrator a copy of the research proposal. The Administrator took the research proposal to the Board of Directors of the facility where official approval to carry out the research was granted. As well, the proposed study was submitted to the University of British Columbia’s Office of Research Studies for ethical review and approval.

Qualitative data were collected through open-ended interviews. To collect data from the interviews I chose the general interview guide approach. The interview guide consisted of six open-ended questions and provided me with the most freedom and flexibility to explore the individual experience of the adult child (Appendix A). A major advantage to the interview guide is that it facilitates establishing a conversational style that helps to put the participant at ease. This is in keeping with feminist thought, and according to gerontologist Kathy Charmaz, interviewing draws on skills from the traditional ‘feminine role’.
She refers to an open and understanding approach that allows for recognizing and responding to the other's feelings and being able to talk about sensitive issues in a non-threatening way (Charmaz, 1986).

By using the interview guide, I was free to adapt the wording and the sequencing of the questions as appropriate to the individual respondent and to the context of the interview at the time (Patton, 1990). The guide provided a way of exploring the experience of the adult child's response to the parental illness. The subject areas included in the guide were feelings, thoughts and responses, to the illness and, support, throughout the illness. They were chosen because of their links to the literature, particularly to the definition of anticipatory grief by Rando. As well these subject areas also seemed to best provide the means of exploring the adult child's experience. The words of the adult children provides the framework for the analysis as well as good internal validity. It is their story from their benchmark life experience.

The first pre-test interview was held with a spouse instead of an adult child. Unfortunately, at this time the eligible adult children for a pre-test interview were not available. The first interview was held with a male spouse in February, 1993 at a facility in a private office. The interview was taped and was one hour long. At this point of the research I had made the decision to follow the standardized open-ended interview approach. I had wanted to keep the interview highly focused due to the time limit of one hour per interviewee. With this particular interviewee I was well able to follow the standardized open-ended interview method.
The second pre-test interview was held with a female spouse in March, 1993 at the spouse's residence. The interview was taped and was one hour long. In this interview, the standardized open-ended question format had to be abandoned due to the anxiety and discomfort of the respondent. I decided the information would be more easily forthcoming from a more spontaneous base of the general interview guide. The questions were weaved in and out often in the form of a probe to a remark or description of some event.

I chose face-to-face interviews with the adult children rather than a focus group interview for two reasons. I was not prepared to handle what I considered too many unknowns in a fairly sensitive area of inquiry. I also knew very little about and had no experience in facilitating and conducting a focus group interview.

Twelve adult children with parents in a special care unit were contacted by phone. I requested a one hour audiotaped interview. The purpose of the interview was explained and the issues of confidentiality and no obligation to participate were emphasized. The twelve respondents all agreed to be interviewed. Only one daughter was unable to keep the appointment at the scheduled time, and a second appointment time was made. The interviews took place between July, 1993 and September, 1993. Due to the study's time constraints, I decided to interview the participant once only, and for a period of one hour. Although some of the interviews did run past the hour, I was not comfortable ending the interview if it seemed inappropriate at the time. While the participant number is small and allows for a richer and deeper
understanding of the phenomenon being studied, the generalizability of the study is greatly diminished.

The design of the study called for participants to be interviewed at the care facility in the same environment, thus reducing bias. This was possible with ten of the twelve respondents. (I met with the other two participants in their homes.) At the facility I met each interviewee at the front door and accompanied them to a private office. Before the interview commenced I clarified with each participant that the focus of the interview was their own personal experience of having a parent in a special care unit. I also reconfirmed their permission to audiotape the interview and reiterated that the interview would be held in strictest confidence. If any material was directly quoted or used in the thesis the participant would not be named but rather referred to as daughter or son. Each of the twelve participants signed a consent form with this understanding.

To put each respondent at ease I began each interview with a standard question that asked about some demographics of the illness. On my part, an open, understanding and receptive approach was vital to being able to engage the individual in conversation about the sensitive issue at hand. At an appropriate time during the interview I would ask the interviewee how she or he was feeling about the interview, and at some point I would indicate verbally to the interviewee that what he or she was saying was relevant and important. There were often times of tears in the interviews, and at these times, although I
extended sincere empathy, I consciously avoided slipping into the counsellor or social worker role.

I was sensitive to the personal nature of the inquiry. In each interview I was very conscious to recognize the degree of (or lack of) feeling, and to respond with sensitivity to assure participant comfort. At times I was required to ask a lot of follow-up questions, probing deeper into the individual's response. I attributed this to the difficulty some of the individuals had expressing their thoughts or feelings. At other times, I was uncomfortable with further inquiry, and it became a matter of professional judgement whether or not to probe further. A skilled interviewer can provide strong validity to a study, but if not competent can negatively effect the validity if the study.

Rapport, trust and sensitivity were key to the interview process. While I was empathic to the individual, I had at the same time to be neutral to the content of what the person was saying. My purpose was to gather data. Personal bias was a major concern, and it was particularly here that I believe that my keen interest in the subject could have coloured my perceptions. I at all times, however, tried to remain aware of the effect of bias.

The need for sensitivity to both the individual and the content required the freedom of the interview guide. I often found myself somewhat inarticulate in phrasing the questions because I was so acutely aware that I did not want to bias the responses of the respondent in favour of my own theoretical perspective. I also felt too sensitive to the moment some times, and this interfered with my phrasing of the questions.
Upon completion of the interview I thanked the interviewee and made sure she or he was sufficiently debriefed before ending the session. Following the interview I made cursory notes of my thoughts and impressions and any significant observations made during my time with the participant. I always felt very tired and emotionally drained after the interview. Often during the interview, I felt the sadness and loss that these adult children were feeling. Also, the sense of impotence that most of them experienced reinforced the helplessness I often felt in relation to the dementing illnesses. Within one to two weeks after the interview I wrote a short note to each interviewee, thanking them for their participation. This was very important for me to do this since I recognized how difficult it was for some of them participants. I have offered to share with them the results of my study and have assured them that I will be in touch with each participant at the completion of the study.

