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A Phenomenological Study of Dementia
of the Alzheimer's Type

by

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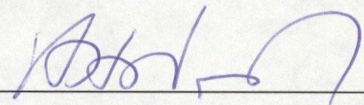
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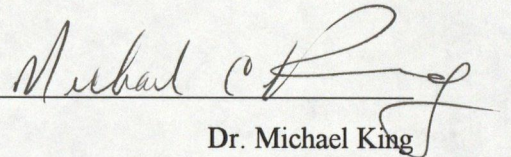
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THE UNIVERSITY OF CALGARY
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The undersigned certify that they have read and recommended to the Faculty of Graduate Studies for acceptance, the thesis entitled "A Phenomenological Study of Dementia of the Alzheimer's Type", submitted by Clare L. Dupuis in partial fulfillment of the requirements for the degree of Master of Science.



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This thesis is dedicated to

Tish and Robbie

with love,

and

AH, JK, JM, RM, and KY

with gratitude and affection.

Abstract

This paper is a phenomenological exploration of Dementia of the Alzheimer Type (DAT). Five individuals with DAT, percentiles ranging from 38.2 to 94.5 ($\bar{X} = 67.04$) on the Mattis Dementia Rating Scale, were repeatedly interviewed and observed. Two research questions were asked: how do individuals with DAT describe their experience and; how does the disclosure of the diagnosis contribute to the experience of dementia?

Data was analyzed thematically and the experience described around six themes: awareness, personal significance, sense of self, perception of daily life, valued activities and concerns. Participants were found to provide insight into their experience and to be sensitive to the emotional appraisal of others. The benefits of disclosure of diagnosis were evident.

Discussion centered on issues common to the participants, benefits of disclosure of the disease, and coping strategies identified by the participants. Future research might explore the effects of a) autonomy, b) community membership, c) disclosure of the diagnosis, and d) inherent coping mechanisms of individuals with DAT.

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Chapter I

Introduction

A diagnosis of Dementia of the Alzheimer Type (DAT) brings with it an expectation of cognitive, affective and behavioral decline. While the titles of publications such as Loss of Self (Cohen & Eisdorfer, 1986) and Losing a Million Minds: Confronting the Tragedy of Alzheimer's Disease and Other Dementias (Congress of the United States, 1987) emphasize the personal losses associated with DAT, there has been little attempt to systematically investigate this experience from the perspective of the diagnosed individual.

This lack of inquiry is surprising considering the amount of research recently published on the caregiving experience related to dementia. The topic of caregiver burden, which encompasses the financial, social, emotional and physical well being of the caregiver (George & Gwyther, 1986), received a great deal of attention during the latter part of the 1980's. Research in this area includes work by Fitting, Rabins, Lucas, & Eastham (1986), George & Gwyther (1986), Gwyther & George (1986), and Zarit, Todd & Zarit (1986). In the early 1990's, the research began to focus more on specific elements of 'burden' such as depression and the negative feelings associated with caregiving (Boss, Caron, Horbal, & Mortimer, 1990; Semple, 1992; Shields, 1992; Skaff & Pearlin, 1992) and stress, the psychological strain experienced by caregivers (Pearlin, Mullan Semple, & Skaff, 1990). Coping skills, the use of intrinsic and environmental resources to manage stress, have also been studied (Fortinsky & Hathaway, 1990; Smith, Smith, & Toseland, 1991; Wasow, 1986; Wright, 1991; Zarit & Toseland, 1989). Even the developmental aspects of caregiving have been researched (Kobayashi, Masaki, & Noguchi, 1993).

This trend to understand the perspective of the caregiver, while ignoring that of the diagnosed individual, continues. A review of the PsycLIT Abstracts (1990-1995) on social

support, the sharing of knowledge and giving of assistance to other individuals (Gottlieb, 1983, p.28-29), indicates 92.5% of the literature dealing with social support did so from the perspective of the caregiver, compared with 5% from the perspective of the diagnosed individual. The remaining 2.5% dealt with support staff. The discrepancy in research between individuals diagnosed with DAT and their caregivers is surprising considering the potential role of social support for individuals personally experiencing DAT.

This lack of research has lead Lyman (1989) to argue “it is those suffering from the impairment, not the caregivers, who are still ‘hidden victims’ of dementia” (p.603). Lyman suggests this emphasis on the caregiver has been at the expense of the cognitively impaired individual. She argues, the “demented person is viewed as burdensome but not burdened ... as a stressor, not as one who is experiencing stress” (Lyman, 1989, p.603). Evidence indicates, however, the diagnosed individual does experience stress. Research dealing with the depressive and anxiety symptoms of individuals in the early phase of the impairment confirms the presence of an affective response to the disease (Burns, Jacoby and Levy, 1990; Lazarus, Newton, Cohler, Lesser, & Schweon, 1987; Reifler, Larson, & Hanley, 1982; and Teri, Borson, Kiyak, & Yamagishi, 1989).

If there is evidence for an affective response in the individual experiencing DAT, why has there not been systematic investigations into the perspective of the individual with DAT? Reasons for this neglect are found both in the characteristics of DAT and in the scientific model traditionally employed in the social sciences. The omission of systematic research into the perspective of individual with dementia is easily dismissed as an inevitable consequence of the problems inherent in the dementia process: communication difficulties, memory problems, and confusion. These difficulties can be cited as rationalizations for denying the validity of the perspective of the diagnosed individual, however, they are only partially responsible for the neglect

of the "victim's" perspective. The exclusion of the perspective of the individual with dementia also has its roots in the underlying philosophy of the prevailing paradigm of science, the logical positivist paradigm, and its preferred methodology, the hypothetico-deductive model.

The hypothetico-deductive model is premised on the neutral observation of a phenomenon with the objective of determining the underlying laws of the 'real' world (Robinson, 1986, p. 205). It is assumed by taking the 'etic' or outside position, the investigator will be able to observe reality for what it is and not have the observations biased by pre-existing conceptions. This preference for objective scientific inquiry favors the use of third party methods of observation to study the phenomenon under investigation (Robinson, 1986, p. 398). Preferably, observations are made by third party observers trained in objectivity who use instruments of measurement with a stated degree of reliability and validity.

In addition to objectivity, the positivist position strives for a reductionist explanation of behavior and affect. In the study of dementia, the reductionist explanation would be one that explained the related behaviors in terms of neurochemical or pathological deficit or imbalance. In its extreme form, this neurochemical position on dementia would imply that the behaviors associated with dementia are elicited by brain pathology and exist independently from the social milieu or personal experience in which its symptoms were expressed.

With the prospect of a neurochemical explanation of behavior and affect, the need for a phenomenological understanding becomes nonessential: unlock the mystery of neurochemistry and you can unlock the mystery of behavior. The perspective of the individual might be seen as interesting but not vital. This reductionist position, while useful in the explanation of behavior and emotion, is not sufficient. It is not sufficient for it denies the influence that 'meaning' gives to a situation, both the meaning given to the situation by the individual and the meaning of the behavior and emotions imputed by the "objective observer". The implications of taking the extreme view of

reductionism in the study of DAT is voiced by Cotrell and Schulz (1993) who warn: the “afflicted person is viewed as a disease entity to be studied rather than someone who can directly contribute to our understanding of the illness and its course” (p.205).

There is a trend toward acceptance of more subjective input into the field of human science. The medical profession, traditional proponents of the positivist approach, have recently accepted the validity of the individual’s description of illness (Armstrong, 1984). Danziger (1990) suggests the status of observer, or informant is sanctioned only for those with social status. In the eyes of many, ‘the old and the demented’ have little status and their experience should not therefore be taken seriously. Perhaps this would help explain the reluctance of the scientific community to investigate the perspective of the individual with DAT while accepting the perspective of the caregiver.

Cotrell and Schulz (1993) remind us the individual with DAT is not a passive individual “succumbing to deficits”, but an actor “responding and adapting to a disease” (p.206). If we assume the individual diagnosed with a dementia gives meaning to situations in which he or she is involved, it is through our understanding of that meaning that we can expect to gain insight into the psychosocial forces which affect his or her behavior. Behavior is affected by our perception of reality (Myers, 1987, p. 229). This emphasis on the individual with DAT as an interactive being who reacts to, and responds to, his or her interpretation of a situation warrants investigation.

The effect on behavior and affect as a result of the interpretation given to a situation is illustrated by an actual case observed by the author involving the experience of a family whose father had been diagnosed with DAT. The children of the diagnosed individual, based on a concern the father would react negatively and be unable to cope with a diagnosis of dementia, decided not to inform the father of the diagnosis. Due to the decision to withhold information from the father, the children engaged in behaviors they believed to be in his best interests. They felt the need for

him to be closely supervised and therefore arranged to have someone with him at all times. The family informed the father of what they were doing, but they did not discuss with him the reasons why they were behaving in this way.

The decision of the family to intervene in the father's life met with resistance on his part. For instance, the children attempted to dismiss a caregiver whom they thought was taking advantage of the father. In apparent reaction to their interference, the father stopped letting health care workers into his house and emotionally distanced himself from his children. The children then became more concerned about his ability to make reasonable judgments and intervened by trying to invoke a power of attorney. Several weeks later, the father broke off contact with his children, moved out of his house and did not inform them of where he was living. This alarmed the children even more and they sought more control which resulted in a lengthy and bitter court battle.

If one were to judge the behavior of the father, in isolation from the behavior of others, it would appear irrational. If, however, one looks at the interaction of the children's and the father's behavior, the pattern becomes more rational. As the family's course of action became more focused on 'controlling' the behavior of the father, his behaviors seemed to become more 'uncontrollable'. The reaction of the father escalated from resistant to rebellious within a few months. The escalating reaction of the father could be seen as bizarre if one did not know about the parallel escalation for control being played out among various relatives.

From the perspective of an outsider, this experience raised many questions. The distress experienced by the children was evident; but what about the father? How did he perceive the constant supervision and control he was under? Did he perceive his children's attempts at intervention as bids for control over this independence? How did he interpret the legal bid for power of attorney? What was it like for him to be involved in this interpersonal struggle and legal argument? How many of his "bizarre" behaviors were rational according to his interpretation of

what was happening? Did the decision not to inform the father of the diagnosis act as a catalyst to increase the distress which the family had tried to avoid? Would the dynamics of this situation have changed if he had been informed of the diagnosis?

The interactive nature of behavior might make it appropriate to take Cotrell and Schulz's (1993) reminder that the individual with DAT responds and adapts to a disease and broaden the statement to include the idea that individuals with DAT are not only reacting and adapting to a disease but are also reacting and adapting to their perception of their personal world.

Research Rationale

If we are to understand the behavior of the individual with DAT, we must do so from more than one viewpoint. The biological explanation is necessary but is not sufficient. The behavior and emotional reaction of the affected individual must also be examined in relationship to the psychosocial forces which affect them. This must be done for several reasons, one of which is the moral obligation to provide a high quality of life for the individual. In order to do this, we must determine what is important to 'quality of life', from the perspective of the individual. Second, we must determine the contributing factors to the behavioral and affective response of individuals with DAT. Certain questions asked of the individual will help identify contributing factors. Are individuals with DAT concerned or indifferent about their memory loss? Do they withdraw because others speak too quickly and confuse them? Finally, from a practical point of view, Gerhardt's (1990) advice for the treatment of the chronically ill is applicable to the treatment of those with dementia. Gerhardt suggests that professionals can't "adapt their treatment and advice to their [the client's] everyday reality if they [don't] know what the latter is like." (p. 1149). If we want to understand denial, withdrawal, non-compliance, aggression, anxiety and depression, we must understand them from the perspective of the individual experiencing them. The only way to understand their perspective is by allowing them to share their experience with us.

Research Objective

The objective of this study is to gain an understanding of the experience of the person with a Dementia of the Alzheimer's Type.

Chapter II

Literature Review

Dementia of the Alzheimer Type (DAT) is a chronic and progressive disease of the brain characterized by memory loss. Although characterized by memory loss, it is disruptive to a variety of other cognitive, behavioral and affective responses. Problematic responses, other than memory loss, are poor judgment, communication difficulties, sleep disturbance, motor and visuo-spatial disturbances and in the later stages, incontinence.

The association between a specific brain pathology, neurofibrillary tangles (NFT), and the clinical syndrome of dementia was first described by Alois Alzheimer in 1907. The other characteristic pathological change associated with DAT, senile plaque (SP), was first described by Blocq and Marinsec in 1892, but was not clinically related to dementia until 1910 when the connection between this pathology and dementia was made by Simchowicz. At approximately the same time, Simchowicz also described granulovacuolar degeneration (Blessed, Tomlinson, & Roth., 1968; Davies & Wolozin, 1987).

The connection between senile plaques, neurofibrillary tangles and granulovacuolar degeneration were believed to be specific to senile dementia until 1933. At that time, Gellerstedt found these pathological changes in aged individuals who had not been suspected of having a dementia. Of those 'normal' aged brains studied post-mortem by Gellerstedt, 97% had NFT, 84% SP and 40% had granulovacuolar degeneration (Blessed et al. 1968).

The syndrome, as described by Alzheimer, referred to those under 65 years of age and therefore was called a pre-senile dementia (Katzman, 1988). More recently, the diagnosis of Dementia of the Alzheimer's Type, is given based on clinical symptoms and signs, and is not restricted to those under 65 years of age.

Summary of Research

Research into dementia has traditionally focused on physiological and clinical characteristics. Recently there has also been an emphasis on the psychosocial understanding of dementia as professionals recognize the importance of quality of life to the experience of DAT. A summary of research into the clinical, physiological, and psychosocial aspects of DAT follows.

Diagnostic Criteria

One of the diagnostic criteria for DAT is the exclusion of other disorders that could account for the symptoms of dementia. There are at least 50 other known conditions that create symptoms of dementia, approximately 5-10% of which are reversible (Mayeux, Foster, Rossor, & Whitehouse, 1993). Although certain laboratory tests, such as the computerized tomography scan (CT scan), can be helpful in excluding other disorders, they cannot be used to make a diagnosis of DAT. The criteria for a definite diagnosis of DAT requires both clinical symptoms typical of the disorder and a pathological confirmation from either a biopsy or an autopsy. The clinical symptoms include the progression of memory loss and at least two other cognitive deficits. These deficits must occur in the absence of a delirium. Finally, the cognitive deficits must be established by assessment. Since a definite diagnosis cannot be made until a biopsy or autopsy has been performed, there are three classifications applied to indicate the degree of certainty one has in the diagnosis of DAT: probable, possible and definite Alzheimer's disease (McKhann, Drachman, Folstein, Katzman, Price, & Stadlan, 1984).

Epidemiology

Dementia of the Alzheimer's Type is age-related and shows an exponential rise in prevalence with each decade after the sixth. Two studies have recently looked at the prevalence of DAT in the population (Breteler, Claus, van Duijn, Launer, & Hofman, 1992; Rocca et al., 1992). Both studies used the survey method of examining previous research and, both included in their

conclusions only those studies which had used either the Diagnostic and Statistical Manual (DSM) or the National Institute of Neurological and Communicative Disorders and Stroke-Alzheimer's Disease and Related Disorders Association (NINCDSM-NINCD) criteria. The basic difference between the two studies is that Rocca et al. limited their summary to studies done on the European population, whereas the Bretener et al. survey included North America and Japan. Results between the two studies were similar. The prevalence rates of DAT, according to the Rocca et al. study, listed by age category followed immediately by prevalence, are: 30-59, (0.02%); 60-69, (0.30%); 70-79, (3.2%); 80-89 (10.8%). These figures are similar to those reported by Bretener et al.: age 65-74 (0.5%); 75-84 (3%); and 85 and over (10%). Both of these studies only investigated DAT. If other age-related dementias had been included, the figures would be higher since DAT accounts for up to 50% of all chronic progressive dementias (Cummings, 1987). Approximately 20% of those individuals diagnosed with DAT also experience a multi-infarct dementia (Davies, 1988).

The degree to which DAT is affected by gender is still controversial. Studies consistently report increased prevalence for DAT in women (Rocca et al., 1991) but the Canadian Study of Health and Aging (1994) found no increased risk for females. Campbell, McCosh, Reinken and Allan (1983) credit the increased longevity of the female for the greater prevalence of DAT in females. Fratiglioni (1993) supports the equality in vulnerability according to gender but cautions this might be true of late-onset DAT only.

Etiology and Risk Factors

There is as yet no known etiology of DAT, however, there are at present four popular theories: genetic transmission, toxins, viral infection and the aging process itself. Risk factors associated with the disease were compiled by Fratiglione (1993) as part of a survey of previous research. The two consistent risk factors were age and familial history. Other risk factors, which had been researched and judged by Fratiglione to be worth further consideration, were: advanced

age of mother at time of birth (early onset only); alcohol consumption (late onset only); problems with the law (early onset only); and occupation as a manual laborer (late onset only). The presence of Down's Syndrome should be added to this list as at least 33% of individuals examined in clinical studies, who had Down's syndrome, had a dementia, and the pathological evidence is the same as that shown in DAT (Davies & Wolozin, 1987).

A Canadian population based study (Canadian Study of Health and Aging, 1994) assessed risk factors other than age. Factors which were shown to have a considerable risk associated with them were: family history of dementia, education of 0-6 years, and previous head injury.

Neurochemical and Pathophysiological Features

From a neurochemical perspective, the only chemical systematically linked to DAT is the enzyme choline acetyltransferase (ChAT) (Davies & Wolozin, 1987; Thal, 1988). ChAT is a precursor to acetylcholine, a neurotransmitter that projects to the neocortex and the hippocampus. The reduction in ChAT has been found to range from 40% to 90%. There is also evidence of reduction in three other neurotransmitters, norepinephrine, serotonin and amino acid glutamate but these are not as consistently found as is the deficiency of ChAT (Katzman, 1988). There is suggestion that individuals with DAT differ from controls in the pattern of neurotransmitter deficiency. That is, there is a systemic change in which several neurotransmitters are affected (Kolb & Whishaw, 1990).

Correlated to the deficiency of ChAT, but not known to be causally related, are the pathophysiological characteristics of intracellular neurofibrillary tangles, extracellular neuritic plaque, granulovacuolar degeneration and Hirano bodies. Neuronal loss in the nucleus basalis of Meynert (the source of the cholinergic pathway) and certain nuclei in the brainstem often accompanies DAT (Wedding & Cody, 1990).

