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.

Department of \underline{Educational and Counseling Psychology and Special Education}

The University of British Columbia
Vancouver, Canada

Date \underline{June 18/03}

DE-6 (2/88)
Abstract

It is only in the last 25 years that Alzheimer's disease has garnered much interest in the world of research. Most of this has been of a quantitative nature, focusing on etiology, treatment, genetics, characteristics, and behavioural aspects of the disease. The purpose of this study was to examine the increasingly salient but comparatively under-researched issue of Alzheimer's disease from the perspective of the affected individual. An exploratory study was conducted in the Lower Mainland area of British Columbia with 8 participants who had been diagnosed as having Alzheimer's disease, currently in the early stages. Purposeful sampling was used to recruit participants via referrals, personal contact, and networking. Using the qualitative approach of Critical Incident Technique, participants were interviewed individually twice and their accounts were examined. Specifically, the goal of this study was to enrich the understanding of the experience of living with early stage Alzheimer's disease by developing a set of categories describing those factors that help and hinder individuals' ability to live with their illness. Implications for counselling affected individuals and their families and directions for future research were discussed. It was concluded that the resulting categories can be utilised in numerous ways for those living with Alzheimer's disease as well as those working with them, both formally and informally.
Table of Contents

Abstract .............................................................................................................................................. ii
Table of Contents ................................................................................................................................ iii
List of Tables ......................................................................................................................................... vi
Acknowledgments ............................................................................................................................... vii
CHAPTER I INTRODUCTION ............................................................................................................ 1
  Statement of the Problem .................................................................................................................. 3
  Purpose of the Study ......................................................................................................................... 3
  Research Question ........................................................................................................................... 4
  Rationale ........................................................................................................................................... 4
CHAPTER II REVIEW OF THE LITERATURE .................................................................................... 8
  Management of Alzheimer’s Disease .............................................................................................. 9
  Ramifications of Alzheimer’s Disease to Caregivers .................................................................... 11
  Ramifications of Alzheimer’s Disease to Affected Individuals ...................................................... 15
  Methodological Review .................................................................................................................. 24
CHAPTER III METHODOLOGY ......................................................................................................... 28
  Design ............................................................................................................................................ 28
  Study Setting .................................................................................................................................. 28
  Participants ...................................................................................................................................... 29
  Procedures ....................................................................................................................................... 31
  Collection of the Data ...................................................................................................................... 34
  Analysis of the Data ......................................................................................................................... 36
  Confidentiality .................................................................................................................................. 38
CHAPTER IV  RESULTS.............................................................................................................40

Part I: Description of the Categories..................................................................................40

What Would Have Helped ..................................................................................................62

What Words of Wisdom Would you Offer ........................................................................63

Part II: Validation Results ..................................................................................................63

Exhaustiveness .....................................................................................................................63

Participation Rate ................................................................................................................64

Participant Cross-Checking .................................................................................................64

Independent Rater Agreement .............................................................................................66

Theoretical Agreement ..........................................................................................................67

Self-Help Behaviours ...........................................................................................................67

Emotional Supports ..............................................................................................................68

Practical Supports ................................................................................................................69

Faith ....................................................................................................................................70

Personal Attitudes ................................................................................................................71

Being Informed ......................................................................................................................72

Effective Medication Treatment and Management .........................................................73

Experiencing Symptoms of the Illness ...............................................................................74

Experiencing Consequences of the Illness .........................................................................75

Limited Resources ...............................................................................................................76

Personal Responses .............................................................................................................76

Attitudes of Friends, Family, and Others ..........................................................................77

Additional Medical Conditions .........................................................................................78
List of Tables

Table 1: List of Categories, Frequency of Critical Incidents, and Participation Rates ..................41
Acknowledgments

There are a number of people whom I would like to thank. My thesis supervisor, Dr. Bill Borgen, for his reassurance, guidance, unfailing availability, and invaluable input. There is none better. To my committee members, Dr. Deborah O'Connor and Dr. Rod McCormick, for their expertise.

Many thanks to my colleagues at the Community Geriatric Mental Health Team for their enthusiastic encouragement, tireless support, and pertinent advice and counsel. To Nikkie Cordy, my manager, for letting me take time off at short notice when needed. Thanks also to Ann Westwood and Michelle Coulombe for their help as independent raters.

My appreciation to the Alzheimer’s Society for its role in helping me connect with participants. I would also like to express deep gratitude to the eight participants for their courage and honesty. Your example was inspirational.

Words are not enough to express my gratitude to my parents for their constant support and to my family, David, my husband, Genevieve, Kyla, and Eleanor, my daughters, for their endless patience, encouragement, faith, and love.
CHAPTER 1

Introduction

One in 13 Canadians over the age of 65 has some form of dementia; after the age of 85 years, this ratio increases to one in three. Estimates for the number of new cases by 2011 are greater than 111,000 (Canadian Study of Health and Aging, 1994). While there are multiple types of dementias, Alzheimer’s, a progressive, degenerative, neurological disease that destroys vital brain cells, is the most common, (Brechling & Schneider, 1993; Callaway, 1998) accounting for 50% (Marin, Sewell, & Schlechter, 2002; Gauthier, 1999) to 75% (Schindler & Cucio, 2000). A Canadian Study on Health and Aging (1994) estimated that by 2031 there will be more than 750,000 Canadians with Alzheimer’s disease or a related dementia, 95,000 of which will be in British Columbia.

In the past fifty years, the world’s population has more than doubled, with a concomitant increase in the proportion of the elderly (Gauthier, 1999). As advances in medical technology and improvements in standard of living extend the lives of people, more and more are reaching the age at which the prevalence of Alzheimer’s and related dementias increases rapidly. In 1991, those aged 65 or older comprised 12% of Canada’s population and were anticipated to remain the fastest growing segment, with projected numbers expected to be 7.8 million by the year 2031 (Canadian Study of Health and Aging, 1994). As there is currently no cure or prevention for Alzheimer’s, which predominantly affects those over the age of 65, we can expect to see a significant increase in its prevalence as the population ages.

Alzheimer’s disease, which affects memory and a person’s ability to learn, to think, to accurately perceive the world, to communicate, and to look after oneself (Bolla, Filley, & Palmer, 2000; Brechling & Schneider, 1993), received relatively little attention immediately following its
discovery by Alois Alzheimer in 1906. It is only in the last twenty years that interest and research in this area has developed (Gauthier, 1999), with significant focus on the causes, treatment, clinical presentation, and effects on the caregivers of people with Alzheimer’s (Phinney, 1998). What has received considerably less attention is the experience of living with the disease for the affected individual, due, in part, to the difficulty in definitively diagnosing this illness, resulting in people not being diagnosed until the later stages, when communication is already compromised.

With improvements in diagnostic procedures and increased public awareness resulting in more prompt diagnosis of the illness (Gauthier, 1999; Goldsilver & Gruneir, 2001; Kuhn, 1998) comes a new source of information: the affected Alzheimer individual him or herself. Comparatively little literature focuses on the experience of living with Alzheimer’s disease from the individual’s perspective (Feinberg & Whitlatch, 2001), yet people with mild dementia are often able to speak articulately about their feelings and experiences, making them an important source of rich information (Phinney, 1998). In their examination of the perspective of the patient with Alzheimer’s disease in the literature, Cotrell and Schulz state “in-depth interviewing and administration of more detailed psychological tests are still possible at this stage. The most valuable insights regarding the psychological and experiential responses of persons with dementia likely will be obtained during the mild to moderate levels of impairment when the individual is still able to verbalize and maintain an effective span of attention” (1993, p. 208). They further suggest that how the person perceives and responds to the changes that are taking place in him/herself and their families are likely to continue being significant factors as the disease progresses, underscoring the importance and urgency of accessing this information while the individual is still in the early stages.
No cure or prevention means treatment is the primary way to manage this illness at present. Current treatment predominantly is comprised of medications and behavioural approaches to managing the behavioural and psychiatric sequelae of Alzheimer’s disease, approaches that so far have failed to incorporate valuable input from the central figures in this illness. What is missing is the voice of the Alzheimer’s individual.

Statement of the Problem

Alzheimer’s disease is a devastating illness that is affecting ever increasing numbers of people. With no cure in sight, every effort needs to be made to understand the nature of this disease in order to ease its burden for those involved and ensure that interventions and management of the illness are the most appropriate they can be. While research abounds on investigating causes, treatment, and caregivers, relatively little attention has been given to the experience of the illness from the affected individual’s perspective, particularly during the critical earlier stages.

Purpose of the Study

The purpose of this study was to enrich the understanding of the experience of living with early stage Alzheimer’s disease by developing a set of categories describing those factors that help and hinder individuals’ ability to cope with their illness. Because the subjective experience was of interest in this study, a qualitative approach was used. It was hoped the study would contribute new and useful insights to the existing knowledge of Alzheimer’s disease. Specifically, by identifying what helps and hinders individuals in the management of their illness, this study can help counsellors and other health care professionals to better understand and work with affected individuals and their families. The study also provided qualitative data from which
practitioners and subsequent researchers can extract information and design and implement better interventions.

**Research Question**

This investigation sought to further understanding of the topic by addressing the specific question "what facilitates and hinders an affected individual’s ability to live with early stage Alzheimer’s disease?"

**Rationale**

It was through the researcher’s work experience as a case manager on a Geriatric Mental Health team that she became interested in this topic. Working on a daily basis with individuals with Alzheimer’s disease, their families, other health care professionals, and the community at large has given her sustained exposure to the issues involved. Of the many interesting facets of working with this population, one factor stands out: the individuality of those affected and their desire to communicate and take part in decisions about their care, even into the more advanced stages.

Because of her close contact with this subject, the researcher was very aware of the potential for bias and preconceptual influence. With this in mind, she embarked on a self-reflective process in an endeavour to keep these visible. Identified assumptions were: that affected individuals wish to have a say in their care and the course of their life after diagnosis; that these individuals should be allowed a say in their care, despite the nature of the illness; that knowledge of their preferences should be aggressively sought and honoured whenever possible, for as long as possible; that there would be a commonality to the experience, related to what
people with Alzheimer's find helpful or unhelpful; and that affected individuals would be able to reflect on and willing to talk about their experiences.

There were multiple reasons to examine the experience of living with Alzheimer's disease from the affected individual's perspective. Dementia is "perhaps the most distressing and burdensome illness affecting the elderly and the most costly in its impact on health care services" (Rockwood & Stadnyk, 1994, p. 253). Steady growth in the number of elderly as the population ages makes the study of all facets of Alzheimer's disease a pressing issue. Nursing home care costs alone are approximately $40,000 per resident per year in the United States (Leon & Moyer, 1999) with the average lifetime individual cost of care estimated to be $174,000 (McCracken, 1999; Shah, Tangalos, & Petersen, 2000). Current American statistics estimate the overall annual cost of Alzheimer's disease is $100 billion (Shah et al., 2000) while Canadian figures are more conservative at $3.9 billion (Ostbye & Crosse, 1994). Clearly, Alzheimer's disease is costly. With no cure or prevention currently available, treatment is the key to working with this illness but has so far focused on management of the associated psychiatric symptoms and behavioural problems from the biomedical viewpoint. What is missing is the affected individual's perspective (Cohen, 1991; Hutchinson, Leger-Krall, & Wilson, 1997; Phinney, 1998), contributing to "a lack of representation of patient needs in the selection of care strategies" (Cotrell & Schultz, 1993, p. 207). With escalating health care costs, it is essential to include this critical information in order to develop and keep only the most effective clinical strategies and interventions.

The overwhelming mass of the Alzheimer's disease literature is quantitative in nature with a focus on etiology, treatment, genetics, and characteristics and behavioural aspects of the disease (Bahro, Silber, & Sunderland, 1995; Cotrell & Schulz, 1993; Lyman, 1989; Phinney, 1998). When psychosocial inquiry has been undertaken, it has focused mainly on the "study of its
impact on caregivers with little attention to impact on patients” (Cotrell & Schulz, 1993, p. 205).

While there is a growing body of work beginning to address the experience for the individual with Alzheimer’s (Bahro et al., 1995; Cohen, 1991; Crisp, 1995; Harris & Sterin, 1999; Kitwood, 1990; Orona, 1990; Sabat, 2001; Sabat & Harre, 1992; Woods, 1999), the predominant perspective has been an outsider’s one, with elucidations from caregivers and clinicians (Phinney, 1998). By addressing gaps in methodology and target group focus, this study has implications for expanding and elaborating upon the existing body of knowledge and understanding of Alzheimer’s disease.

In their examination of the status of dementia patients, Cotrell and Schultz found that this population is frequently “relegated to the status of object rather than legitimate contributor to the research process” and suggest that “much can be gained from a systematic study of individuals’ views regarding their illness and care” (1993, p.205). Within the body of research investigating the perspective of the individual, some studies have been done with people in the early stages, but nothing has been published focusing exclusively on factors that help or hinder this group’s coping with their illness. Lack of research with Alzheimer’s individuals can be largely attributable to the nature of the disease itself, which robs it victims of memory and eventually renders them incapable of easy communication. Reliability and validity of information collected can therefore be questionable (Brod, Stewart, Sands & Walton, 1999; Feinberg & Whitlatch, 2001). However, recent improvements in diagnostic procedures, enabling earlier detection of Alzheimer’s (Gauthier, 1999; Goldsilver & Gruneir, 2001), means Alzheimer’s individuals are now accessible when communication is still relatively straightforward.

There is considerable variability in the presentation and progress of Alzheimer’s disease (Buckwalter, Gerdner, Hall, Stolley, Kudart, & Ridgeway, 1995), but impairment is generally
mild in the earlier stages (Brechling & Schneider, 1993; Yale, 1999), making this a critical time for conducting studies. Counsellors, health care professionals, families, and caregivers need to be able to help individuals with Alzheimer’s disease manage their progressive illness on a day-to-day basis in the most effective ways possible, focusing on what is helpful while addressing what is unhelpful. By conducting in-depth interviews with a small number of Early Stage Alzheimer’s individuals, the researcher hopes to expand the narrow view of Alzheimer’s and enrich understanding of this devastating illness. Adding to the existing qualitative data could lead to the development of more effective, client-driven interventions and help enhance the quality of life for the Alzheimer’s person (Cotrell & Lein, 1993) while enabling them to “decline a bit more gradually and gracefully” (McCracken, 1999, p. 5).
CHAPTER II

Review of the Literature

The literature on Alzheimer’s disease can be divided into two broad categories: biomedical and social/psychological research. The first group, pertaining to Alzheimer’s etiology, risk factors, diagnosis, clinical presentation, prevalence, pharmacological treatment, prevention, and cure, constitutes the majority of the literature (Burgener & Dickerson-Putman, 1999; Cotrell & Schultz, 1993; Lyman, 1989). Social/psychological research, comprised of studies on the effects of Alzheimer’s disease and helping affected individuals and their caregivers, makes up the remaining literature and is the area of interest for this study.

While one goal of the psychosocial research is to investigate better ways to meet the needs of individuals with Alzheimer’s, the predominant focus has been the needs of the caregivers (Cotrell & Lein, 1993; Cotrell & Schulz, 1993; Goldsilver & Gruneir, 2001), in part because “evidence supports the idea that the patient’s family, where available, is the key to truly helping the patient” (Cohen & Eisderfer, 1986, p. 12) and because family caregivers “face extreme hardship and stress that increases in intensity over time” (Gauthier, 1999, p. 36).

Additionally, the nature of the disease means affected individuals have been predominantly seen as unable to contribute to their care, or to ideas about their care.

A gap in the literature is qualitative research investigating the experience of individuals, particularly those in the early stages of Alzheimer’s disease (Yale, 1999), and what affects their ability to cope with their illness on a day-to-day basis, from their perspective. This study hoped to diminish the gap by eliciting information from those diagnosed with Early Stage Alzheimer’s, regarding what helps or hinders their living with their illness. The literature reviewed in this chapter is arranged into two groups: (1) management of Alzheimer’s disease; and (2) the
ramifications of Alzheimer’s disease to caregivers and to individuals diagnosed with Alzheimer’s disease.

Management of Alzheimer’s Disease

Literature on the treatment of Alzheimer’s disease can be divided into pharmacological and non-pharmacological management. Individuals with Alzheimer’s disease will exhibit a broad range of cognitive impairments, behavioural problems, and mood changes (American Psychiatric Association, 1997). This applies to each individual across the duration of his/her illness, as well as the presentation of the illness across individuals. Interventions and treatment modalities are aimed at coping with these symptoms. Research on pharmacological management focuses on the underlying disease and its symptoms while non-pharmacological management, pertinent to this review, aims to alleviate and/or minimise the symptoms of the illness (Cotrell & Schulz, 1993) and focuses on behavioural approaches, family intervention, education, counselling, and support services (Freed, Elder, Lauderdale, & Carter, 1999).

In their Practice Guidelines for the Treatment of Patients With Alzheimer’s Disease and Other Dementias of Late Life, the American Psychiatric Association reports their emphasis is on behavioural symptoms as “most of the effective treatments available for dementing disorders are in this realm” (1997, p. 1). Yet they further report that behaviour-oriented treatment approaches have not been tested via randomized clinical trials. Nevertheless, they are widely used in the clinical setting. In their examination of the status of dementia patients with regard to depression, psychosocial components of problem behaviour, and current treatment efforts, Cotrell and Schulz note that “treatment of psychiatric symptoms and behavioural problems associated with such disorders reflects the absence of the patient’s perspective on dementia and has led to a lack of representation of patient needs in the selection of care strategies” (1993, p. 207).
According to Burgener, Shimer, and Murrell, "the empirical basis for clinical management approaches is often minimal or nonexistent" (1993, p. 13). In their study examining the expressions of individuality in cognitively impaired elders, using observation, repeated measures, and unstructured interviews, they found that even severely demented individuals strove to convey expressions of who they were. The authors state that more studies are needed to explore the relationship between individually based care and positive outcomes and suggest that specific "psychosocial interventions could be designed to assist elders in coping with the many losses they encountered throughout the dementing process, especially during the early stages of dementia when awareness of losses may be heightened" (Burgener et al., 1993, p. 18).