Subject area used in the guide were feelings, thoughts, behaviours and support (Appendix A). From a line-by-line analysis of the transcripts, a number of categories emerged, including awareness and accommodation to the illness, the concept of time, loss, lack of diagnosis, insidiousness of the illness, mortality, role reversal, role adoption, sibling relationships, and felt obligation. During the analysis of the interviews, some categories, overlapped with categories, and so in the final analysis were then collapsed under one major category. The data of the "special care category" particularly overlapped other categories throughout the interviews. In the final analysis, it was discarded. Throughout the interviews (mainly because of the interrelatedness of the many
processes of grief) there was a lot of crossing over, and the classifications of categories are by no means absolute. Through continued analysis, four major categories did emerge. The interview categories channelled into these main categories, namely uncertainty, loss, adaptation, and family relationships.

The concept of uncertainty accounted for the sense of not really knowing what was wrong and what was to happen to the parent. The feeling of loss of the parent in so many different ways was reiterated time and time again and consequently became the most dominant feeling throughout the study. Adaptation to the illness included all those responses of the adult child to the continuous mental and physical deterioration of the parent. The final major category, family relationships, represented the interrelationship between the parent, and the adult child, and included the effect on the adult child, sibling relationships, and the relationships of the adult child with community and health agencies.

Themes within each major category became evident as they emerged during the line-by-line analysis of the twelve transcripts (Miles & Huberman, 1984; Strauss, 1987). Under the major category of uncertainty, a consistent theme was how much more confident and competent the adult child felt in care of the parent once a diagnosis was established. This was consistent with the literature that states that prior to Alzheimer disease diagnosis, adult child caregivers were frustrated, angry, embarrassed and hurt. Following diagnosis they felt more patient and understanding of the affected parent (Blieszner & Shifflett, 1990). Under the category of loss, a consistent theme was that the loss
of the personality of a parent was very difficult for the adult child to handle. It was difficult, if not impossible, to maintain a relationship with the severely demented individual. This concurs with the findings of York and Calysnm (1977). Under the adaptation category, a consistent theme was the adult children’s sense of parental violation as human dignity was gradually lost through the illness. This addresses the ethical and moral issues associated with the Alzheimer and related dementing disorders raised in the literature (Logue, 1991). Under the family relationships category, it was interesting that none of the adult children had attended a caregiver’s support group. They preferred, instead, to seek support from within the family, a close friend, or colleague. The effectiveness of support groups have been varied. Measures of caregiver’s feelings of burden, stress and sense of well-being have not shown significant changes (Haley, Brown and Levine, 1987).

These four major categories all channelled into the one overriding theme of anticipatory grief. This central theme was evident throughout the interviews as the various interrelated processes that define anticipatory grief were heard from the inner life perspectives of the adult children.

Conclusion

The words of the adult children were used for the analysis of the data collected through open-ended interviewing. Throughout the interviews, great care was taken to respond with respect and sensitivity while at the same time gather information in the least biased way possible. The choice of the use of the interview guide and the subject headings in the guide proved to be fruitful in
drawing out the various component parts that comprise anticipatory grief. What emerged from the analysis of collected data were the parts of the whole that eventually flowed into one central theme, anticipatory grief.
CHAPTER IV: FINDINGS

Introduction

Anticipatory grief experience is unique and is determined by a combination of interrelated and often overlapping processes. The findings from the analysis of the interviews are presented under the headings of the main categories that emerged in the study. The core categories are uncertainty, loss, adaptation (to the parental dementing illness), and family relationships. They provide the framework for analysis of the adult child's experience.

These categories form a common pattern amongst the adult children, and are indicative of some of the properties of anticipatory grief. They, therefore, lend support to the suggestion that the adult children experience grief. The interrelatedness of the categories and their subsequent themes illustrate anticipatory grief as a multi-dimensional concept.

Uncertainty

There was a vast discrepancy in time between the initial symptoms and the actual diagnosis of the parent's dementia. One daughter related "... the diagnosis was very slow, and it wasn't a diagnosis for a long, long time, and I think that was really hard ... I didn't know what to expect or what was going on ... he just kept mentally deteriorating...".

Another daughter said her mother felt
... terrified because she was alone ... she never told anyone, you would just watch and see this happening. We didn’t know what was wrong and that was the scariest thing ... could she get better? what was going to happen to her?

Still with no confirmed diagnosis and too much at risk in the community her parent had to be admitted to a facility. The facility staff had

... accused her of all different kinds of things ... it was terrible for my mother and horrible for us ... I would go and find her locked up in her room, just terribly upset because she didn’t know what was wrong ... she really didn’t know what was happening to her...

As well, she recollected tearfully,

... I would bath her and put her in bed and pray that it would be ok. I had to go home and go to work ... that Home kept saying they weren’t equipped to look after her ... and she was way up there on the eleventh floor, she could open her sliding door and go right off. I kept picturing her going out there...

The majority of the adult children reported that the diagnosis of the dementia in their parents occurred one to two years prior to their admission to the special care unit (see Figure v). For most of the adult children the diagnosis accompanied a parental crisis that necessitated medical intervention.

Most of the adult children stated that the insidiousness of the illness created uncertainty. After some time, one son "... suddenly woke up and realized that something actually was wrong with his mother" and by all accounts, was shocked. The symptoms are that insidious at the onset of the
The protracted length of time of the illness evokes uncertainty in the adult children's lives. From the recognizable onset of the illness there are no measurable signposts that indicate for how long or to what degree the adult child will be involved in the care of the parent. The adult child is left to wait and see as the disease unravels the parent. For a period of time some daughters spend a portion of every day with a parent. Others provide consistent and regular bi-weekly and weekly support to the caregiving parent as well as to the affected parent. Some travel many miles on a frequent basis, particularly as the home situation of the parent starts to deteriorate to the point of crisis. As the illness progresses, the adult child feels uncertain about leaving the parent for any length of time, fearing a potential 'at risk' situation that might arise.