It is the presence of neurofibrillary tangles and neuritic plaque which are the confirming characteristics of DAT (Koo & Price, 1993) and these characteristics are quantitatively, not qualitatively, distinct from those found in the brain of a 'normal' aged individual (Blessed et al., 1968). Neuritic plaques are most dense in the areas of the temporal and frontal lobes of the cerebral cortex, the anterior of the amygdala and the hippocampus (Davies & Wolozin, 1987; Koo & Price, 1993). Neurofibrillary tangles are more widespread than plaques and are found in the cerebral cortex, the amygdala, the hippocampus, the basal forebrain and the hypothalamus. Granulovacuolar degeneration is only shown in the pyramidal cells of the hippocampus, the areas in which Hirano bodies are also most likely found (Davies & Wolozin, 1987; Koo & Price, 1993). Neurofibrillary tangles have a higher correlation with the symptoms of DAT than do neuritic plaque (Wedding & Cody, 1990). Although the presence of neurofibrillary tangle and neuritic plaque, obtained either by biopsy or autopsy, is necessary to the confirmation of DAT, it is not sufficient (McKhann et al., 1984). Clinical evidence of severe memory loss is a co-requisite to the diagnosis of DAT (Spar & Larue, 1990).

Damage to the brain progresses in an anterior fashion through the parietal, temporal and frontal lobes. Certain structures invariably involved are the hippocampal formation, in particular the entorhinal cortex, the amygdala, and the basal forebrain cholinergic system including the nucleus basalis of Meynert (Koo & Price, 1993). Other structures more differentially effected are the parietal lobe which effects visuo-spatial abilities (Wedding & Cody, 1990), including the perception of distance and direction (Zgola, 1990); Broca's area, Wernicke's area and the secondary sensory cortex, which effect our ability to communicate; the motor and sensory strips of the posterior frontal lobes, which effects the ability to make certain movements; and the frontal lobes, which effect our ability to plan ahead, make sound decisions and engage in abstract reasoning. These areas are not effected uniformly and each individual shows a somewhat different

pattern of brain pathology which means that each individual will show a somewhat unique pattern of symptoms.

Cognitive and Behavioral Symptoms

The progressive nature of the disease suggests that effects of the disease might eventually be seen as in all areas of cognition, behavior and affect. Although the disease is global in nature there is no inevitable pattern of decline. Each individual shows a unique pattern of disability, as well as, a unique pattern of remaining skills. Keeping in mind the unique pattern of progression of the disease a compilation of the “typical” progression of DAT follows.

Typically, memory is the first function affected and is often characterized by forgetting where one is going or why one is doing some particular thing. The ability to consolidate new memories is also influenced however the loss of this skill is not absolute and some memories can be stored. Episodic memories tend to be lost in the reverse order to how they were laid down: the most recent are the first to go and the earliest are those spared the longest (Zgola, 1990). Gradually deterioration is widespread and memory loss is pervasive. Eventually, there will be perceptible memory loss in virtually all areas.

Aphasia, or communication disorder, is often the next cluster of symptoms to become symptomatic. The initial signs of aphasia are difficulties in naming items, difficulty in finding the right word, and difficulty in completing a task of letter writing (Bayles & Tomoeda, 1991). Since these symptoms are relatively common and can be created by depression, anxiety or fatigue, the signs are often minimized by oneself and others. In some cases, the individual may be aware of the symptoms but is likely to try and hide them from others (Mace, 1990).

As the disease progresses, cognitive function deteriorates further. Judgment, abstract thinking and attention span are all negatively affected. There is a slow, but constant, progress in memory loss; after a year or two of definite identifiable symptoms the individual may lose the

memory of familiar over learned material (Zarit & Zarit, 1983), including independent activities of daily living (IADLs). Aphasia worsens and is followed by apraxia and agnosia. Apraxia affects the ability to make purposeful movements, while agnosia effects the ability to recognize familiar objects including faces. Apraxia usually begins with difficulties in fine motor movement and progresses to gross motor skills in the late stages of the disease (Mace, 1990). Agnosia is likely due to deterioration of the parietal lobe where visuo-spatial processing occurs. The agnosia can be to such an extent that the individual cannot recognize his or her own children or his or her own reflection in the mirror (Mace 1990).

As apraxia and agnosia settle in, the functional effects of aphasia continue. Language dysfunction may progress to the point of not being able to understand the spoken or written language and in the later stages, mutism may occur. Weaverdyck and Coons (1988) suggest, despite communication difficulties, the client is still able to respond to the emotional tenor of a message or situation. Similarly, Rabins (1990) suggests nonverbal cues are important to the individual with DAT. With the progression of the disease, the affective, as well as the objective, memories deteriorate and the individual is at the mercy of immediate environmental cues.

Cognitive dysfunction is the hallmark of Alzheimer's disease but the progression of the disease often brings with it behavioral problems. Mace (1990) lists several behaviors associated with DAT: "angry outbursts, violence, apathy, stubbornness, resistance to care, suspicion, accusations, wandering, incessant repeating of the same question, being awake and active at night, use of obscene or abusive language, talking to deceased relatives, rummaging through other patients' rooms, stealing, getting lost, urinating in unsuitable places, hiding things" (p. 82).

Personality change is another behavioral change linked to DAT (Davies, 1988). Cummings (1987) suggests that indifference is the most common personality change followed later by combativeness and agitation. Using a factor analytic technique, Rubin, Morris and Berg (1987)

found approximately 90% of the participants, as indicated by caregiver response, were passive, and two-thirds developed self-absorption and agitation as the disease progressed. In a follow-up study of Rubin & Kinscherf (1989), similar results were obtained.

Bozzola, Gorelick and Freels (1992) studied 80 individuals diagnosed with probable DAT using the Blessed Dementia Scale as a measure of personality. Using this measure, it was determined that the following personality changes took place: apathy and diminished initiative (61.3%); less interested in hobbies (55%); and inflexibility or rigidity of personality (41.3%). In another study, Chatterjee, Strauss, Smyth and Whitehouse (1992), using retrospective caregiver evaluations, determined the DAT individual experienced changes in neuroticism and became more introverted, less assertive, less conscientious and more disagreeable.

Affective Symptoms

Several authors (Lazarus et al., 1987; Reifler, Larson et al., 1982; Teri, Borson et al., 1989) have described negative affect in some individuals diagnosed with DAT. One of the common forms of affect researched is depression and/or depressive symptoms. Wragg and Jeste (1989) reviewed 18 articles which had reported on the co-occurrence of depressive symptoms and DAT. The median value of the 18 studies, for percentage of individuals reported to be experiencing either depression or a depressed mood, was 41%.

One reason the Wragg and Jeste (1989) study reported such a high incidence was that it included studies such as the 1988 study by Merriam, Aronson, Gaston, Wey and Katz. The study of Merriam et al. indicated a 86% presence of depression in individuals who had been clinically diagnosed with DAT. The Merriam et al. study had used as its criteria the DSM-III for depression which included such symptoms as, loss of interest in activities, diminished ability to think, psychomotor agitation, or retardation and insomnia. The inclusion of these symptoms in a diagnosis of depression is confounding since these symptoms may be cognitive consequences of the

impairment rather than symptoms of depression. Despite this confound, Reifler, Larson, Teri and Poulsen (1986) used the same DSM-III criteria for a DAT sample and found only 31% to show signs of major depression.

In an earlier study, Reifler, Larson et al. (1982) found a 19% prevalence for the co-occurrence of both DAT and depression. The criterion for this study was the Research Diagnostic Criteria. Furthermore, the differences in depression were statistically significant according to severity of cognitive impairment: 33% in the early stages of the impairment were diagnosed with depression; 23% in the moderate stages; and 12% in the severe stages.

In an attempt to differentiate between the symptoms created by depression and those created by cognitive impairment, Lazarus et al. (1987) assessed individuals diagnosed with DAT using the Hamilton Depression Scale and the subscale for depression on the Sandoz Clinical Assessment- Geriatric Scale (with the cognitive factors removed). Using these two scales, 40% of the impaired individuals were found to have at least a mild depression, 9% had moderate to severe depression and 11% had severe depression. This compares with a total of 12% which showed at least a mild depression in the control group. Using descriptive terms, rather than diagnostic criteria for depression, Teri, Borson et al. (1989) found 24% of impaired individuals were “unusually sad and depressed” as reported by caregivers.

Despite the problem of using different criteria, these studies suggest a fairly substantial (at least 20%) prevalence of either depression or depressive symptoms co-occurring with DAT. Although this might be explained by the deficit of serotonin, a neurotransmitter known to be linked with depression, it doesn't fit with the fact that depression is found more often in the earlier phase of DAT. If the depressive symptoms were strictly the result of a deficit in serotonin, it would be expected that symptoms would worsen as the neurochemical deficits increased with the progression of the disease. There is not a positive association between severity of depression and severity of

brain pathology however, and there is some consistency in the reporting of a higher incidence of depression, or depressive symptoms, for individuals in the earlier phase of the disease.

The association between depressed mood and mild cognitive impairment has been well documented (Burns et al., 1990; Cotrell & Lein, 1993; Reifler, Larson et al., 1982; Reifler, Larson et al. 1986; and Pearson, Teri, Reifler & Raskind, 1989). This association is important for it suggests the mildly impaired individual is possibly aware of, or self-conscious of, personal loss (Cotrell & Lein, 1993; Reifler et al., 1986). The potentiality of awareness is supported by the effects of reminiscence therapy for individuals experiencing DAT. Individuals participating in reminiscence therapy showed a significant improvement on the variable of affect when compared with both a control and a support group (Goldwasser, Auerbach, Harkins, 1987).

Interpersonal Difficulties

From an interpersonal perspective, the reported changes occurring within the DAT individual can be devastating. The individual with the disease becomes increasingly more dependent on others for physical and emotional well-being and the demands placed on family members can be overwhelming. Davies (1988) points out that due to the incapacitating nature of the disease the family is considered the “second victims”. Behaviors, such as fecal and urinary incontinence, wandering, catastrophic reaction, and sleep disturbance (Sheldon, 1982), take their toll in a relationship where one individual becomes increasingly dependent on another (Pearlin et al., 1990).

Critique of Previous Research

The research does provide support for the negative expectations that accompany a diagnosis of DAT since associations have been found between DAT and depression, negative personality change, dependency and problematic behaviors such as incontinence. What is not clear, is the extent to which this deterioration is inevitable. Although studies of the behaviors associated

with DAT are consistent in reporting the difficult behaviors, there is no consensus on the underlying cause of such behavior. A brief review of the literature illustrates this point.

Medicalization of Dementia Behavior

In a study by Reisberg, Borenstein, Salob, Ferris, Franssen, & Georgotas (1987), 57 individuals diagnosed with DAT had their charts reviewed for problem behavior. Of the 57 patients, 33 or 58% were reported to have displayed problem behaviors. The most frequent behaviors reported for the individual were delusions of theft (48%), agitation (48%) diurnal disturbance (42%), motor restlessness (36%), violence (30%), verbal outbursts (24%), and tearful episodes (24%).

While Reisberg et al. (1987) conceded the sample used in the study might not be representative of the DAT population, they failed to find fault with the fact that these symptoms and their frequency were likely reported by caregivers and not reported in the context of the antecedents to the behavioral problems. The first of these limitations, the use of retrospective caregiver accounts, is problematic for Cohen, Kennedy and Eisdorfer (1984) have found that caregivers often misrepresent behavior, by either over- or underestimating its prevalence. The second limitation is more serious than the first. By not recognizing the antecedents and/or consequences there is an underlying suggestion that certain behaviors are inherent to the disease rather than influenced by the interaction between an individual and his or her environment.

The inadequacy of the Reisberg et al. (1987) study to address the issues of factors other than those inherent in the disease was addressed one year later in a study by Teri, Larson and Reifler (1988). The Teri et al. study had divided participants into three groups of impairment as measured by the MMSE: mild, moderate and severe. The caregiver was asked which common behaviors were present or absent. There was a statistical trend for certain behaviors to increase with the degree of impairment: incontinence, hygiene, and wandering. Three other behaviors also

increased but not statistically: hallucinations, falling and suspiciousness. Teri et al. interpreted the positive correlation between some behaviors and the degree of impairment as an indication that certain behaviors were inherent in the disease process while others, which did not show a correlation, were considered idiosyncratic.

Teri, Borson et al. (1989) looked at the prevalence of behavioral problems in a later study. In this study, the caregiver was asked to rate the behavior of the individual with DAT on a Likert scale according to the frequency of problem behaviors during the past month. Results similar to the previous study were reported: the most frequent behavioral disturbances were under activity, anxiety, loss of interest, “depressive symptoms” and apathy. This study, however, failed to find a correlation between the frequency of behavioral problems and cognitive decline suggesting that factors other than cognitive decline were affecting behavioral response.

In the following year, Teri, Hughes and Larson (1990) again looked at the relationship between cognitive decline and behavioral disturbance. At this time they found a relationship between three variables and the rate of cognitive decline: a history of alcohol abuse (even when no longer present), agitation, and other neurological problems. For our purposes, it is important to note that the research rationale for this particular study was an acknowledgment that emotional, behavioral, physical and social problems can exacerbate the disabilities associated with dementia.

Through the four studies listed, we can see differences in attitude concerning behaviors and emotional reactions associated with DAT. In the first cited study, the researcher listed symptoms as if they were inherently part of the DAT process (Reisberg et al., 1987). In the following year, Teri, Larson et al. (1988) emphasized the distinction between those behaviors which were inherent in the dementia process and those, which for one reason or another, were idiosyncratic. In addition, Teri, Larson et al. (1988) emphasized the percentages of individuals who did not have problem behaviors, thus supporting the idea of variability of behavioral symptoms. Teri, Borson et al.

(1989) later tried to determine the relationship between frequency of behaviors and cognitive decline. Finding no relationship, Teri, Hughes et al. (1990) proceeded to study the possible effects of interpersonal factors such as a history of alcohol abuse and concomitant neurological disorders. The important point is the movement from seeing all problem behaviors as residing in dementia *per se*, toward investigating factors other than dementia, which might contribute to the behavior.

Despite this important shift in investigation, the Teri et al. studies were still lacking an important focus. Several questions were not being addressed. What was the context of the behavior? What was the contribution of the “other” to the behavior. Other researchers have made an attempt to answer these questions. For example, McEvoy (1990), a behavioral gerontologist, emphasized the antecedents and consequences of behavior. McEvoy points out that there is no single rule for explaining verbal outbursts. Each incident should be seen as having its own antecedents and its own consequences.

The research on personality change also requires some criticism. While Chatterjee et al. (1992) admitted that personality changes are affected by pre-morbid dispositions, and Bozzola et al. (1992) acknowledged the limitations of retrospective caregiver reports, neither of these studies indicated the possibility that factors other than dementia (Bozzola et al.) and pre-morbid personalities (Chatterjee et al.) could have influenced the characteristics. These studies failed to address some necessary confounding factors. For example, did the individual become more withdrawn because he or she perceived him or herself to be ignored. Did the individual become less interested in hobbies because he or she had a sensory loss which limited participation? Did the individual regress because he or she was being treated as a child? Evidence from Brody, Kleban, Lawton, and Silverman (1971) indicates at least some of this “personality change” of apathy and regression can be reversed through appropriate interventions. If this is the case, we must be careful in suggesting that personality changes are inherent in the disease and question whether it is not the

individual's ability to independently nurture the personality which has changed. Shomaker (1987) suggests personality does not change but becomes more intense and the diminished ability of the individual to dampen his or her personality results in an increase in the frequency of personality-related responses. In other words, the individual would continue to respond, or cope, in a manner similar to the way he or she always had, but the deterioration of inhibition would result in the individual responding in a more extreme form and at inappropriate times. Although inappropriate responses are varied among those individuals with DAT, they often result from an inability to "inhibit inappropriate behavior" (Mace, 1990, p.83).

It is unknown to what extent these behavioral problems are inherent in the disease. Mace (1990) clearly points out that not all individuals display problem behavior, and the inappropriate behaviors shown in this subpopulation vary substantially. Zarit and Zarit (1983) similarly report wide interpersonal variation; some patients display no behavior problems, some have no significant personality change, and some continue to show appropriate social skills. Mace suggests that the extent of behavior problems could be the sum of several factors including underlying brain damage, a lifelong pattern of coping, present affect, co-existence of complicating medical problems and the influence of "physical, interpersonal and internal environments". The suggestion of Shomaker (1987) that personality change is in fact the accentuation of a previous personality, but in an inappropriate way, allows for at least some of the behavioral variability found in coping strategies to be explained by pre-morbid personality styles and begs the questions: "What in the environment elicits these coping strategies or inappropriate personality traits?" and "Is there anything that could be done to enhance behavior through an environment rather than blame the individual?"

Inadequacy of Biological Explanation

Mace's interpretation of the dynamic nature of behavior is supported by evidence for the inadequacy of a pathophysiological explanation to account for what is labeled "demented" behavior. At present time, a neuropathological explanation of dementia, while necessary, remains insufficient. Neuropathology must be considered, at least in the present state, an insufficient indicator of DAT since the diagnosis of DAT cannot be made on neuropathological evidence alone (Mayeux et al., 1993; McKhann et al., 1984). Blessed et al. (1968) found cases of individuals who had a low count of plaques while showing a clinical picture of dementia and conversely individuals who showed more than the mean number of plaques for a pathological confirmation, had not shown clinical symptoms. There has been some suggestion that the criteria for classification is sometimes reduced to include individuals "known" to have shown dementia-like behavior (Lyman, 1989). Finally, the number of plaques and tangles required for a DAT diagnosis is not absolute, but is relative to age (Lyman, 1989). The implication is that the presence of dementia, and by extension the presence of dementia symptoms, is likely buffered by some unknown factors and encouraged by others. These factors might be an unknown biological state, an unidentified psychosocial state, an unspecified environmental condition or a combination of all three.

Labeling and its Effects on Behavior

We are still unaware of the systemic effects of labeling on subsequent behaviors. Lyman (1989) draws our attention to the role that labeling can have in the progression of the disease and suggests we must clearly distinguish between the traits inherent in the disease and the traits resulting from " [the individual] being identified and treated as if one were demented"(p.600). She suggests the ill-effects of labeling can be seen in both the stigmatization of the diagnosed individual by others, and the awareness of, and reaction to, stigmatization on the part of the diagnosed individual. For example, in a study she had conducted at a dementia daycare, she recounted tales of

indignity and devaluation perpetuated towards the demented individuals, which in some cases (if not all), the individuals were painfully aware of the stigmatization.

In addition to the effects of stigmatization, Lyman (1989) suggests we look at the effects of the expectations created by the staging of dementia. The expectation could result in the attribution of pathology to normal behaviors and the imposition of dependency before its time. The potential to impose dependency on others was shown in a study by Baltes, Burgess and Stewart (1980) who found, in a participant observation study of a nursing home, independent behaviors were discouraged and dependent behaviors encouraged.