Historically, supports and services for individuals diagnosed with Alzheimer’s disease have focused on caregivers. Currently, there are inadequate supports for people in the early stages of Alzheimer’s disease as most existing support groups and interventions are for those with more advanced stages of the disease or for caregivers (Goldsilver & Gruneir, 2001). After diagnosis, the focus tends to be on the disability, not on retained abilities as “it is quickly forgotten how capable and functional individuals with early stage dementia are” (Goldsilver & Gruneir, p. 113). In their study evaluating the implementation of one of the first support groups for early stage Alzheimer’s, Goldsilver and Gruneir found that 74% of those responding to a post-group evaluation form believed the group had helped them cope more effectively with their problems. Ninety-six percent experienced the group as satisfying and would recommend it to others and 55% of caregivers felt participation had impacted either their or the attendee’s life. The authors have run three such groups and recommend that their format, followed by ongoing support groups, be used as a “starting point on the continuum of dementia care” (p. 113). While these groups appear to fill a gap in services and provide much needed and long overdue support for
individuals with early stage Alzheimer’s disease, it is also important to note that there is no indication that anyone with early stage Alzheimer’s disease was consulted regarding the format of the groups or the content to be covered. Topics were “suggested by the facilitators and were chosen for their interest and educational value” (Goldsilver & Gruneir, p. 111).

Education is another focus of the non-pharmacological literature on management of Alzheimer’s disease. Affected individuals should be key informants for the educational aspect of Alzheimer’s management, yet rarely, and only recently, have they been involved in research as contributors, rather than as subjects to study. The American Psychiatric Association has developed a Practice Guideline for the Treatment of Patients with Alzheimer’s disease and Other Dementias of Late Life (1997) which primarily uses expert opinion as the premise for its recommendations, not clinical trials (Schindler & Cucio, 2000). Yet, for “a guideline to be relevant, it must take into consideration the relative value placed on different outcomes by the patient and his family” (Schindler & Cucio, p. 57). This is difficult to do with dementia, however, as cognitive deficits interfere with the communication of opinions and preferences unless these are first ascertained while the individual is in the early stages. Again, the paramount importance of giving early stage Alzheimer’s people a voice is evident. Knowing what is helpful and what is a hindrance can aid in the development of truly effective interventions. Having a voice in early stage will help ensure that Alzheimer’s individuals have a say in the goals of their treatment, rather than these being determined at a later stage by the person’s family and/or the primary care physician.

Ramifications of Alzheimer’s Disease to Caregivers

Caregivers can be informal, such as family and friends, or formal, such as paid home support and other health care professionals working with affected individuals and their families.
Research on the impact of caregiving is copious, with much of it focusing on the informal caregiver. Most of this literature supports the position that caregiving is a difficult task that has serious repercussions for those who adopt this role (Cummings, 1996; Schulz & Beach, 1999; Schulz, O’Brian, Bookwala, & Fleissner, 1995). In their longitudinal, prospective, population-based cohort study of 392 caregivers and 427 noncaregivers between the ages of 66-96 years, Schulz and Beach found that mortality rates for spouse caregivers who reported feeling strained were 63% greater than their control counterparts, even after adjustment for sociodemographic factors and physical health status. Caregiving for people with dementia is particularly arduous, with greater caregiver strain, mental and physical problems, impact on work and leisure time, and impact on family conflict (Ory, Hoffman, Yee, Tennstedt, & Schultz, 1999), as well as increased depression and anxiety when compared to nondementia caregivers (Hooker, Monahan, Bowman, Frazier, & Shifren, 1998; Schulz et al.). Dementia caregivers also spend more hours per week caring for their family member and use more formal services than caregivers of nondementia people (Ory et al.).

In their review of the dementia caregiver literature, Schulz et al. (1995) found that depressive symptomatology, clinical depression, and anxiety were reported in almost all of the 41 studies examined, while the association between physical morbidity and caregiving was more equivocal. Different hypotheses exist as to why the mental health of dementia caregivers is affected so much more than the mental health of non-dementia caregivers. Some research indicates that caregiver depression correlates to problem behaviour in the dementia individual. Other researchers postulate that knowing the situation is unpredictable, uncontrollable, and progressive leads to more caregiver strain (Ory et al., 1999), or that it is the burden of socially unrecognised and unsupported anticipatory grief over the “gradual ‘death’ of a loved one’s
memory and personal identity from Alzheimer’s disease” that leads to such negative consequences to the dementia caregiver (Meuser & Marwit, 2001, p. 658).

The two main groups comprising informal caregivers are the Alzheimer’s person’s spouse and his/her grown child or children. It is estimated that 80% of people with Alzheimer’s disease are cared for in the family setting (Orona, 1990) and studies show that women caregivers suffer more ill effects than their male counterparts (Hooker, Manoogian-O’Dell, Monahan, Frazier, & Shifren, 2000; Rose-Rego, Strauss, & Smyth, 1998; Yee & Schulz, 2000). Different coping styles may account for the different effects between genders (Hooker et al.; Rose, Strauss, Neundorfer, Smyth, & Stuckey, 1997), with wives exhibiting higher distress levels and more often using the coping strategy of wishfulness and husbands more often evidencing lower stress levels while using acceptance and problem-focused strategies (Rose et al.). Research is not consistent with regard to whether or not caregivers suffer physically from their roles. The research is consistent, however, in reporting that caregivers’ mental health suffers from their roles, with increased risk of depression (Cummings, 1996; Stuckey, Neundorfer, & Smyth, 1996), anxiety, and use of psychotropic medications (Schulz et al., 1995).

Caregiving for people in early stage Alzheimer’s disease involves issues distinct from caregiving in the later stages due to the subtleness of the symptoms and a lack of sufficient supports and services, most of which remain geared to people in the middle and late stages and their families (Kuhn, 1998; Yale, 1999). Whereas behavioural problems, incontinence, wandering, and nursing home placement are often issues of concern in the later stages, discussion of these topics in support groups can be distressing, anxiety provoking, and even frightening to early stage caregivers (Kuhn; Yale), who face such issues as the “slow and confusing disintegration of a long-standing primary relationship” (Cummings, 1996, p. 87), their feelings in
response to the changes they see in their spouses, and adjusting to their changing roles and responsibilities.

In her work running psychoeducational support groups for spouses of people in early stage, Cummings (1996) observed over the course of five years that these caregivers face four common emotional challenges as their spouses and marital relationships change during the early stage: accepting the diagnosis, accepting the implications of the prognosis, redefining their image of the marital relationship, and grief related to the multiple losses associated with the early stages - loss of a partner and companion, of future plans, and of freedom. Because the signs and symptoms of illness at this stage are so subtle and usually progress so slowly, family and friends not in intimate contact with the affected individual may not be aware of, or believe, the diagnosis. Often, spouses choose not to inform others of their partner’s illness. In both cases, the result is that the caregiver is left to manage with inadequate supports and to grieve in isolation (Cummings).

In his exploratory study interviewing primary caregivers of people with early stage Alzheimer’s disease, Kuhn (1998) reported that, unlike Cummings’ findings, most caregivers freely discussed the disease with others. Despite this, few of them turned to family, friends, or formal services for help. Changes in their relationships with the affected individual elicited emotional responses that were not dealt with, with spousal caregivers, especially, feeling isolated. Another theme noted by Kuhn was that caregivers “expressed the need to consider the viewpoint of their relatives with AD in order to gain a better understanding of their changing roles and responsibilities” with an emphasis on the need to “develop an empathic approach with their relatives” (Kuhn, p. 195). By developing a set of categories describing those factors that help or hinder individuals’ living with Alzheimer’s this study has the potential to be practically helpful
to those looking after affected individuals, in addition to giving them a viewpoint of people with early stage Alzheimer’s. It is hoped this will aid caregivers in their desire to develop an empathic approach with their relatives and a greater understanding of their changing roles.

Ramifications of Alzheimer’s Disease to Affected Individuals

Alzheimer’s Disease is defined in the American Psychiatric Association’s (2000) Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR) as:

the development of multiple cognitive deficits manifested by both

(1) memory impairment (impaired ability to learn new information or to recall previously learned information)

(2) one (or more) of the following cognitive disturbances:

(a) aphasia (language disturbance)

(b) apraxia (impaired ability to carry out motor activities despite intact motor function)

(c) agnosia (failure to recognise or identify objects despite intact sensory function)

(d) disturbance in executive functioning (i.e. planning, organizing, sequencing, abstracting) (2000, p. 88).

Furthermore, these deficits significantly negatively affect social and/or occupational functioning, are also a significant decline in previous level of functioning, have a gradual onset, and are progressive in nature. The impact of this illness on individuals is profound. They will experience changes in their mental and physical abilities, their emotions and moods, and their behaviour, leading to a decrease in their autonomy (Harris & Sterin, 1999) and quality of life; a premature stripping away of their retained abilities (Mayhew, Acton, Yauk, & Hopkins, 2001); a loss of voice and personhood (Kitwood, 1990; Lawton, 1994; Mayhew et al.); loss of significant
roles (Harris & Sterin) and depression (Cotrell & Schultz, 1993; Lawton). The overall effect for the individual is an increasingly narrow world, a greater sense of isolation, tremendous losses, and ostracism from friends, family, and society.

The nature of Alzheimer's disease and its concomitant methodological challenges have traditionally resulted in the exclusion of affected individuals from active research participation and input into their care (Brod et al., 1999), silencing their voice as effectively as the illness itself. Memory and communication problems, perceived comprehension problems, and the progressive element of the disease have influenced a prevailing belief that data collected from this population will be unreliable and therefore not valid (Brod et al.; Feinberg & Whitlatch, 2001). Yet this position is refuted by several studies. Burgener and Dickerson-Putman (1999) examined the relevance of patient perspectives in their longitudinal study assessing 84 patients in the early stages of irreversible dementia. They found, despite indications of cognitive impairment, that participants' responses were consistent over time, at least from the time of baseline interviews to a six month interval, giving support for the reliability, and therefore the meaningfulness, of their responses.

Similarly, in her study examining practical and methodological issues using a health survey to measure and monitor health status in elderly people, McHorney (1996) found that cognitively impaired people were able to complete a 245-item self-administered survey with comparable results to cognitively intact individuals with regard to scaling success, internal-consistency, and construct validity, with only a few exceptions. These finding were consistent with those of Brod et al. (1999) who designed and tested a dementia quality of life instrument to examine the conceptualization and measurement of quality of life in dementia. Their data showed that “persons with dementia can be considered good informants of their own subjective states”
and stated that given "the good reliability and promising validity of direct assessment of subjective domains, there is little reason not to use direct assessment in these domains" (p. 34).

Reliance on input from caregivers, family members, and others while excluding the affected individual as a vital source of information also discounts the level of awareness some studies indicate exists for some individuals with Alzheimer's, even into the later stages of the disease. Typically, people with Alzheimer's disease are considered to experience anosognosia, or an unawareness of their deficits, even in the early stages of the disease (Grut, Jorm, Fratiglioni, Forsell, Viitanen, & Winblad, 1993; Knopman, Donohue, & Gutterman, 2000; Lopez, Becker, Somsak, Dew, & DeKosky, 1994; Seltzer, Vasterling, Yoder, & Thompson, 1997). In their study examining early probable Alzheimer's disease as it relates to awareness context theory, Hutchinson et al. stated that because Alzheimer's disease affects cognition "families, friends, and even physicians often do not view the client's awareness as an issue, acting instead as if the client is 'not all there'" (1997, p. 1407). However, not all of the research is consistent with this position. In her interactional analysis of one Alzheimer's individual, Hamilton's (1994) description of the client in early stage included awareness of when memory loss, the predominant symptom of this stage, and the resultant social discourse occurred and when they did not. Furthermore, this awareness led to compensatory behaviour in which the client made excuses for her poor memory. Acton, Mayhew, Hopkins, and Yauk (1999) examined communicating with individuals with dementia from the affected person's perspective and found that people in the mild to moderate stage frequently showed an awareness of their cognitive changes.

Similarly, results from Burgener and Dickerson-Putman's study on patient perspectives in the early stages of irreversible dementia clearly indicate that "individuals with irreversible dementia are very much aware of some of the changes and losses attributable to the dementing
disease" (1999, p. 39). While participants for this study had a recent diagnosis of dementia (i.e. in the past 12 months), and they included multi-infarct or mixed dementia not just Alzheimer’s, the range of scores for the Mini Mental Status Exam (MMSE) was 12-26, indicating that even with fairly significant levels of dementia, awareness was still present. Even more dramatic are the results of Mayhew et al.’s (2001) qualitative study interviewing and videotaping five severely demented individuals (MMSE scores ranged from 0 to 7). These researchers found that even people with advanced cognitive impairment seemed to be aware of their deficits and displayed a sense of self.

The historical pattern of relying predominantly on caregivers for input regarding what is best for the Alzheimer’s individual is disturbing given the results of some studies on agreement between patients’ and their proxies’ reports on quality of life in Alzheimer’s disease. In their inter-relator reliability study examining this topic, Novella, Jochum, Jolly, Morrone, Ankri, and Blanchard (2001) assessed health related quality of life indicators using interviews and a 17-item questionnaire. Novella et al. found a poor to moderate degree of concordance between proxies and Alzheimer’s individuals, with the proportion of exact agreement ranging from 26.3 to 52.6%. Agreement tended to be higher for more objective measurements such as disability but was especially low on subjective subscales such as perceived health. In light of their findings, Novella et al. conclude that people with mild to moderate Alzheimer’s disease are aware of and able to report on their own health related quality of life indicators, therefore, “proxies should be used with caution for patients with mild to moderate Alzheimer’s disease” (p. 450). This is also consistent with other researchers’ findings that many affected individuals in the early to moderate stages have the ability to understand and answer questions about themselves and their circumstances (Brod et al., 1999; Gerety, Chiodo, Kanten, Tuley, & Cornell, 1993; Grut et al.,
Thus, while caregivers have been central figures in the management of the AD individual, and must remain so due to the degenerative nature of the illness, these studies illustrate the critical importance of going to the source when eliciting information on the multifaceted experiences of living with Alzheimer’s disease and planning interventions and care.

Decision-making capacity, or lack thereof, is an additional reason why individuals diagnosed with Alzheimer’s disease have traditionally been excluded from taking part in their own care management, whether that be at the intervention or research level. As Woods has noted, “there has been the assumption that people with dementia are unable to communicate in a meaningful way, invalidating their participation in decision making about their own situation as well as rendering their lived experience and their perspective as being impossible to research” (1999, p. 36). Yet again, recent research belies this position. In their qualitative, exploratory study examining the decision-making capacity of cognitively impaired people, Feinberg and Whitlatch (2001) interviewed 51 respondent dyads (affected individual and their spouse or adult child caregiver) with regard to care preferences and choices. Consistent with previous research (Gerety et al., 1993; Sansone, Schmidt, & Nichols, 1996), these researchers found that people with mild to moderate cognitive dementia (MMSE scores ranged from 13-26) are “able to articulate certain preferences and choices for themselves, and to be accurate and reliable in their responses” (p. 381). This study was part of a larger research project examining choice, decision making, values, preferences, and practices in daily care for cognitively impaired individuals and their caregivers living in the community. It provides valuable information regarding the reliability of responses of this population as participants in research and their care. However, the focus of this study and the larger project is different from the question of interest in the proposed
study, namely “what helps and what hinders affected individuals’ coping with Alzheimer’s
disease?”

In recent years there has been more interest in understanding the experiences and preferences of people with dementia (Bahro et al., 1995; Feinberg & Whitlatch, 2001; Downs, 1997; Woods, 1999), with much of the research being qualitative in nature (Feinberg & Whitlatch). Even with this increased interest, however, the majority of the literature continues to use alternate sources of information, such as the caregivers or clinicians (Phinney, 1998). In their qualitative exploratory pilot study on awareness and denial in the person with Alzheimer’s disease, Cotrell and Lein (1993) used intensive interviews to examine the existence of the affected individual’s awareness of the extent of their illness, their use of coping strategies, whether or not they progress through recognisable stages of acceptance, and whether caregiver interaction affects the individual’s ability to cope. Interestingly, while the focus of this study was the individual, the authors still chose to use the caregivers’ perspectives to collect their data despite identifying observation of a support group for Alzheimer’s victims and individual interviews with participants as effective ways of collecting data on the victim’s perspective of the dementia experience. Although they promote this as a desirable research option with the potential to “provide useful insights regarding the adaptive efforts undertaken by the victims” (p. 118), they did not undertake research of this nature due to the unavailability of early stage support groups. From the results of their study, these researchers emphasize the importance of collecting data directly from the affected individual and suggest that “the most valuable insights regarding the victim’s perspective of the dementing experience are to be gathered during the milder, verbal stages of the illness” when “clinical interviews can be collected directly” (p. 127). They further promote the psychosocial research perspective as a means to identify “factors that hinder or
enhance the successful adaptation of the individual to dementing illness” (p. 128) in order to develop humane, effective treatment and care practices based on the affected individual’s reality.

Yet, when studies directly involving cognitively impaired individuals have been done, they have produced meaningful, consistent, and often poignant results. In her qualitative descriptive study exploring the Alzheimer illness experience from the affected individuals’ perspective, Phinney (1998), while including the caregivers in the study, also interviewed the Alzheimer’s persons themselves using a semi-structured format. Two interviews were conducted with the individuals, each lasting 45-60 minutes. Spouse interviews were included to enrich and confirm the findings, as were field notes of observations and quantitative measures. The participants mean score on the MMSE was 19, with a range of 17-23, meaning they were in the early stages of Alzheimer’s disease. Phinney found that two main themes emerged: (1) being unsure; and (2) trying to be normal. ‘Being unsure’ described how these individuals’ fluctuating experience of their symptoms contributed to their feeling uncertain and uneasy as they try to live their lives in a world that is becoming increasingly unfamiliar. This category was comprised of factors such as memory loss, conversation breakdown, disorientation, and fluctuating awareness, that together conspired to create “gaps in the flow of their day-to-day lives” (p. 11). ‘Trying to be normal’ described their “active efforts to counter the impact of dementia to maintain continuity in their lives” (1998, p. 11). It was the main concern for the participants and included strategies such as self-monitoring, keeping an active mind, staying engaged, and downplaying the concept of ‘disease.’ This researcher also identifies the importance of eliciting the patient’s perspective to facilitate a better understanding of living with cognitive impairment in order to develop more effective interventions and management strategies.
In their study examining the expressions of individuality in cognitively impaired older people, Burgener et al. (1993) used observation and unstructured interviews with the elders living in a facility to collect information about their current sources of support, their needs for contact with others, and their use of past behaviours. The participants’ mean mental status score using the Mini-Mental State Exam (MMSE) was 6.9. Scores below 23 usually denote dementia of some sort, if no other underlying physical condition is responsible, meaning these subjects had severe dementia. Even so, the authors found “elders at low levels of mental functioning often giving meaningful and consistent responses” (p. 16) and conclude their results support the “belief in individual expressions of self in cognitively impaired elders” (p. 16). Their findings included evidence of a sense of despair amongst some of the participants, of loneliness, the need for connecting with others (through touch and seeking out the companionship of others e.g. staff, the researchers, other residents), retained social skills, expressing and responding to humour, and striving for a sense of mastery.