The nature of the progress of the disease and its many ramifications evoke perhaps the most uncertainty. For these adult children, there is a cruel irony of the predictability of a succumbing life. The adult children know the disease is progressive, but they do not know what further physical or mental assault will
befall the parent. They do know the parent will become more frail and more dependent, but they do not know when and to what degree. Said a daughter "...I don't want to see him suffer any more...I would hate to see him tied in a wheelchair and I know that will come...". They do not know what will be targeted next and what the consequences will be. The parent will die but when and in what state or situation they do not know. Stated a son "...I don't know how he will die. The others hurry up and die. I worry about when he gets to that stage...."

Loss

The feeling of loss was pervasive throughout the interviews, showing expression through the heaviness of silence, the quietude of tears, but mostly through the nuance of disclosure. Loss includes a past, present and future (Rando). Shared activities of the past, now no longer possible, were recalled by most of the adult children. One son, an engineer, missed the sharing and discussion of scientific knowledge with his father. He missed his father's expertise and advice. A daughter expressed the loss of the close connection she had with her father through their mutual love of music. She said, 

...music is my life and it was really important in his life too. You know once a week we would get together and compose and we would have tapes in the house and huge stacks of handwritten music. I would write music. He would write the lyrics and I would copy down his notes. I miss those times...
Another daughter related how she had learned some of the Icelandic language as a teenager. Her "Poppyin", himself an Icelander, would encourage her and together they would have an exchange in the Icelandic language. "...We would go back and forth and you know he used to enjoy that...".

Limitations placed on the life of the adult child, or loss of a certain lifestyle mean that something has been taken away because of the illness. A son who lived at home with his parents recalled how he and his father gradually took over the household chores, and how his father looked after the personal care of his mother,

...it was an awful strain on both of us...there was a point there where he couldn’t go anywhere unless I was home, so we would arrange it if he had to do something I would be home...couldn’t leave her alone...

One daughter married with young children visited her father at his house every day for six-and-a-half years. She would take two weeks holiday each year. Towards the end of her father’s living at home this daughter would sometimes visit twice a day, morning and evening. She would help get her father ready for bed.

Particularly difficult losses for these adult children are the ongoing physical and mental losses of progressive debilitation of the parent with a dementing illness. The parent is slowly reduced to a shadow of his or her physical self. The sense of balance and coordination gradually becomes greatly diminished. The parent falls and suffers bruises and sometimes cuts that require
stitching. The parent slowly loses control of the elimination processes. The parent who has Parkinson’s disease drools, and often walks with a shuffling gait or becomes awkwardly immobilized in walk. The parent’s ability to eat, to wash, or to dress slowly diminishes. There is no reprieve.

These losses are enough in themselves, but the loss of the personality is even greater. The emotional and intellectual loss of the parent is the most difficult and causes the most pain for the adult children. They have lost the most primary of attachments, and with that loss goes too some of their own history. For most, a fleeting moment of the ‘old’ parent or a time of the slightest recognition by the parent gives the adult child bitter sweet respite. A son related,

... the way I see it is. of all the things that could happen to a person, this is one of the worst...as a person she has gone, but physically she is still here ... it’s always on your mind ...I don’t think she knows me ... you know I just wonder on the outside chance that she might recognize me a bit, she seems to get to a point where she might recognize me a bit and then not the next time...

Eventually there is no recognition of the adult child, only blank stares from vacant eyes. A daughter stated,

...people sitting and kind of staring and him starting to do the same thing, I find that quite a change and a shock ... it upsets me because it’s showing the emptiness of thought and action and desire and all those things not there any more...
The adult child grieves for losses yet to come. They know their parent will become more frail, more dependent, more vulnerable, more intellectually lost. A son when asked if his father recognized him, said,

... that is still something I have to cope with because he still recognizes me not always as a son, but he always recognizes me-- and he is always happy to see me...I think that will be hard...

As well the adult children grieve the loss of future times with the parent. Some mentioned not having grandpa or grandma as part of the family and part of family celebrations like birthdays and Christmastime. Some expressed regret over being unable to enjoy future activities with the parent, such as taking the parent to a favourite sport or entertainment event.

As well, the adult child grieves future losses on behalf of the parent. Prior to the interview one son spotted a picture of his father on the residents’ bulletin board at the home. His father was standing beside a piece of woodworking that he had helped to create. His father had been an engineer. The son became tearful as an emotional chord was struck. The realization came that never again would his father be able to do what he loved and did so well, designing and building. This same son, in a thoughtful attempt to share with his father the death of his mother said,

...after my mum passed away I went up to the hospital there and took him out and got some rum and coke, that was his drink, so we sort of had a toast. I thought that would be the best way to kind of impress the home situation...
His father did not understand. At this poignant time, the son became tearful. The realization that there was no 'family' left for either one, and thus no future for the family, was suddenly reinforced as he told his story.

For half of the adult children the future death of the parent is experienced with degrees of ambivalence. Once the parent has lost awareness, or any sense of life enjoyment, or has become totally dependent on others, the future can then hold a welcome death. Death can provide relief and finally release the perceived suffering of the parent and the experienced suffering of the adult child. Yet death also means finality and goodbye. One son suffered with the lengthy duration of his mother's illness, feeling the Alzheimer's had cheated his mother of life for the past five years.

...people shouldn't lose their mind shouldn't be subjected to that...they should go out with their own personality, it seems to me a real waste...everybody goes eventually it has to end...you almost would like someone you love you know to live forever...

Some daughters clearly stated that death was the kindest release. For some adult children, death was inevitable but when it would occur was not their concern. Some left it in the hands of God, others felt the parent had a strong will to live.