Excess Disability as a Source of Behavioral Variability

In the case of dementia, there is a real danger the labeling might lead to an excess disability. The concept of excess disability is central to the debate about the inevitability of decline. Excess disability is defined as the presence of disabilities more pronounced than expected by the objective deterioration. The concept was first introduced into the area of dementia by Brody et al. (1971). At that time, the authors suggested there was not a corresponding relationship between organic impairment and functional impairment and the degree that social and functional behavior was impaired was likely dependent upon other factors such as psychological disturbance, physical impairment, social environment and cultural factors. Since 1971, the desire to understand the extrinsic effects on the behaviors of the DAT individual has continued. Dawson, Kline, Wianko, and Wells (1986) indicate excess disability in DAT may arise from lack of stimulation, showing up as disruptive behaviors such as shouting, restlessness and pacing. Weaverdyck and Coons (1988) stress the potential effects of excess disability on the symptoms of DAT and point out that the individual, in the middle stages of DAT in particular, may seem to be much more impaired than is justified on the basis of physiological damage.

If it can be accepted that individuals with dementia are subject to excess disability, the focus then shifts to the identification and understanding of factors which contribute to this excess disability. Two factors commonly referred to in the literature are depression and anxiety. Depression, either reactive to one's situation or resulting from a pathological process of the disease, is known to create its own dementia syndrome thereby intensifying the behavioral and/or cognitive effects of the disease. This concept is supported by evidence that treatment of depression has a residual positive effect on IADLs (Teri et al., 1989) and functional behaviors (Reifler et al., 1986). The link between affect and behavior is illustrated in a study by Pearson et al. (1989) in which not only was there a relationship between the level of cognitive impairment and depression, with those in the mild stage of cognitive impairment showing more depressive symptoms, but there also was a significant link between depression and the performance of IADLs. A negative correlation between depression and the performance of IADLs was evident: individuals with similar scores on the Mini Mental Status Exam (MMSE) differed significantly in their ability to perform IADLs dependent on the presence or absence of depression. By extrapolation, this suggests that awareness and interpretation of the disease process in individuals with mild cognitive impairment might not only contribute to a depression but the resultant depression can interfere with functional abilities beyond the effects expected from the cognitive impairment alone, that is, excess disabilities.

Excess disability is also believed to be brought on by stress. The effects of stress on the aphasic individual may also be particularly damaging. The lack of communication may lead to the potential for a downward spiral in interpersonal contact (Mace, 1990) and the lack of clear communication may facilitate 'inappropriate' behaviors (Conrad & Guttman, 1991).

Depression and stress are not the only variables believed to contribute to excess disabilities. Woods and Britton (as cited by Zgola, 1990) suggest that sensory deprivation and

inadequate “input from the environment” contribute to the cognitive and behavioral deterioration of the individual. Zgola further suggests as apraxia, aphasia and agnosia develop, the individual with DAT becomes increasingly dependent upon constant and immediate environmental cues. If this requirement is not provided or is worsened by sensory deprivation the results are particularly damaging (Zgola, 1990).

The Effects of Caregiver Strategies

There is little argument that many behaviors of the individual experiencing a dementia are challenging for those in the care of the DAT individual. Symptoms inherent in the disease, such as the progressive loss of cognitive ability, decline in daily living skills and behavioral repertoires, require that the individual with DAT be given constant care. The demands on the caregiver are relentless and the progression of the disease brings with a unidirectional dimension in which the caregiver receives few, if any, reciprocal interactions with the patient (Pearlin et al., 1990). The constant strain of such a relationship is considerable for the caregiver who is subjected to limited resources as he or she interacts with numerous environmental pressures. The excessive demands leave the primary caregiver at risk for depression and/or stress related disorders. Rabins and Fittings found 39% of primary caregivers suffered from emotional disorders (as cited in Rabins, 1990).

Rabins (1990) suggests that caregiver stress and family environment are more highly correlated with behavioral difficulties and IADLs than is cognitive impairment. While it is unknown to what extent the relationship between the caregiver and the individual with DAT influence the display of inappropriate behaviors such as aggression, it can be reasoned that as the individual becomes less able to inhibit inappropriate behaviors they will react rather than respond to the behavior of the other, or perhaps more importantly to their perceived behavior of the other.

In a way, the caregiver must create an environment in which “triggers” can be reduced so that the uncontrollable reactions can be reduced.

The dynamic relationship between the individual diagnosed with a dementia and the caregiver is illustrated in a study by Paveza, et al. (1992). In this study, the relationship between the DAT individual and the caregiver was examined in respect to violence (i.e. hitting, punching, biting and kicking). It was reported that 17.4% of the families experienced violence. The two variables which were found to be significantly associated with violent behavior were caregiver depression and having a caregiver other than a spouse. Although the greatest degree of reported violence was initiated by the DAT individual, the correlation between caregiver depression and violence underscores the effect of one individual’s behavior on another’s.

Summary of Critique

The research to date has been unclear on the inherent nature of behaviors commonly associated with DAT. We are, at this point, unable to determine the extent to which behaviors such as apathy, withdrawal and aggression are intrinsic to the disease, and to what extent they are triggered and maintained by idiosyncratic features such as a) personality, b) ineffective coping skills on the part of the diagnosed individual and/or the caregiver, and/or c) concomitant physical and/or emotional/psychological problems. In addition to idiosyncratic factors, there are also social factors which could influence the display and progression of problem behaviors, such as the effects of labeling and the effects of institutionalization. In addition, we are unaware of the interaction between individuals and their social and physical environment.

New Directions

Attributions and The Need for the Perspective of the Individual

The investigation into the distinction between inherent and environmentally induced disability must include the perspective of the diagnosed individual. Cohen, Kennedy and Eisdorfer

(1984) suggest that the attributions that individuals make will affect both the affective and behavioral aspects of the illness process. This suggests a need to include information regarding the individuals perspective on the attributions of behavior, however, the investigation of perspective can be difficult. The task would be even more challenging when investigating the behavior of individuals experiencing a dementia. For this reason, it is often helpful to investigate how the individual perceives his or her situation or environment and infer the relationship between perception and behavior. For example, if the individual shows agitated withdrawal and describes the environment as loud and annoying, it might be inferred that the individual is experiencing some form of stimulus overload from which he or she tries to withdraw. If, on the other hand, the individual shows withdrawn behavior and describes feeling devalued and discredited, the behavior might be interpreted as a sign of depression. One would also want to determine the reason for the depressive symptoms. Certain questions might be asked. Does he or she feel hopeless about the future? Does the individual worry about becoming a burden or being abandoned? Does the individual label him- or herself demented and subsequently interpret all behavior in light of the label?

Disclosure of the Diagnosis of Dementia of the Alzheimer's Type

One of the issues in the diagnosis of a dementia is the decision to inform, or not to inform, the individual of the diagnosis. Erde, Nadal and Scholl (1988) suggest that there are two schools of thought: the deontological and the consequentialist. The deontologists believe the competent individual has the moral right to know the truth regardless of the consequences; the consequentialist school believes the individual should only be told the truth if there is a benefit to be gained through the disclosure of the diagnosis. One way to determine the benefits of advising individuals of the diagnosis is to find out the meaning that the experience of disclosure or non-disclosure has for the individual. It is possible that some individuals may feel that having the diagnosis discussed with

them, while in the early stages of the disease, allows them an opportunity to come to terms with its consequences, prepare for the future and tie up loose ends in their life. Would the individual have preferred, or been better served by, the withholding of the diagnosis, or did the individual appreciate being informed of the diagnosis?

There has been virtually no research in the area of disclosure of DAT to the affected individual. Drickamer and Lachs (1992) discussed the issue hypothetically and speculated that the trend to inform the individual with DAT of the diagnosis, might undergo the rapid change in attitude as seen in the medical profession toward the disclosure of cancer. Novack, Plumer, Smith, Ochitill, Morrow, and Bennett (1979) surveyed physicians in an attempt to determine their attitude towards giving the diagnosis to cancer patients. In their study, they found that 98% of the responding doctors had a policy to tell the patient the truth. This can be compared to 24% from a 1961 survey (cited by Novack et al., 1979). The authors suggested that the reversal in attitude may have come in part from the increased knowledge about the experience of dying.

The authors of the previous study (Novack et al., 1979) indicate that one of the areas physicians had become more informed about was the “concerns and needs of the dying patient” (p. 899). It is possible that, just as physicians attitudes toward disclosure and the cancer patient changed as the medical profession learned more about the experience of dying, the attitudes toward disclosure and the individual with dementia will change as we learn of the experience of living with a cognitive impairment. Would it be helpful for the individual to discuss his or her experience and the meaning the experience held for the person? Does the lack of opportunity to discuss the matter add an even greater pressure on the individual experiencing the disease? From a developmental perspective, is there a need to find or create meaning in the face of continual decline: Wong (1989) warns that we may be overlooking the fundamental need for meaning when we consider the needs of the elderly. By giving the individual an opportunity to express oneself, will we gain a better

understanding of the consequences of truth telling in the diagnosis of DAT. The perspective of the individual has the potential to add a great deal to our understanding of the behavior of an individual with dementia.

The Emic Viewpoint as Meaningful Information

The importance of the perception of the individual is described by Shaw & Halliday's (1992) model of the family and chronic illness. According to this model, it is necessary to understand the perception of the individual since the individual reacts to his or her perception, not to what others might determine to be 'reality'.

The discipline of sociology has also become involved in the examination of illness behavior and has examined the perspective of the individual. The topics of role definition and self concept of the chronically ill are the area of interest in what is referred to as the social construction of illness. The social constructionists have emphasized the subjective experience of living with an illness.

The shortcomings of the etic viewpoint to understanding illness behavior is highlighted by Wynne, Shields, and Sirkin (1992) who emphasize the transactional nature of the illness experience. These authors point out that illness refers to both the objective behavior of impaired functioning and the subjective experience of illness. They further suggest, once an illness has been diagnosed, the dynamics of personal relationships change as previous roles are either limited or taken away and the new role of "patient" is prescribed for the individual. The prescription of the new role is usually provided by others on the basis of the "the other's" view. Usually the medical profession provides a label which dictates certain expectations. Wynne et al. suggest, however, that this ritual of diagnosis and prescription fails to take into account the subjective experience of the diagnosed individual. In order for the ritual to be followed in accordance with the expectations of "the other", the individual must accept the etic version of what the "problem" is and then accept the proper roles which go with the diagnosis. They further suggest this process requires continued

negotiation between the involved individuals and the community, with a positive outcome presumably being the acceptance of the prescribed sick role. One of the dangers of prescribing new roles, rather than negotiating them, is the possibility the diagnosed individual refuses to accept them which leads to the imposition of terms such as “non-compliant” or “denial”.

While Wynne et al. (1992) emphasized the loss of roles and the creation of new ones, Charmaz (1983) emphasized the loss of self and the need to create a new self in the face of being diagnosed with chronic illness. In referring to individuals who develop chronic illness, Chamaz suggests there is “a crumbling away of their former self-images without simultaneous development of equally developed ones” (p.168). Just as Wynne et al. suggested the adoption of the new role is a negotiated process which depends upon diagnostic procedures and the acceptance of the diagnosis by the ill individuals, Charmaz suggests that creation of the self is a negotiated procedure between the conditions created in chronic illness and the interpretations given to the newly imposed conditions. For example, in one study all individuals who required daily kidney dialysis were forced to live restricted lives; however, it was the degree of choice they experienced within the framework of that restriction which mediated the effects of the disability on their sense of self. From an etic viewpoint, objective illness behavior, such as the daily use of dialysis machine, might be the variable believed to govern the effect on self-perception; however, from an emic viewpoint it was the degree of choice an individual believed him or herself to have that mediated the redefinition of self.

It seems, the response to illness, in this case dementia, will not be the same for all individuals. The response will be affected by the meaning given to the experience by the diagnosed individual. In turn, the meaning given to the experience will have an unknown influence on the affective and behavioral response. At the center of the reaction is the meaning the individual gives to the experience. This is not to deny the biological restraints that a disease of the brain has on

behavior. Biology, however, is only one part of the behavioral dynamic and meaning and interpretation is another part.

Phenomenology

Phenomenologists place meaning at the core of their theories. The concept of meaning is fluid but its influence on the understanding of behavior is central to many theories of behavior. Alfred Schutz, a sociologist, was influential in shaping the modern phenomenological movement. Schutz (1970) envisioned behavior as a phenomenon influenced by two types of motivation: goal oriented motivations which he referred to as "in-order-to" motives, and historically explained motivations which he referred to as "because" motivations. According to Schutz, behavior involved both of these types of motivation: any individual, at any point in time, acted towards a goal, with behavior reflecting not only the present state but also the wealth of past experiences. For this reason, Schulz believed that behavior was an intrinsically unique activity understood only in the context of an individual's subjective understanding of the situation (Schutz, 1970).

An example of this would be an individual with dementia who engages in wandering. Although the objective behavior is wandering, the subjective experience might be walking "in-order-to" find a particular person "because" in the past the sought-for individual had participated in a particular activity with the "wanderer". Another individual with dementia might wander "in-order-to" engage in a physical activity "because" she was agitated and couldn't stand sitting any longer. According to Schutz (1970), any attempt to explain a specific behavior as a universal law would be futile, for any given behavior must be viewed in the context of the life one has lived.

Although Schulz emphasizes the need for a subjective understanding of the individual experience, phenomenologists do not see each incident, or each individual, as isolated in experience from others. Van Manen (1990) reminds us that phenomenological inquiry, while recognizing the subjective nature of experience, has the intent of uncovering experiences which contain essential

elements shared by many. It is this shared essence which the phenomenologist seeks: not universal laws which drive behavior, but subjective experiences which mediate behavior. An understanding of the experience allows us insight into the "in-order-to" and the "because". By understanding the experience of the individual, we can begin to appreciate both the commonality and the uniqueness of human behavior.

Research Questions

This study will investigate the experience of living with a Dementia of the Alzheimer Type (DAT) from the perspective of the diagnosed individual. Two specific questions will be addressed. The primary question is, how do individuals with Dementia of the Alzheimer's Type describe their experience? The secondary question is, how does the decision to inform individuals of the diagnosis contribute to their experience with dementia?

Chapter III

Method

Research Design

This study had as its objective the broad understanding of the experience of living with DAT from the perspective of the diagnosed individual. The lack of previous systematic research into this perspective suggested the study be exploratory in nature. A qualitative research design with a phenomenological approach was chosen in order to a) elicit the individuals' interpretation of their experience, b) investigate the relationship between the meaning attributed to the experience and the emotional and/or behavioral response of the individuals, and c) allow the communication of these variables through the description of the experience.

It was determined that a small sample of individuals would be interviewed and observed over a period of several weeks and the data analyzed according to inductive techniques. Trustworthiness was ensured through triangulation of methods, repeated observations and numerous interviews. In addition, recognizing the impossibility of complete objectivity, the researcher provided a disclosure of possible research bias written before data collection began (Locke, Spirduso, & Silverman, 1993, Appendix E).

The steps taken in implementing the research design are described in detail in the following sections.

Participants

Having determined the purpose of the study was to gain an understanding of the potential in experience, a purposeful sample, rich with information, was the preferred.

Four conditions for the selection of participants were considered necessary to the integrity of the research: the participant must a) have been given a provisional diagnosis of DAT by a

qualified professional; b) not have shown signs of a functional psychosis at an earlier time in his or her life; c) have retained at least a minimum of verbal abilities and; d) have consented to the research (and/or have obtained consent from the caregiver).

The Alzheimer Society of Calgary was asked if they would help in the identification of potential participants. The Society agreed to approach families who had a family member actively participating in Club 36, a social and recreational program for individuals experiencing DAT. The criteria for inclusion were given to the Society which then approached seven families whom they felt met the criteria and would be willing to participate. Five agreed to participate.

The researcher provided the Society with two letters to be sent to the families: one was written to the family and caregiver (Appendix B); the second was written to the diagnosed individual (Appendix C). Each of these letters explained the purpose, voluntary nature, research method, possibility of harm, commitment to confidentiality, time commitment, and possible uses of the research findings. Approximately one week later the researcher met with the family and the potential participant to verbally restate the purpose, method, commitment responsibilities and ethical considerations of the research. At this time a consent form was signed by both the diagnosed individual and the caregiver (Appendix D).

The five participants ranged in age from 62 to 80. All had been given a provisional diagnosis of DAT; all had histories of adequate vocational and interpersonal functioning. Four of the participants were male and one was female. Each of four male participants were cared for in his home by his spouse; the female participant was cared for by her daughter in the home of the daughter. Two of the participants, one 80 year old male and the 77 year old female had moved to Calgary as a result of having been diagnosed with a dementia. The female had left her native city to live with, and be cared for, by her only daughter and the 80 year old male and his spouse had left

their home and moved to Calgary to be close to relatives who would give emotional and instrumental support.

Materials for Data Collection

The researcher used five main materials for data collection: notebook for summary fieldnotes, interview guides, audiotape recorder, family photographs, and the Mattis Dementia Rating Scale (DRS, Appendix G).

There were four interview guides, each one reflecting one of four topics: assumptions, beliefs and attitudes toward dementia; social relationships; cultural expectations; and power relationships. The topics evoked by the guided interviews were intended as catalysts only. It was expected the interview would provide an opportunity for the individual to explore his or her own thoughts to these topics of interest. During all interview phases, the researcher used standard interviewing techniques such as descriptive, structural and contrast questions (Gilchrist, 1992); and circular questions including triadic-, difference-, behavioral-effect-, and hypothetical-questions (Loos & Bell, 1990).

The development of the interview guides went through several steps. A pilot of the original questionnaire was given to an 85 year old woman who was free of cognitive impairment. Questions which elicited yes-no responses or generated a response that reflected a misunderstanding of the topic of interest were revised. Once these revisions were made the questionnaires were given to the researcher's supervisor for comment and approval. Changes were made when appropriate. Finally the questionnaires were faxed to the program manager of the Alzheimer Society of Calgary. The program manager reviewed the interview guides with other employees familiar with the communication patterns of individuals experiencing a dementia. Staff of the Alzheimer Society suggested revisions when they suspected the wording would be confusing to the individual and/or

have the potential to violate ethical principles. The finalized version of the guided interviews can be found as Appendix A.

Family photographs significant to the participant were provided by the family and looked at and discussed with the participant.

The Dementia Rating Scale (DRS) is a brief, normed, measure designed to assess the severity of cognitive and behavioral decline in individuals already diagnosed with a dementia. The global score of the test is derived from five sub-scales: a) attention; b) initiation and perseveration; c) constructional ability; d) conceptualization; and e) memory. The correlation of the DRS with the Wechsler Adult Intelligence Scale (WAIS) and the Wechsler Memory Scale is .67 and .70 respectively. The split-half reliability for the DRS is .90 (Mattis, 1988). The DRS was added to the research material to gain an objective estimate of the stage of dementia for each of the participants. The inclusion of an estimate of the stage of dementia reinforces findings of this research across several stages of dementia.

Timeline

In April 1995 data collection began. The researcher spent approximately two to four hours a week, for up to twelve weeks, with each of the participants. The last session took place on July 1, 1995. A session for summarizing the findings and obtaining feedback on the trustworthiness of the data was carried out several weeks after the initial phase of data collection had ended but before the results and conclusion were finalized.