Bahro et al (1995) used interviews and observations with seven patients recently diagnosed with mild to moderate probable Alzheimer’s to examine their coping strategies and any changes to their internal sense of reality. They asked questions related to the patients’ perception of the disease, awareness of it, explanations for changes to their abilities, and their future outlook. The authors found that these patients used denial (partial or complete), avoidance in naming the illness, dissociation of affect, vagueness, and circumstantiality when discussing their illness, as well as minimising functional decline, externalising the problem, displacement, somatizations, and self-blame. However, while these researchers interviewed the affected individuals themselves, they did not ask directly what strategies the participants used to cope. Rather, the researchers observed participants’ responses to questions asked, then interpreted these
responses. For example, all participants were seen as inpatients at a geriatric ward and were asked why they thought they were admitted. When one woman responded she was there for evaluation of her memory and likened her stay on the ward to “a nice holiday at a hotel” (p. 44), her coping strategies were identified as denial and distortion.

Werezak and Stewart (2002) examined learning to live with dementia specifically from the subjective perspective of people in the early stages. While they did not confine their study to those with Alzheimer’s disease, five of their six participants had this illness. Similar to the current study, they also conducted two interviews in person, using a semi-structured format in the initial one, with the second, less structured interview being used for clarification and confirmation. However, using the qualitative methodology grounded theory, their aim was to generate new theory, which is quite different from the goals of the current research. Their emerging theory described a “continuous process of adjusting to early-stage dementia” (p. 72), comprised of five core categories. ‘Antecedents’ involved various precursors to receiving the diagnosis; ‘anticipation’ reflected on people’s feelings about obtaining and divulging the diagnosis, and contemplating future losses; ‘appearance’ related to participants’ reactions to others noticing their memory loss as well as the feeling that they remained the same person despite their illness; ‘assimilation’ was the stage at which the illness was incorporated into people’s lives, both internally and externally; and lastly, ‘acceptance’ which was integral to being able to move forward and enjoy their life rather than focusing exclusively on the illness.

Within the literature focusing on individuals with Alzheimer’s disease, there is a body of work that does not support the traditional view that the ‘self’ is lost or somehow completely disappears as the disease progresses. Instead, this dissenting viewpoint maintains that the self, or some form of it, is retained despite the dementia (Downs, 1997; Kitwood, 1990, 1997; Sabat,
2001; Sabat & Harre, 1992; Woods, 1999, 2001). Among the earlier research focusing on the individual in Alzheimer’s, Cohen and Eis dorfer identified this as “the essential humanity of the person turned patient remains” for “people do not consist of memory alone” but “have feelings, imagination, desires, drives, will and moral being” (1986, p. 22). In their qualitative study interviewing 17 people and 15 of their respective caregivers, Harris and Sterin (1999) examined the concepts of self and personal identity in early Alzheimer’s disease. They asked what happens to the self, how is it defined, and what affects it? Their findings indicated that the self was in a state of flux, subject to the multiple losses associated with Alzheimer’s including respect, autonomy, and competency. This is consistent with Phinney’s (1998) thematic categorisation of participants’ ‘being unsure,’ in which they described feeling uncertain and uneasy trying to lead their lives in an increasingly changing and uncertain world. From their results, Harris and Sterin formulated a typology of five reaction patterns people use to maintain their sense of self and generated three core values of self-identity.

**Methodological Review**

A qualitative approach is used when the researcher’s purpose is “to learn about some aspect of the social world and to generate new understandings that can be used by that social world” (Rossman & Rallis, 1998). This approach is preferable when there is a need to increase understanding of people’s lived experiences (Rossman & Rallis) and a desire to make sense of circumstances or situations “without imposing preexisting expectations on the phenomena under study” (Mertens, 1998, p. 160). As the goal of this research was to enrich understanding of the experience of living with early stage Alzheimer’s disease from the affected individual’s perspective, and no attempt was being made to control or predict the experience as would occur in a quantitative study, a qualitative approach was the most suitable choice.
Tesch (1990) identifies 26 different types of qualitative research. Because this study sought to understand what helps and what hinders individuals’ coping with their illness by identifying and categorising these factors, an in-depth, detailed approach was desired. Phenomenological inquiry was considered for this study but was rejected for three reasons. First, one or two studies have already been done using the phenomenological method. While it might have been beneficial to do another study of this nature to determine if similar themes arise, it was considered more useful to use an alternate methodology, with the potential to expand the existing knowledge base on Alzheimer’s disease. Second, consultation with health care professionals working with Early Stage Alzheimer’s groups indicated a more structured interview would be easier for the participants to work with, rather than the unstructured format of the phenomenological interview. Lastly, phenomenology focuses on the meaning of a lived experience, which was not the focus of this study.

Case studies seek to understand a larger phenomenon by studying one specific case intensively (Rossman & Rallis, 1998) and would not have enabled the development of categories to the desired extent. The grounded theory approach was not used because generating theory is not the goal of this research and focus groups were rejected because it was the individual’s perspective of what helps, what hinders that was the information of interest, not how these individuals form a schema of their problem, as would be the objective with focus groups (Mertens, 1998). Clinical research might have been suitable as it uses in-depth interviews and participant observation to examine biomedical problems by investigating the “physical, behavioural, cultural, historical, social, emotional, and spiritual ramifications” (Mertens, p. 173) of what is happening with someone’s body and their life, and the disposition of power with regard to these factors. However, the goal of this approach is to better understand the efficacy (or
non-efficacy) of recommended treatments or therapy in the context of factors affecting the individuals' daily life (Mertens). While this might be a desirable study to undertake, it was not consistent with the goal of the proposed research, namely to identify what the individuals themselves considered to be helpful or unhelpful factors regarding coping with their illness. Additionally, it was a goal of this researcher to move away from the biomedicalisation of the topic and keep the research firmly in the psychosocial realm.

Critical Incident Technique (CIT), a type of qualitative methodology which includes "short, clear instructions to the participant and can result in a vivid exemplar that portrays the heart and soul of the event from the writer's perspective" (Rosenal, 1995, p. 115) was chosen for this study. Developed by John Flanagan (1954) during World War II to identify effective pilot performance by eliciting information from the pilots regarding factors that were helpful or harmful to their flying experience, CIT is described by Flanagan as a flexible set of principles that must be individualised to the specific situation under study. After World War II, the use of CIT expanded to include research in industrial and organizational psychology, leadership, and counselling, being used in the development of ethical standards in psychology, the measurement of task proficiency, the selection and classification of personnel, and the identification of effective counselling (Woolsey, 1986).

After the late 1950s, when the social science research emphasis turned toward quantification, use of CIT declined. Interest in, and use of this approach has subsequently enjoyed a revival since the early 1980s (Norman, Redfern, Tomalin, & Oliver, 1992), with increased application to counselling research in the last 10-15 years. Amundson and Borgen (1988) used CIT to examine factors helping and hindering group employment counselling and McCormick's (1995) study investigated factors affecting the healing of First Nations people in
British Columbia. Additional applications of CIT have been in the study of psychology intern performance (Ross & Altmaier, 1990), quality of nursing care (Norman et al.), and exploration of the learning needs of nurses (Rosenal, 1995).

Evidently, CIT has a variety of applications and can be used in a wide variety of situations. It also has satisfactory methodological rigor according to Andersson and Nilsson (1964), who evaluated its reliability and validity. It is particularly suited to this research question because the ‘critical incident’ component enables the identification of those factors helping or hindering an individuals’ ability to manage their chronic, degenerative illness. By ‘incident,’ Flanagan (1954) meant “any observable human activity that is sufficiently complete in itself to permit inferences and predictions to be made about the person performing the act” (p. 327) and by ‘critical’ he states that “an incident must occur in a situation where the purpose or intent of the act seems fairly clear to the observer and where its consequences are sufficiently definite to leave little doubt concerning its effect” (p. 327). Additionally, CIT provided the opportunity for participants to share their knowledge, thoughts, ideas, and feelings - an opportunity that is not present in many other methodologies:
CHAPTER III

Methodology

This chapter addresses the methodological design, study setting, participants, procedures, data collection and analysis procedures of CIT. Limitations of the study and implications for counselling are also discussed.

Design

The critical incident technique (CIT) is a set of procedures for collecting and analysing descriptive information from people about their direct observations of their own or others' behaviour (Flanagan, 1954). The focus is on observed or experienced events that significantly affected the outcome of the experience (Woolsey, 1986). This methodology is considered to be flexible and adaptable to various situations and is especially useful when exploring a phenomena in a relatively new field or adding to existing research (Flanagan; Woolsey). For this study, an incident was considered critical if the participants consider it to have been either helpful or a hindrance. Analysis consisted of grouping data according to similar themes in order to create categories.

Study Setting

The research took place in Vancouver and the surrounding suburbs of the Lower Mainland area of British Columbia, Canada. These locations were chosen for convenience. However, as this was a descriptive not a quantitative study, and generalising the findings to populations other than the participants themselves was not a goal, a local site was considered adequate.

Interviews took place in the participants' home. While a room outside the individual's home might normally have been preferred in order to promote "serious, purposeful interaction"
(Genshorek, 1997, p. 44), consideration was given to the nature of Alzheimer’s disease, with the concomitant likelihood that environments outside of the norm might be disruptive and disorienting to the affected individual.

Participants

Participants were comprised of eight purposefully selected individuals with Alzheimer’s disease, living in the Lower Mainland area of British Columbia and its surrounding suburbs. Participation was voluntary with the inclusion criteria for the study as follows:

1) currently in Early Stage Alzheimer’s disease, either early or late onset
2) diagnosed with Alzheimer’s disease or probable Alzheimer’s by family physician or other health care professional
3) able and willing to provide informed consent
4) able and willing to communicate in English
5) able to reflect on his/her experience of living with Alzheimer’s and be able and willing to discuss those experiences that have helped and hindered their ability to cope with the process
6) willing to be audiotaped

Individuals who were categorised as being in Early Stage Alzheimer’s but who were no longer able to communicate easily and articulately were excluded from this study, as were participants who did not meet the above criteria and those who did but were not able to clearly describe or reflect on their experience of living with Alzheimer’s disease.

While it was a prerequisite that interested individuals be able and willing to provide informed consent, because the proposed study involved those with Alzheimer’s disease the potential existed for them to be unable to give fully informed consent. When deciding who had
the capacity to give informed consent, several factors were considered: the characteristics of the participant, the characteristics of the situation, and the level at which the standard for competency should be set (Macklin, 1983). Additionally, the range of relevant factors when considering seeking consent from research participants of uncertain mental capacity suggests “it may be desirable to set different standards of competency in different contexts or for different purposes” - the notion of variable consent (Macklin, p. 29).

In this case, the potential participants fell into the “questionable mental capacity” category rather than the “clearly incapable” and acceptable participants would not have been declared legally incompetent. The study was not invasive, dangerous, or intrusive, nor would it cause physical harm. No discomfort was anticipated and there were no side effects. Neither was the study difficult to grasp in terms of its procedures, the relevant information, and the potential risks. Given these factors, it was reasonable to set the standards for competency fairly low, which was also the most respectful stance regarding the principle of autonomy and was most congruent with the premise of this study - namely that people who are cognitively impaired are able to speak for themselves and have the right to be heard.

For this study, the standards to assess the capacity of prospective participants to give informed consent were:

(i) to ensure that the person understood what the study was about and what was required of them - this was done by having the participants repeat back to the researcher in their own words what their understanding was. If their response was consistent with the study’s parameters and their role in the study, then they were deemed to have met this criterion.
(ii) to ensure that the person understood the consequences of participating - this was done by having the participants identify potential consequences of the study. If they were able to, then they were deemed to have met this criterion.

Ability to satisfy both criteria indicated that the person was capable of giving informed consent for this study.

Procedures

This study was conducted by the researcher, a graduate student in the UBC Master’s Program in Counselling Psychology who had completed all course requirements with the exception of the thesis, has a Bachelor’s degree in Nursing, and works in the area of mental health with individuals and families affected by Alzheimer’s Disease. The research was conducted under the supervision of Dr. Bill Borgen, professor, UBC Counselling Psychology program.

Participation was solicited by posting notices of the research (see Appendix B) with a contact phone number on the bulletin boards in the Counselling Psychology program office at UBC, and circulating the poster to the Alzheimer’s Society Resource Centre’s Early Stage Support groups throughout the Lower Mainland (after obtaining their permission - see Appendix E). The soliciting process proved challenging. Initially it was planned that potential participants would initiate telephoning the researcher or, in the case of Early Stage support groups, fill out a form (see Appendix D) expressing their interest and desire to be contacted. Over time these methods proved inadequate, with insufficient response (two participants only). As originally desired, the researcher was permitted to attend several Early Stage support group meetings, with this face-to-face contact proving to be the most suitable method of attracting participation with
this population. The poster (see Appendix B) was distributed at these meetings, with any interested party giving permission to the researcher at this time to contact them if they had not telephoned the researcher within the week. This arrangement was made to appease prospective participants’ anxiety over whether or not they would remember to contact the researcher. Additionally, initial selected participants were encouraged to inform other potential candidates of the study, and recruitment also took place by word of mouth from colleagues, work peers, and acquaintances.

Of the 15 responses to this study, one did not meet the criteria (wrong diagnosis), three self-selected out of the study in the initial 15 minute screening call, one was unable to take part due to illness, and two were deemed by the researcher as not suitable (met the criteria but were not able to clearly describe or reflect on their experience of living with Alzheimer’s disease). This unselected group was comprised of five men and two women. Of the eight who became the participants, three initiated telephone contact (one via their spouse), one was through face-to-face contact via colleagues who had informed them of the study, and four gave face-to-face permission in the early stage support groups for the researcher to contact them for the screening interview. The final participants were comprised of five women and three men (see Appendix F for demographic information).

The procedures for this study included an initial 15 minute screening telephone call, an initial face-to-face interview of one to two hours duration, and a second, follow-up interview in person, approximately half an hour to one and a half hours in length. The total time commitment for each participant was between two to three and a half hours. Initial telephone contact involved screening according to the inclusion criteria (see Participant section above). A mutually agreed
upon time and location was arranged for the first set of interviews for individuals who agreed to participate and met the inclusion criteria. All interviews took place at the participants’ home. Written informed consent (see Appendix A) was obtained at the outset of the initial interviews. Interviews were conducted face-to-face using a semi-structured, conversational style. At the end of this first meeting a second interview, again in person and approximately half an hour to an hour and a half in length, was arranged for within three weeks of the initial interview. A second meeting, rather than a follow up phone call, was chosen with regard to the nature of the illness under investigation and the likelihood that face-to face meetings would be better tolerated by the participants than phone calls, which proved to be the case.

Data collection was done sequentially rather than concurrently due to the nature of the participants’ illness and the possibility of deterioration over time in their ability to communicate. At this second meeting, which added a phenomenological component to the study, the participants were presented with the categories arrived at to date through data analysis, with the request that they review their own data for its veracity as a reflection of their experiences and agreement in terms of title and ranking of importance. At this time, participants had the opportunity to add information, clarify responses, and suggest alternate names for the tentative categories that had formed. Additionally, the second interview acted as a type of validation procedure.

As memory problems were a fundamental and potentially distressing issue for these participants, the researcher took care to reassure each of them in the first interview that they need not worry about their ability to remember, as there would be a second interview during which they could examine the tentative results and make any changes they felt were required (e.g. add
anything that they had remembered in the interim or occurred to them in the second interview).
At the outset of the second interview, they were again requested not to be concerned with remembering the content of the first interview, but to review the written information provided by the researcher, and determine whether or not it accurately reflected their experience of living with Alzheimer’s disease. Additionally, it is short-term memory that is affected in Alzheimer’s disease, so participants’ memory for events in the past were no less reliable than the general population’s. Because short-term memory was a problem, participants tended to repeat the same themes several times during the course of each interview, lending credence to the importance of these events to these individuals.

The researcher’s goal throughout was to render the participant’s views as honestly, accurately, and completely as possible, thus ensuring the trustworthiness of this study (Rossman & Rallis, 1998). At the end of the final interview, participants were thanked for their involvement and encouraged to contact the researcher at any time if they had any post-research concerns or problems. A summary of the results was made available to participants who indicated interest in receiving one.

Collection of the Data

When the prospective participants first made telephone contact, the study’s purpose was outlined, namely that it was a requirement for a Master of Arts degree at the University of British Columbia and that it would be useful in increasing understanding and knowledge of the experience of living with Alzheimer’s disease and what is considered helpful or a hindrance in coping with this illness. Candidates who remained interested in participating and met the inclusion criteria for the study were then given more information on what the study entailed (see
Procedures section). A time and mutually agreed upon location for the first meeting was arranged and all information was recorded.

During all interviews, after an appropriate tone had been set and consent had been obtained, the audiotape was switched on and the entire session was audiotaped unless otherwise requested by the participant. These sessions followed a semi-structured format and each participant was identified by a code name only and the number of the interview. These sessions were then transcribed and analysed using the critical incident technique, to form the categories that were reviewed in the second interview for confirmation by the participants.

The initial interview involved two component parts: first, establishing rapport, clarifying the nature of the study, answering any questions the participant may have had, discussing their and the researcher’s expectations, reviewing confidentiality, reviewing the option to withdraw at any time, and signing the consent form. Second, the critical incidents were elicited by making the following statement and question: “think back over the time since you were diagnosed with Alzheimer’s Disease. Can you tell me a little about what your experience has been?” Additional questions were asked in order to elicit more in-depth information about helpful and unhelpful events (see Appendix C). This process continued until no more incidents were forthcoming from the participants. Questions were also included regarding what would have helped participants cope but had not happened, and what they now needed to do to help them cope with their illness.

The audiotapes of the interviews were transcribed and analysed and critical incidents were extracted and grouped thematically to form categories. Extraction was predicated on the following criteria: (1) completeness of the participant’s account of the incident; (2) clarity of event or factor identification; and (3) whether or not the outcome relates to the purpose of the study (Flanagan, 1954). Incidents meeting these criteria were then recorded for sorting. Any
further data arising from the second interviews, also audiotaped and transcribed, was incorporated into the final research product. Validity and reliability checks (see data analysis section) were performed on the categories.