Adaptation

Awareness and Gradual Accommodation

The study found initial awareness and gradual accommodation to the illness was variable among the adult children. Taken from the adult children's
interviews, factors included marital status of the ill parent, doctor response, nature of long term care involvement, mental health of the parent prior to onset of illness, awareness and response of the affected parent, degree of caregiver spouse disclosure about the affected spouse, health of the caregiver spouse, geographical location of adult child to parent, number and relationship of involved siblings in care of the parent, adult child’s access to information about the illness from formal and informal sources, adult child’s experience with dementia, self education, and psychological readiness.

The onset of the dementing process is very slow. The ‘forgetting little things’, a slip in a previous area of competence, or a slight change in the character of the parent were gentle nudges which made the adult child aware of the process that was beginning to take place. Throughout the study the adult children used similar phrases to describe the illness, such as, "it was very, very slow," "it was a long, long time", "it was just so gradual". All perceive the course of the illness as a slow, gradual deterioration over many years. Stated a son, "...the deterioration just seems to be a slow curve downwards...the grieving has been spread out over a period of years...".

Awareness of the illness was deepened with time as "things got worse and worse" or "things just got so bad" or "as things went on it got more and more stressful" or "it happened so gradually that I guess you find you don’t notice it until it got fairly bad". A daughter who lives out of town recalls that it was after her father’s car accident that she really noticed changes.
...he didn't know my name and didn't know who my mother was...in the morning he would say there was a man in the bed from the night before...that was the first time it really hit me...that things had really progressed...

A daughter said of her mother,

...her 'garbage' talk, that bothered me the most...it bothered mum so much at the beginning because she was really trying to communicate, and she seemed to know what she was trying to say...the responses she gave you and the look on her face and her eyes and that was she couldn't understand why you couldn't understand what she was saying...

Often a crisis would impress upon the adult child the deepening seriousness of the illness. A daughter gave the example of being called over to her parent's apartment by the landlord. Her mother was hallucinating, had a knife, and had barricaded herself in the apartment. Another daughter told of being fraught with fear when her mother did not return from a ferry when expected. The daughter spent the next hour frantically contacting the authorities in the search to find her mother.

The slow physical deterioration of the parent and the gradual loss of the parent's personality affords the adult child accommodation to the losses. One daughter stated about the relationship loss with her father, "... it passes all with time ... it was such a gradual thing..." Another daughter says,

...I remember the loss of recognition. It was kind of gradual...you had to go over and over who you were
and then all of a sudden she would know you the next time...

As the descent slowly continues and the parent slips into an abyss, the adult child prepares for the final loss, the physical death of the parent. All adult children expressed a certain degree of preparedness when they voiced the acceptance that death of the parent was inevitable. Most said there was no hope of recovery.

**Emotional Adaptation**

Acknowledging experiencing and managing the emotional reactions to the demands of the dementing terminal illness is part of anticipatory grief. Feelings of denial, fear, uncertainty, anxiety, anguish, sorrow, depression, despair, frustration, resentment, anger, guilt, hypervigilance, and exhaustion were experienced. Different feelings would surface and recede depending on the phase of the illness and the experience of the adult child. For example, some experienced denial with the initial onset of the illness. Says a son,

...the family kind of discounted it because it really wasn’t noticeable. Mum, she sort of hid it. None of us talked about it...

Coming to accept the reality of their parent’s illness was harder for others. A daughter shared,

...I guess for the longest time I didn’t believe it and I went along with her. When she said ‘I’m getting better aren’t I?’ I felt, YES YOU ARE...how much did I
actually believe? I think I believed quite a bit...I wanted her to get better...

Anger was frequently experienced. Said one daughter "...I would get mad, like really angry, because she wouldn’t take her pills, she needed them and she couldn’t see it...". Another daughter said, " I get angry with myself sometimes because there is nothing I can do about it...sometimes I think I feel angry, too, because he is going on and on like this...". One daughter said of her mother

...she was suffering...she would look at me with terror in her face and she would say ‘I’m not going crazy, am I?’...I used to think, why doesn’t it hurry? Why is this phase going on? This is cruel...I could imagine how she must feel...

Another daughter spoke of her anger with the medical profession and how she felt they overmedicated her mother. She believed the drugs had done irreparable damage to her mother..."you really blame the system, you blame the medical doctors that all they do is give an elderly person a pill...". Tearfully a daughter said, "...I am really angry...I think I’m angry, I miss her yes I miss her and I hate to see her like this, I hate it...".

Adult children also experienced guilt and self reproach for feeling that they had waited a little too long before getting their parent into care, for feeling resentment because of the heavy burden they felt, for not being attentive enough, for not spending more time with the parent, for not seeing what was going on, for not visiting enough, for not doing enough for the parent. A daughter tearfully says,
...I do feel guilty, I really do... she would have talked more... would have talked on a one-to-one. She would have been brighter and she would have been more aware she could have kept doing a lot more things for herself. I don't know where she would be today... I've lost her now...

Once placement had occurred, all of the adult children felt relief that finally the parent was in suitable care. For most, the special care unit meant safety and security for the parent and the end of interrupted and sleepless nights for the adult child. As well, placement represented a more predictable and consistent parental life pattern. The end had come to emergency visits to the hospital from home, frequent hospitalizations and returns home, and temporary institutional accommodations until the care facility of choice was available.

One daughter related, "...it was a great relief to get him out of hospital because there was part of watching him be so confined...to have the freedom to walk around...". Another daughter stated,

...he ended up in hospital and then he came here... it was those mixed feelings of relief and guilt... we were worried when he was in hospital we were never going to get him out of there... he could have died in there, he wasn't moving around... he wasn't happy... we wanted to see him settled in a family life environment... we just couldn't accept that was going to be the best we could do for him... we still kept hoping that something would break at the home...