The twelve sessions were made up in the following manner:

1. Week 1. Consent forms were signed and personal introductions to the study were made. At this time both the participant and the caregiver were given an opportunity to express any concerns and discuss the process with the researcher.

2. Weeks 2 - 4. The next three sessions were used to build trust and rapport with the participant. During this time the strategy of observation, including conversational interviewing, and participant-observer was used. One individual had one extra week in this phase since he had started earlier than the other participants.

3. Weeks 5 -9. During this phase the conversational interviewing and participant observation continued and the interview guides were introduced. Ideally a different topic was covered each week, however, one individual required that the four interviews be condensed into two sessions. This arrangement was necessitated by the participant's absence due to illness and holidays and the technical failure of one recorded interview. In the case of one other participant, the interview had to be repeated due to technical difficulties. At the end of the guided interview phase, all individuals, except the gentleman who had missed sessions, were given a week of respite: either the session was missed entirely or the researcher spent leisure time with the participant.

5. Week 10. The final data gathering session was spent in the completion of the Dementia Rating Scale.

6. Week 11. During either the last week of June or the first of July, the individuals were seen in order to explain that the research was now completed. They were asked if they had any questions and were told that we would meet again at a Club 36 dance.

7. Week 12. During the month of November, after the results had been completed, the participants and the family were visited to discuss the findings. The completed section of the results was discussed paragraph by paragraph with the caregiver and more briefly with participant. In some cases, the two were seen together but this was not always the case.

Procedure

The data collection process was structured around three techniques: participant observation (Bogdewic, 1992; and Douglas, 1970); guided interviews (Patton, 1987, p.109) and

conversational interviewing (Patton, 1987, p. 109). All three techniques were repeatedly employed over a period of 11 weeks. There was variation in the number of weeks each individual was involved in the study with a range of five weeks (minimum seven, maximum twelve) and a mode of eleven.

Participant observation a) provided a context from which to frame questions and interpret subsequent responses, b) allowed the researcher to gain the trust of the participant and c) provided insight into the individual's coping style and boundaries while sensitizing the researcher to issues not explicitly stated. Participant observation involved whatever activity or activities the individual and/or family, in conjunction with the researcher, determine to be beneficial and/or non-threatening to the individual. Activities included: walking; bicycle riding; building Mechano; going to a golf range; visiting museums, Canadian Legion or family members; and playing games such as cribbage and tile rummy. The home of the individual was the environment most often utilized, however all individuals seemed to enjoy getting out of the house so this was accomplished whenever possible. All activities were individually negotiated with the participant, his or her family or guardian, and the researcher.

Each guided interview was audiotaped with permission of the participant. One of the four interview guides was to have been administered to each individual on four successive weeks, however, due to illness and/or recording problems this pattern was not always possible. In the end, there were two recorded interviews for one individuals, three for another, and four for the remaining three. Despite the variation in recorded interviews i) material from all guided interviews was administered and ii) there was no discernible systematic discrepancy dependent on the number of interviews. This anomaly may have been partly due to the repetitive nature of the participants responses. It was the redundant nature of the responses that resulted in the elimination of the plan to administer a repetition of the guided interviews, a strategy which had been included in the

original research design. The tape recordings from these guided interviews were the principal source of information for this study.

Fieldnotes, short descriptions of conversational interviews and observations made by the researcher, were kept for all sessions including those in which only participant observation and conversational interviewing were employed. Notes on the sessions, written as descriptively as possible, were kept on one side of each page in spiral notebooks: the second side of the page was reserved for reflections written either at the time of entry or later, following further reflection. A separate notebook was kept for each individual. A conscious effort was made to separate the descriptive recollections from the inferential reflections. For purposes of analysis the summary notes were considered a secondary source of data.

The use of family photographs had limited value and was used only on one occasion for most individuals. Four individuals participated in this activity; the fifth seemed unable to take an interest, and/or recognize, individuals in the photographs. Of the four individuals who participated in the photograph activity, only three showed any real interest. The fourth was compliant but seemed unenthusiastic and anxious to end the task. The original intent of this activity was to aid in the focusing and concretization of abstract concepts but this intent had limited value and the use of photographs was viewed more as an opportunity to gain a history from which to understand the background of the individual.

Data Analysis

Data analysis was inductive and themes were pulled from the data rather than imposed from previous research or theoretical positions. The purpose of the analysis was to identify themes found in the research data.

While two sources of data, transcripts of recorded interviews and fieldnotes, were used, recorded interviews were the primary source of data. Fieldnotes were used more for

supplementation and interpretation. The main reason for the weighting of these two sources was the greater degree of reliability that could be placed in the recorded text. Regardless of the source of data, bracketing was used as an integral step in analysis. Bracketing is a technique in which the researcher makes conscious his or her bias in interpreting the phenomenon thereby encouraging an alternative viewpoint (Douglas, 1970; Patton, 1990). Alternate themes are generated as a defense against bias.

Data was thematically analyzed by progressive refinement of themes. The kind of thematic analysis undertaken was what Patton (1987) referred to as Analyst Constructed Typologies; themes are imposed from the viewpoint of the researcher rather than based on linguistic distinctions made by the participants. The themes represent the researcher's interpretations of what the participant was saying and doing.

Procedures for Data Analysis

1. During the data collection stage, in addition to the descriptive summaries of a) the observations of participant-observer and b) the informal conversational interviewing, personal reflections on the interviews were kept in the fieldnotes. This latter procedure, referred to as reflective journaling, is the process in which the views, interpretations, and insights of the researcher are noted. These reflections were based on the reflections of previous descriptive journaling and spontaneous insights and interpretations (Morse, 1994).

2. Once the process of data collection had ended a formal inductive analysis of the data began. All collected data was read thoroughly for a general sense of the material. The transcribed interviews were then read two more times, using bracketing techniques and descriptive words to summarize the interviews. The aim was to identify as many descriptors as possible.

3. The process of identifying themes then began. Themes were isolated by teasing out the underlying, common elements of the descriptive terms.

4. Once tentative themes had been drawn out, the transcripts and the fieldnotes were re-read. Each statement that described the individuals experience from either sources was written on a cue card and each cue card was assigned to one of several categories. Each category was then read for internal consistency. If a statement was found to be inconsistent with a theme it would be removed. This process was repeated numerous times until two internally consistent themes were isolated: perception of DAT experience and coping skills.

5. Both themes, perception and coping mechanisms, were analyzed independently for sub-themes. Both negative and positive statements for each theme were copied from their original transcripts and placed in a separate document. After several readings, and using bracketing for each passage, sub-themes were identified. Seven sub-themes were identified for coping mechanisms and six were identified for perception of DAT experience

6. An independent audit was arranged for the material on coping. The document, with theme names omitted, was sent to an individual at the University of Ottawa. Without any information concerning the possible topic of themes, other than they had to do with coping, the external auditor evaluated the internal consistency of each tentative theme. The auditor, having confirmed the internal consistency, then gave each theme a tentative name to describe the essence of the theme. Finally the suitability of the match between the author's named themes and the auditor's named themes was determined. There was total concurrence between five of the seven themes and a concurrence in principle, for the other two.

An external audit was not sought for the themes of perception since the themes were to be used for descriptive rather than explanatory purposes.

7. As a safeguard to the trustworthiness of the data the caregivers were asked for their evaluation of the result for their specific family members.

Trustworthiness of the Study

One of the most important tasks of this research was the need to safeguard the trustworthiness of both the data and the researcher's interpretations of the data. Trustworthiness is a term used by Lincoln and Guba (1985, p. 290) to refer to the issues of reliability and validity. The design of this study ensured that steps were taken to secure the satisfaction of all these criteria (Lincoln and Guba, 1985, pp 289-331).

Several measures were introduced to increase the trustworthiness of the research findings.

1. Measures were introduced to increase the credibility of the research. Credibility is the extent to which the researcher accurately represents the truth as presented to him or her (Lincoln & Guba, 1985). Two specific measures used in this study to increase the credibility of the results were a) the reliance on the transcripts of recorded material and b) the placing of the evidence in a clear context. Rothe (1993, p.122) suggests that the integrity of the data before interpretation is vital to the validity of the study. In this case the transcripts were a more accurate reflection of what was said, what comments preceded the statements, and what other possible interpretations could be given to the comments. Summarized fieldnotes were considered important but played a secondary role.

2. Another measure used to increase the trustworthiness of the study was the use of triangulation. The three points of triangulation were the statements of the individuals, the observations of the participant-observer and, confirmation of results with caregivers. The degree to which findings are believable to those who live with the situation is a rigorous reflection of the degree of validity of the data (Rothe, 1993).

4. Confirmability, the extent to which the data would be interpreted in a similar fashion by two different people, was another standard to maintain trustworthiness. The concurrence of the external audit was a measure of confirmability as was the confirmation with caregivers.

5. Dependability, or what Kirk and Miller (1986) refer to as diachronic reliability refers to stability of observation over time (p.42). The assurance of dependability is based on the premise that responses will not be identical but similarities can be inferred if the information is reliable. One of the greatest sources of diachronic reliability was the number of interviews that were held with each participant. For the purposes of this study this was a crucial test of reliability since communication problems sometimes limited the degree of clarification.

Interviewing individuals with DAT had potential problems for trustworthiness, however, this was not a major concern. The communication problems inherent in DAT, often make it difficult to abruptly change topics during a conversation however this tendency to perseveration was used as a tool rather than viewed as a hindrance. The tendency to 'get stuck' was used as an opportunity to explore a topic of interest in different ways in an attempt to determine the reliability of what was being said *at the time*. In other words this limitation was used as an advantage.

An essential issue for qualitative research is transferability, the extent to which the findings from one context transfer to another context. This was perhaps one of the strengths of the study since the context of the study was the world in which the individual lived. Individuals were not asked to conform themselves to the researchers world, but were interviewed in the world in which they felt comfortable; they were not asked to conform their ability to communicate into an artificial time frame but were allowed to progress at their own speed.

Ethical Considerations

In accordance with the requirements of confidentiality, the collected data was kept in a locked briefcase. The issue of anonymity was addressed by allowing the participant and/or his or her guardian to choose between being identified either by their real initials or pseudonym initials.

Written permission for audiotaping was obtained (included in Consent Form, Appendix D) and the participant was informed at each session during which audiotaping was employed. The

participant was free to refuse taping at any time. The individual was also informed at the beginning of each interview that the interview was being conducted for research purposes and he or she could refuse to answer any question without any negative consequences. A consent form for the administration of the DRS was completed by the caregiver (Appendix F).

The open-ended structure of the interviews allowed the participant to control the depth to which he or she wished to engage the researcher while providing a framework from which to explore relevant issues. The interviews were not intended to be therapeutic and the researcher did not encourage the disclosure of intimate details of past relationships.

It was understood that the content of the material might have inadvertently contributed to the psychic stress of the individual. The researcher acknowledged the professional and moral responsibility to immediately inform the primary caregiver if there were any observations that would raise any concerns regarding the harmful affective and/or behavioral responses of the individual resulting from the research process.

In the event that the research participant became emotionally upset, crisis counseling had been arranged.

Chapter IV

Results

In order to describe the experience of the participants, themes encompassing the essential elements of the described experience were drawn from the interview material. After a rigorous examination of transcripts and fieldnotes (See Methodology) six themes were identified.

The identification of these themes required several successive designations of the descriptions of their experience. Themes were isolated on the basis of the interpretation of common elements underlying the interview material. Although the isolation of themes was subjective, it was guided by a rigorous process of bracketing of biases, sorting of potential themes, looking for disconfirmation of themes, regrouping, and beginning the process again.

The process went through several steps including the initial isolation of two major themes: perceptions and coping strategies. Cue cards, with references taken from the interview material were initially used as a sorting tool. Once the task became one of isolating sub-themes the use of cue cards became inadequate however because cue cards did not give a true picture of an interaction (i.e. they were misleading) since they did not allow for the context of the interaction.

In the identification of the sub-themes, it was necessary to extract conversations taken from the transcribed interviews and create computer documents with these sub-themes. In this way the relevant part of interviews could be kept in context and be easily moved. Any statement or conversation that was considered relevant to a theme was marked. All statements, grouped together, were then examined for internal consistency. If a statement, originally believed to be a member of a theme, did not fit into an underlying essence of that theme, the passage would be removed and the grouping process started once again.

Using this method, along with the technique of bracketing and disconfirmation, six themes were isolated: awareness of impairment, personal significance of impairment, sense of self, perception of daily activities, valued activities, and concerns. The themes are operationally defined as follows. Awareness of impairment refers both to the individual's awareness of symptoms and his or her awareness of the implications of these symptoms. Personal significance refers to the personal meaning that the impairment held for the individual. Sense of self refers to how the individual thought about him or herself. Perception of daily activities simply relates to the way individuals explained how they spent their day and how they felt about those activities. Valued activities are those behaviors which individuals indicated gave them pleasure. Finally, concerns deals with the issues that individuals perceived as causing worry or stress.

Using these six themes as a framework the experience of the five participants will be described. Following this, the experience of the individuals will be summarized according to these themes.

A table of summary characteristics for each individual is included as Table 1. Characteristics listed are age, gender, percentile rank on the Dementia Rating Scale, living accommodation, and number of years at place of residence. The percentile rank on the DRS are based on normed scores provided by Mattis.

The five participants are identified according to initial only: AH, JM, RM, KY and JK. Conversations taken from transcribed interviews are identified by the initials of the participant, the number of the recorded interview, and the line numbers for the printed text. Fieldnotes are identified according to the date of entry.

Table 1
Summary of Participants' Personal Characteristics

Participants Initials	Personal Characteristics				
	Age	Gender	DRS % ile	Living Accommodation	No. of Years in Accommodation
AH	77	F	46.0	with daughter	< 1 year
JK	62	M	38.2	with spouse	> 5 years
JM	77	M	86.4	with spouse	> 5 years
RM	81	M	69.1	with spouse	< 1 year
KY	75	M	94.5	with spouse	> 5 years

AH's Experiences with Dementia of the Alzheimer's Type

Awareness

While AH willingly described her experience of dementia, her statements indicated her awareness of the effects of the disease varied. Only by considering all facets of her perception can we arrive at a conclusion regarding her overall state of comprehension.

It appeared AH had a fairly accurate perception of her impairment for certain skills such as recall, writing, independent activities of daily living (IADL) and communication. In referring to her poor memory, AH often made comments such as "I don't remember". She never made any attempt to deny her memory loss. In addition to memory loss, AH appeared to be well aware of other cognitive impairments such as anomia and confusion in language. For example, in acknowledging her need for help in finding words she humorously admitted "my little antennae isn't working (AH3, 359)" and, when explaining the reason she needed her daughter's help for

IADLs, she reasoned “because I can’t you know I maybe don’t get the message here” (AH3, 232-233), pointing to her head.

AH was also aware of her inability to write. On two occasions (AH1, 429-433; Fieldnotes, 21/06/95) AH acknowledged she was not able to write.

AH: because writing is not one of my good pppoints. I can’t uh (pause) I don’t even write letters.

CD: So you have difficulty writing?

AH: Because I have uh (long pause) (AH1, 429-433)

In another interview, however, she commented on her inability to write and pointed to her eyes. Having previous knowledge of a cataract operation, and knowing she considered the operation a failure, it is more likely that the gesture to her eyes, when speaking of her writing impairment, indicated she attributed this impairment to her visual problems and did not connect it with DAT.

AH was well aware of her communication difficulties. We had been talking about Club 36 when she appeared to become confused and responded:

I don’t know (pause) that’s the trouble you see that you know (pause) you get something in your head and then something else comes out. (AH1, 689-691)

Communication was not the only context in which AH was aware of a discrepancy between her desires and her behavior. During the administration of the DRS, AH showed considerable perseveration (18.4% ile). The inability to change her ‘mind-set’ when doing a constructional task was quite evident to her as she commented:

Well you get something fixed in your head (points to top of head), and what you have fixed in your head isn’t. (Fieldnotes, 21/06/95)

It appeared then that AH was well aware of certain impairments such as anomia, confusion, agraphia, perseveration and aphasia but it is not as certain that she made the association between these impairments and DAT.

While AH appeared to be quite cognizant of certain symptoms she seemed oblivious to others. For example, while she had previously admitted confusion in communication, she did not seem to appreciate that DAT was causing her confusion in her behavior. A conversation during our first interview illustrates this point. AH was agitated and confused about a conversation that had apparently taken place between herself and her caregiver. She talked in an agitated manner and commented that people couldn't be telling her the "truth". I asked her what she meant. She stated "they" couldn't be telling her everything and "they" must be keeping something from her. I asked her again what she meant but her answer was unclear. I then asked her if she was referring to her memory problem. She said "yes" and then again repeated that they (presumably her family) weren't telling her everything. I asked her again if it was the memory problem that she was concerned about. She replied "yes" and "there must be more to it" for if it was only a memory problem why was she doing the "crazy" things they were telling her she was doing (AH Fieldnotes, 19/04/95). It is apparent that despite her ability to recognize her limitations for such tasks as writing or speaking she did not have this same ability to monitor and be aware of uncharacteristic behavior.

Just as AH had not been consistently aware of her DAT symptoms it is not clear that she was consistently aware of the significance of the disease. Contradictory evidence exists, some of which supports the view that AH appreciated the consequences of the disease while other information argues in favor of a dissociation between a cognizance of symptoms and an internalization of consequences. For example while reflecting upon her participation at Club 36 she commented upon what appears to be her realization of the effects of the disease,

Well you see (pause) you are all the same there (pause). I wouldn't be there if I didn't have to be (pause). I feel now that I have to be (pause) whether I (long pause). And you (pause) you're with people who have the same and I only have to look at one very elder lady there and I don't know how she manages at all you know (pause). So (pause) that's gonna be what it's gonna be (pause). Through her to be more prepared to suffer.

(AH3, 509-517)

It is interesting how AH appeared to make the connection between involvement with Club 36 and the inevitable progression of the disease while being unaware of the fact that she would have been as impaired as the other woman since Club 36 is organized around degree of impairment. It is also of significance that AH did not state specifically that the precise similarity they shared, was Alzheimer's disease. This pattern of knowing that something was wrong, but either not specifically stating what it was or attributing the problem to another reasonable cause was apparent in the comments made by AH. In the end, it can be stated that AH was aware of experiencing deficits but may not always have been aware of the relationship between these deficits and DAT.

Personal Significance of the Impairment

Evidence indicates AH had some awareness of her cognitive impairment, therefore the next question becomes "What is the personal significance of the impairment for her?" What does it mean to AH to live with a cognitive impairment? The answer is "that depends".