**Analysis of the Data**

Inductive reasoning was used to analyse the data for thematic content, using three steps. First, incidents were extracted from the audiotaped, transcribed, and coded data, then recorded on index cards. Extraction was predicated on the following criteria: (a) the behaviour, factor, or event was relevant to the purpose of the study; (b) a detailed account of the behaviour, event, or factor was reported by the participant; and (c) the behaviour, event, or factor was considered critical by the participant. If incidents did not initially meet this criteria, they were not included at this point but were checked with the participants in the follow up meeting for clarification and validation. Any incidents subsequently meeting the extraction criteria were included in the analysis. Each incident was recorded separately on its own index card, with each criterion itemised. Identifying categorical information was omitted from the index cards to facilitate a blinded check by independent raters as part of the validation process.

Next, categories were formulated by sorting the incidents into similar clusters thematically, to form the initial, tentative group. These categories were added to and modified throughout the analysis process, with new categories being formed as needed when incidents arose that did not fit into existing categories. Each incident was recorded according to its source, the event or factor (i.e. what actually happened or what action was taken), and the outcome. As anticipated, a “kind of trial and error procedure” took place as category formulation was “unavoidably subjective” (Woolsey, 1986, p. 249). As expected, the clearest categories emerged first, with incidents appearing ambiguous as to categorisation being cross-checked with the
participant as part of the validation procedures in the second interview, for the participants’
selection of the most appropriate category. Where applicable, new categories were formed to
accommodate these incidents. Participants were asked to confirm the initial categories and
suggest alternative titles during the second interview.

Lastly, validity and reliability of categories was established by paying attention to
descriptive, interpretive, and theoretical validity, using the following validation procedures: (1)
participant cross-checking; (2) independent raters; (3) theoretical agreement (4) exhaustiveness;
and (5) participation rate. Audiotaping and transcribing the interviews, clarifying and checking
information with participants during the interview process, and second interview cross-checking
with participants regarding category names, ambiguous incidents and those not included in the
initial category formation collectively addressed descriptive validity (i.e. accuracy of account)
(Catapia, 2001). Participant cross-checking in the second interview also served to address
interpretive validity (or what the incidents mean to the participants), as did “using the language
and concepts of the participants as much as possible” (Catapia, p. 40). Theoretical validity was
assessed by investigating the corroboration of the categories in the existing literature on coping
with early Alzheimer’s disease. Comparing categories with previous research helped to identify
both consistencies and discrepancies (Baines, 2001; McCormick, 1995). Consistency indicated
the soundness of the category, while lack of consistency resulted in the category being labelled
questionable, for further examination for agreement from participants. If this was present, then
the category was either retained but identified as not present in the literature (Catapia) or
considered as a possible category until future research supports or disproves its validity (Baines).

Two independent raters, a number suggested as adequate for this process (Andersson &
Nilsson, 1964; McCormick, 1995), were used to sort the incidents into the identified categories.
One of these was a graduate of the Master’s of Counselling Psychology program at the University of British Columbia. The other was a master’s level nurse working in the field of geriatric mental health. After being familiarised with the categories and the categorisation process by the researcher (e.g. they were given a demonstration of the sorting process by being shown two examples of critical incidents on index cards and their appropriate category), they were asked to sort 30% of randomly selected incidents into the formed categories (Catapia, 2001). In their study investigating the reliability and validity of the critical incident technique, Andersson and Nilsson state a level of agreement between 75-85% is required for the categories. Accordingly, categories were considered valid if they achieved an agreement rate of 80%. Exhaustiveness was tested by withholding approximately 10% of the incidents from examination until all of the categories are formed. If these categories could be placed within the existing categories, then the category system was considered comprehensive (Baines, 2001; Catapia). Lastly, participation rate was determined by calculating the percentage of participants with responses in each category. A 25% participation rate was considered sufficient to identify a category as valid (Borgen & Amundson, 1984).

Confidentiality

Only two people had access to the full data: Dr. Bill Borgen, UBC Counselling Psychology professor and the researcher, Kathryn Bowen-Roberts, an MA student in the Counselling Psychology program. Two independent raters were given anonymous, randomly selected portions of the transcribed data on index cards for validation and reliability purposes regarding the initial formation of the categories. No identifying data was or will be made available to any person or agency outside the University of British Columbia. Anonymity and
confidentiality has been ensured by assigning each participant a code name once written informed consent was obtained in the initial interview. Participants’ names and corresponding codes will be kept separately from the remaining data in a locked filing cabinet at all times. This is the only record of the participants’ names, whose identities are known only to the researcher and who were subsequently referred to in the data only by use of the code name. The audiotapes and computer files are being kept separately, also in a locked filing cabinet. Transcribed data, audiotapes, and computer files will be kept for five years after the termination of the study, then destroyed by the most appropriate means: shredding, erasure to make data irretrievable, or erasure through demagnetization.

It was anticipated that there would be no risks involved to the participants in this study. No participant stated they experienced any discomfort as a result of their participation, with five people expressing deep appreciation for the opportunity to express themselves, and gratitude to the researcher for taking time to listen to them. If any psychological distress had occurred, the opportunity for counselling would have been made available. Similarly, this service would also have been made available to anyone else involved in the study who might have experienced psychological distress (e.g. independent raters). There was no monetary gain or other tangible compensation for the participants but their best interest was forefront at all times during this study.
CHAPTER IV

Results

A total of 140 critical incidents were extracted from the interviews with the eight participants, five women and three men, regarding what helps and what hinders their living with early stage Alzheimer's disease. These 140 incidents formulated a total of 15 categories: seven helping and eight hindering. These are described in the following section while the validation procedure results are discussed in Part II.

Part I: Description of the Categories

The seven helping and eight hindering categories are presented separately. Those with the highest participation rate are discussed first with categories having the same participation rate presented in order of the greater frequency first. Critical incident events or factors and outcomes are described for each category, with examples of incidents. Table 1 lists all of the categories, their participation rates, and frequencies.
<table>
<thead>
<tr>
<th>Helping Categories</th>
<th>Frequency</th>
<th>Participation Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Self-Help Behaviours</td>
<td>32</td>
<td>7 (88%)</td>
</tr>
<tr>
<td>2. Emotional Supports</td>
<td>17</td>
<td>7 (88%)</td>
</tr>
<tr>
<td>3. Practical Supports</td>
<td>12</td>
<td>7 (88%)</td>
</tr>
<tr>
<td>4. Faith</td>
<td>7</td>
<td>7 (88%)</td>
</tr>
<tr>
<td>5. Personal Attitudes</td>
<td>15</td>
<td>6 (75%)</td>
</tr>
<tr>
<td>6. Being Informed</td>
<td>3</td>
<td>3 (38%)</td>
</tr>
<tr>
<td>7. Effective Medication Treatment and Management</td>
<td>3</td>
<td>2 (25%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Hindering Categories</th>
<th>Frequency</th>
<th>Participation Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Experiencing Symptoms of the Illness</td>
<td>10</td>
<td>6 (75%)</td>
</tr>
<tr>
<td>2. Experiencing Consequences of the Illness</td>
<td>10</td>
<td>5 (63%)</td>
</tr>
<tr>
<td>3. Limited Resources</td>
<td>8</td>
<td>4 (50%)</td>
</tr>
<tr>
<td>4. Personal Responses</td>
<td>7</td>
<td>4 (50%)</td>
</tr>
<tr>
<td>5. Attitudes of Friends, Family, and Others</td>
<td>5</td>
<td>4 (50%)</td>
</tr>
<tr>
<td>6. Additional Medical Conditions</td>
<td>5</td>
<td>3 (38%)</td>
</tr>
<tr>
<td>7. Worrying Thoughts</td>
<td>4</td>
<td>3 (38%)</td>
</tr>
<tr>
<td>8. Process of Receiving the Diagnosis</td>
<td>2</td>
<td>2 (25%)</td>
</tr>
</tbody>
</table>
Helpful Category 1: Self-Help Behaviours (32 incidents, 88% participation rate)

Self-help behaviours encompassed a wide range of behaviours that could be grouped into engaging in meaningful activities, maintaining and enhancing abilities, keeping the mind active, and maintaining health and involved strategies such as writing things down, keeping occupied, developing a system for managing, and trying to stay informed. Types of behaviours described included keeping a record of events on the calendar, using a shopping list, recording activities in a book, self-care activities such as physical exercise and applying make-up, comparing self to others, playing chess, using the computer, baking, socialising, doing volunteer work, helping others, gardening, going on outings, sharing thoughts and feelings with others, learning new ways of managing, self-reflection, and trying multiple remedies for Alzheimer’s treatment.

The outcomes were feeling more relaxed, being able to remember better, having fuller days, being able to contribute instead of always being care taken, being involved in decision making about their lives, being able to express themselves, feeling heard, feeling less overwhelmed, learning to let go of things, improved quality of life on a daily basis, better able to cope, feeling less bothered, feeling fortunate, being able to stay positive, problems seem smaller and more manageable, improved mood, feeling better about oneself, feeling energized, feeling connected, feeling understood, focusing less on having Alzheimer’s, improved physical health, feeling less uncertain, more in control, maintaining ability to function, feeling more on track, feeling prepared, feeling that impact of Alzheimer’s is being minimised, feeling productive, feeling appreciated, enjoying self, less frustrated.

EXAMPLE 1

And there’s a little red book up there that lists what I should do day by day. Um, this I think is um is the biggest help because what I hear, now, and, in another hour’s time I will
have forgotten... (spouse) writes my chores down on and I, I can recall, I can refer to it, to make sure I’m doing what I’m supposed to be doing and, uh, this is a good way um, I would recommend it to anybody in a like position cause you can refer to that now and uh, at least be occupied on something that you know you should be doing, and that, that is a big thing.

EXAMPLE 2

Well, keeping you’re brain active, if you don’t, like the old saying goes ‘if you don’t use it you lose it.’ And it’s true. Well even now if I don’t, if I don’t, for example, it’s a small thing but, if I don’t look at my calendar and see what’s happening tomorrow, I won’t remember. But if I go at night and in the morning take another look at it, then I’m set for the day. It is important.

EXAMPLE 3

I think I’m fortunate in that I, I mean __’s my caregiver. Some of the one’s there, their caregivers are, I suppose they’re a pain... I, you know you only have to read the paper and everything else and, there’s people that are, I keep thinking that there are people that are far worse off than I am, that are alone, and uh, there are some that come to the support group...they’re alone, and uh, have got Alzheimer’s...I just have...a lot of pluses. I’m grateful.

EXAMPLE 4

Another thing that’s been good is that, uh, rather than to have to completely give up any, um, work activities, I’ve been given the opportunity to work on the ___ of the ____, so what they recognised is that people with dementia can still function in different environments, and so, um, we’re involved in a lot of the activities, we’re asked for input into the ______, and that, that’s really good... it’s very positive and it’s an opportunity. In my previous career I did a lot of public speaking and training, so now I have an opportunity as a ___ member, actually the first one ____ with dementia on the ______, to actually, um, be involved with speaking to the public and making decisions, so, that’s really positive and I think that really reflects well, again, sort of recognising that people that are being managed on their disease are still functioning.

Helpful Category 2: Emotional Supports (17 incidents, 88% participation rate)

There were three predominant types of emotional supports: a) belonging to a support group; b) support from family; and c) contact with friends. In addition, participants found the presence of a pet and the approach of professionals to be beneficial.
Outcomes were: feeling on an even keel, feeling on the right track, feeling like they are not having to deal with Alzheimer's on their own, feeling supported, fortunate, respected, calmer, grateful, feeling spoiled, having a focus apart from themselves, feeling comforted, understood, feeling secure in the knowledge that support is close by, normalization, continuation of long-standing routines and rituals, companionship, feeling connected, having the opportunity to be supportive to others, being able to express feelings, feeling more positive, being able to see the humorous side of their situation, feeling less isolated, better able to problem solve around issues that arise, able to take advantage of other people's experiences, feeling hope, admiration, inspiration, feeling less of an oddity, learning additional coping skills, feeling part of a group, enjoyment, more settled, feeling a sense of belonging.

EXAMPLE 1

The support group's terrific. That's one of the best things, yeah...everyone is going through the same thing and, uh, there's lots of circumstances that are, where there's laughter ... I think the support group is just great. I feel badly for anyone that doesn't take advantage of it...and the facilitators that handle it, they're very good too...Just their attitude and uh, they never make you feel any less than you are ... it's gotten to be just a group of friends sitting around now and, uh, sharing what went on in the week... I think the only people that understand truly are when I go to the support group. And there's others sitting round there, or, I don't know, not that many but. And they, they're all going through exactly the same thing. And we have lots of laughter... and uh so, there I have no, you know, everyone's going through the same so you feel they understand.

EXAMPLE 2

But I'll tell you what really does, it's like a shot in the arm, is when out family comes. You know? If they come, even, if they come for dinner or for lunch... we have a wonderful family so, you know we have a lot to be thankful for and a lot, and we're grateful for that. And there's a lot of love in our family... And we, we've got, we've got wonderful friends too. Friends came and brought us, had a visit the other day and brought us that lovely plant. Sometimes you feel kind of spoiled. We wish everybody had that... I, I really feel sorry for people that don't have family that's close. Oh, it's, it's just like electricity through you, you know? You just, forget about everything and there they are, happy, wonderful people.
EXAMPLE 3

Um, friends have uh, helped me stay on track with items by phoning me to just confirm appointments or pleasant things like notes. And so they sort of adjusted to that. They just know that, to give me a buzz just a short while before any activity and we can continue on. So that’s just a way of keeping track. They also uh, yeah, and uh, life goes on the same. We, we’re not doing different things but they just have to remained me to do things. And um, that’s... Continuing with the normal social life for me, I don’t feel like there’s any big change in, my relationships with my friends hasn’t changed. Um, they don’t feel, I don’t think, a burden in any way to have me as part of the group. They just know they have to remind me to do something, or to be a certain place at a certain time. So, so that’s been easy.

EXAMPLE 4

The most wonderful girl started that club and she was a nurse...she was great...because you knew she was um...you knew she was interested to help you if you needed it... she was always um, happy um, and kind and I’m, have never seen many of the group who have been distressed, and um she, if somebody um has to go into one of the homes um, she was always right there saying um, you know, trying to comfort people.

Helpful Category 3: Practical Supports (12 incidents, 88% participation rate)

Practical supports encompassed several areas: financial support, living arrangements, support from the medical community, and support with having daily needs met, and were instrumental in facilitating a better quality of life than would have been possible without them. The outcomes included feeling that living with Alzheimer’s is a more positive experience with these supports in place, greater ability to cope, feeling a sense of relief, able to maintain independence, feeling secure, able to take medications that would otherwise be unaffordable, able to maintain standard of living, able to maintain a stable household, lower stress levels, feeling encouraged, improved mood, feeling supported, crying less, being better informed, feeling safer physically, receiving medications as prescribed, receiving the most appropriate medications, greater ability to deal with family issues, learning new ways to manage activities of
daily living in terms of behaviour changes and coping skills, decreased frustration, better ability to organise self and daily life, more able to be effective on a daily basis, less confused, able to manage more activities, able to say ‘no’ to things and retreat from taking on too many projects, able to identify when to take a break, clearer mind, able to let things go.

EXAMPLE 1

I’m very fortunate because I did work for a company that had provided me with a disability income. It’s very positive for people that still have reduced income but are able to pay the rent or whatever they need to do. I’ve met people in groups that are not in as fortunate a situation as me and they are, their stress levels are much higher. So, good things are, yeah, a good income.

EXAMPLE 2

For me a positive thing is that I’m so close to where I have to go - it’s a block and a half away...I can walk to wherever I have to go by myself. It’s not that I have to rely on him (husband) for everything...you can shop, and, uh, pick up groceries. So, and the library, that’s just a block and a half down the lane, so, and um, I read a lot.

EXAMPLE 3

The neurologist in ___ that I go to, Dr. ___ wonderful man, and he um, he has uh, helped me a lot. Because, I was, I was crying all the time. I mean really crying...But um, since, since he’s been helping me, uh, it’s improved a lot... He’s uh, he’s really encouraged me. He’s encouraged. And that encourages me, if I can encourage him. Do you know what I mean? ... it’s given me uh a boost. And uh, I look forward to seeing him every month. And he’s like an old friend... A big support. Yeah.

EXAMPLE 4

My, my son has been helping me with my pills. I have a lot of pills that I have to take, and he’s been helping me... he sorts them out for me... he makes certain that I take the right dose, dosages... I was, because I, he was sitting and, he takes quite a bit of medication too. And we seemed to be taking them at the same time and he had one eye over what I was doing and when I, what he was doing. And he realised there was a number of times when he had to correct me about my medications because I had, I had forgotten to take one med, you know, when I was filling up my meds, and I uh missed taking the med.
Helpful Category 4: Faith (7 incidents, 88% participation rate)

Participants described their religious convictions and participation with church activities as being a fundamental source of strength in helping them manage. Outcomes were: feeling grounded, feeling that time is spent meaningfully, feeling a sense of purpose, supported, feeling that they will be taken care of no matter what happens, feeling looked after, feeling guided, less alone, better able to cope, feeling that help is there at all times, feeling that the destination is known, feeling worry free, peace of mind.

EXAMPLE 1

Well, we know the outcome of things...we know what the outcome is going to be for everyone...In our religious teachings we know just what’s going down and what’s not... Take it, word for word. You either believe it or you don’t. It’s that simple, so you believe it - not a worry in the world. No problems... Well we know from whence the help is gonna come, and we know why. And if we remain faithful then we won’t have any problems...it gets stronger everyday. Cause you don’t know how, what, what’s coming. With yourself... it’s why I can have the attitude I have, I don’t worry about things... The guy upstairs is looking after us. Up there... I’m not concerned or worried about this life or anything else... Peace of mind.

EXAMPLE 2

Well it’s just knowing that uh I can talk to God about it and he will understand... I don’t think God sends these things, I think they are learning experiences, I think he knows who can handle them and who can’t...I know that, it was the same thing when I was going through the ____, I knew. It was sort of a, it was just sort of He and I, going through it. And it’s the same with Alzheimer’s. It’s nothing that I can’t handle or that He’s going to allow me to handle on my own.