However, even with the relief of admission to the special care unit guilt continued to haunt some of the adult children. Some felt guilt for the personal violation that had happened to the parent. Others experienced feelings of
having abandoned the parent, and wondered if they should take the parent home. When one daughter would visit her father he would say, 'oh, you've come to take me home'. She said "...that was horrible it was ghastly...I felt I was abandoning him...I had left him where he felt he didn't belong...".

Another daughter said,

...I hate to leave. Sometimes on good days...he asks, 'when are you coming back?' and that really causes you to think, because you think, how often does he feel like this? and how long does he remember that I was here, and miss me? and you're going off in your nice car to your nice home and all your comforts...

A son says he often has feelings of abandoning his father.

...tough time...he hates to see me go, even when bringing him down there after a six or seven hour drive...similar kind of feeling when I take him out going to have to leave he is on one side and I'm on the other side...

As the illness progressed with the parent in special care, feelings of loss and sadness dominated the emotional experience of the adult children. For all adult children feelings of hopelessness and helplessness accelerated as the illness continued. As well, feelings of anxiety and sometimes anger would heighten when a parent fell ill with an infection, sustained a fracture, stopped eating or entered a phase of the illness where the parent became more agitated, more angry and (consequently less accessible to the adult child).
One daughter said of her father's condition,

...there is no hope even if you go visit someone in hospital there can be some future coming home and getting on with their regular life and there is no chance of that: it's utterly hopeless and it strikes you every time you come and visit...I feel depressed after each time I leave the unit...

She related how on a weekly basis, she visits her father with her mother. She said, "...we go home we talk about it and then you think about it all night and I don't sleep and then I have to go to work...".

Another daughter related

when I leave the unit, then I can let down my defenses, and once I've gone, then you can start thinking about everything...it overcomes me, I just want to cry...you just feel a great sadness and loss it's like you're always grieving...it just seems you're always sort of mourning though the person is here...

Reflecting her own feelings, a daughter states that,

...I don't like coming here at all. Sometimes I leave and just get in the car and cry. I used to feel more guilty about not coming here so often, but I thought to myself, there is no point, he isn't benefiting and I'm deteriorating myself...it just gets too heavy...dad has gone, but I still have to go and visit...Its a horrible chore again, and then I feel bad...
One daughter, devastated by the deterioration of her mother, tearfully and angrily reflects,

...they had that strike ...the activity workers couldn’t have anything to do with her... and mum, something happened to her hip and she wouldn’t allow anyone to touch it ...I really feel strongly that she didn’t regain one hundred percent ... she just went from almost night to day, she has never come back, and then all that construction, those things all affect people... [she says] ...there is nothing there now ,she grasps my clothes and yanks me to the door, when I go to see her she says you’re a terrible person...she won’t let me touch her, can’t take her out, can’t do her hair, can’t even talk to her. She won’t let you...

All of the adult children acknowledged that it was going to be painful when the parent finally died. A daughter shared,

...I know that things go their natural progression. We are going to lose him physically too, we have lost him mentally already, and that is going to be very tough to go through ...

Another daughter tearfully said, "...I know I’m going to fall apart when he dies..".

Cognitive Adaptation

For most of the adult children, there is a heightened preoccupation with and concern for the parent now and in the future. They recollect their own past losses, and in this group of adult children, there were many. For example, one son had lost his sister to cancer a year ago and lost his best friend ten years ago.
Since the onset of the parent’s illness four of the adult children had lost their other parent.

They had all contemplated their own existence and their own death. All were verbal about their own personal death as they watched the deterioration of their parent. They identified with the process and wondered if this, too, would be their fate. A daughter relates that her husband’s father died of Alzheimer’s, and said, "...I have a mother like that ". She said her husband dreamt the other night that, "both of us got Alzheimer’s". None of the adult children talked directly of themselves moving up the generational ladder to be the next to die, but this was inferred a number of times throughout the interviews. Most made reference to the idea that they would not want to put their own family through what they as adult children had gone through and continue to go through.

When asked what they would do if they developed a similar dementia, eight of the adult children said that they would want to end their own life at a time of their choosing. One adult child clearly stated, "...I don’t think the quality of my life would have to be as anywhere as near affected as my mother’s is before I would take my own life...". Another daughter referred to the Julie Atkins case, where the physician assisted her suicide. She said, "...I think that is a good choice, I really do...". Two of the adult children were just as clear that life is not to be taken. One adult child said, "...people go when they go like naturally: there is a time for everyone...". This adult child would put personal affairs in order, and when necessary, go into care.
All the adult children believed that their parent had very little if any quality of life left once the parent had reached the stage of admission to the special care unit and the illness continued to take its terrible toll. They experienced the pain of a life with little or no dignity. Most questioned the purpose of that life. One daughter stated, "...I would like to see my mother die. There is nothing for her now. There is no joy...". A daughter concerned "what people are reduced to in the end" reflectively summarized what most of these adult children said or felt:

...the relationship has been destroyed, has gone, and I can’t get it back...that has gone for ever...it felt almost like a death, but it isn’t a death, and I don’t like seeing him go through this...part of me wishes that he could let go...there is no life...the quality of life has completely gone...

Behavioural Adaptation

Anticipatory grief implies many interpersonal processes with the dying patient (Rando, 1984). One such process is continued involvement with a loved one. It is thought of as a time to nurture a relationship with the dying person, to resolve old hurts, (and perhaps to intensify attachment), and to help the dying person prepare for death. This, however, is not possible for the adult child with the dementing parent. There is no memory. Reason and judgement lay fallow. So what does the adult child do? In this study, the adult children’s commitment to the parent resulted in dedicated involvement throughout the entire illness.
This process of involvement was a common theme for most of the adult children. Eleven out of the 12 adult children interviewed have remained involved with the parent since the onset of the illness and over the duration of the illness, even though the parents no longer recognize their adult children. They have remained as involved as possible with the parent, promoting whatever kind of communication, interaction, control and dignity that remains available. They have financially, socially, physically and emotionally focused energy on caring for the parent.