It appeared memory loss per se did not have much significance for AH. As mentioned in the Awareness section, when her memory failed her, as it often did, the loss did not appear to cause her any significant degree of distress. This lack of distress was illustrated by the nonchalance she exhibited when asked directly about her memory lapse. She commented:

Yeah. But then in the next aaaaa go-round it aaa it straightens itself out.

(AH3, 257-258)

This statement, along with the apathy she often showed when dismissing her memory lapses with “I don’t remember”, suggests that AH was indifferent to the effects of her cognitive impairment despite the fact that she was, at least sometimes, cognizant of the permanency of the impairment.

Evidence for the awareness of the permanence of DAT is found in the following statement:

Oh (pause) no doubt it helps (pause) to know that that other people (pause) have been through the same thing. Cause it’s not (pause) it is an on-going thing (pause) it is and there’s no point in trying to kid yourself that you’re going to get (pause) you know (pause) uhuh (pause) ssssnap your fingers and it’s all going to go away.

(AH4, 154-160)

It appears, while AH was aware of her cognitive impairment, at this point, it held little intrinsic value for her.

Can the same be said for the loss of dependency? Did it bother AH to be dependent upon someone else? Apparently not. She often mentioned she was dependent upon her daughter (e.g. AH1, 166-167; AH4, 543-545) and acknowledged it was her daughter who “feeds me, clothes me and sees that I have everything I want (AH4, 543-545).” She also commented freely that it was her daughter who handled all of her financial affairs (AH4, 376-377). These comments were uttered as statements of fact and generally did not hint at any hidden resentment. On one occasion, AH indicated financial dependency was for her a positive step:

AH: So you see I’m I really don’t have problems ‘cuz fir (pause) first of all, I I can’t carry money.

CD: Uh huh.

AH: but that’s [for] me one of the things ... but eh (pause) they have things figured out and they and they and and you’re not, you know, have to (pause) (AH4, 617-626)

If the criteria used to determine the personal significance of impairment are memory loss and dependency for IADL's, AH attached very little negative personal significance to her cognitive impairment.

She did, however, attach significant personal meaning to her impairment if other criteria are included, such as, loss of personal accountability or the perceived loss of personal value. If these two areas are included, the answer to the original question "What is the personal significance of impairment for AH? " becomes much different.

Distress over the lack of accountability was expressed by AH on two occasions. On both occasions, the admission was accompanied by sorrow. On the first occasion, AH appeared to be very upset about an apparent disagreement she had with her daughter. When she reflected upon the incident, and tried to explain the situation, her earlier indignation turned to sorrow. She pondered,

AH: Well it's just (pause) now uh (pause) it's always hard to (pause)

CD: To find the words?

AH: (sadly and quietly) yeah (pause) and "what what did I say or what" (pause) you

know (pause, very quietly and appearing disheartened) that I that I can't remember saying. (AH1, 76-82)

It appeared for that moment at least, AH was reflective as she pondered the kinds of behavior, the kinds of hurt she might have inflicted upon her daughter.

This same concern for not being accountable was evident a second time when she expressed her perception that others did not accept the extent of her memory loss. Specifically, she described how she felt others believed she didn't try hard enough to remember things (AH4, 35-41). The thought that others believed her to remember *what* she wanted, *when* she wanted, appeared to hurt her deeply and she said:

AH: 'Cause nobody wants to (pause) go (pause) you know (pause)

CD: Uh huh

AH: thinking (pause) well gee what have I (pause) done now? (AH4, 71-75)

In both of these instances, anger and agitation turned to regret as she reflected upon her inability to be accountable for her own behavior.

Perhaps of even greater significance for AH was her perception that others discredited, or devalued, her thoughts and feelings. During our first meeting, AH was vehement in her anger as she repeated sarcastically several times that others *knew* what was best for her (Fieldnotes, AH 19/04/95). The presumption by others, that they knew better than she, what was best for her, clearly angered AH. This anger was echoed in a later interview when AH commented that others were trying to tell her how she felt, a belief to which she took objection. In recounting an incident between herself and her daughter AH commented:

she [her daughter] was going at great lengths about “but but you don’t know (pause) but no that isn’t the way you feel really.” Well that’s not so. I know what I know.

(AH1, 131-134)

This perception of being denied a legitimate “voice” was expressed again when AH described an experience in which she felt discredited. She recounted that others believed themselves to know better than she what she was feeling.

[her daughter] doesn’t mean any harm but it’s not easy. But she goes over and over and “but you don’t understand (pause) You don’t understand.” She shouldn’t be telling me that I don’t understand because I understand a lot that she doesn’t. She’s never been through it (AH1, 116-123)

It appeared then that AH was angry because she felt that her feelings were being discredited, her years of experience negated.

AH reacted not only with anger to her perceptions of being devalued but also with regret. On another occasion, as we drove to a coffee house, she commented “I don’t like it when people talk to me like I’m not there (Fieldnotes, 03/05/95).” It was one of several comments she expressed as we drove along, and one which needed to be elaborated upon if the opportunity arose. Eventually that opportunity did arise and the question was put to AH,

CD: You mentioned once before AH that sometimes people treat you as if you’re not there.

AH: Oh they do (excitedly). They do.

CD: Uh huh.

AH: But I uh (pause) I uh just go on my own little way.

AH: Yeah. But (pause) I (pause) hhave ddone (pause) uh whwhat I think (pause) is (pause) the right thing.

CD: Uh huh.

AH: An (pause) and (pause) and (pause) I I’ve tried to make it (pause) you know as easy as possible for anybody when when if they get embarrassed. You know when uh when talking to em or (pause)

CD: Uh. Do you understand why anybody would be embarrassed?

AH: No. I don’t. But it happens.(AH4, 245-273)

So it appears AH not only felt devalued by an ‘invisible status’ but also felt she could have an ‘embarrassment status’.

AH also interpreted apparent attempts to lighten a situation with humor, or to humor her along, as indications that she was being belittled. The perception of having her memory the brunt of jokes came up on three different occasions (AH1, 41-48; AH4, 80-103; AH4, 198-201). On a fourth occasion, when she again brought the topic up she reflected upon the apparent reason for

humor. On this occasion she seemed able to move beyond the hurt and make excuses for those who initiated the jokes.

AH: Eh, she doesn't mean it. She doesn't know what she is saying. It isn't, it isn't a joke for me.

CD: Uh huh.

AH: But she treats it as a joke. Now whether that's because she can't, she can't accept it (pause)

CD: Uh huh.

AH: So that's what I, I have to put it down to that. (AH4, 435-444)

Although AH could sometimes rationalize the hurt, it did not detract from her perception that others sometimes made jokes at her expense. Interestingly AH sought insight into the behavior of others, not a behavior commonly attributed to those with DAT.

Perception of Daily Life

It is difficult to ascertain how AH perceived her daily routine. On the one hand AH seemed to believe her life had changed little because of the Alzheimer Disease. When asked how living with DAT had affected her life AH responded:

AH: I don't think (pause) that it does.

CD: Uh huh

AH: But then there (pause) there you are. That's 'cause I do the things uh I've always done. (AH4, 26-30)

Despite this statement, AH was well aware of the constraints to her daily life. She readily admitted limitations to the IADLs such as cooking or taking care of finances (e.g. AH1, 497-498; AH3, 217-231) and on one occasion indicated her frustration that she couldn't do more for herself (AH Fieldnotes, 12/06/95). An awareness of the restrictions to her daily living other than IADLs

was also expressed by AH. For example she acknowledged that she could no longer knit, an activity which had been her favorite pastime, and she attributed this inability to the frustration that knitting now caused her. Her perceptions of other daily activities such as walking were reflected by the following statement:

Well when I go I go for a walk every every day and uh not too far 'cause uh everybody drums into you "Well don't go too far" which is my own [street]. (AH1, 332-336)

This description of being able to go for daily walks but within limits had also been described by AH on another occasion (Fieldnotes, 19/04/95).

Regardless of how AH perceived her daily activities, one theme which appeared without any contradictions was that of loneliness. In describing her day AH stated:

I don't spend a lot of time with anybody (speaks quietly then laughs softly, pause) I have my little routine and I can go around, walk (pause) this way so far and (pause) things like that (very quiet). I don't have friends in because it's not (pause) somehow it doesn't fit with the rest of the (AH1, 440-447)

The theme of loneliness was repeated only one more time during the recorded interview (AH4, 501-510), but AH gave the impression that loneliness was an undercurrent which ran through her life at the time of the interviews.

Sense of Self

The overall impression of AH was that she was a woman who thought of herself in terms of strength.

Several statements of AH indicated she thought of herself as mistress of her behavior. Statements such as "I just go on my own little way (AH4, 250)" when describing how she handled perceived slights and "I I aaaa don't know whether I go around in a or not could be but I'm not

going to give in (AH3, 391-193)” when referring to her refusal to give in to a negative reaction when dealing with frustration, indicated a woman who thought of herself in terms of self-control.

In addition to self-control, AH also conveyed a self that wanted to be responsible for her own activities. For example when asked if she ever found herself confused she responded that she did but then gave an example of misplacing her purse and then added: “but it helps to know what it is” an apparent reference to knowing that her confusion was the result of dementia. This would indicate that when she had “knowledge” of having a dementia it allowed her to accept moments of confusion and place them in a context in which she abdicated responsibility.

In addition to self-control and self-responsibility, statements were repeated during two interviews that seemed to indicate an inner resolve towards acceptance and accommodation of the dementia experience. For example, when she was asked how she first reacted to being told she had Alzheimer’s Disease she responded:

AH: Oh yes I was very upset not to aaaaaa you know go crazy but aaaaa but I’m, I know what I know and otherwise I don’t think that I could have done it.

CD: Could you explain to me a little bit more about “I know what I know”?

AH: aaaaaa Yeah that’s kind of silly “I know what I know”.

CD: You have to tell me what you know (laughter).

AH: But I, it’s like other things. Like if you were told you had to have an operation, well I liken it to that and aaaa it will come out. It’ll be all right. I’ve never been a downer.

(AH3, 271-285)

This acceptance was again illustrated when she commented on the importance of support from those who understood the disease, a reference to Club 36. It seems, one of the reasons this type of support was so necessary was the fact she was aware that there was no solution to her problem and she therefore had to learn to accept it. The following statements reflects this resignation:

AH: It really is 'cause we can all laugh and we can all (pause)

CD: Uh huh

AH: You know.

CD: Uh huh.

AH: And uh (pause) See I doubt that you can (pause) You have to (pause) you have to
(pause) know (pause) 'cause I didn't have a clue. 'N (in high pitched voice) (pause)
aaaand (pause) it's it's not as though it hurts or anything.

CD: Uh huh.

AH: It's just that you know (pause) and you know that other people know.

And uh (pause) I didn't I (pause) I knew there was such a thing as (pause) as
Alzheimer's and I can't remember when I first (pause) went (pause) to see
somebody. I really don't.

CD: Uh huh.

AH: You know.

CD: Uh huh.

AH: If you have [a] toothache you go to a (pause) and get the tooth pulled out. But
(pause) with this you can't (pause)

CD: Uh huh. So it's kind of an on-going thing?

AH: Yeah. And you just have to (pause) you have just take it as it comes.

(AH4, 168-244)

It may have been that all aspects of her strength came together to guide AH. This strength is reflected in a response she gave to a question on the disclosure of the diagnosis:

CD: As far as having the disease and finding out you had it, do you think that people who have Alzheimer's disease should be told the truth about having had it or having problems like this?

AH: Well now that that's a hard one because I'm one person who would want to know.

CD: Right.

AH: But that doesn't mean that other people would want to know. And I think that if there were, if there were (pause) I eh (pause) figure, I've had a good

CD: Yeah

AH: shot at it, and eh lets see what comes next. (AH4, 548-565)

In the end, the impression that AH gave was of an adult who a) wished to be kept informed about her life, b) took responsibility for her behavior c) had learned to accept the consequences of her disease and d) sought support to help in the acceptance of that experience. This information suggests that AH felt that she had a tangible sense of self that accepted the burden of difficult times.

The idea of a tangible self is reinforced by AH's comments during another taped interview in which she often referred to not "feeling any different". Each of these statements should be looked at individually since the phrase itself may have been may have been a remnant of perseveration, a well established trait of dementia. On at least five occasions, however, the reference seemed to refer to a difficulty in reconciling the knowledge of being someone with a disease with the fact that she didn't feel "different". This difficulty in comprehension is illustrated in the following passage:

AH: Yeah. I couldn't believe it when they told me I have (pause)

CD: Uh huh

AH: 'cuz I don't ffeel any different. I don't eh (pause) it it just eh.(AH2, 499-503)

It could be then, as confusing as this was for AH, that the sense of self, at least at this stage of the disease process, didn't experience a change. Despite awareness of memory impairment, communication difficulties, and possible agraphia, the self of AH appeared to be intact.

Valued Activities

AH had left her native city to live with her daughter when she, AH, was no longer able to look after herself. One of the implications of this move was reduced social support from old friends. Despite the reduction in social support, AH appreciated the relationships and companionships she did experience. She often mentioned how lucky she was to have her daughter, how she enjoyed our conversations and particularly how she enjoyed the time she spent at Club 36. The importance of the club was described by AH in the following excerpt:

CD: So relationship is still

AH: That's right. They are very important.

CD: Uh huh.

AH: And uh, you know, when I go up to to the uh Alzheimer's (pause)

CD: Uh huh.

AH: I'm there (pause) The rest of us are there.

CD: Uh huh.

AH: The rest of us who have Alzheimer'sAnd I I can't uh (pause) feel any different.(AH2, 562-573)

As mentioned previously, we cannot be sure of what AH meant by this phrase "feel any different". Perhaps in this instance it referred to her not feeling any differently than she always had about wanting to be with people, perhaps she meant that she wouldn't allow herself to feel any different than she always had, perhaps she couldn't feel any differently about Club 36 even if she wanted to,

or perhaps she meant that when she was at Club 36 she didn't feel different from others. Credence is given to this last interpretation as she later added,

AH: I'm perfectly happy the way I am. And I am with people who are the same.

CD: Yeah.

AH: Because that's (pause) We are you know, when we get together. (AH2, 662-667)

On another occasion, when she brought up Club 36 she explained

AH: Oh (pause) no doubt it helps (pause) to know that other people (pause) have been through the same thing. Cause it's not (pause) it is an on-going thing (pause) and there's no point in trying to kid yourself that you're going to get (pause) uhhh (pause) ssnssnap your fingers and it's going to go away. But I think that the Club (pause) Alzheimer's

CD: Uh huh

AH: is the best thing that any (pause) body ever thought of. (AH4, 154-164)

AH appreciated the opportunity to belong to a community where she felt she belonged, a community which included individuals who experienced similar difficulties as herself.

Another reason AH might have valued the club was for the role it played in the fulfillment of intimacy and emotional support. The need for intimacy or a close friendship was expressed one day when she was asked if it helped to have someone to talk to. She responded, "Oh yes. Outside of the family." (AH1, 345-349). It was suggested to her that type of relationship would be difficult for her considering she had recently moved to Calgary. On that occasion AH changed the topic by mimicking the sound of the crickets. The topic of support was brought up on another occasion however. On this occasion AH commented how she wanted support other than what could be provided by her family

AH: I don't know because I I (pause) I never (pause) like I I (pause) from from the time I
(pause) had Alzheimer's Disease

CD: Uh huh

AH: I haven't looked to M or H

CD: Uh huh.

AH: I have looked to the Alzheimer's you know.

CD: Uh huh.

AH: Just just ta, just (pause) to know that [there's] al always someone there. (AH4, 516-525)

But is wasn't just the emotional support AH seemed to value at Club 36. She also appreciated the activity available to her through this organization. When asked what it was about Club 36 she enjoyed she responded:

AH: Well I hope they won't take the Alzheimer's away ever because we uh have more
laughs than (?)

CD: Oh really?

AH: Honest to goodness, it's great. It's just, it's just great. (AH1, 555-559)

CD: Do you like the company?

AH: Yes. Yeah. I like to be in their company (pause) this Alzheimer's business is just
crazy (pause) it's funny.

CD: Could you tell me more? (AH1, 571-575)

...

AH: Well it's just like one big family uh there most of the time and uh they do these
things you know (pause) they have (pause) this one girl (pause) Girl I don't know

whether you'd call her a girl or a woman (pause) She's in there anyhow. I just think she's terrific. Crazy (pause) not not crazy. (AH1, 589-595)

AH: I don't golf (pause) what do they do?

CD: Go golfing?

AH: (pause) and uh well what's (pause) for day you know (pause) What's for today? I think you could laugh till you (pause) tears.

CD: Oh that's good. That must feel really good.

AH: It is good (AH1, 618-629)

In addition to participating in 'here-and-now' activities, AH seemed to take great pleasure in mentally returning to her past. She particularly enjoyed talking about a childless couple who had been very special to her in her youth. It is quite possible AH felt comfort in the memories of this era for these would likely be the memories that were the most intact. It is also possible that the memories to which she returned had an emotional significance for her. Support for the emotional significance of certain memories was given by a surprising statement which AH made one afternoon. We were talking in a coffee shop about some of the distress she experienced and she was asked what she did when she had difficulty coping. She answered quite quietly and quite clearly

I make my way back to D. and J.

As she said the words, she used her finger to draw a zigzag path across the table. I asked her:

To where it's safe?

Looking at me she responded:

To where it's safe.

It seemed that AH, if only for a moment, was aware that she returned to an area, a 'comfort zone', when the stresses or stimulation of the external world became too great.

In the end, then it seems that personal relationships, intimacy, fun and a return to what might be referred to as a comfort zone were very important to AH.

Concerns

As discussed in Personal Significance of the Impairment AH, did not appear to be concerned about certain effects of dementia such as memory loss or dependency. This should not indicate that she had no concerns. In fact, there is evidence that AH was concerned about two issues and both had to do with the future.

One issue for AH was the possibility of Club 36 shutting down. Although this fear did not appear to be obsessive in any way, it was mentioned by her on several occasions. The first indication she was concerned about the possible closure of the club came on our first recorded interview and it was mentioned several times after. One night, she was asked why she was concerned about the closure

CD: You mentioned the last few times that you are very concerned that they might close Club 36.

AH: I hope they don't.

CD: Is there a reason for you being worried about that?

AH: Well it's just that I've got used to the people there (pause) and I look forward to going.

CD: So is it anything somebody said. Something like, has somebody said to you "Oh maybe they'll get rid of Club 36" or is it more that you worry on your own about that?

AH: I worry on my own about that. (AH3, 471-481)

The other specific concern which was mentioned on occasion was that of being placed in a nursing home. As with the closure of Club 36, the issue of being placed in a nursing home was not

in anyway a strong undercurrent, nor did it bring with it anxiety. The significance of both issues resides in the fact that AH did reflect on her future and it shows a concern for her support system.