EXAMPLE 3

I don’t go regularly to church. That’s something I don’t do and I should do but I don’t know. I don’t go very much anywhere anymore but uh, but I still have faith... It gives me a purpose here. You know it’s meant, faith had asked me to believe that what I, I have lived in life, think that I have tried to be a good Christian.... And that I have helped others... It helps me, helps me, supports me. It will see me through. Whatever road it brings me, it will see me through... The path is there. The path is there. It shows you where to go... shows us the way.
EXAMPLE 4

Well, just my faith and uh, the good Lord. I’m sure he doesn’t mean for me to act and react the way I am doing... It’s the only thing. Most important, most important. Because you’re prompted, guided from inside, and often I realise that uh, something is not as it should be and, uh, it’s just that you’re being prompted to do the right thing at the right time. And, uh, without faith I don’t know where I’d be. The good Lord knows my situation and, uh, He treats me accordingly as far as I can understand... Without that, well then, you’re like flotsam and jetsam... It’s something I can’t imagine I’d ever get along without now.

Helpful Category 5: Personal Attitudes (15 incidents, 75% participation rate)

This category involved expressions of determination, gratitude, appreciation, acceptance, a sense of humour, and positive attitudes as being helpful in living with the illness. The outcomes were described as feeling less frustrated, more grateful, able to move forward, better able to cope with things, able to make the best of the situation, refusal to give up, feeling better, able to prevent self from going under, ability to problem solve, feeling less upset, feeling calmer, having confidence in ability to manage, increased enjoyment, less worrisome, taking on the advocacy and educator roles for the public about people with dementia, ability to maintain stability in household, clear boundary setting, appreciation for the humourous aspects of their situations.

EXAMPLE 1

But I just take it one day at a time. And I enjoy it and then the next day comes along well, it could be a bad day but... It does help me manage. I just think well, um, now tomorrow we’ll do that, but we won’t do, do it today, because it’s not necessary... and I feel good.

EXAMPLE 2

We’ve tried to take everything each day at a time, one day at a time. And that’s about all you can do, because you don’t know what’s going to happen at the moment... You just deal with it and, hope you can deal with it at least. Yeah, and if you can’t well then get help. And help isn’t too far away, so... It’s all I’ve done all my life, is manage. Now I’m managing to manage... You know you, you have, you’ve got to have confidence in
something or someone, or whatever. And if you haven’t got it within yourself or your family, well, you’re in trouble.

EXAMPLE 3

Just look around at the wonderful world we are at. Look at Nature. It’s wonderful. Appreciate it... When I walk around and see, the flowers are growing, how nice it is around here, and lucky people to make wonderful gardens and, things like that... I just feel better.

EXAMPLE 4

Knowing that I can’t do anything about it. I’ve had to accept that. And it helps, it really helps. So, I, I haven’t got that frustration... Well what else can you do?... It could be, we could have a lot worse. Cancer or, you know, something like that. But this uh, you have to learn to cope with it and get through the day and you know, try and be happy. But you know to be down-hearted and down about it, it isn’t something that you’re in a lot of pain with. Which is something to be thankful for, right?... it just makes me able to cope with things.

Helpful Category 6: Being Informed (3 incidents, 38% participation rate)

Participants described obtaining a diagnosis, learning the source of repetitive internal sounds, and believing they knew the source of Alzheimer’s disease as being beneficial.

Outcomes included having peace of mind, not worrying, being able to move forward, determination to make the best of the situation, ability to accept the situation, and relief.

EXAMPLE 1

It meant that I wasn’t crazy. I mean there’s always that, certain lot of days where you think you’re ‘going out of my mind, what’s wrong?’ and nobody will believe you. So once I finally had a diagnosis, I realised that I was right in some ways, unfortunately. That I had a diagnosis meant that, at least then you can go forward with your life and not be in limbo all the time... there’s nothing worse than not knowing what’s preventing you from being as effective as you were before. And uh, it’s like having a broken limb and nobody sets it. Um, the worst part is not knowing what the stumbling block is. Once you’ve been diagnosed you can get on, you can see that maybe there’s some unpleasant still ahead but you know what you can do between then and now to have a really good day every day that you can.
EXAMPLE 2

Well, I think knowing where those noises come from and knowing that I can’t do anything about it... I just accepted that it wasn’t some occult or uh, you know, some kind of scary thing, and that it was uh, that it was something to do with my brain and it was uh, you know, certain pitches that uh, and sounds like oh, the fridge for example... So, when I realised it was the pitch of uh, that triggered my brain, then there, there really is nothing I can do about it. So when, when you know what it is, you can’t do anything about it, but you know, just make the best of it... Very relieved.

Helpful Category 7: Effective Medication Treatment and Management (2 incidents, 25% participation rate)

In this category, participants identified being started on medications and determining the right medications and dosages as being essential to their re-gaining and maintaining their health and stability. Outcomes included improved memory, better able to manage Alzheimer’s and other medical conditions, feeling physically well, better able to function, higher quality of life, feeling that options exist if or when current medications are no longer effective, crying less, able to participate in valued activities, and better mood.

EXAMPLE 1

In my particular case the fellow also has a degree in pharmacology so he’s been just a wonderful advocate to work with to get the drugs that work most effectively and as we’ve changed through the different prescriptions he’s been able to ensure that I am getting the maximum benefit...that’s been really, really positive because we had gone through three or four generations of medication prescriptions and, uh, now I’m really comfortable with what I’m on and if there’s any changes he continues to work with me, so that’s really been really, really important because if you’re not feeling well or functioning well your whole quality of life deteriorates quite a bit.

EXAMPLE 2

I mean, if Aricept does what it’s done for me, why not?... my, my children think, like I said hey, maybe my, my memory has improved so much from the time I was diagnosed with Alzheimer’s until last May it’s gradually improved... So they won’t hear of me stopping... I actually think that it has made a lot of difference because I’ve been able to struggle with these other things, psoriasis and you know, high blood pressure, and these strokes that I had, and uh, you know.
Hindering Categories 1: Experiencing Symptoms of the Illness (10 incidents, 75% participation rate)

Symptoms of the illness described as hindering by participants included problems with memory, not knowing what to do, difficulties with finding the right words, repeating self, being confused, and speaking without thinking.

Outcomes were getting into a tizzy, becoming emotional, doing things out of the norm, increased frustration, being short-tempered with others, being told by others that one is repeating oneself, feeling stupid, redoubling efforts to prevent behaviours, withdrawing, not participating in conversation, stopping previously enjoyed activities, inability to use the phone, becoming disgusted with self, becoming angry with self, feeling less secure, disappointment, difficulty planning, difficulty sharing, feeling embarrassed, humiliated, feeling as if one is losing capability, difficulty making decisions, becoming upset with self, feeling that one may have hurt others, feeling distressed, feeling foolish.

EXAMPLE 1

I get upset with myself when I realise I may have said something out of, for no good reason whatsoever, which has hurt somebody else and, this distresses me no end because it’s not me. But it’s whatever this blooming disease is causing. You don’t, you don’t, you don’t think before you speak and that is, that is, a wrong thing... It’s a miserable situation. I, I, I, find I’m letting off steam within, it’s as though somebody, how, how can I explain it? You realise within minutes your being mad with somebody or your getting distressed with somebody um, but you’ve tackled it all the wrong way. Um, you blunder more than anything else, you say the first things that come to mind, uh, and this is ridiculous, I don’t know why, why it happens. I’ve no idea. But you feel foolish afterwards. This is, this is something that I can’t comprehend and I can only thing that it’s a result of what’s taking place... It’s uh, it’s something I dislike uh, something that I’ve got to work on. Whether you’ve got to count up to 10 or count up to 60 it’s uh, it’s something that will have to be worked out.
EXAMPLE 2

It’s not getting the words out it’s, um... To find the description... I get disgusted with myself... I think well, just that I um, you’re not trying enough.

EXAMPLE 3

I don’t know, I - because I don’t know what to do...like uh, I’ll stand by the fridge and uh, and people would say they do it too but uh, I just don’t know what I, what I want and that comes up a lot in, in everything, and I don’t want to do it... That’s a terrible feeling, really. Your turnips are down in the fridge just looking and you think “ahh!”... Get angry. Not throwing things around but angry in myself, yeah... It’s getting worse.

Hindering Categories 2: Experiencing Consequences of the Illness (10 incidents, 63% participation rate)

There were a wide variety of consequences of the illness identified by participants as hindering: having driver’s license taken away, losing job, adjusting to medications and struggling to find the right dosages, reduction in stamina, missed opportunities, difficulties adjusting to decreased memory, and a sense of urgency to keep moving.

The outcomes included reduction in income, changes to sense of identity, increased frustration, loss of mobility, increased dependence on others, increased isolation, lack of choices, sadness, inability to take part in previously enjoyed hobbies and activities, death of dreams for the future and anticipated activities, having to modify the type of activities engaged in, attempting to reconcile oneself to the nature of Alzheimer’s, difficulty planning financially, difficulty planning activities and moderating energy levels accordingly, feeling worn out, increased clumsiness, breaking items, feeling driven, uncertainty, becoming angry with self, feeling frustrated, and believing that people around them are upset by their behaviour.
EXAMPLE 1

We all work for money, which has a profound impact. But for many of us, our jobs, our careers were part of our social life, our identity, and also our sense of um, accomplishment... Well, losing my job which I thoroughly enjoyed... I had another 10 years to work... It was just an automatic thing that when I was diagnosed I had to leave my job, you couldn't continue with dementia.

EXAMPLE 2

There is no question it's been devastating and I'm still dealing with the part where all of a sudden you've been given a diagnosis of so much time. I have no idea what the time is but I do know that the time won't be quality time regardless of the tenure. So that, that's still a hard thing... It's not just like you can excise this piece or that piece, sew it up and it's okay, that's it... I'm trying to let go of it. It's kind of like, if you've got a broken leg they'll tell you in two months you'll be back walking on it. With dementia or these kinds of diseases, you really don't know what your prognosis is going to be like, because it seems that every individual is different. And the kinds of drugs they take can make a difference, but also where the disease is and how it impacts your functioning is really not that well known yet. Some people seem to hang on for a lot longer and the diagnoses, as I'm seeing it, are not always accurate. No, it seems to fit this category but in fact it doesn't, and people are managing or living longer than predicted. Or shorter. So it's not black and white, it's not like a fracture, getting over the flu. And so there is a bit of an issue there, because you don't really know how to plan financially, like you could cram everything into the first twelve months and go off on that holiday that you never had, and you could live for twelve years. And you don't have any money. So, you balance all these things...the other side of it, it's not just the financial, it's the physical abilities that you'll have and you really can't burn yourself out too soon, but you don't want to miss life as it's going on.

EXAMPLE 3

I guess one of the things I, I, I feel sad about is losing my intelligence. I've worked so hard to get it. Yeah... You know that's the thing, too, is that there, in other times in your life that something happens, but there's always another side that you can make it better. You can do something to make it better. Like do something to improve things or you can take a different path, which you were thinking of taking. And uh that will reach the same kind of goal but uh that wasn't what you had expected to do, the path you had expected to take in the first place. But now you don't, you don't have any choice which path it's going to be. And, and you don't have any choice as to what's going to be at the end of that path. That's been pretty well ordained... Lack of choice. No more choices. And when you get older and retired and you thing 'oh well now I'm retired, look at all the choices I have' you know? 'I'm gonna do this and this and this and this.' And it's great, you know, you think 'that's great, big wide horizon in front of me,' you know? And then you get there, and what's there? A flat line. Nothing beyond it.
Hindering Categories 3: Limited Resources (8 incidents, 50% participation rate)

Three main types of limited resources were described as hindering: 1) insufficient or reduced services; 2) limited finances; and 3) having insufficient information. Insufficient services resulted in participants having to travel distances for services, using up limited finances and precious time and energy. Reduced services also meant that beneficial and previously enjoyed activities were no longer provided, leaving participants without comparable services. Limited finances threatened previously enjoyed lifestyles in the case of participants going on disability insurance, and the threat of having to stop taking vital but exorbitantly priced medications for participants on fixed incomes. Having insufficient information hindered by creating uncertainty about the progression of the illness in some cases and by making it unclear to one participant about whether or not s/he actually had Alzheimer’s.

The outcomes included having less time to do preferred activities, having less time to take advantage of supports, feeling run ragged, worrying about financial situation, seriously considering stopping beneficial medications, reducing participation in activities outside the home even further, having to do without other things in order to pay for required medications, feeling anxious about ability to manage financially in the future, feeling disgruntled that medications are not paid for by the government for this illness when they do pay for medications related to other illnesses, feeling like a burden to family members, increased stress levels requiring the use of additional medications, increased anxiety, feeling unsettled, feeling directionless, feeling purposeless, being unable to plan, being unable to move forward, feeling like there are few options.
EXAMPLE 1

There just isn’t the specialists out here. And in order for our doctors to, you know, they’re only limited in certain areas that they can practice in so, they have to send you off to somebody else. And it’s, I had to go to ___ hospital to have this thing with the ___. And I had to go into ___ for a dermatologist, have to go into ___ quite a bit for the eye specialist and the neurologist in ____. So, you know that’s an expense travelling with gas and the car and um, it just all adds up to a whole lot.

EXAMPLE 2

I mean if it wasn’t for our, our family pitching in, I mean we, we’re both on pensions. We don’t have a lot of money... I mean the medication we take, take well I don’t know we pay - well some, some medications they won’t pay for. And Aricept is one of them, that’s probably one of the biggest ones. So when you’re paying $150... it’s a lot of money. Plus all the others, added on to it... What are you going to do when you don’t have any, a thing left. We’ve never, we’ve never been on welfare or never been, you know, never, ever. All our lives, we’ve always worked, the two of us... I haven’t counted up the, if I could show you the, the stacks of printouts from the uh pharmacy, the last year and already this year. You’d flip. I mean it’s just incredible... Well we sure have to watch what we’re doing. We can’t, no we can’t do the things we, we like to do. We can’t go out and buy gifts for your kids and all your grandchildren. Can’t buy any, you know... it’s, we manage. We manage but we don’t know for how long.

EXAMPLE 3

I hate having loose threads around... you know, if I’ve got something wrong with me I’ll, I’ll do everything I can to clear things up. If I know I’m hurt or sick or something I’ll do everything and anything to help them, you know. And uh, that’s the way I am. Have been most of my life, you know. And uh, solve things when I can. Yeah. No I like Dr. ___, he’s very, very nice. Very clever obviously. It’s just I was a bit dis- I was just a bit uh, surprised that he didn’t, he didn’t tell me more, you know. I thought that he would tell me more, but... you feel like you’re wandering around in a wasteland. Yeah. You don’t know what the direction is, you don’t go. Um, why are you there? You know? What are you supposed to be doing?? Purposeless. Absolutely. And for me that’s, it’s, like death. Because of the, the way I’ve lived my life. Because I can’t, I can’t, now um, I mean I can’t um, plan. Any plans. The door is partially closed now. And then, too, the person that I, that I try to be, is gradually diminishing.

Hindering Categories 4: Personal Responses (7 incidents, 50% participation rate)

Participants identified emotional responses such as anger, frustration, uncertainty, and reactions to accepting help as having a negative impact on their ability to manage. The outcomes
were venting feelings on closest person then immediately regretting behaviour, feeling foolish, feeling remorseful, becoming more angry with self, increased frustration, feeling tense inside, being unable to move forward, no longer attempting to do things, feeling in limbo, fear of making a fool of oneself, feeling aimless, feeling helpless, feeling more settled initially, trying hard to control temper, feeling like a burden.

EXAMPLE 1

Now of course it’s something that blows up right away. You’re, you’re not thinking through before you blow your cork... I get frustrated with myself. That I’ve reached this point for no reason whatsoever doesn’t do me any good. It’s uh, it’s, as the saying goes, you always hurt the one you love. It’s, it’s uh, why should I vent my wrath on ___ (spouse) when it’s nothing at all to do with ___. I realise this as soon as it’s happened and I feel a fool that I’ve done this... this, this is the unfortunate part of the whole thing. You, you really don’t mean to because you’re frustrated in yourself. But um, blowing your cork doesn’t do any good anyway. It’s the easiest way of, sort of, settling yourself down again. But I’m fighting that, I’m trying hard to do something about it because that is not the answer. It doesn’t get you anywhere.

EXAMPLE 2

Something that bo - that gets me is the fact that (tearful and unable to speak)... My family. Um. They do so much... for me. And I’ve always done for them (tearful). So I’m not used to that... I do think about it a lot. I think it’s a burden on them. At least some of them. A couple of them, it’s not a burden, but the others, they work hard and they, they struggle for their living, and they have, you know. So I think, hey, we’re just another one... But they don’t make us feel that way. We get a good bailing out about it. But that doesn’t really help what’s inside of you. You know, you’re, you’re your own person, you’re yourself. So, something’s got to give I guess.

EXAMPLE 3

I guess I’ve been angry about it all along... You know you get, I get angry and um, it just doesn’t help... if you get angry you’re frustrated, ‘Dammit and so and so and so and so on.’ Kick the bucket and kick the cat. I don’t think it helps at all, you know... I, I know my own feeling... Yes, well, this Alzheimer’s is, I’ve prided myself I’m fairly intelligent and uh... a normal person. And um, I’m no longer a normal person. That’s the uh, bad point... Well uh, other people see it, I see it. I am that, but I’m angry that I am that...... It’s a helpless sort of anger.
EXAMPLE 4

Since that time myself I've found that I am feeling, um, noticing, I'm unsure of myself a lot of times. Whether it's the uh, suggestion that's been placed in my mind or whether it actually is happening to me I know, I don't know uh, what, how do you know at first?... You know because before I, I, you know I felt I could do things, I could do, I'm capable of doing things, but now I'm not so sure about that. You know I don't want to, well, for instance, I, I don't want to try to do things that I end up not being able to do... I can't move.

Hindering Categories 5: Attitudes of Friends, Family, and Others (5 incidents, 50% participation rate)

Participants described attitudes of impatience, dismissal, irritation, frustration, assumption, anger, and overzealousness as hindering their ability to manage. The associated behaviours included overstepping boundaries with the caregiver role, talking about the participant when they are not present, being unhelpful, being uninformed, losing temper, finishing sentences when the participant is trying to speak, not really listening, joking about the illness.

Outcomes included feeling like an object, feeling intensely angry, feeling invalidated, wishing they had never told anyone about having Alzheimer's, feeling unsupported, becoming tearful, feeling hurt, disrespected, disheartened, having increased stress levels, having to develop new coping skills to respond to challenging attitudes and behaviours, feeling not understood, feeling as if people do not really listen, feeling helpless, patronized, giving up, and feeling diminished.