The adult child’s involvement has varied according to circumstance and parental need. They have arranged for the sale of their parent’s home. They have attended the funeral of their other parent. They have taken on such onerous tasks as applying for and becoming the Committee for the parent. They have withstood criticism from other family for ‘not taking action sooner’. They have left their house late at night in response to calls from the security guard that their father is at the gate and can’t find his way back to his apartment and won’t let anyone help him. Some became confidantes and a great support for the caregiving parent. They have had to do painful things such as initiating the process to have the parent’s driving licence revoked. They have been their parent’s advocate, making sure the parent receives proper medical care. They become hypervigilant when the parent shows a change in behaviour or a deterioration in physical well-being.

Whether the parent was at home or in care, the adult children have remained as involved as is possible. On average, 11 out of the 12 adult children
visit weekly. Throughout the illness, the adult child not only must face the awareness and accommodate the reality of the deterioration of the parent, but must also learn survival behaviour. The adult child must learn to respond to the parent in ways that show understanding for the deterioration of the parent's behaviour. One daughter related that she would take her father shopping,

...but it got to the point quite quickly where I would take him shopping, and he would buy a few items, and then I would take him back home, and then I would have to go shopping by myself to buy all the groceries because he didn't really want to spend any money...

They must learn not to respond personally to the hurts they can experience from the assaults of the illness manifested in the parent's behaviour toward the adult child and others. A daughter related how a staff member had told her that her mother would push some of the people she lived with. "...that's horrible, pushing, but that is part of Alzheimer's...". Talking of her mother's behaviour towards herself she says tearfully,

...she didn't say I was terrible last week. That is the first time probably in three months that she hasn't been horrible, grabbed your clothes...she actually takes me to the back door, opens it, and says goodbye...you have to have pretty thick skin...it really hurts...you have to keep busy when you leave...

Responding with behaviour appropriate to the illness requires great strength from within (not always available to an adult child already feeling vulnerable) and support from outside (not always there). The most difficult challenge of
all, however, is balancing between letting go of, and holding on to, the fading parent. Adult children often have to fight with themselves to keep from visiting as frequently. (So often the question asked is what is the point?). Often the visit seems to make little or no difference to the parent. Yet, at other times, a glimmer of the 'old' parent makes the adult child want to return sooner than later. The shroud of guilt of parental abandonment entangles and convolutes the psyche as the adult child retreats, but must later return. Says a daughter, "...I have to come...I have to see how she is ...".

Family Relationships

According to Rando (1984) and Worden (1991), anticipatory grief stimulates a number of family and social changes that illustrate the loss of the person in a social context. What was found in this study was changing roles and new family configurations.

Role reversal, whereby the adult child slowly starts to take charge of the parent’s welfare, was a major family theme. The adult children were very uncomfortable with the role change that became necessary as a result of the parent’s illness. They deeply felt the loss of control and independence that the parent would experience. A son tearfully related how his father

...in his own house forgot to drain the water and the pipes all froze...and I would want to help and while he was still there it was his kingdom and I didn’t feel able to usurp his authority ...I would have to let him do it and it got so I would go up there on weekends and work on things a bit at a time ...
A daughter who was the sole caregiver for her widowed father relates,

...then I was terribly worried about his driving...the car meant everything to him and finally I took the keys to the car myself, but I was a dog. He would stop people in the street and say, you see this person? she is my daughter and she has taken my car. I died but I knew I couldn’t give him back the keys...I always felt guilty, guilty when I took away his control over things...I found it very hard to tell him not to drink because he was my dad. I shouldn’t be telling him what to do...

The role reversal created conflict for the parent child relationship norm. A daughter related of her father,

...he was a very strong person...everything was for you when you’re growing up...he was always the one that was supportive and now it was sort of about-face and you’re the one that does the nurturing, you become the parent, literally and so that was sort of an adjustment to make...I guess you have sort of resentment, too, because you’re used to the roles being the other way...that person isn’t there the way they used to be...

For those families where there was more than one adult child, the family would reorganize itself in carrying out the responsibility of caring for the parent and the caregiving spouse. For some, they would try to follow a consensus model regarding care decisions, but consensus was not always achievable, and conflict would erode the sibling relationships. For others, one adult sibling would be chosen as the main co-ordinator of care and would communicate progress of care to the other family members. This adult sibling assumed this
role because of being the oldest in the family. The adult siblings seemed to naturally want to assume certain care roles, such as offering to ‘walk the family through’ the decisions and the emotions, acting as an advocate, providing personal care to the parent, acting as friend and confidante, or being the main support to the caregiving parent, or by being the consistent visitor to the facility.

All of the adult children inferred a sense of familial obligation and duty to take on the responsibility of caring for the ill parent in whatever way was necessary. This sense of obligation was expressed as a reciprocation for parental care given to the adult child over the years. A daughter who had sole responsibility for her father stated that, "...I was the only one left to give to him ... I just felt that it was a duty...". Another daughter responsible for both her mother and father (both in different care homes) reflected about her father,

...it’s an obligation I think, it’s so built in with family that you have to visit. So, for whatever reason, you go just do it. There is a responsibility, an obligation, he is a family member...

Another daughter related about her father,

...he would go to whatever means to help you out and so I feel a commitment... so whatever we can do to make things easier for him...I think back when you’re growing up and now it’s time for you to do something...
Conclusion

"Definition of scientific phenomena should be based on the phenomena as we see them. We have no business to base our definition on ideas of what we think phenomena ought to be like" (Pantin, 1958 in Bowlby, 1980, p. 7). The grief of the adult children shares some similarities with anticipatory grief as cited in the literature. However, what resonates throughout this study is that the adult child's grief is qualitatively different from the traditional anticipatory grief brought on by palliative physical illness.

The adult child is primarily grieving the loss of communication with the parent, yet the parent lives on. The mental deterioration of the parent over which the adult child has no control creates the non-voluntary nature of the loss.