JM's Experiences with Dementia of the Alzheimer's Type

Awareness

JM was the most elusive in his statements about his awareness of AD. On the one hand, JM reluctantly admitted a memory problem while on the other he minimized any memory problems that he was experiencing and denied any ill effects of memory loss. In the end, only a 'best guess' can be made as to JM's awareness of his cognitive impairment.

One of the difficulties in judging JM's awareness is the inconsistency found within his conversations. For example, in one conversation JM, although downplaying its severity, admitted that he did experience memory loss.

JM: But I don't think my memory is that bad, that's my opinion.

CD: Uh huh.

JM: There're other people who think it is but (pause)

CD: Does that bother you when other people think maybe it's worse than you think it is?

JM: No. I know I have to live with it. So I have Alzheimer's there's nothing I can do about it.

CD: Uh huh.

JM: Doesn't bother me.

CD: When you first uh were diagnosed with it uh did it bother you then do you know?

JM: I don't think it's as bad as they let on. (JM1, 601-613)

It is interesting that JM did not respond to the question of how he had reacted to the diagnosis of the disease.

During the next recorded interview, JM downplayed his impairment to the point of denial.

The words “memory problem” had barely been mentioned when JM reacted

CD: Okay. I was wondering if you could uh explain to me the kind of memory problems
that you have?

JM: That’s kinda hard, see myself I don’t figure I have much memory problem.

CD: Uh huh.

JM: That’s what I don’t figure.

CD: Right.

JM: Maybe somebody else figures different though.

CD: Uh huh.

JM: Good, it’s not affecting my memory. I can remember what I did every day. I can
remember what I did years ago.

CD: Uh huh.

JM: In fact years ago easier than I can now.

CD: So you’re aware of the fact that (pause) I’m just going to adjust this [the
microphone] just in case it’s not getting you properly (pause) you’re aware of the fact
that your memory for years ago is better than it is for recent things.

JM: Uh huh.

CD: ya, ok, uh is

JM: but

CD: I’m sorry JM, go ahead.

JM: but I I don’t, you know, I can go uptown or shop myself or never get lost. I can go
any where I want to say to myself and that so

CD: Uh huh.

JM: You know, I know my way around and that

CD: Uh huh. Have you ever gotten lost when you were out?

JM: Not that I know of.

CD: Huh. Has someone mentioned to you that they they were afraid that you might lost?

JM: I don't really think so.

CD: Huh.

JM: 'cuz really, it's very seldom that I go away from the house without M. (JM2, 15-54)

In the preceding script, JM downplayed his impairment and then proceeded to list accomplishments which supported his claim. This was a common process for JM. Often he would first acknowledge a limitation in memory and then proceed through a process which negated and contradicted the acknowledgment. For example, in another excerpt JM began with an admission that he did not have a driver's license, which he loosely linked with having DAT, only to proceed to a statement that he did have a driver's license.

JM: I like gettin' out you know.

CD: Sure.

JM: If I had a driver's license (can't make out). I haven't drove the car for so long.

CD: Uh huh.

JM: And uh I just have a little bit of Oldtimers.

CD: Uh huh

JM: Talked to the doctor about it he says "You're okay to drive."

CD: Oh really?

JM: Yeah, didn't say "couldn't drive" or nothing. "You you can drive any time you want."

CD: Huh. Do you choose not to drive then?

JM: I just don't like driving any more.

CD: Oh. Do you know what it is about driving that you don't like?

JM: No eh.

CD: Uh

JM: And I figure well hell I'm older and I could get the kids to drive me where I want. I phone up D. right now and say I want to go to Edmonton tomorrow, if if he could make plans he'd take me.

CD: Yeah?

JM: So why bother eh? I mean, I have my driver's license an' everything but...and M likes to drive and that. (JM1, 778-804)

It appeared that JM became more and more convinced of his capabilities as the conversation progressed. In our three recorded interviews he specifically referred to his memory impairment in ten instances; of these ten, nine reflected this pattern of acknowledgment followed by minimization and/or denial. The question remains then as to how aware JM was of his cognitive impairment. It would be reasonable to assume JM had at least a minimum of awareness of his memory loss and attempted to reduce the emotional effect of the loss by minimizing its importance.

The interpretation of denial is given credence by a comment of JM's regarding the other members of Club 36. In referring to the policy of staff at Club 36 to keep track of participants, JM commented,

JM: 'Cuz I'd say maybe half the guys to to our club, people have memory problem.

CD: You don't think all the people that go do?

JM: No no. Things I've noticed there. Like have the club and big yard an' we have a garden an everything there eh. Some of the guys will walk out and go somewhere an' the girls will "Where are you going, where are you going?"

CD: Uh huh.

JM: "We'll go with ya." ya know.

CD: Uh huh.

JM: They're not going to let them stray away or anything.

CD: (laughs) Yeah.

JM: No they're keeping very good track of us. (JM2, 590-606)

The prospect of emotional denial is unavoidable here since one would question JM's cognitive ability to see impairment in others but not himself, a characteristic usually associated with denial. In addition, JM included himself in the comment "they're keeping track of us" Why would a 77 year old feel pleased about being kept track of unless he feared there was something amiss?

JM extolled the capabilities of his remaining skills far more than any of the other participants. For example, in order to determine his perception regarding his driving ability, he was directly asked questions about driving. JM answered directly but seemed oblivious to the "rationalization" which appeared to govern the response

JM: Like I I have my driver's license I I can get in the car now and drive to Saskatoon or or B...the States or something. I know the roads, I don't even need a map (laughs).

CD: Uh huh.

JM: I can still do it you know.

CD: Would you do it though?

JM: Uh?

CD: Would you drive?

JM: All by myself?

CD: Yeah.

JM: No. It wouldn't make sense going on a trip by yourself. (laughs)

CD: Okay. (laughs) But if M were driving would you drive part of the way?

JM: Oh definitely. Most of the way.

CD: Yeah? On the up .. the upcoming trip to Saskatchewan, or Saskatoon, will you do some of the driving?

JM: Oh we're flying.

CD: Oh you're flying. AH. So you're going to take it easy. Yeah. Okay. (JM3, 34-55)

Despite his willingness to answer, the improbability of his response appeared to escape him, at least on a conscious level. The likelihood that awareness lingered at a deeper level however was evident in the biting of the lip at the end of our conversation, an indication of an underlying anxiety. The biting of the lip had been present during another interview in which he momentarily appeared anxious because of the questions (Fieldnotes, 26/05/95).

The possibility JM was at least partially aware of the discrepancy between what he said and what he knew was evident in the nervousness that he began to show on two occasions, one of which is the excerpt just cited. Since this trait was only observed on two occasions, this was interpreted as an indication of distress, the mood of the interview was changed immediately to protect his well-being. We will never know if this behavior was the result of JM having his defense mechanisms attacked, to borrow a psychodynamic term, but this assumption appears to be a reasonable one.

Whether or not JM was aware of living with a cognitive impairment, he described two symptoms which have recently been associated with AD: dislike of crowds and dislike of noise. JM gave an interesting descriptions of his perception of the "noise" and his subsequent reaction to it

Like our social club in seniors. There are so many there eh and they (pause) the music is loud and the talk (pause) just a buzz to me. (JM2, 652-658)

and,

JM: and music is so loud 'n noisy and that. And a lot of music bothers me.

CD: Yeah?

JM: You can get twenty, thirty people together and yap and that. I just close my mind to them. (JM2, 478-483)

In conclusion, JM appears to more aware of symptoms than one might expect considering his preference for downplaying the effects of DAT. This conclusion is based on three observations. JM acknowledged a memory loss, albeit reluctantly; he described an awareness of other symptoms associated with DAT, such as, sensitivity to, and difficulty coping with, stimuli, and he expressed concern over getting lost and needing to be kept track of. These are concerns that would reasonably arise from an awareness of either confusion or disorientation. Despite the evidence for at least a minimum of awareness, JM denied both his concern for the cognitive impairment and its effects on certain skills such as those required for driving.

Personal Significance of Impairment

It's difficult to determine the personal significance JM attached to his cognitive impairment. On the one hand, JM repeatedly denied being bothered by the symptoms of the disease. If one were to take him at his word, it would be accepted that the effects of the disease had little personal significance for him. On the other hand, if JM were engaged in some form of emotional denial, it could be assumed the loss of cognitive functioning, or the fear of loss of cognitive functioning, had such personal significance for JM that it created a barrier to acceptance. It might be that both scenarios have some validity. There might have been moments when JM was cognizant of his impairment, actively engaged in minimizing the effects of the symptoms and soon engaged in a confabulation in which the symptoms did not exist, and hence did not have personal significance for JM.

Just as it is possible to infer possible negative significance, it is possible to infer positive significance. JM was very proud of his family and equally proud of how his family cared for him. He spoke of each of his children and how each tried to help he and his wife. Although the following statement was made in regard to a specific family member similar, statements were made for all.

JM: She's a nice girl, A-M. They all are.

CD: They're good kids?

JM: Uh huh. Sure trying to look after M and I anyway.

CD: That's what you said about D too.

JM: Yeah. D's real good too. They're all, they're all good kids

(JM1, 75-81)

JM felt pride in being valued and cared for by his family.

In the end, JM appeared to find significance in the way others treated him and did not focus on his cognitive limitations.

Sense of Self

It appeared JM drew heavily upon others, in particular his family, for his sense of self. Almost all relationships to which he referred had a dependency element. He made constant reference to the support he received from his family and often referred to his four children in terms of the care and help they provided for he and his wife. In one conversation, JM referred to either the help or the support he received from his children a total of nine times (JM1).

JM added further to the image of dependency as he described his relationship with the staff at Club 36. Whereas all of the other participants spoke of Club 36 as a place where they could enjoy friendship, peer support and/or activities, JM espoused the value of being somewhere where he received support from the staff. All of JM's references to the Club involved an element of dependency similar to the one cited below:

CD: Do you think that's been really important to you, is having the support obviously from M [his wife]

JM: Yeah.

CD: and your family and Club 36?

JM: Yeah. Oh definitely. This Club 36 they're just so good to us. Not just me, there're other guys who go there. Memory problems eh.

CD: Uh huh.

JM: And they're right there with us all the time. ... And the girls there all formerly trained nurses. ...they keep track of us.

CD: Yeah.

JM: So I just love going to the Club. (JM2, 395-414)

It is quite possible, despite his denial, JM felt quite vulnerable and apprehensive of the consequences of living with DAT; a possibility given weight by the previous statement in which JM again indicated that he was being kept track of. For JM the fear of living with DAT may have outweighed the estimation of what he could emotionally handle and he therefore took comfort in the thought of being cared about by his family and other professionals.

Although JM did not present a strong sense of a personal self, he did strongly identify with his occupational self. JM had been an aircraft mechanic during World War II and a heavy equipment mechanic after the war. He often referred to the war years and took great pride in both his occupational capacity and his involvement in the war. He appeared to feel a similar pride in his post-war occupation of a heavy duty mechanic.

Perception of Daily Activities

JM appeared to perceive his daily activities fairly accurately. He was well aware he spent a couple of days a week down at Club 36 and appeared to be relatively oriented to the comings and

goings of his family. JM did not show evidence of confabulation for his everyday activities although his statements regarding his driving ability would have to be considered an exaggeration of his abilities, if not dangerously close to confabulation. Once again, it must be cautioned that any interpretation of JM's beliefs about his impairment, or lack of impairment, must be guarded.

JM enjoyed being occupied. During our first conversational interview, the importance of remaining active became clear. JM had spoken about the social and recreational club at the local Alzheimer society and stressed that they remained active there. The importance of remaining active became evident one day when we visited a museum. JM talked to one of the hosts and found that the individual volunteered at the museum. During the rest of the interview, JM made comments that the individual at the museum must have felt good about himself because he was 'doing something'.

JM's chief source of activity was building Mechano. It is likely that this activity came easily to him because he had constructed things in his younger years. Despite the apparent enjoyment JM received from his hobbies, he confided one day it really was just a way for him to pass the time and relieve boredom

I really enjoy going there, an it's it's, you know gets me outta here. We're together for 24 hours a day, day after day. It kin get kind of boring or something. (JM4, p.18)

In addition to enjoying the activity of the club, JM also mentioned a couple of other features he found agreeable: the small number of participants and the scheduled nature of the activities.

The only other activity that JM appeared to really enjoy was reminiscing. For JM the return to the past was a return to the war years; his months training in the United States and his years in active duty in Europe.

Concerns

While on the surface JM made statements such as:

There's not a thing in this world that bothers me right now...Got our house, we got

(pause) our children, we got our bank account. There's nothing we need to worry about.

(JM1, 819-825)

JM seemed very aware and appreciative of the support that he received from his family and the Alzheimer Society (JM2, 390-402; JM2, 409-416; JM2, 587-608). Although at some level most individuals, even those free of cognitive impairment, are aware that they are in need of some form of social support it might be argued that most individuals speak of support in the context of facing a difficult situation. It seems rather incongruent then that if JM truly believed himself to be as free from worry, as he let on, why was the presence of support such an important issue for him.

RM's Experiences with Dementia of the Alzheimer's Type

Awareness

RM was a very interesting participant who, on the surface, appeared oblivious to his impairment but when encouraged could show considerable insight. In the end, it was difficult to determine the extent to which RM was aware of his cognitive impairment for three reasons: the degree to which RM engaged in cover-up, the apparent fluctuations in his levels of awareness, and the apparent presence of a comprehensive aphasia.

RM had an strong tendency to 'cover-up' his cognitive impairment. Cover-up can be described as an attempt to hide his cognitive impairment. RM used two strategies in his efforts to cover-up his impairments: humor and giving socially appropriate answers. RM used humor often. When he was asked his age he looked up at his wife, wrinkled his brow and said "Well you should know that." He then proceeded to tell the story of asking his wife when he was born, to which she apparently replied "Well you were there, not me!". By using humor RM was able to derail the

conversation while maintaining a pleasant disposition. Having changed the conversation, he was then free to interject a topic or comment that allowed him to control the conversation.

In addition to humor, RM also used socially appropriate, logical response. The first evidence for his form of cover-up came on the second interview. His wife had just left the house and RM was setting up a cribbage game. I asked him if he remembered me and he responded "Sure I do." He then looked around and added "Sure I remember playing crib with ya last week" (RM Fieldnotes, 3/05/95). We had not previously played cribbage. His habit of incorporating environmental cues was likely the basis of a similar response at another interview. On this second occasion RM was again asked if he remembered me. Again he suggested he did and this time incorporated my recording devices into the answer (RM2, 59-62). Although it is possible that his response was factual and he did remember me and all my equipment, it is quite unlikely considering his very sketchy memory for everyday occurrences.

One of the dangers in doing phenomenological research with individuals with a dementia is the lack of credence that might be given to their perceptions. This could be particularly true of someone like RM who was shown to engage in covering-up. The danger is, upon realization of the individuals tendency to cover-up, others might dismiss his statements as untrustworthy. This would be unfortunate since the tendency to cover-up does not invalidate all responses, but it does require we scrutinize responses for clues indicative of this tendency. Responses that showed a tendency toward socially appropriate superficiality were regarded with suspicion but not totally discounted. On the other hand, responses which reflected personal depth and elaboration were given more credence.

A distinction should be made between cover-up, confabulation and temporal confusion. Whereas cover-up is a controllable strategy used by the individual, confabulation and temporal confusion are the unconscious processes. Confabulation is the unconscious process of trying to

make sense of one's world by piecing together information from the environment to give a reasonable explanation of the situation. Temporal confusion, on the other hand, is a switching between different periods in one's life and confusing past memories with present realities.

While interviewing RM there was no direct evidence of confabulation there were, however, instances in which it was suspected (e.g. Dr. incident). There were, however, several instances of temporal confusion. For example, he believed he drove the car regularly, he played cards weekly with friends who lived hundreds of miles away and his long-deceased father was still alive. It was important then to distinguish between those statements of RM's which were purposefully misleading and those which were a consequence of a temporal confusion. If he was aware of those instances in which he intentionally mislead others, an effort would need to be made to appeal to RM to answer as candidly and in as an uncensored way as possible. If this could be achieved, we would have a much clearer indication of how "aware" RM was of the symptoms of his cognitive impairment.

The opportunity to address this issue of cover-up presented itself one day when RM was being asked how he felt when people insisted he knew something when in fact he didn't know

CD: I've noticed with other people sometimes they'll say "Oh you remember that!".

RM: Uh huh.

CD: "You remember that!"

RM: "You remember that."

CD: How do you feel

RM: That isn't always the case.

CD: No. So if you don't remember and someone's telling you you do remember, how do you feel?

RM: You have to up with a different answer to get around it in a different way. (Pause).

Yeah you have to get around that somewhere. Get your people thinking about

something else. (pause) Down another alley. Down another lane. (RM2, 438-459)

There is evidence, on this occasion at least, that RM was aware of his habit of covering up and felt the behavior was under his control.

Shortly after, RM admitted his desire to cover-up and promised to tell the truth for questions asked of him during the interview. The following conversation took place which lead to RM's commitment to honesty:

CD: So your memory problem doesn't bother you?

RM: No! No it doesn't bother me that much no.

CD: Okay.

RM: Yeah.

CD: Do you think then (pause) that it bothers perhaps other people (pause) more than it bothers you?

RM: (pause) Who would those other people be?

CD: Well do you think maybe (pause) you know like I'm doing research. Do you think other people (pause) are more concerned about it (pause) than you are?

RM: Yeah that could be (pause) that could be. (sighs) They figure that I should remember eh (pause). Well that's (pause) that's a good point (pause)

CD: What do your think would happen if we just kind of said "Well (pause) that's just (pause) the way RM is 'n let's forget about it."? (pause) Would you like that?

RM: Yeah.

CD: Would you prefer that?

RM: I'd be as happy as hell about that.

CD: You would eh? (laughs)

RM: (laughs) But you gotta have someone to work on (pause) well if you gotta be working on me (pause) you might as well (clears throat)

CD: (laughs) So you really don't like answering these questions then?

RM: Well I (pause) don't mind some o' them.

CD: Uh huh. And you'll tell me if there's

RM: I'll tell you (pause) I'll tell you the truth (pause) about it. I'll tell you truthfully whether I know or whether I don't know (pause) it's (pause) I won't steer you on to a long (pause) a long drawn out trail (pause) 'r somethin' like that, you know. (RM2, 120-156)

The cited excerpt followed a course through apparent a) resentment to the implication that he should be bothered by his memory, b) relief the focus was being taken away from him and placed onto others c) co-operation once he was asked for his opinion and d) commitment to being involved in the process as a valued member. It seemed when RM was provided with a way of placing the 'blame' on others, rather than shouldering the burden himself, he became less defensive and more willing to acknowledge his limitations. In becoming less defensive, he was also able to shed what we might refer to as cover-up and answer in a forthright manner. It is interesting to note that during this interview RM seemed to be the most focused, the most cognizant, and the most admitting of his cognitive impairment. This is not meant to imply that RM was capable of controlling all forms of unawareness but it is meant to suggest that not all statements that suggest unawareness are truly reflective of unawareness, some may be reflective of face-saving coping skills.