EXAMPLE 1

I, I hate this. Um... unless I never told anybody I can't immediately think of somebody, you, you're treated as um, being foolish and that, I, that makes me so bloody angry... You know, you, you... can't accept his judgement etcetera, etcetera... I've been a fool telling people, that I have it... You just become a, an object.
EXAMPLE 2

Everybody has an idea of how you should do things. And that can be different than your own... there is a real huge issue over this need to care give, and everybody’s having to learn to manage it, because that becomes very intrusive sometimes and it takes away dignity. So that’s become an issue... The family thing is really a very awkward one. Uh, parts of my family have been really, really supportive, other ones have become um, much more engaged in trying to take over the role of caretaker. And that has caused some huge problems. Um, since the initial diagnosis I’d thought we’d worked through most of it but it’s erupted again, where um, the behaviour of a particular family member has gone too far and created a lot of problems for me. Which raises my stress level and um, causes me to have to develop different coping skills within that part of my family.

EXAMPLE 3

What’s hard sometimes is when people try to fill in, for you, with what they think you’re wanting to say and remember, um, ___ (spouse) does it sometimes and, I know, he’s so good that I don’t reprimand him or anything. I mean he’s fantastic but...but, uh, sometimes that’s hard ... sometimes in the afternoon about 4:00-5:00 I’ll be sitting here and I’ll, I’ll have to ask ___ (spouse) well, what did we do this morning? Um, and sometimes, you know, he’s edgy about it and uh, says ‘for goodness sakes’ you know, this kind of thing ... If the answer back is sharp then that, or you know... ‘I just told you that,’ and you feel really, you know, I mean , I don’t go off and cry my head off but I’ll, tears’ll come to my eyes and I’ll go into the kitchen... ___’s (spouse) been so great but he did get upset with me. He just said ‘for Heaven’s sake, just write it down if you can’t remember it!’ You know. That hurt. He’s never done that before but I guess he’s just... I’m not blaming him because he’s been great, but I guess it just frustrates him. To tell me things over and over...It’s hurtful, I feel disrespected. I, I just cry that’s all and then he says he’s sorry, and we carry on. But all I wanted to do is um, ask his opinion. You just carry on until the next time, I guess.

EXAMPLE 4

People do phone and I hear snatches of ___’s (spouse) conversation on the phone. And, I mean, it’s then that they ask him how I am. They don’t talk about anything that’s happening with me, with me. But I hear him saying things. I would rather they asked me. But you know, you say to people that you have short-term memory loss and everyone’s response is ‘oh, that’s nothing, I go to the fridge and I forget why.’ Or, you know. And it’s, and I try to say to the, ‘that, that, sure, everyone does that. But this is’... I mean I’ll totally forget in the afternoon everything that’s happened. And I’m not going to start telling people, other people, that, I just, I don’t know. Maybe I should. But I don’t know if they’d understand because sometimes, a couple of times I have and they said ‘oh well, I can’t remember things either, I go to the fridge and I don’t know what I just bought.’ So, they’re not really listening to me... It is unhelpful... I’ve never said that to a person.
because I do remember what I went for when I go to the fridge. But you think to yourself 'uh, forget it!'

**Hindering Categories 6: Additional Medical Conditions (5 incidents, 38% participation rate)**

Other medical conditions made it more difficult for participants to manage with their Alzheimer’s in several ways: time, energy, and finances were used for other conditions, meaning less of these were available to direct toward the Alzheimer’s; the other conditions prevented the use of coping skills previously developed to manage the Alzheimer’s; and symptoms associated with the other conditions directly affected the participants ability to cope with their Alzheimer’s.

The outcomes included having to be less active, being less mobile, giving up cherished activities, increased confusion, increased isolation, having to stop exercising, increased stress levels, having inadequate time to do enjoyable activities, feeling overwhelmed, increased financial burden, having less time to socialise, having less time to access existing supports.

**EXAMPLE 1**

The hearing, the hearing, it, it compounds the uh, problem with uh hearing. You know, I can’t, I, I was saying to you I get confused? And I get confused because I, I can’t hear properly.

**EXAMPLE 2**

Well I think when everything gets um, there’s so much medications and there’s so many doctor’s appointments... have to have appointments with the doctors, the chiropractor, and uh, my back has been really bad and uh. That’s uh, nothing to do with my brain, but. The other medical problems I have that um, if I can, and I’m trying to get each one looked at. I just was at the hospital having x-rays just the other day, and um, of my ___ and I have to go back for my ____. But I, those are the things that uh, hopefully, I’ll have gradually, looked after. I have another cancer thing on my ___, so that’s, I don’t know whether, I’m going to have to have that looked at. I have to go to the plastic surgeon in ____. So those are things that, if I could just stay home and just do what I like to do... I think I can cope with, with just the Alzheimer’s if it wasn’t for all the other things. But I can’t forget about those other things either. So I’m working on them, too... I don’t like to
be on the go all the time. I like to have time for other people and you know, I don’t. I don’t have the time that I really want.”

EXAMPLE 3

And now I have osteo, so I have to deal with that. And then I had a fractured foot, which is when they found out about osteo...so that reduced my mobility and I couldn’t exercise, and exercise is a stress reliever. So, it becomes a cycle... I may very well have developed osteo regardless, so I, I don’t see it tied into the disease specifically other than the fact that it now limits some of those things that I’m trying to do.

Hindering Categories 7: Worrying Thoughts (4 incidents, 38% participation rate)

Participants reported concerns about becoming a burden to others, thoughts of their caregiver dying first, and worries about becoming violent as having a negative impact. Outcomes were feeling worried about how they would manage in the future, being fearful of the progression of the illness, being fearful of having to move into a facility, being unable to sleep at night, feeling that death would be preferable, developing headaches.

EXAMPLE 1

But I don’t feel any different. And I don’t feel that I would wander away for there was a lady in this area...she got lost...But uh, I , I wouldn’t uh... I don’t think I would do anything like - you know, well she didn’t, but she was more so than I. How do I know?...That’s why it worries me if it you become violent. Who knows? I don’t know. Or, or do you just go on like I am?... I don’t want to be, I don’t want to be in one of these homes or anything. I want to stay here as long as I can. But I can’t stay here if I get rambunctious or anything. I don’t think that will happen... I’m very, um, I can’t, when I go to bed, I go about, uh, half past nine to ten, depending on what’s going on in the television, and um, I often, uh, lie awake for a long time and I, I don’t know why, and I have nothing in my mind. That’s what I can’t understand, and then sometimes I have a lot of... home made worries, you know?... it’s becoming more and more.

EXAMPLE 2

Yes, yes. I think, uh... uh, being a negativity, a nuisance, that’s why I hope I don’t get very ill... I’d try to die... Well, I want to live as long as I can, and uh, not be a vegetable. That’s why I don’t want to become a vegetable. I, I would be a burden to other people in that state, and then I, I’d be in the state of ending it, then.
**Hindering Categories 8: Process of Receiving the Diagnosis (2 incidents, 25% participation rate)**

In this category, participants expressed that the process of receiving their diagnosis negatively impacted them and affected the way in which they managed with their illness. Outcomes were feeling angry even months later, decreased self-confidence, hindered ability to move forward, uncertainty about how to behave or what to do on a daily basis, lack of family support, feeling let down by the medical profession, feeling disrespected, ignored, mistreated, confused, despondent, distraught.

**EXAMPLE 1**

People are powerless when they are diagnosed, with situations like, who are in the process of being diagnosed and I had a really difficult experience out at _____ when I was going through the diagnostic treatments, or, a, processes, rather. I actually, um, found, some of the specialists out there to be quite cold, um, clinical, and not empathetic. When I was actually given my diagnosis I had spent a half a day out there having various tests and the Alzheimer’s specialist had not spoken to me directly and given me my diagnosis at all and my sister and me were prepared to leave, still not knowing what was going on, and I was quite rattled after half a day of testing, and the...uh...the social worker, who was a very unpleasant character, said something to my sister, in my presence, about uh my having Alzheimer’s. At that point I had no idea what was wrong, and, uh, she said that in my presence and, uh, I questioned that and I wanted to talk to the specialist because he had not told me this and he had gone for the day. That meant, this was Friday, all the weekend I had no clarification of what my diagnosis was. I went back to the doctor, my own personal physician on the Monday - I was distraught, and confused, and really despondent, and ended up, several months later, writing a letter to the ___. The social worker, as far as I’m concerned, should be fired. She was asking questions in my presence about whether or not I...was functional...for caring for myself.

**EXAMPLE 2**

Um, there was no real confirmation that I have Alzheimer’s disease. I uh, had a stroke and um and uh, a couple of strokes actually, and I ended up in hospital and when I came out of the hospital they, I had, was interviewed by Dr. ____ and he said to me uh, he did some tests on me and he said he thought I had uh, Alzheimer’s. And uh, but that he was going to wait and see and he - Well I went back to see him and they’re still not certain that I have Alzheimer’s... I thought you know I’ve known Dr. ____ for some time having worked on, I served on the _____ out here, and I met him then and of course I’ve met
him since. And I thought well, he’d be honest enough with me to tell me if, if there was something wrong with, you know that I had, uh, probably um Alzheimer’s but he didn’t. And I thought that well gosh darn, you know, and he said ‘well, we’ll see yah.’ I’ve only seen him, I’ve only seen him, three times, that’s it. He gave me, twice he gave me the um, um... the... well you probably know. The last time he didn’t say it was Alzheimer’s, he just said it was the same as it was before... ‘You made the same mistake as you did before’ that was, that’s the last time, that’s what he said the last time. And that was all he said. And um, so that’s as far as he got in the um, that testing that you do. So, if that meant that from that one test, he’d given it to me that before that, but if that were, confirmed in his mind that I was you know, going to be, uh having Alzheimer’s, was on my way to having Alzheimer’s, he didn’t tell me that, but his actions, you know, may have, um. It’s my belief that that’s what he was saying, indirectly.

What Would Have Helped

No additionally meaningful information was garnered from asking this question. Two participants were unable to answer the question. The paraphrased comments of six of the participants are as follows:

1. Financial support for medications to facilitate staying in the home as long as possible. Would like them to find a cure.

2. Having more information about Alzheimer’s prognosis and progression offered in the support groups.

3. Reading Alzheimer’s related research. Would like to see a treatment breakthrough in psychology or medication.

4. Would like someone to come up with a cure for Alzheimer’s disease.

5. Making a note of what to do during the day should be helpful. People need to develop a system of how to manage that works for them, such as keeping yourself occupied on a particular project.

6. One of the things would be reading, particularly Alzheimer’s material. I like to know what’s happening to me.
What Words of Wisdom Would you Offer

Two themes emerged from asking this question: (1) attitudes and (2) practical suggestions. Six participants responded and two had nothing to say. The following statements are paraphrases of participants’ comments:

1. Obtain a diagnosis as soon as possible if not already diagnosed. For those that have been diagnosed, try and find a support group. This opens up a whole door and gives access to knowledge and people who care about what’s happening to you.

2. Try not to let it get you down, it could be worse. I think these things are learning experiences.

3. Try to keep your mind and body active. Appreciate the wonderful world that we live in.

4. Don’t get too excited about it. Stay cool.

5. People need to share how they are feeling with others.

6. Accept what comes along. Accept life as it is.

Part II: Validation Results

Exhaustiveness

Andersson and Nilsson (1964) consider that categories emerge after a few critical incidents are classified. Consistent with McCormick’s (1995) study and, as described by Andersson and Nilsson, 10% of incidents remained unclassified until completion of the category formulation. All of these unexamined incidents fit into the identified categories without the need for additional categories to be formed. Hence the categorisation system was considered to be comprehensive and the exhaustiveness criteria met.
Participation Rate

Participation rate is calculated by identifying the number of participants who contributed incidents in any given category then determining the percentage out of the total number of participants in the study. Participation rates of 25% or higher are considered sufficient to view a category as valid (Borgen & Amundson, 1984). In this study, the participation rates ranged from 25% in two categories (Effective Medication Treatment and Management and Process of Receiving the Diagnosis) to 88% in four categories (Self-Help Behaviours, Emotional Supports, Practical Supports, and Faith). A higher participation rate is considered to indicate greater validity of the category (Flanagan, 1954).

Participant Cross-Checking

The purpose of this validation procedure is to address descriptive and interpretive validity (Catapia, 2001). The second interview was used to check initial tentative category names and to clarify ambiguous incidents. Participants were asked for their input so as to ensure the veracity of the analysed data and the accuracy of the categories. No participant asked to change the name of any given category, but some categories did disappear after the second interview.

Contrary to the usual way in which data collection and analysis is conducted with CIT, data for this study was collected and analysed sequentially rather than concurrently, given the nature of the participants' illness and the possibility of increased communication difficulties over extended time periods. This meant that the second interview was conducted within three weeks of the initial one, and very often prior to the next initial interview with another participant. This presented two challenges. First, time constraints were problematic, as trying to complete the analysis of an interview within a tight time-frame was often challenging. To accommodate this,
whenever possible, follow up interviews were scheduled later rather than sooner (i.e. three weeks apart instead of one).

Second, complete corroboration for the final category names for all participants was not feasible. All input from participants was used for the inclusion of critical incidents and, as possible, for the final naming of the categories. During this process, in order to ensure their inclusion, categories that had existed and been approved by the participant in the second interview required merging with a broader, also approved category, in four instances: (1) Acceptance was merged with Personal Attitudes; (2) Proximity and Availability of Resources moved into Supports; (3) Obtaining a Diagnosis was incorporated into Being Informed; and (4) Lack of Information went into Limited Resources. Developing Additional Medical Conditions was changed to simply Additional Medical Conditions, to include incidents from those who already had pre-existing conditions that hindered their ability to manage. Attitudes of Friends and Family and Responses of Others were amalgamated to Attitudes of Friends, Family, and Others to accommodate all relevant data. Supports was split into two separate, more distinct categories, Emotional Supports and Practical Supports, to more accurately reflect the impact of these disparate types of support. In order to keep participation rate up and ensure that all critical incidents were retained, three aggregate categories were formed from smaller ones. The first, Self-Help Behaviours, encompassed the previously existing categories of Engaging in Meaningful Activities, Maintaining and Enhancing Abilities, Maintaining Health, Being Informed, Trying Alternative Treatments, and Keeping Mind Active. The second and third ones were Experiencing Symptoms of the Illness and Experiencing Consequences of the Illness, which divided incidents from the original category, Nature of the Illness, and incorporated additional
tentative categories of Job Loss, Reduced Abilities, Reduced Income, Adjusting to Medications. The result of this process was the ultimate formulation of seven helping and eight hindering categories into which the Independent Raters were able to accurately sort the data. At all times, the essence of the participants' meanings was kept forefront when changes were made.

Independent Rater Agreement

Two independent raters took part in sorting the incidents into the identified categories. Both sorting sessions were one-to-one with the researcher and lasted approximately one hour. One rater was a graduate of the UBC Master’s of Counselling Psychology Program with no experience with people with Alzheimer’s. The other rater was a Master’s level nurse working in the area of people with dementia. The sorting session involved the researcher reading the descriptions of the 15 categories, clarifying these definitions when asked, and demonstrating the validation procedure by sorting two example incidents into their respective categories. The raters were given a list of the categories and 42 critical incidents (30%) on index cards randomly selected from each category. Originally, 15% of the incidents was considered an adequate amount for this validation check, but, with 140 critical incidents and 15 categories, this would have meant less than 2 incidents per category to be sorted, which was considered insufficient for agreement. The independent raters sorted the 42 incidents into the 15 categories with the first rater obtaining 98% agreement and the second one 93% agreement. Agreement rates of 75-85% between raters are considered acceptable (Anderson and Nilsson, 1964). For this study, categories were considered valid if the agreement rate was 80% or greater.
Theoretical Agreement

The fifth and final method of determining the validity of the identified categories was addressed by assessing theoretical agreement with past research. Comparing each category with previous research enables identification of consistencies and discrepancies (McCormick, 1995). Consistency indicates the soundness of a category while discrepancy calls into question a category's validity. Any new categories emerging from discrepancies are considered 'possibilities' until their validity is confirmed or disproved in future research. Theoretical agreement was found for 14 of the 15 categories. Limited Resources was the exceptional category, with research supporting only one of its component parts as a hindering factor in living with Alzheimer's disease. This category was preserved, however, with the hope that future research will elucidate or prove its validity. Thus, it is considered that the existing research supports the validity of these categories. The results of agreement between previous research and the current categories are as follows:

Self-Help Behaviours

Many of the behaviours in this category were thoroughly documented in the literature as being strategies people used to help manage with Alzheimer's, with outcomes such as staying on top of the disease, leading meaningful lives, believing they were preventing further deterioration, and staying interested being comparable to outcomes identified by participants in this study. Engaging in meaningful activities was noted variously as connecting with others (Burger et al., 1993), meaningful productivity (Harris & Stern, 1999), one of "five great needs" proposed by Kitwood (1997, p. 19), and staying engaged (Phinney, 1998). Maintaining and enhancing abilities and keeping the mind active were comparable, or in some cases identical, to reports of people
using internalized mnemonics, reducing cognitive load, enhancing learning (Woods, 2001), and keeping an active mind (Phinney). Comparing self to others related to the coping style ‘minimising’ noted by Bahro et al. (1995) and the strategy of ‘discounting symptom severity’ reported by Hutchinson et al. (1997) which helped reduce stress about having the illness. Additionally, helping others, staying actively engaged both physically and mentally, developing a system of managing, and trying to stay informed were all supported in the personal literature (DeBaggio, 2003; Snyder, 1999). Trying alternative treatments was also noted by one of the participants in Snyder’s collection of personal reflections.

**Emotional Supports**

Support groups are identified in the psychosocial literature (Goldsilver & Gruneir, 2001; Hutchinson et al., 1997; Yale, 1999) and by participants as being beneficial. Goldsilver & Gruneir’s evaluation of one of the first support groups for people with early stage Alzheimer’s found that 74% of those responding to a post-group evaluation form believed the group had helped them cope more effectively with their problems. They have run subsequent groups and recommend that such groups be used in the continuum of dementia care. Family and social interactions are also noted as contributors to quality of life for people with dementia (Brod at al., 1999) and connecting with others was observed by Burgener et al. (1993) as a way of expressing the self in their study of participants with more severe cognitive impairment than those in this study. Burgener and Dickerson-Putman’s study with people in the early stages of dementia found that friends were identified as supportive for “understanding my situation” and “including the patient in enjoyable activities” (1999, p. 38), both sentiments described by participants in this study. Presence of family members was also noted to be supportive in Burgener and Dickerson-
Putman’s research. Kitwood’s work has led him to identify a recurrent theme “of reassurance, through the company and support of other people” (1997, p. 15). He further suggests that people with dementia have “five great needs,” three of which (attachment, inclusion, and comfort) can be met by belonging to a support group, support from family, contact with friends, and the presence of a pet. A fourth need for ‘occupation’ could also be met by the presence of a pet, as described by one participant in this study.