Feelings of pain, sorrow and devastation were predominant for the adult children. They empathize and grieve for what the parent is losing and for what they see as a violation of the parent as the disease continues to take its terrible toll. They are helpless in their bystander role. They say there is no hope. The illness allows no quality of life for the parent in the last stages which require special care residence.

The grief of the adult children is both chronic and acute. For over a decade they have adapted to and accommodated loss, their own and that of the parent. They have watched the slow deterioration. Plateaus do not last. Things only get worse, and at points along the downward curve of the illness, the adult child experiences a resurgence of acute emotional grief.
Grief associated with these dementiac is more protracted than with any other illness. There can be no closure until the death of the parent, 10 to 15 years after the onset of the illness. Indeed, full closure may not occur even after the parent’s death (Mace, 1991).
CHAPTER V: SUMMARY

The purpose of this study has been to explore the phenomenon of anticipatory grief to account for the experience of adult children with parents with dementia. A qualitative approach was taken and 12 adult children were interviewed to hear from them their experiences. The data from these interviews was examined to identify themes indicative of anticipatory grief.

Studies of anticipatory grief are associated mainly with physical death that occurs within a relatively short period of time and has a clear progression towards death. Literature that specifically addresses anticipatory grief and dementia is scarce. This study was an attempt to further add to the literature pertaining to the concept of anticipatory grief and to address singularly the anticipatory grief of adult children caregivers.

Out of 12 adult children who were interviewed, 10 were daughters. The caregiving literature often cites the sandwich generation, or women caught in the middle as the fast growing group of adult children caregivers providing child, family and elder care simultaneously (Brody, 1981). The women in the study were being pulled in different directions of work, home, and responsibilities for aged parents (Gotlieb, 1987).

The adult children in the study felt relief when the parent was placed in care. yet, as caregivers, they found no lessening of feelings of depression. The findings are similar to those of Stephens (1991). In addition, the adult children continued to feel responsible for the parent following facility placement. This was reflected in the regular number of visits to the facility. All the adult
children visited at least once a week and some visited twice a week. Two out-of-town daughters visited twice monthly, travelling four hours each way. In a similar fashion, George (1984) investigated the experiences of family of institutionalized relatives with dementia and found family often feel a strong sense of continued responsibility after placement.

A number of the adult children experienced feelings of guilt following placement, even though they knew there was no other choice. They felt they had abandoned the parent or felt guilt for enjoying their own lives. Brody (1977) also found that regardless of the need for institutionalization, many caregivers felt guilt and perceived placement as personal failure. One daughter felt her parent would not have deteriorated so much if she had looked after her at home.

All the adult children experienced feelings of uncertainty. This was consistent with the findings of Wright (1986) whose study showed that caregivers to institutionalized patients reflected beliefs that the world was unpredictable and uncontrollable.

Part of the adult children’s uncertainty was created by the knowledge of how, and at what stage of the illness, the parent will die. From their study, Pagel, Becker and Coppel (1985) speculated that caregivers were more likely to have feelings of sadness because of prior knowledge of continued patient deterioration rather than concerns over loss of control over life changes.

The grief for the continuous loss of dignity that the parent endures created feelings of sadness, pain, and devastation. As well, adult children had their own sense of loss, the greatest of which was loss of the relationship.
Bowlby’s attachment theory helped to explain how as infants we make strong affectional bonds to preferred others, how in most cases our first attachments are to our parents. Although generally these early attachments become modified in adults they usually persist. When these bonds are threatened through loss we have strong emotional responses. The words of John Bowlby say so well what the adult child experiences. "Loss of a loved person is one of the most intensely painful experiences any human being can suffer. And not only is it painful to experience but it is also painful to witness, if only because we are so impotent to help" (Bowlby, 1980).

The loss of communication with the parent was painful for all the adult children. An intellect once alive with the wonders, the sadness, the history of life, now is quiescent. This is the devastation of parental mental deterioration. The importance of social and psychological interaction before loss has been well documented (Gut, 1974). This interaction is also well documented in Rando’s anticipatory grief literature. She states that nurturing the relationship with the dying patient is a significant process that can occur in the anticipatory grief period. When the interactions do not take place, there is a question whether the subsequent grief will be effected. Mace and Rabins (1991) state that because communication with the relative with dementia is almost impossible as the disease progresses, caregivers are at high risk of experiencing unresolved grief when the relative dies.

The adult child’s own losses, as well as those of the parent, evoked the full range of anticipatory grief emotions in the adult children. This finding is
reinforced by Rando. Austrom and Hendrie (1990) used anecdotal and clinical information to study the grief response of the Alzheimer’s disease family caregiver. They also found denial, depression, anger, guilt and frustration present in the respondents. A quantitative study by Theut (1991) that measured anticipatory grief in spouses of community patients found similar grief responses.

Another issue which emerged was that the grief of these adult children does not subside. It is chronic due to the lengthy duration of the illness and the many losses that occur over the course of the illness. Volkart (1957) states that the emotional involvement for family in the North American society is unusually intense due to the absence of the extended family. The grief for loss of a close relationship can never be resolved, because even though the personality of the parent has died, the parent lives. Kameran (1988) calls this a quasi-death situation for which society offers no recognized social or ritual support. Every time the adult child visits the special care unit there are reminders of the steady deterioration from the illness. The study by George (1984) shows that continuing to watch the progressive deterioration of the relative prevents relief from emotional distress. New memories suddenly produce a wave of grief. A sudden deterioration in the parent’s health status has the same affect.

The adult children felt a sense of familial obligation and duty to take on the responsibility of caring for the ill parent in whatever way was necessary. This is in keeping with Bowlby’s findings that behaviour complementary to attachment behaviour, that of protecting the individual, is seen in caregiving
(Bowlby, 1980). The protective behaviour was seen with aging parents, particularly when they are ill. This type of behaviour was expressed as a reciprocation for parental care given to the adult child over the years.