As discussed above, RM talked in detail about his awareness of his cognitive impairment. Many of the statements made during the interview were comments about his personal experience. One excerpt indicates a pervasive awareness that resulted in an underlying concern. RM had been

asked if he thought it would be of help to discuss his concerns, about DAT, with his wife. He suggested that he didn't believe a lack of discussion caused any additional distress and then added how concerns seemed to pop into his mind at night and disturb his sleep

RM: Sometimes I get thinking about that thing, same damn thing at night 'n when ya can't sleep eh.

CD: Uh huh.

RM: So what do ya do? (pause) It's running around there so ya can't sleep huh.

CD: So those nights when you can't sleep (pause)

RM: You're worried about it 'n wondering about what (pause) wondering (pause) how this is all going ta turn out 'n (pause) what should I be din' ta (pause) trying ta put on it there (pause) what can be done ta? (pause) There's nothing that can be done. I guess we all know that or we'd be doing that wouldn't we (looking straight at me). I just learn ta live with it 'n think about it as little as possible 'n (pause) don't get too many gray hairs over it (RM2, 1135-1151)

RM was not always consistent in his subject matter, therefore it cannot be assumed the underlying concern he was describing was for DAT. It would be a reasonable assumption in this case, because the conversation before and after this statement definitely concerned DAT.

The distress RM experienced might have been linked to memories of a conversation he had with his doctor. It is unknown whether this is an accurate memory or an instance of confabulation, in any event the 'memory', true or not, caused concern for RM. RM's memories of this conversation were of a harsh reality in which he faced a bleak future. RM recounted that his doctor had been quite blunt with him telling him:

it just keep, just keeps getting worse. Be days (pause) you won't even remember your full name (RM2, 632-634).

Although it is not known whether this ‘memory’ was accurate, it is known that it was not stable for during the next interview RM indicated he couldn’t remember what his doctor had told him.

There is little doubt RM was well aware at times that he was living with a dementia. In the following excerpt RM admitted his relief that his experience of dementia was not as bad as he had feared. He expressed relief that he hadn’t gotten lost, a problem he expected to accompany DAT:

RM: But it isn’t as bad as I thought it might have been. You meet um (pause) I thought maybe I might take the car and go way some place sometime ‘n forget how the hell to get home. That don’t happen.

CD: Uh huh

RM: At least it never happen to me. I can always find my way home. (RM2, 677-684)

What is interesting is RM neither drives a car nor goes out by himself, therefore the probability of his getting lost, while real, was in fact small. Despite this, RM found some reassurance in the fact that this feared behavior had never taken place.

This concern about living with DAT was brought up again in the context of a statement he made, which on the one hand spoke of awareness and fear, and on the other voiced acceptance and humility

RM: But this not really this eh bad eh as it’s gonna get, is it?

CD: Everybody is very different though

RM: As long as I can find my home, find my way home an ‘n ‘n and a a place where there’s a knife and a fork set at the table, I (pause)

CD: Uh huh.

RM: I’ll be all right. (RM2, 637-645)

Perhaps one of the more striking elements of the above excerpt was the sense of dependency that it portrays.

RM's awareness was not constant and fluctuated within, as well as between conversations. Minutes after an apparently coherent conversation about DAT he was asked him if he had ever expected "that this would happen" (referring to his dementia). To this question he answered that both of his parents "had been through it". I assumed that he was referring to a memory problem therefore continued

CD: So your mother and your dad

RM: They both had heart trouble yeah.

CD: Heart trouble?

RM: The thing is if you're able to put it off 'n 'n get by with it as easy as (pause) I thought it would be hard, lot harder ta (pause) ta accept eh.

CD: Uh huh.

RM: 'r maybe I'm just getting used to it. I don't know. But I can get by here for days 'n days 'n not even think about it.

CD: This is the Alzheimer's Disease?

RM: Yeah. (RM2, 1214-1223)

It became unclear then, whether we were talking at that point about heart disease, DAT or a combination of both. What was consistent was that RM was aware that some form of problem existed.

RM readily described what he referred to as inconsistency in his cognitive ability. This belief of RM is expressed in the following statement in which he responded to a question which had previously been put to him asking if, other than memory, he noticed any effects of DAT. RM responded in the negative but then added:

memory's the only one (pause) and it isn't consistent (pause) some days you will be fine eh. Some days you will remember everything you are supposed to do and why you are

supposed to do it and the next day it will be different altogether, you won't be able to remember anything (RM3, 26-35).

He later added that in some ways it was if he was

a little bit blank all the time (RM3, 68)

but that

there are days that are worse than others (RM3, 84-85).

Unfortunately, RM was not always consistent in his description of variability but this may have at least partially been the result of awkward question construction on my part. For example, in trying to clarify my understanding of his experience of variability I asked him: "So you can actually say to yourself that 'my memory is not too good today'?" To which he replied "I didn't think there was too much difference in the way your memory was from day to day" It appears as if his inability to convert the intent of the question resulted in his belief that I was referring to variability in my own memory. So, in the end, we are not really certain to what extent the uncertainty regarding variability is clouded by communication difficulties and how much is the result of RM's confusion about the nature of variability itself. The fact RM began and ended the passage with a consistent statement of variability argues in favor of at least a temporary perception of variability. Temporary perception of variability suggests temporary awareness of disability.

Personal Significance of Impairments

For RM, the personal significance of the cognitive impairment appeared to come mostly from the shame he associated with the impairment.

Many statements that concerned personal significance involved an element of self reproach. RM admitted his memory loss caused him embarrassment and on one occasion he gave a glimpse of how he felt about this embarrassment

CD: Did that ever happen to you where someone comes and (pause) they think you should remember them (pause) and you don't?

RM: Yeah (pause) At odd times.

CD: Uh huh.

RM: Specially things that (pause) was happened years ago eh. They'll come for me (pause) come to me for for information they figure I should have and I've forgotten it too 'n (pause) it's not altogether my fault.

CD: Um (pause) I would think it's not your fault at all (laughs).

RM: (chuckles and kind of coughs) Can't remember 40 years er what happened 40 years ago can ya? (RM2, 81-95)

RM apparently felt the need to point out it was not his fault that he couldn't remember and then appeared relieved when the memory loss was placed in an acceptable context. This might indicate that RM somehow felt humiliation for his memory loss, as if he were to blame. Perhaps it was this reaction to humiliation which caused him to be defensive from time to time.

The idea of RM feeling embarrassed by his memory loss was illustrated on other occasions when he attempted to minimize the impairment.

Oh yeah. I can remem (pause) close things like that yeah (pause) yeah (pause) I can remember Remembrance Day and my Mom's birthday 'n (pause) so I'm not completely dumb (kind of laughs). (RM2, 101-105)

He then added a comment, apparently to normalize his memory loss:

RM: Getting a little older all the time (pause) and (pause) you're bound to forget eh.

CD: Uh huh.

RM: Even young people forget don't they? (looks at me again) (RM2, 175-179)

On the two occasions cited above, RM acted in a defensive manner as he both minimized and normalized the experience. If cognitive impairment did not have personal significance for him, RM would not have felt the need to engage in defensive behaviors.

The personal significance of the memory impairment was also illustrated in the underlying worry which had been evident in an earlier segment of our conversation. RM had been talking about how his memory problem could cause him to become obsessed with a particular thought

CD: You said that you try not to let it worry you.

RM: Yeah.

CD: Does that mean that sometimes it does worry you?

RM: uh (pause) if it's very important it would worry me, yes, yeah p,
(pause).

CD: So if something isn't not important to you, you can say "pst, who cares".

RM: (laughs) Ya, who cares, what the hell (laughs).

CD: If it is important to you (pause)

RM: Then I'll worry about it until I find how to answer it

CD: Uh huh

RM: Yeah, read about it, and try and find out one way or another or
(pause)

CD: Do you know how you react when you, when it is important to you,
and you can't remember.

RM: Well that's were you have another worrying comes in, isn't it

CD: Uh huh. So you'd be a little worried?

RM: Yeah, yeah, and and and to do a little worrying and, 'til you got it
straightened out. (RM2, 253-278)

It seems RM recognized that he would ruminate over a memory loss but apparently only if the memory had personal significance for him, a thought which he re-iterated during the same interview (RM2, 293-299).

Based on these conversations with RM it can be concluded that a) he felt embarrassed or humiliated by his memory loss; b) he attempted to normalize and minimize the experience; and c) he believed he could ignore those lapses in memory which did not have personal significance for him.

Sense of Self

RM gave conflicting messages about his self. On the one hand, RM gave the impression of being strong and wise, on the other hand he appeared to be experiencing uncertainty and self-doubt.

RM appeared to be fearful of something, fearful enough to want assurances of his wife's whereabouts. Although this characteristic did not occur very often when it did show up it was surprising. It tended to occur just as he and his wife were going their separate ways. RM would get a look of anxiety and ask in a slightly distressed manner where she was going or when she would be back. This behavior suggested a self that was uncertain and fearful.

In contrast to this image of fearfulness was that of strength as portrayed by the straight-hitting conversational style engaged in by RM. The following examples illustrate how RM appeared to reflect a sense of self that was strong enough to take life head on. In the first example, RM had just been asked how he felt about being given a diagnosis of DAT. He responded that he was glad that he had been told the truth and indicated that, even though he didn't like the message, he appreciated the forthright manner in which he was told:

CD: Are you glad that they told you the truth?

RM I'm glad they didn't beat around the bush about it, yeah.

CD: Uh huh.

RM: Yeah, yeah I'm glad they didn't beat around the bush about it. Gives ya something to think about. Gives ya (pause) (RM2, 646-652) .

RM: he [the doctor] said " I suspect that you have it (pause) having it come on" or however he worded it, it now meant the same.

CD: What did it mean really to you?

RM: Well not the best, that's what it (pause)

CD: What did it mean RM (pause) to you?

RM: That's what's the life's gonna be like from now on out. Remem remember here 'n remember there 'n (RM2, 571-581)

RM suggested that he appreciated having been told of the diagnosis for it allowed him to *think* about what the diagnosis meant to him. During the next recorded interview he repeated this idea of appreciating that others had been honest with him

CD: When you found out that you had Alzheimer Disease how did that affect you?

RM: Well I knew there was something that wasn't right. I was kind a happy to get it into the open and figure out what the hell it was eh

CD: So just getting it out in the open made you happy?

RM: Well it don't make me feel that happy but I didn't jump up and down on the table or anything like that.

CD: Was it a bit of a relief then.

RM: Bit of a relief then. Yeah. Yeah. (RM3, 555-566)

RM extended his belief that individuals with DAT should be told of the diagnosis when he was asked directly if he thought there should be disclosure of the disease to the individual experiencing it. He replied:

RM: Well now that's a good thing it, to eh kinda 'r (pause) maybe work into it easy an' tell that eh (pause) you're afraid they might be coming on with this or something like you know.

CD: Uh huh.

RM: Maybe not crack it on to them right away but (pause) just tell then that (pause) sounds like Altimer's disease to you 'n you're might be worse 'n might get worse on ya 'n isn't. gives em a few things along those line to think about, doesn't it.

CD: And did you think about it?

RM: Oh yeah, I thought a lot about it. (RM2, 658-666)

The foregoing conversation suggests that RM felt that it was a good thing that he had been informed of his diagnosis because it allowed him to think about and eventually accept the consequences. This indicates that RM had a reflective self that wanted to participate in his own life, even if that meant a self that had to accept the decline of his life.

A contradiction appears in the description of RM as both fearful and strong. On the one hand, he appears solid and steady, on the other, fearful. It is likely that RM is losing some of his solidarity as he adapts to his disease. It should be recalled from Table 1 that RM had lived only a short time in his new residence and was not surrounded by a large social network. The unfamiliarity he dealt with likely added to his sense of insecurity.

Perception of Daily Life

For RM, daily life in some ways resembled the life he lived previously. He often referred to his deceased father as living and he believed he played weekly card games with friends that lived

hundreds of miles away (RM1, 31-39; RM2, 1056-1058). In addition, RM believed he was perfectly capable of driving the car, a task he had not performed in over 5 years. In fact RM stated he drove the car every day (RM2, 690).

So why was RM so unaware of the inconsistency between his depiction of daily life and 'reality'? It is possible that awareness for RM was very transient and dependent upon the individual skill having been 'tested'. If the skills such as driving, remembering or finding one's way were not tested and consciously brought into reality, did RM remain oblivious to his lack of skill? This explanation seems reasonable but RM himself adds a statement about driving that suggests by its' very nature, driving might be a cherished skill to which it is difficult to admit inability, consciously or unconsciously

CD: Uh huh. Is that important to you to to keep you driving like you've been driving?

RM: Absolutely. That's important to me. yeah.

CD: Do you have any idea why that's so important because I've noticed that with other individuals also?

RM: Uh huh.

CD: (pause) It's very important to them, to keep their drivers license

RM: Yeah.

CD: to drive.

RM: Yeah, yes. If you were, if I were to tell you tomorrow that you couldn't drive from here what the hell would it do to ya?

CD: Uh huh.

RM: Aye?

CD: huh.

RM: Oh, I started driving when I was eight years old. An old model T my dad had floatin' around the yard 'n 'n you could never never before the starter was (pause) invented an you had to get up there 'n stub winder. I wasn't quite heavy enough ta (pause) get it spin it ta start 'r, so I rigged up a way ta (pause) ta get my foot on it, and stand on the other side 'n get my foot on it 'n give it a push. But the damn thing started. (RM2, 698-724)

Driving seemed to have a very important place in RM's life. To RM it was not only a skill but it was a cherished accomplishment, one that might have been difficult to admit losing. It might be that certain losses are more difficult to accept and be aware of than others.

Valued Activities

RM seemed to enjoy three activities more than any others: socializing, playing cards and 'thinking about the past'. RM on a couple of occasions revealed his loneliness and the need to talk to people. After one of our first meetings, we were driving home from a coffee house when RM commented that people don't seem to take enough time to talk with each other and enjoy life. He commented that everybody was in such a hurry that sometimes he would get halfway through a story and the other would get up to leave. RM then commented that he enjoyed being out with me and added "It's good to have companionship. It's good to have relationships" (RM1/5/95). When asked just a few moments later what it was that he enjoyed about Club 36 he answered simply "Friendship mostly".

Friendships were very important to RM and the opportunity to talk to people was especially important to him. He mentioned friendship being the attribute of Club 36 he appreciated the most (RM2, 846-851; RM3, 296-307) and expressed the way he felt about being able to talk with people. When asked if he felt that it helped to talk things over with people he responded:

Uh huh. I do. Very much so. In a gentle (pause) knowledgeable way. Yeah ya can sit down ‘n (pause) sit down ‘n talk to somebody ‘n make sense ‘n you get ‘em to talk to you ‘n make sense, what happens (pause) I figure that’s a good friendship. (RM2, 1089-1094)

Talking was definitely something RM enjoyed doing. He liked to tell his stories some of which were fascinating. One day while we were driving, he referred to a story he had told me and commented that usually when he told that story “People think I’m making it up” (Fieldnotes, 10/05/95). This seemed to hurt RM, as did the thought of how he and his wife used to entertain friends more often, and how “it gets pretty lonesome sitting around here when nobody comes in” (RM2, 786-787).

One activity that RM enjoyed when he had company was playing cards. RM enjoyed both cribbage and Norwegian Whist and maintained his ability to play both.

RM’s propensity to think about things from the past was evident in conversations that one had with him. It did not take much of an invitation for RM to begin thinking and speaking about the past. This in itself was not surprising. What was surprising was the importance that “thinking about things from the past” had as both an activity and a coping strategy (briefly mentioned in Atypical Behaviors as Coping Strategies in the Results section).

Concerns

RM tried to convey the image of someone who didn’t particularly worry about the consequences of living with a DAT impairment. RM was asked whether the possibility of his getting worse bothered him. RM stumbled badly through a sentence as he denied his concerns

CD: Does that bother you whether it will get worse or not?

RM: No. I don’t don’t th (clears throat) I try not to bother (pause) not rr not r not not not r (pause) not to let it bother you from day to day. (RM2, 228-233)

This is the only instance I can recall, or have evidence for, RM showing such halting speech.

Despite RM's claim that he didn't let things bother him there is little doubt RM had, at the time of the interviews, periods of concern about living with DAT. Evidence for this claim can be found in dialogue already discussed in Awareness and Personal Significance. One excerpt already mentioned in Awareness (RM2, 637-645) should be briefly mentioned again. In this particular excerpt RM mused that his DAT was not as bad as he had feared and then added that things would be all right as long as he found his way home to a table which had been set. Although this statement might indicate an underlying concern for his physical safety, the fact that he included the welcoming presence of a kitchen table might suggest that he was also concerned about continued emotional support. It seems RM believed that he would ruminate over memory loss, a thought which he re-iterated later (RM2, 293-299).

One perception of RM's that was consistent through the interviews was the awareness of the progressive nature of the disease. Statements such as,

I haven't got to the bad point yet I think there will be days when I won't be able to remember what day it is. (RM3, 95-98)

showed concern for the future based on knowledge of the disease. On many occasions his future appeared almost to disturb him and it was not that unusual for him to interject such comments as:

anyhow (clears throat). It'll get worse before it'll get better eh (looks at me).

(RM 219-221)

which were indicative of an underlying concern about his condition.

In another recorded interview he had been talking about the discussion he had with his doctor. In RM's memory of the incident, the doctor talked to him bluntly about his future to which RM answered "Aw you're crazy." After stating this RM looked at me and stated "But this not really this eh bad as it's gonna get, is it ?" (RM2, 636-638).

KY's Experiences with Dementia of the Alzheimer's Type

Awareness

KY gave the impression of being the least impaired of all the participants and his level of awareness reflected both an intact reflective ability and a propensity to be optimistic in assessing his abilities.

KY easily described symptoms associated with DAT. When asked to describe the memory problems that he was experiencing KY answered:

It's hard for me to pinpoint the exact trouble (sighs). It's not related to a specific (sic topic) or (pause) like that. It might (pause) it might just come all of a sudden (sigh, pause) always when I least expect it. (KY3, 23-28)

This statement indicates that KY felt that the impairment fluctuated in severity over time: he apparently believed that he experienced moments of poor cognitive ability as well as moments of clarity and that sometimes was capable of performing at a normal capacity.