The importance of professionals’ approach is identified by Meyers (1997) in discussing whether or not people should be told of their diagnosis. He maintains that how patients are told may be more the issue, and promotes “communication through ‘patient led’ discussions” (p. 322) as a way to mitigate possible negative effects of people being given this information. No research was found in the more rigorous literature on the helpful benefits of pets, but there was support for this factor in DeBaggio’s (2002) personal account, as there was for the helping aspects of support groups, support from family and friends, and respectful professional care (DeBaggio; Snyder, 1999). In their discussions on the impact of the social psychological milieu on the self-concept of people with dementia, Harris & Sterin (1999) identify the beneficial aspects of “affirming social psychological interaction” (p. 253), analogous to the supports described in this category.

Practical Supports

Little research was found related to the specific types of practical supports described by participants in this study, although there was support for some incidents in this category in the less rigorous personal literature, with ‘help from the medical community’ and ‘having daily needs met’ singled out (DeBaggio, 2002; Snyder, 1999). Harris & Sterin (1999) identify the need for comfort and security as being a core value. This resonates with one participant’s
identification of having all of his needs met as being of critical importance in helping him to manage with Alzheimer’s. The importance of living arrangements noted by participants in this study was not noted per se, but related to the literature on adapting the environment to fit the needs of the affected individual (Cohen & Eisdorfer, 2001). Practical supports identified in the literature included sharing of ideas in support groups (Goldsilver & Gruneir, 2001), becoming familiar with a range of services through support groups, sooner than they might otherwise have done (Yale, 1999), and having transportation provided (Burgener & Dickerson-Putman, 1999). No support was found specifically for the importance of financial supports.

**Faith**

Although spirituality, of which faith is one component, is mentioned frequently in the literature as being an important and positive element in coping with illness (O’Neill & Kenny, 1998), little literature was found regarding its significance in helping people with Alzheimer’s to live with their illness, with more frequent mention in anecdotal accounts. In Snyder’s interviews with individuals with Alzheimer’s, three of seven participants stressed the benefits of their spiritual beliefs. Statements such as “I don’t know what I would do if I didn’t have my faith. That’s the only thing that holds me together” (1999, p. 25) and “God is my foundation. My faith is solid. My faith is within me and it is me” (p. 102) mirror comments made by participants in this study. Burgener et al. (1993) identified spirituality as meaningful even with people in much more advanced stages of dementia than these participants. They further noted the absence of spiritual opportunities (e.g. visits from clergy in facilities) and the discomfort of professional caregivers with spirituality and the cognitively impaired, citing a possible “assumption on the part of the religious community, caregivers, and family members that spiritual support and
practices may no longer be valid or important" (p. 17) for those with dementia. They suggest this is a mistake and, in fact, that spiritual needs are meaningful, and meeting these needs is supportive. While they do not mention faith per se, in their study of the self in dementia Harris & Sterin (1999) identify three core values, one of paramount importance, the need for comfort and security. Faith would appear to meet this need for some people.

**Personal Attitudes**

There is ample literature substantiating the significant role personal attitudes plays in living with Alzheimer’s. Determination, gratitude, appreciation, acceptance, a sense of humour, and being positive were some of the attitudes expressed by these participants and appearing in the literature. Harris & Sterin (1999) proposed a typology of five reaction patterns, with two of these, “I’ll live until I die” (p. 247) and “I accept what I have” (p. 248) being beneficial and corresponding to participant’s attitudes in this study. The first group was engaged in living with the illness by finding ways to maintain control of their lives and the second group was successful in being able to adjust to the diagnosis. Both patterns were present with participants in this study, with some overlap in the category ‘Self-Help Behaviours’. Cohen (1991) describes six phases of change that people with dementia experience, with the fourth and fifth ones, ‘Coping’ and ‘Maturation’ respectively, being similar to attitudes reflected here. Coping refers to an approach of “in order to go on, I must do...” (p. 8). This is comparable to determination and possibly being positive, but again, there appears to be overlap with the category of ‘Self-Help Behaviours’ in this study in that Cohen’s description of ‘Coping’ includes the development of practical strategies for living with the dementia. Maturation is described as “living each day till I die” which again could correspond with determination. A sense of humour was noted as being a
powerful way in which people with dementia in facilities expressed their individuality as well as helping them to manage pain and connect with staff (Buckwalter et al., 1995; Burgener et al., 1993).

Woods (2001) and Kitwood (1997) emphasise the importance that interpersonal differences and coping styles play in understanding the experience of living with dementia from the individual’s perspective, stating that the experience is not always perceived as wholly negative, with some people expressing acceptance of the illness and others gratitude for past joys. Corroboration for some of the participants’ attitudes is again found in the anecdotal literature, with DeBaggio stating the desire to “live as long as I can; that has always been my goal. I am also a realist and I have begun to adjust my life so each day has a structure to it, and a purpose: to enjoy every minute I can...” (2002, p. 29), a sentiment expressed as taking each day as it comes and enjoying each day, every day by several participants in this study. Acceptance was also reported by Snyder (1999).

Being Informed

Being informed encompassed a range of information: obtaining a diagnosis, learning the source of repetitive internal sounds, and believing they know the source of Alzheimer’s disease. Downs (1997) reported that the little literature that does exist regarding receiving a diagnosis “suggests that people with dementia who have been told their diagnosis are less troubled by their symptoms than those from whom the diagnosis has been withheld” (p. 600). This position is supported by two participants in this study, one of whom was able to initiate a plan of action once she was informed. The other, who felt unclear about whether she had actually been given a diagnosis, described herself as in “limbo,” being unable to plan, having trouble convincing her
family that she had Alzheimer’s, being unable to move forward. After a lifetime of taking charge, this participant now felt dominated by uncertainty and described a gradual erosion of the person she had striven to be.

Cohen and Eisdorfer (2001) also maintain that giving information to people with dementia about their diagnosis and prognosis is beneficial and the American Psychiatric Association’s Practice Guideline for the Treatment of Patients With Alzheimer’s Disease and Other Dementias of Late Life (1997) recommends educating the patient and family about the illness and available treatments as one of their treatment guidelines. They further specify that this includes conveying information about the diagnosis and prognosis, the latter being especially important to facilitate the patient and family’s ability to plan for the future. Meyers (1997) maintains diagnostic information is important so that people can take part in decision-making, financial planning, and driving. Yale (1999) reports on the importance of information exchange in support groups but does not specify what kinds of information, while Goldsilver & Gruneir (2001) identify educational information, such as learning about the brain and its impact on daily living, as being seen as useful by support group members. Information from the physician is also considered helpful in adjusting to the illness and making decisions about treatments (Gauthier, 1999). Both of these latter sources correspond with information received by one participant about repetitive noises generated in her head. Believing one knows the source of Alzheimer’s was not found per se but relates to the literature on educational information.

**Effective Medication Treatment and Management**

Multiple medications exist for the treatment of Alzheimer’s dementia and its associated non-cognitive symptoms and conditions. Finding the right combination and dosages needs to be
individualised for each person. Drug studies support the success of Aricept in improving functioning in people with mild to moderate dementia and in preventing further deterioration for some people for a limited amount of time (American Psychiatric Association, 1997; Callaway, 1998; Cohen & Eis dorfer, 2001). Other medications used in conjunction with Aricept when needed include anti-depressants, anti-anxiety, and anti-psychotics (American Psychiatric Association; Cohen & Eis dorfer).

Experiencing Symptoms of the Illness

Common and disruptive symptoms of Alzheimer’s that were all noted and well supported in both the research and personal literature include confusion and memory deficits (American Psychiatric Association, 1997; DeBaggio, 2002; Hutchinson et al., 1997; Phinney, 1998; Snyder, 1999; Yale, 1999), repeating oneself, disorientation, (DeBaggio; Phinney; Snyder), and word-finding difficulties (DeBaggio; Phinney; Sabat, 2001; Snyder). Less frequently noted was disinhibition (Young, 1999). Phinney found two themes emerged from her work, one of which was “Being Unsure,” describing how peoples’ fluctuating experience of their symptoms contributed to their feeling uncertain and uneasy as they try to live in a world rendered increasingly unfamiliar. This theme and the resultant feelings correspond to the outcomes for participants in this study, variously described as getting into a tizzy, feeling less secure, feeling embarrassed, distressed, humiliated, and as if one is losing capability. Brod et al. (1999) examined quality of life indicators for people with dementia and identified nine domains. One of these, Interaction Capacity, identifies problems with communication and social interaction resulting from symptoms of the illness such as word-finding difficulties and memory deficits. Basic conversation for people with dementia is therefore more difficult and social interaction
becomes more strained, with inadequate understanding on the part of others and feelings of embarrassment on the part of the affected individual, contributing even further. Comparable outcomes for these participants were being short-tempered with others, being told by others that one is repeating oneself, feeling stupid, withdrawing, not participating in conversation, becoming disgusted and angry with oneself, feeling embarrassed, and thinking that one may have hurt the feelings of others.

Experiencing Consequences of the Illness

Consequences of the illness happen as a result of having the illness. Consequences noted by these participants included having their driver’s license taken away, losing their job, reduction in stamina, missed opportunities, and difficulties adjusting to decreased memory. These are summarised in the research and personal literature as experiencing losses, increased isolation, and increased dependence (Burgener & Dickerson-Putman, 1999; Brod et al. 1999; DeBaggio, 2002; Harris & Sterin, 1999; Phinney, 1998; Snyder, 1999). These researchers also found the detrimental effects of these consequences included greatly hindered social interaction, disadvantages interacting with the world, changes to the sense of self, and having to deal with emotional reactions such as frustration, embarrassment, anger, and despair. Experiencing negative side effects from illness related medications, from either correct or improper usage, is well documented in the research literature (American Psychiatric Association, 1997; Cohen & Eisdorfer, 2001) and DeBaggio mentions accidentally taking an overdose of medications with negative consequences in his personal account of living with Alzheimer’s. Detrimental effects can include increased confusion, increased agitation, delirium, sleeplessness, nausea and
vomiting, and even physical harm. A sense of urgency to keep moving was not found in the literature.

Limited Resources

Three main types of limited resources existed for these participants: insufficient or reduced services, limited finances, and having insufficient information. Only the latter was substantiated in the literature, and even that was infrequently mentioned. Most family physicians do not inform their patients of this diagnosis. When diagnosis is conveyed, it is often done so quickly and without supportive information regarding prognosis, treatments, and resources. Additionally, often family members are the ones informed, with the affected individual being left to find out from them or not at all (Cohen and Eisdorfer, 2001). Consequently, the individuals and their families are left to deal with their reactions to the diagnosis alone. Frequently it is the family members themselves that object to the Alzheimer’s person being given information about the diagnosis. Even though the patients’ right to know is considered a prerogative, little is known about the preferences of affected individuals, including their attitudes and emotional reactions to having diagnostic information (Meyers, 1997).

Personal Responses

Hindering emotional responses identified by participants and well supported in the psychosocial literature as well as in the less rigorous, although no less pertinent, personal accounts of living with Alzheimer’s disease included intense anger, intense frustration (American Psychiatric Association, 1997; Burgener & Dickerson-Putman, 1999; Cohen, 1991; DeBaggio, 2002; Harris & Sterin, 1999; Kitwood, 1997; Sabat, 2001; Snyder, 1999), uncertainty, not knowing what to do, and doubting self (Kitwood; Phinney, 1998). The last three correspond to
Phinney’s theme of ‘being unsure,’ whereby participants in her study reported they felt tentative and distrustful of themselves as a result of fluctuations in their abilities over time. Kitwood (2001) maintains that an affected person’s ability to manage is intrinsically linked to the interplay of their biography, life experiences, and personality style, the latter of which influences their emotional responses. Negative reactions associated with being helped was also noted in the literature, with depression up to one year later being one of the outcomes (Newsom & Schulz, 1998).

**Attitudes of Friends, Family, and Others**

The detrimental effects of actions and attitudes described in this category are supported in both the personal and the research literature. Harris and Sterin (1999) identified an awareness of the reactions of others as one of the shared experiences for people struggling to maintain their sense of self with Alzheimer’s disease. Like Kitwood (1990), who posited that a ‘malignant social psychology’ has detrimental effects on people with Alzheimer’s, Harris and Sterin found that the social psychological milieu does appear to influence the affected person’s self-identity, although this effect can be both positive and negative. Kitwood identified ten aspects of ‘social malignancy’ that he theorises contributes to depersonalisation of the person with Alzheimer’s. Those that correspond with outcomes experienced by these participants include disempowerment, infantilisation, stigmatisation, invalidation, banishment, and objectification. Sabat and Harre (1992) maintained that the self is not lost as a result of Alzheimer’s itself but by “the ways in which others view and treat the Alzheimer’s sufferer” (p. 443). Cummings (1996) noted that family members and friends not in close contact with the affected individual may not be aware of, or believe, the diagnosis due to the subtleness and slow progression of the signs and
symptoms at this stage. In her collection of personal reflections from individuals with Alzheimer’s disease, Snyder’s (1999) participants describe comparable attitudes to those experienced by participants in this study including lack of compassion, indifference, insensitivity, casualness, being demeaning, reluctance to discuss the illness, and lack of appreciation of retained abilities on the part of health care professionals; stigmatisation by the general public due to misunderstanding about the illness and inability to deal with it; and attitudes of family members such as irritation and impatience.

Additional Medical Conditions

The presence of other medical conditions is known to either exacerbate dementia or make it more difficult to manage with the illness. Additionally, medications needed to treat other conditions can also negatively influence dementia (American Psychiatric Association, 1997; Woods, 2001) as can associated pain (Cohen, 1991), and sensory deprivation related to hearing or visual loss (Cohen & Eisdorfer, 2001). Woods identifies physical health as a key factor interacting with social environment, personality, life experience, and neuropathological changes to affect the overall experience of dementia.

Worrying Thoughts

Worrying thoughts expressed by participants included becoming a burden to others, thoughts of their caregiver dying first, and worries about becoming violent. This category is not widely noted in the literature but support does exist, with most of this being in the personal accounts of living with dementia. Brod et al. (1999) reported participants’ concerns about being a burden to others and DeBaggio (2002) expressed worry that he might hurt his wife and son by exposing his Alzheimer’s. Werezak and Stewart (2002) also found concern about the responses
of others to the diagnosis of Alzheimer's disease to be an issue for people in the process of learning to live with this illness. No literature was found regarding worries about becoming violent.

Process of Receiving the Diagnosis

Although not widely documented, support for this category does exist in the research and personal literature. In their study examining the relevance of patient perspectives in assessing people in the early stages of dementia, Burgener & Dickerson-Putman (1999) found a strong adverse reaction to neuropsychological testing, with participants clearly indicating the negative impact this had had, such as sleepless nights and refusal to return for follow up visits. The researchers concluded that patient-centered approaches to the testing process need to be considered, indicating it was the manner of delivery of the tests that was seen as responsible for participants' reactions. Diagnostic uncertainty was a finding for Hutchinson et al. (1997) in their examination of early probable Alzheimer's disease and awareness context theory. While there were several reasons for this, one contributing factor was the manner in which physicians imparted the diagnosis, "handing out literature about AD without corresponding dialogue" (p. 1402). When clients were told of the diagnosis, the prognosis was not shared. Cohen and Eisdorfer (2001) also note that most family physicians do not inform patients of their diagnosis or, if they do, deliver the information in a quick and impartial manner, offering no hope and, in many cases, without accompanying information on treatment options. Consistent with a participant in this study, Cohen and Eisdorfer report that family members are often informed rather than the affected individual. DeBaggio (2002) and three of Snyder's (1999) participants reported comparable experiences to the participants in this study, with criticisms such as
indifferent, unprofessional, lacking in compassion, dehumanizing, dismissive, evasive, adversarial, exasperated, angry, and reluctant to discuss the illness directed at a range of health care professionals: neurologists, psychologists, and, in the case of a participant in this study, a social worker. Outcomes were sustained hatred and intense anger toward the professionals involved even months later, consistent with the anger expressed by a participant in this study.

What Would Have Helped

Three participants stated having more information would have been helpful (e.g. regarding the nature, prognosis, and progression of Alzheimer’s disease). Having insufficient information was discussed in the theoretical validation of the Limited Resources category. In an American national survey of patients and caregivers, 24% of patients were not told about their diagnosis (Cohen, 1991). Even when information is given, it is often insufficient and delivered to the family members rather than the individual (Cohen & Eisdorfer, 2001), leaving that person out of the loop, with consequent feelings of depersonalisation, humiliation, anger, and uncertainty. One participant cited having financial support for cost of medications to facilitate remaining in the home as long as possible would be helpful for many people although it was not an issue for this person. Limited finances was also reported in the limited resources category of the theoretical validation section. However, no literature was found to substantiate this issue. Three participants stated they would like to see a cure developed for Alzheimer’s disease, and one identified finding a system for managing that works (e.g. making note of what one should be doing, trying to keep occupied) would be helpful.
What Words of Wisdom Would You Offer

Four participants promoted attitude as a way of coping. These were 'things could be worse so look on the bright side, don't get excited/stay cool, foster appreciation, and accept what life has to offer.' Practical suggestions encompassed obtaining a diagnosis as soon as possible, joining a support group, developing a system for managing, and keeping your mind and body active. Both themes are discussed extensively in the theoretical validation of their respective categories.
CHAPTER V

Discussion

The aim of this qualitative study was to enrich understanding of the experience of living with early stage Alzheimer's disease by identifying those factors that facilitate or hinder individual's management of their illness. After conducting interviews with eight participants, 15 valid and reliable categories were generated from 140 incidents. Seven of these categories were facilitative: self-help behaviours, emotional supports, practical supports, faith, personal attitudes, beneficial information, and effective medication treatment and management; while eight of them were hindering: experiencing the symptoms of the illness, experiencing consequences of the illness, limited resources, emotional responses, attitudes of others, additional medical conditions, worrying thoughts, and process of receiving the diagnosis. This chapter addresses general findings related to these categories, limitations of the study, implications for practice, and implications for research.

General Findings

Living with Alzheimer's is a particularly challenging task due not only to the progressive and terminal aspects of the illness, but also to the nature of the degeneration. Constant changes in the person's abilities require continuous adaptation. This, alone, is a difficult enough process but is compounded by the concomitant erosion of the person's repertoire of coping skills. For participants in this study, awareness of these factors brought additional emotional responses which required additional management techniques.