The small sample size of the study is gender non-representative as there were only two sons out of the 12 adult children interviewed. While both of these male adult children have been very involved with care of the parent, what is generally found is that women are more likely to assume caregiving responsibilities to elderly parents than men (Shanas, 1979). In this study, the daughters’ involvement in parental care concurs with such findings. When the health of the adult child is in question, we are looking usually at the health of women in parental caregiving roles.

A final issue raised by the adult children throughout the interviews was their parents’ quality of life. Most wished that the parent would die and be liberated from the physical shell of life that remains. For many it was cruel that in the race to extend life, medical technology had been neglectful of the consequences. The quality of life and the individual’s perspective had been sadly neglected (Avorn, 1986).

**Implications for social work**

From a social policy perspective there are a number of issues. First,
Social policy is needed which clearly recognizes the need for the role of the social worker in long term care institutions. Currently this is not the case. Care of the frail elderly and their families is complex and requires the skills and knowledge of a professional social worker to address the psychosocial issues and to deal with the growing complexities of problems. In reality, the changing clientele, in terms of numbers and needs, will eventually force long term care facilities to integrate the social worker role into the long term care setting (Fabiano & Martyn, 1991). The issue will be further pressed when the baby boomers assume more of the administrative positions in health and social welfare as they head into old age. They will demand better services for the old and their families.

Furthermore, it is my opinion based on the experience of a social worker in a facility that it is not in the best interests of the relative or the family member to have the relative placed in any other than the preferred facility. Neither is it always in the best interests of the relative or family member to have the demented frail elder relative transferred to hospital should he or she become physically ill. Appropriate nursing and medical supervision will need to be made available to provide the necessary care in the facility.

It is in the best interests of relatives and family members to have all special care units deemed essential services so that in the event of strike or lockout, the very frail, dependent and vulnerable individuals are not affected by labour and management strategies. To do otherwise is a violation of the ethics of care. Also, it is in the best interests of relatives and the family caregiver that
the long term care system have in place facility policy and direction regarding advanced directives, to be signed by the caregiver on the behalf of the relative, that directs the medical care of the relative. This prevents reactive decision-making at the time of medical crisis, and allows for dialogue and a decision-making process over time. The final assault of the illness renders the individual unable to walk and to transfer from bed to wheelchair. It is at this time that the system is likely to be very punitive. It requires the individual, now nearing the end of life, to be transferred from the facility to an extended care unit. The demented frail elder then lose the familiarity of staff and routines.

The extended care relocation policy of the long term care program is also difficult for the adult child. The adult child has to face the unavoidable further loss in the deteriorating parent as well as the loss of familiar staff, facility routines and surroundings. The staff represent love and security for the parent, and a sense of extended family for the adult child. The adult child is asked to start all over again the process of searching out the preferred extended care unit. This can only rekindle the emotions brought on by the initial placement process.

Education is desperately needed to inform the public of the services of the long term care program and how to access the long term care system. That caregivers can remain unassisted by any formal health system up until the time of admission to a special care unit is unconscionable in today's world of health professionalism and advanced technology and communication. Social work
advocacy, education and research are vital links in providing accurate information and accessibility of care.

Diagnosis of the Alzheimer’s, Parkinson’s, multi-infarct, and alcohol-related dementias as early as is medically possible is key to alleviating some of the stress for this particular adult child population. Continuing physician education and geriatric education in the curricula of medicine, nursing, social work, and rehabilitation medicine should be mandatory for accreditation. Once a diagnosis of this type of dementia has been made, education and long term planning with client and family should be initiated by the long term care case manager and mainly carried out by a long term care social work consultant. Delivery of services in this way provides the much needed continuity and consistency of care that this particular group of adult children caregivers require. As well, by encouraging the development of directives early in the disease process, then the resident-to-be, not the family, sets out the parameters for future treatment.

In this study, the need for open communication between staff and family was also stressed by all the adult children. Education of staff regarding grief and the amount of grief that these adult children experience helps them to understand behaviours of the adult children, sometimes interpreted as oversolicitous or uncaring. Involving family members in both resident’s conferences and care planning is vital to the support of this group of adult children. The adult child needs to be included in, not excluded from, care of the parent.
At the education level, the social worker supporting this group of adult children needs to have a knowledge of grief and experience in facilitating grief work. A social history will indicate the nature of the family relationship with the relative, sibling conflict, and any unresolved losses of the past. Rather than a caregiver's support group, a specific adult child's grief work group could be initiated, and evaluated. A follow-up bereavement group for adult children who have lost a parent in the last year would help bring about final closure for these adult children.

There is also growing recognition of the need for institutional ethics committees to foster open debate about care, including the right to die. Lawyers, social workers, administrators, ethicists, and chaplains all provide important perspectives. Lay membership brings with it community input. Providing such a forum improves decision-making. The very existence of institutional ethics committees contributes to a culture that foster ethical attitudes (Mappes & Zembaty, 1991).

Finally, I would like to end the study on a matter of ethics. The right to die is considered by some to be one of the moral issue of the nineties. Most of the adult children in this study believe in the right to die for themselves should they develop one of the severe dementias. They know that dementias strip victims of human dignity and quality of life. Let us not fool ourselves into thinking that there is any remaining quality of life for victims of the dementias. There isn't.
BIBLIOGRAPHY


Charmaz, K. Intensive interviewing, Gerontology Program, Sonoma State University, Robert Park, CA, December 1986, unpublished manuscript.


1. How long has it been since your _______ was first diagnosed with dementia?

2. How would you describe your personal feelings around _________ illness?

3. What feelings describe your own personal experience having your _________ in special care?

4. What are the changes in your _________ that affect you the most?

5. What kind of support, personal, and practical would help you during your duration of time your _________ is at the care facility?

6. Has there come a time or do you foresee a time when you question the Quality of Life for your _________?

7. What are your own thoughts and feelings around your decision for your life should you develop a severe memory loss?