Existing models and frameworks of the dementia experience from the individual's perspective recognise the dynamic and interactive nature of living with dementia (Werezak and Stewart, 2002; Woods, 2001). Kitwood's work focused on the dementing process in the context
of the social-psychological milieu, and the psychosocial needs of the person with dementia, taking into consideration interpersonal differences such as personality, biography, and coping styles (1990; 1997). Similarly, the experience of dementia for participants in this study appeared to be a result of the interaction and sum of several key factors: the person (personal attitudes, self-help behaviours, personal responses, worrying thoughts, and faith); environmental influences (attitudes of friends, family, and others, emotional and practical supports, process of receiving the diagnosis, beneficial information, and limited resources); manifestation of the disease (experiencing the symptoms and consequences of the illness, and effective medication treatment and management); and any additional medical conditions. For example, individuals exhibiting determination tended to engage in self help behaviours such as keeping their minds active, being physically active, continuously looking for ways to make things work or to minimise the impact of their illness. They were helped considerably by the presence of informal and/or formal supports, with the overall experience being greatly impacted by the presence or absence of other medical conditions and related sequelae and, fundamentally, by the way in which their illness was affecting their daily lives.

Changes to any one of these component parts affected the gestalt. For example, emotional responses such as anger or uncertainty tended to elicit hindering behaviours such as self-chastisement leading to increased anger, or a temporary giving up due to an inability to problem solve at that time. Consequences of the illness took on greater significance for some people than others. For example, losing one’s driver’s license was a considerable loss for one participant even though there was a readily available source of alternate transportation. Another participant reported looking forward to not having to drive, even though this would render them less mobile.
Developing new medical conditions or exacerbations of existing ones meant precious resources were diverted, leaving little left to deal effectively with the Alzheimer’s. Memory loss was universally problematic, but some participants used a sense of humour to lessen the impact while others were self critical.

Coping theory provides one context for understanding some of the facilitating and hindering factors of living with the complexity of Alzheimer’s disease. More current theory views coping as a process rather than exclusively a personality style, in which “coping changes over time and in accordance with the situational contexts in which it occurs” (Lazarus, 1992, p. 235). Lazarus describes several principles of the coping process and suggests that whether a coping strategy is beneficial or not is person-specific and situationally dependent. For example, participants viewed the exact same behaviours on the part of others as both helping (emotional supports; self-help behaviours) and hindering (attitudes of others). Cognitive and behavioural strategies are viewed as contextual and therefore variable, attention is paid to what the individual is thinking and doing in order to cope, and coping can be either problem- or emotion-focused. Problem-focused coping is used to “change the troubled person-environment relationship by acting on the environment or oneself” (p. 238) and can be represented by the categories of self-help behaviours, practical supports, and effective medication treatment and management. Emotion-focused coping functions to impact either “a) the way the stressful relationship with the environment is attended to (as in vigilance or avoidance) or b) the relational meaning of what is happening” (p. 238) and can be seen in the categories of faith, emotional supports, personal attitudes, beneficial information, and self-help behaviours.

Some coping strategies, such as the ‘comparing self to others’ exhibited by participants and referred to by Lazarus as ‘positive reappraisal,’ are considered both more stable than others
and as having a beneficial impact on negative emotional states. “Planful problem solving” (1992, p. 239), such as many of the strategies employed in the category self-help behaviours, is also known to mediate emotional outcomes. In a hindering capacity, certain types of coping is considered to have a more distressed emotional outcome. This is identified by Lazarus as ‘confrontative’ and could be represented by some of the behaviours associated with attitudes of other people. These beneficial and potentially detrimental strategies should be taken into consideration when addressing implications for practice.

Of note was the predominance of emotion-focused coping as compared to problem-focused which Lazarus (1992) notes occurs when the stressful situation is considered to be “refractory to change” versus “controllable by action” (p. 239) respectively. This may be the case with Alzheimer’s disease in which experiencing the symptoms and consequences of the illness, attitudes of others, emotional responses, and worrying thoughts resulted in such hindering outcomes as intense frustration, withdrawing, becoming angry with oneself, uncertainty, inability to move forward, feeling in limbo, feeling helpless, being fearful of the illness’ progression, and feeling that death would be preferable. Equally noteworthy, and again, having implications for practice and research, is that emotion-focussed strategies may well be the better choice in certain scenarios, such as when the situation cannot being changed (Lazarus).

While coping process theory provides some context for viewing the findings, it is limited in scope, not addressing the impact of emotions in the coping process or of the meaning individuals impute to events in their lives, both elements of significance in fully understanding the experience of living with early stage Alzheimer’s. For example, much has been written about the loss of self in the dementia process, yet only one participant, who had devoted a lifetime to
developing the mind, expressed "disgust" and "hatred" for the changes the illness had wrought, while several of the participants expressly stressed how they were still themselves, not their illness, with the remainder making no mention of this issue.

A finding of particular note was the significant role that other people, in various capacities (emotional and practical supports, attitudes of friends, family and others, being informed, and process of receiving the diagnosis), played in either facilitating or hindering the experience of living with Alzheimer's disease. Some participants stated responses from others were helpful while others found family, friends, the general public, and, particularly disturbing, professionals' attitudes to be detrimental to their coping, having clinical implications and rendering imperative the need to focus on this area in future research. Social well-being theory may help explain the positive and negative impacts of other people's responses, whereby social integration, reflected in the categories of self-help behaviours and negatively in attitudes of others and limited resources; social acceptance, pertinent to emotional and practical supports; social contribution, positively represented in self-help behaviours but threatened by experiencing the symptoms and consequences of the illness, attitudes of others, and emotional responses; social actualisation, evident by virtue of each participants' willingness to take part in this study; and social coherence, represented by some of the self-help behaviours and, again, by participation in this study, are used to gauge positive social health (Keyes, 1998). Outcomes such as feeling objectified, invalidated, unsupported, disrespected, patronised, and diminished suggest experiences of depersonalisation and dismissal, supporting Kitwood's assumption "that human beings are far more deeply affected by the social psychology that surrounds them than is commonly recognised" (1990, p. 181).
Limitations

This study has a number of limitations. In terms of methodology, the use of self-report and reliance on memory are inherently problematic. Memories are known to be subject to distortion and people were free to divulge or not as they felt comfortable. Elicited events were those that participants were either aware of, could articulate, or could remember at the time of the interview, meaning additional relevant information may have been excluded, resulting in incomplete categories. This factor was especially pertinent due to the nature of the participants’ illness, in which short-term memory is missing or diminished. However, long-term memory remains intact in the early stages, meaning memory for these events was likely only subject to the same inadequacies as anyone else. Two participants did seem to have some language or comprehension difficulties, resulting in their contradicting themselves during the interviews, with some information therefore being discarded. In terms of self-report, some participants appeared to be reluctant to say anything that might cause conflict, such as negative or critical information about their caregivers or professional help they had received. This was apparent when individuals volunteered additional information once the tape was turned off. In all cases, participants were agreeable to having the tape re-started and the information included, but the possibility that other information was withheld remains. However, the second follow up interview did provide an opportunity for participants to modify or add to their original responses, helping to minimise some of these effects.

The sample size, population, and participant selection are additional limitations. Of the eight participants, five women and three men, all but one were from Early Stage support groups. People who join groups may be intrinsically different from those who do not, possibly
introducing bias. Additionally, all of the participants were Caucasian and most of them were older. These variables were difficult to control for given that selection was by self-volunteering. Issues for older individuals are most likely different than for younger individuals with Alzheimer’s disease, and cultural differences are also likely to exist, so a wider range of participants would have been desirable. The sequential design of the study prevented checking of the final categories with participants, meaning aggregate categories were formed without confirmation from the participants. From this point of view the more traditional design of doing all of the initial interviews and analysis first, then returning to the participants for confirmation and clarification of categories would have been desirable. However, sequential design was considered preferable due to the nature of Alzheimer’s disease and this probably was the better choice, as at least one potential participant was unable to take part due to ill health. Most participants were noted to be very tangential during the interviews, requiring frequent redirection to the topic under discussion. Thus a more structured interview style may be more desirable when determination of specific information is the goal, with less structured interviews being desirable for phenomenological inquiry. The researcher was also careful to include everything during the analysis process and reporting of the results, to guard against the possibility of introducing bias during analysis by the tendency of investigators to support pre-existing beliefs.

Location was another element possibly introducing room for error. The interviews took place in participants’ homes and, in some cases, with caregivers present. Both of these circumstances are considered desirable for people with dementia but diligence must be, and was, used to ensure no interference from others. Causation cannot be implied and correlation cannot be measured with this type of study. Nor, with qualitative research, can the results be generalised
to other groups or a broader population of people with Alzheimer's disease, but statistical
generalisation was not the goal of this study, and the findings could be used by counsellors and
other health care professionals as a tentative starting point for discussion with Alzheimer’s
affected individuals and their families.

Implications for Practice

This study presents valuable information that deepens understanding of the experience of
living with early stage Alzheimer’s disease and can be used by counsellors, health care
professionals, educators, with counsellor training, and with others involved in working with
affected individuals (e.g. Alzheimer’s support groups, staff in long-term care facilities).
Counselling practice can benefit from the findings in numerous ways. First, they will alert
counsellors to the fact that a range of factors can influence the experience of dementia and
expand the repertoire from which counsellors can draw for increased understanding of the issues
when working with people in the early stages and their families. Second, the categories and
findings can provide a tentative framework which counsellors can use to guide their practice
when working with individuals, their families, and other professionals. With the individual,
counsellors must gain an understanding of the person with the dementia, not simply the illness,
and be diligent about maintaining this position during all interactions with the client. They need
to:

(i) Be aware that spirituality may play a role for clients and, understanding that individuals
may need a forum for the expression of emotions, worrying thoughts, and the meaning of
their illness, provide individual counselling as needed.
(ii) Assess and work with the client to identify existing supports. Work with client to enhance these as needed.

(iii) Provide information, both written and verbal, under the direction of the client.

(iv) Support the client's efforts to engage in meaningful activities, foster preservation of existing skills and helping personal attitudes. Be aware that some coping behaviours are considered to be more effective in certain situations and work with the individual to identify and maintain those that are helpful and to modify those that are no longer working.

When families are involved, counsellors need to model respectful behaviour for family members toward the individual at all times; ensure that the individual is included in conversations, if this is the client's desire; help families, as needed, to identify beneficial versus detrimental ways of communication and interaction and support their efforts to change; and, as with the individual, educate the family about meaningful activities, maintaining abilities, and beneficial coping approaches. When working with health care professionals and others involved with people with Alzheimer's, counsellors play a role in education. The relationship between professionals and these health care consumers was repeatedly mentioned. While some of this was in a supportive context, the negative incidents were particularly noteworthy. Clearly there is a need for informing others about the impact of their communication style and the need for it to be more respectful.

Findings from this research could be used both on an individual level when working with those who are newly diagnosed, at higher stress times, or simply as desired, as well as on a group level by providing a framework from which to run certain types of support groups for both
individuals and family members, such as an early stage caregiver group with the focus on learning empathic communication. These results could also contribute to the design, implementation, and evaluation of more pertinent and effective interventions and supports for those affected by Alzheimer's disease. The goal would be to increase understanding of factors influencing the experience of dementia, with an aim to minimise the impact of the illness for all concerned. Additionally, the findings provide impetus for professionals to examine their manner of interacting with affected individuals and serves as a caution to maintain awareness of our behaviour at all times. With Alzheimer's and other types of dementia increasing as the population ages, helping professionals must develop an understanding of what impacts the experience of living with Alzheimer's disease. The categories emerging from this research provide a framework from which practitioners can draw for this purpose.

**Implications for Research**

Further research needs to be done to appraise the validity of the category, limited resources, particularly regarding the effects of insufficient services and limited finances. Additional research ensuring representation from a wider age range, different cultures, rural settings, and including interviews with caregivers and family members could build on this study by increasing the number and types of critical incidents engendered. Other areas to investigate would be the effects of emotions on coping, meaning making in dementia, the role of faith, the role of beliefs, and examining attitudes of health care professionals toward working with people with dementia. Any interventions or support groups developed as a result of this research could be studied. Additional qualitative research would be beneficial to help validate each of the categories that emerged here and allow a fuller picture of the early stage dementia experience.
More structured interview methods might be useful if more specific information is required, and quantitative methods might be desirable to help evaluate effectiveness of coping strategies and interventions.

**Conclusions**

The primary goal of this study was to enrich the understanding of the experience of living with Alzheimer's disease by developing a set of categories that represent those factors facilitating and hindering people's ability to manage. The emergence and validation of 15 categories, seven helping and eight hindering, satisfied this goal. The resulting data can be used to deepen clinicians' awareness and understanding of the issues involved in living with Alzheimer's disease and to serve as a framework to help guide them when working with affected individuals and their families. A second objective to provide qualitative data from which practitioners and subsequent researcher can extract information and design and implement better interventions was also met. And lastly, the desire to provide some benefit to the participants was achieved through the interview itself, as a majority of them expressly indicated how much they appreciated being heard.
References


Risks:

It is not anticipated that there will be any risks involved to the participants in this study. However, if it becomes apparent during the study that anyone is incurring psychological distress, the opportunity for counselling will be made available.

Confidentiality:

Any information resulting from this research will be kept strictly confidential. Only two people will have access to the identifying data: Dr. Bill Borgen and Kathryn Bowen-Roberts. Once the informed consent form is signed, you will be given a code name or number to ensure confidentiality is maintained. No participant names or initials will be used on any reports of the completed study. All information will be anonymous, identified by code name or number, and kept in a locked filing cabinet. Data will be stored on a computer disk for analysis during the study. No names or initials will be entered into the computer or any disks. Transcribed data, audiotapes, and computer files will be kept for five years after the termination of the study, then destroyed by the most appropriate means: shredding, erasure to make data irretrievable, or erasure through demagnetization.

Remuneration/Compensation:

There will be no monetary compensation for participation in this study.

Funding:

There is no funding or sponsorship for this study.

Conflict of Interest:

There is no actual or potential conflict of interest on the part of the researchers.

Contact:

If you have any questions or concerns at any time during the study, or if you require further information, you may contact Dr. Bill Borgen or the graduate student involved, Kathryn Bowen-Roberts, at the telephone numbers listed above.

If you have any concerns about your treatment or your rights as a research participant, you may telephone Mr. Brent Sauder, Director, Office of Research Services at the University of British Columbia at (604) 822-8083.
Consent:

You have read the information regarding this study and understand that your participation in this study is completely voluntary. You further understand that you may withdraw from this study or refuse to participate at any time without consequences to treatment or medical care. You understand that you do not waive any of your legal rights by signing this consent form.

You freely consent to participate in this study. You have received a copy of this consent form for your own records.

Signature of Participant Date

Printed Name of Participant

Signature of Investigator Date
APPENDIX C

Interview Question List

1. Think back over the time since you were diagnosed with Alzheimer’s Disease. Can you tell me a little about what your experience has been?

2. I would like to talk with you about some of the positive and negative things that have happened to you since then. I wonder if we could start with the positive? (for each positive incident/event, ask questions # i-vi inclusive).
   i. What was the incident and what do you remember about that incident?
   ii. What led up to the incident? Please tell me what was happening at the time.
   iii. What happened after the incident? What was the outcome of the incident?
   iv. What helped you through that incident? What hindered your ability to meet that challenge?
   v. How do you know it was helpful/ a hindrance?
   vi. What was meaningful about this incident?

3. I wonder if we could now focus on the negative things that have happened (for each incident/event, repeat questions # i-vi inclusive).

4. What else would help you to live with Alzheimer’s disease that hasn’t happened?

5. How do you know this would be helpful?

6. What do you need to do now to further facilitate your living with Alzheimer’s disease?
Discussion on this study and arrangements regarding time and place to hold the interviews will take place during the preliminary, participant-initiated contact between the investigator and the participant. Total time involved for each participant will be approximately 2-3 hours.

Risks:

It is not anticipated that there will be any risks involved to the participants in this study. However, if it becomes apparent during the study that anyone is incurring psychological distress, the opportunity for counselling will be made available.

Confidentiality:

Any information resulting from this research will be kept strictly confidential. Only two people will have access to the identifying data: Dr. Bill Borgen and Kathryn Bowen-Roberts. Once the informed consent form is signed, you will be given a code name or number to ensure confidentiality is maintained. No participant names or initials will be used on any reports of the completed study. All information will be anonymous, identified by code name or number, and kept in a locked filing cabinet. Data will be stored on a computer disk for analysis during the study. No names or initials will be entered into the computer or any disks. Transcribed data, audiotapes, and computer files will be kept for five years after the termination of the study, then destroyed by the most appropriate means: shredding, erasure to make data irretrievable, or erasure through demagnetization.

Remuneration/Compensation

There will be no monetary compensation for participation in this study.

Contact:

If you have any questions or concerns at any time during the study, or if you require further information, you may contact Dr. Bill Borgen or the graduate student involved, Kathryn Bowen-Roberts, at the telephone numbers listed above.

If you have any concerns about your treatment or your rights as a research participant, you may telephone Mr. Brent Sauder, Director, Office of Research Services at the University of British Columbia at (604) 822-8083.

Consent:
## APPENDIX F

### Demographics of Participants

<table>
<thead>
<tr>
<th>Age Range</th>
<th>50 - 89 years old (average age - mid 70s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>5 Female, 3 Male</td>
</tr>
<tr>
<td>Present Occupations</td>
<td>7 Retired</td>
</tr>
<tr>
<td></td>
<td>1 On Disability Insurance</td>
</tr>
<tr>
<td>Previous Occupations</td>
<td>2 Business Persons</td>
</tr>
<tr>
<td></td>
<td>1 Armed Forces</td>
</tr>
<tr>
<td></td>
<td>1 Secretary</td>
</tr>
<tr>
<td></td>
<td>2 Apartment Managers</td>
</tr>
<tr>
<td></td>
<td>1 Broadcasting Industry</td>
</tr>
<tr>
<td></td>
<td>1 Nurse</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>8 Caucasian Canadians - 3 of British origin</td>
</tr>
<tr>
<td>Time since Diagnosis</td>
<td>2 participants</td>
</tr>
<tr>
<td></td>
<td>6 months - 1 year</td>
</tr>
<tr>
<td></td>
<td>4 participants</td>
</tr>
<tr>
<td></td>
<td>1 - 3 years</td>
</tr>
</tbody>
</table>