KY was also aware of symptoms associated with DAT other than memory. When asked about the possibility that DAT could cause confusion in either himself or other Alzheimer's patients KY responded:

Ah yes I think that is entirely possible eh you know but I think if you just like I said accept the fact you are aaaaaa well you are, well you are not normal. (KY4, 49-52)

It seemed KY was able to stand outside of the subjective experience of living with a dementia and comment objectively on potential experience. In support of this ability of his to take the position of the other he later added, in response to a query about a hypothetical situation in which someone told him that he had done something previously that was not in character he answered:

in my state of mind I wouldn't be entirely sure that what I said before was the right thing.
(KY4, 87-88)

In fact, KY suggested that he would be aware at the time of doing something that it was not quite right (KY4, 126-128). During the course of the research there was no evidence which either refuted or supported this belief of KY's.

KY's reflective nature and calm awareness was well articulated again as he reflected upon the effects of his dementia on his family. The following passage not only reflected KY's awareness in understanding the impact of his memory impairment on others, but also hinted at the personal acceptance of one of the consequences of the disease, dependency:

CD: Do you think maybe it's hard (pause) on those around you? Do you think it affects them?

KY: Oh I think uh well (pause) Yes, I think you know it effects them.

CD: Do you have any idea why you're affecting them?

KY: Well (pause) you know they have to be (pause) constantly thinking about (pause) reminding me of things that (pause) that I have to do and (pause) they have to (pause) more or less put themselves in my place and (pause) try and anticipate my (pause) things that I might forget, you know. (KY3, 200-213)

It appeared, however, that KY, while cognizant of his memory loss, did not dwell on it. After completing the DRS on our last interview, I asked him if he had minded participating. He replied "No." and went further to state that it was good for him because generally he wasn't conscious of using his memory. He thought that the completion of the DRS had made him more conscious of his memory and made him aware that he should exercise it more often (Fieldnotes, 01/07/95). It appears while KY was aware of his cognitive impairment, the impairment held a peripheral rather than a pervasive spot in his consciousness.

Personal Significance of Impairment

It was difficult to judge the personal significance the cognitive impairment had for KY. There were times when KY appeared unaffected by his memory impairment while at other times the loss seemed to have deep personal significance for him. Although KY did experience moments of agitation, a characteristic which he associated more with the onset of the disease, he stated that in general the memory loss did not bother him:

CD: So when um you say you know that it doesn't affect you that much, is it something that um you're able to live with and you just say "Well (pause)"

KY: (sighs) Yeah I think so. (coughs) If I forget anything or (pause) I don't worry about it too much actually.

CD: Uh huh. Do you think that's always been the case that when you first, when you first, noticed you had a memory problem did it bother you then?

KY: Well yes I must admit that it did. (pause) But as I get older I don't (pause) I don't think I (pause) let it bother me as much

CD: So it was harder for you in the beginning?

KY: Um. Oh yeah! (pause) Yeah.

CD: Can you remember what it was like when you first started to notice you had a problem?

KY: Well, I used to be irritated. (pause, sighs). That's about all I guess. Uh huh.

CD: Are you able to recall what would irritate you?

KY: Just the fact that I couldn't remember (pause) what it was that I was trying to remember (slight laugh in his voice). (pause). But after awhile I (pause) I (pause) you know (pause) figured that I would be able to (pause) recall it sometime or another.

(KY3, 36-64)

The above statement suggests that KY perceived himself generally to be undisturbed by his loss of memory, a fact that was substantiated by observation. A response common to KY, when his memory failed him, was simply “I don’t remember”.

Perhaps one of the reasons KY was not overly concerned with his memory loss was that he saw memory loss as being secondary to character and/or inner desire in determining the quality of his life. The weight which he attributed to personal desire in affecting his quality of life is seen in the following statement in which he indicates the only things in his life which limited his ability to do as he wished were his age and his inner desire:

CD: Is there anything in your life now that’s preventing you from doing what you would really like to do with your time?

KY: Except for age?

CD: Uh huh. Except for age.

KY: Um (pause) No I don’t think there’s anything that would stop me from what I want to do. (pause) yeah except my (pause) well how great my desire is to do whatever.

(KY2, 377-386)

In fact age seemed to be a buffer for the consequences of DAT:

There are things that I forget too but then after all (pause) I’m (pause) you know sseventy-five. Lived a quarter, three quarters of a century so it’s (pause) I’m bound to forget something. Eh? (KY3, 30-34)

It seemed KY downplayed the significance DAT had on this daily life and indicated life still was more dependent on his inner qualities than on his cognitive impairment.

This impression of acceptance bordering on indifference was misleading. Although KY was often able to say simply “I don’t remember” and have no emotion attached to this admission this was not always the case. In one interview, when he was being asked about his family, KY was

suddenly unable to recall the name of one of his children. In this case, KY did not indifferently state “I don’t remember” but rather became agitated. He commented several times that he was stupid, got up from his chair and began to ‘wander’ around the house. KY came back after several minutes and sat down. I asked him if he would like me to put in a CD something he usually liked. He said “no” and just sat quietly. He looked at me and said “You can talk if you want” but gave the impression of preferring to withdraw himself (Fieldnotes, 11/05/95). It was apparent that being unable to recall the name of someone he loved had deep personal significance for him.

This pattern of forgetting followed by agitation was apparent on one other occasion. KY’s wife had gone out of the house for an hour or so and KY and I had been left on our own. During that time KY had answered the phone. Upon her return his wife asked if there had been any phone calls. KY responded “No.” that there had been no calls but I reminded him that there had been one. He stated that he couldn’t remember. Despite his wife’s further questioning KY could not recall anything. The questioning seemed to agitate KY and for the next several minutes he engaged in what appeared to be purposeless behavior - getting out of his chair and walking to the window and back a few times in succession (Fieldnotes, 5/05/95). In this case the negative reaction might have resulted from what he perceive to be a belittling of his abilities.

KY generally showed indifference to this cognitive impairment. The apparent indifference may have been assisted by a) his ability to minimize the loss by linking it to advanced age; and b) his belief that the only obstacles to his accomplishing what he wished were his internal desire and his physical health. The personal significance of cognitive impairment was effected by the meaning the loss had for him. If the loss affected him in a personal way, then it took on personal significance for him, otherwise he was able to minimize the personal significance.

Perception of Daily Life

Perhaps one of the reasons memory loss per se did not have a particularly strong significance for KY was he did not see memory loss per se affecting his daily life. When asked how he spent his day, KY responded that he did yard work, listened to music, tended a garden, puttered in his shop and played golf (although not as often as he would have liked). He stated in general DAT did not have any bearing on his life (KY2, 377-435). In many ways KY's life continued as it had for the previous several years. His health had begun to fail over the last several years which resulted in restrictions on some physical activities such as golf but he lived in the same home, continued to enjoy many hobbies such as gardening, and still retained the company of his family and friends.

Sense of Self

At the time of the interviews KY appeared to maintain a strong sense of self.

The cohesive sense of self is exemplified in several passages in which KY refers to himself in terms of strength and control. For example, when asked how he would feel if his family had made decisions for him rather than involving him in the decision making process KY responded:

I would take exception to that just because your ummmm mind loses having Alzheimer's it still it doesn't mean that you know you are like that all the time. There are occasions, and a good many occasions, in which you are in a normal way and I'm not different from anybody else actually. (KY4, 107-114)

KY not only felt capable enough to be consulted in decision making but also felt confident enough to be non-threatened by the decision-making power of his wife. When queried about the decision-making roles that were in place in his family he responded:

Oh, oh, I would have to say most of it would be my wife I guess right now. I let her do it and very seldom I contest anything she might decide. (KY4, 132-135)

KY's self assuredness went beyond decision making and included the ability to be amused with the precautions his wife had in place for his safety. When he was asked if his wife worried about him the following conversation took place:

KY: Well if she had to leave me at home it bothers her until she gets back home.

CD: Do you know why she worries about you when she's gone?

KY: Well I guess it's because she won't know probably what I will be doing. She leaves instructions about what to do and what not to do (laughter, cough). Excuse me.

CD: What do you think about that, about leaving instructions for you?

KY: Oh yeah, I read them but I don't do too much to the contrary yeah.

CD: Do you think it's necessary that she leaves instructions?

KY: No not really but she does anyway. (KY4, 167-182)

Although it is possible KY's attitude, as reflected in the above statements, reflected a passivity or an apathy, it is also possible that it suggests a man who, being self-assured, was not threatened by the prospect of having his power or control taken away from him.

Perhaps it is due to KY's self-assured perception of himself that he was able to describe himself as a valued and respected member of his family and community and indicate his belief that he still had a valuable role to play within society. In several instances he refers to the mutual enjoyment of his friendships (e.g. KY1, 155-161) and the valued position within his family (KY2, 281-300). On one striking occasion he went on to indicate how he felt about being a contributing member of the community

CD: Is it good for you then when you feel needed?

KY: Oh yeah. Yes. A person yeah has to feel needed (pause) Yeah. (pause) If he's not he may just as well be dead (pause).

CD: What do you think would happen to you if you no longer felt needed? Do you think

KY: Well I guess I would feel bad so (pause) It wouldn't be the end of the world I guess.

(pause) I guess what I might do, I might do is go look around to see what I can

(pause) do (pause) to be needed. If we look around there's lots (clears throat) lots of things a person can do now (clearing throat). Oh he can go to the foo food bank uh all that kind of stuff. Yeah. (KY2, 301-314)

This exchange indicates KY not only viewed himself capable of contributing to his community but went beyond that and accepted responsibility for the fulfillment of his contribution.

It is likely his family encouraged the maintenance of this self-perception. An indication of this was seen one day when we were discussing gardening. In conversation with he and his wife the researcher mentioned a hybrid shrub which was new to both KY and his wife. His wife was particularly surprised. She looked at KY and said "Is that true KY? Could that be true?" It appeared then, that despite the dementia, KY maintained a respected position as a knowledgeable individual within the family.

KY was still in the early stages of the disease but he appeared at this time, to have maintained his self-confidence and described himself in terms of stability, mutual relationships, self-reliance and social involvement. It is unknown a) to what extent KY's life-long personality contributes to the present one; b) what influence the family had in maintaining his self-confidence; and c) the extent his mild degree of impairment influenced his sense of self but it is likely that all three factors had a bearing on KY's attitude towards himself.

Concerns

The only real concern expressed by KY during the several weeks of interviewing was concerning the relationship that he had with one of his daughters. This particular daughter had a mental handicap and lived at home with her parents. When asked one day if he spent much time with her indicated that he didn't but wished that he did. He spoke as if there was regret but did not

elaborate. He then indicated that he wouldn't be sure what to do with her because their interests were so different.

Valued Activities

KY was able to engage in a wide range of activities. According to KY his activities had changed little since he had been diagnosed with DAT. At the present he enjoyed listening to music, golfing, gardening and tinkering in his workshop.

Although KY did not spontaneously reminisce, he did show considerable interest in talking about his adolescent experiences in an internment camp. It was this topic that most easily elicited spontaneous conversation with KY.

JK's Experiences with Dementia of the Alzheimer's Type

Awareness

JK communicated the greatest awareness of his cognitive symptoms. The evidence is strong that JK was consistently aware of many of his cognitive impairments which included episodic memory loss, aphasia and agnosia.

Much of JK's life is subject to memory loss. In general JK explains his memory problem by describing the confusion he experienced in everyday activities. He would forget, or become confused about, what it was he was supposed to be doing (JK1, 408-411) or what it was he was trying to say (JK1, 621-624). In addition to this short term confusion JK also appeared to suffer from rather severe long term memory deficits. For example, he was never able to state how many children he had, where he was born, or why he had to stop working.

Considering JK's communication difficulties it is difficult to say with confidence that all instances of memory loss are in fact due to memory impairment and not due to either receptive or expressive aphasia. In fact it is likely that both memory loss and aphasia contributed to the lack of information he could provide. Certain information, such as his place of birth, seemed to create a

brief mental search on the part of JK which ended in frustration as he seemed unable to retrieve the name from his memory store (Fieldnotes, 18/04/95). The impression of anomia resulted from this type of mental search since it appeared that JK had some form of mental memory to which he was unable to attach a name. Other forms of cognitive impairment however appeared to stem from genuine lack of memory, perhaps only temporary, for the incident itself. Typically for these instances in which there appeared to be no memory, JK would also indicate no real concern and would not make any concerted attempt to retrieve the information. For example, when he was asked why he had stopped working, JK seemed blank and rather uninterested

CD: Do you have any idea why you stopped working or

JK: What's that?

CD: Why did you stop working?

JK: (pause) I really don't know (pause) I don't remember I don't know (pause) but not yet really I'm not you know the (pause) sometimes I I I can say I know many things you know and other days you know "what what now what was I going to say?" (JK1, 541-550)

For other memories, such as the history of friendships, it is difficult to determine whether his inability to fill in the details resulted from lack of memory or inability to express the memories that were there or both (JK2, 110-219).

JK's expressive aphasia was the most notable characteristic of this cognitive impairment and JK was well aware of its presence, often lamenting the obstacles that it brought him. A sentence representative of this awareness follows:

eh, I eh, I like to say say something in sometimes you know and as you notice I want to say something and all of a sudden now "what was I sup supposed to say." (JK4. 11-14)

It is reasonable to assume that difficulties in communication were an ever-present reminder of his impairment.

Agnosia also played a significant role in this impairment. Of the 14 references to memory loss five had a particular reference to his inability to remember people. The following excerpt illustrates this loss for us:

That's the thing you know and I knew people (pause) so much and now you know I don't remember (pause) I know I see that guy and I forget you know, what (pause) who is he? Yet you know (pause) and that is ss (pause) iit's hard. (JK2, 283-287)

One of the strongest indications JK was aware of his cognitive impairment was his admission that he feared getting lost. In the following excerpt JK described how he walked the same route everyday and admitted that a change to the route might have resulted in his getting lost

CD: I was wondering if you were if you were able to go for a walk by .

JK: by myself, yeah. This is the thing that hurts me.

CD: Uh huh.

JK: I traveled all (can't make it out) (pause) and yet (pause)

CD: Do you know why (pause) they don't want you to go for a walk by yourself JK?

JK: They think that they (pause) that I'll be (pause) I'll dd (pause) I'll be, don't know which way to go kind of thing. Uh I'll walk you know, but I'm not too far. That's the thing that I I like. But if uh uh (pause)

CD: When they tell you that they're worried about you (pause) going (pause) on a walk by yourself

JK: Yeah.

CD: Do you understand why they have a concern?

JK: Yes and no. You know because okay I walk many times by myself
(pause) and I didn't go far.

CD: Right. You have your little route that you go on. Uh huh.

JK: But going far (pause) further, I wouldn't want to go by myself.

CD: So you realize that maybe you shouldn't be going too far by
yourself?

JK: That's right.

CD: How do you know that it might not be too good for you to go too far
by yourself?

JK: I really don't know uh.

CD: Do you (pause) Is there anything, a little warning signal that goes off
in your head that says "maybe this isn't a good idea."

JK: Yes.

CD: Uh huh (long pause) Do you ever worry yourself that you'll get lost
JK?

JK: Yes (trembling voice).

CD: Yeah.

JK: Yes. I'll tell the truth eh. (JK2, 668-709)

In this passage JK not only acknowledged he was aware that others did not want him to go too far but admitted that he himself was aware of the danger of getting lost. JK made several references to this limitation (e.g. JK6, 17-22).

Personal Significance of Impairment

The experience of impairment for JK appeared painful and he expressed his unhappiness several times in statements similar to the one below:

many times you know I wish wish that I was (pause) many times I wish that I was dead you know. You know (sniffles from crying, pause) this this way that I'm gone kind of thing (tears coming down his cheeks, pause). (JK1, 55-62)

Although it was clear that JK was painfully touched by his cognitive impairment the reasons for the strong personal significance might not be those anticipated.

For JK one of the most significant consequences of living with a cognitive impairment, was the experience of personal loss that accompanied his agnosia. The experience of an amnesic syndrome for JK was sometimes a recognition of familiar faces without the ability to recall the name or personal details that went with the face (JK2, 556-559). It seemed as if, when he looked upon familiar faces, he did not really know how that face had fit into his life. Not only was there a problem placing a familiar face within a context (JK2, 283-287) but there was also the dilemma of not knowing if he had liked the individual (JK2, 258-259). In effect, it was as if he had been robbed of his personal history and by extension his identity. This was particularly distressing for JK at the time of a friend's funeral

JK: but sometimes you know (pause) like this this guy like R. explained you know is dead you know it's altogether different it's going to be just like I'm going to be going there in there anyway eh (pause) and yet I don't really remember I remember that guy and yet I know I knew that guy and yet I don't.

CD: Is that what you find so depressing? Is that hard for you?

JK: (pause) Yes. I sh should know that guy you know kind of thing very well (pause) and yet (pause) and yet he is a very nice guy.

CD: (pause) I was going to ask you (pause) Is it hard because you don't know or is it hard because others think you should know?

JK: (pause) No. It's that I don't know.

CD: (pause) It's hard that you don't know?

JK: (pause) Yes. Yeah I would like to know. (JK1, 136-154)

It would of course make sense that he would like to know. We are social beings and our identity must in some way be closely linked to those individuals with whom we have spent our lives.

As difficult as were the cognitive consequences of living with a dementia, there is evidence that, for JK, the significance of the loss came less from the memory loss per se and more from the social isolation that he perceived the loss to have created for him. In a moving description, JK tries to describe how he felt about going out among friends whom he perceived as no longer treating him as an equal

JK: and yet they they don't don't talk to me actually because they're they're talking by by themselves kind of thing and I'm just a (pause)

CD: So people ignore you kind of thing? (JK1, 157-161)

...

CD: Do you feel that they also talk to you? Or do you feel sometimes that you're left out?

JK: I'm left out. (strongly)

CD: You're left out?

JK: That's right. (pause) Yeah. (pause) Yeah. (pause) Yeah.

CD: And what does that make you feel like?

JK: (pause) Like I'm out you know (indicates an "out" sign that an umpire makes)(pause).

You know (pause). ... (sniffing) Many times I I feel (pause) I wish that I was dead, honestly. (JK1, 174-186)

This theme, of not being included in conversations, was repeated again by JK during another interview in which we were talking about his loneliness

JK: ike I say an' an' they are talking. And everybody's talking, an' nobody talked with me.

(JK5, 583-585)

JK had previously been asked if others understood the loneliness he was experiencing and he responded

JK: (quite definitely) No I don't think so. No. (pause) 'Cause they go their own way, eh eh their own way. I waste their time (or a waste of time, I can't determine which, pause)

Sometimes I wish I wish I was gone you know (pause) I have to admit it. (JK1, 73-78)

The loneliness illustrated in the previous passages indicates that, for JK, the significance of the impairment appeared to come more from the social consequences of the cognitive impairment rather than from the cognitive impairment itself. In other words, JK seemed to suffer as much, if not more, from the stigma and the isolation of impairment than the frustration of memory loss.

The relative importance of the loss of memory, as compared to the loss of social belonging, was illustrated strongly when JK was asked directly if he felt others with Alzheimer's disease should be told that they have the disease. In apparent reference to his own experience of knowing that he lived with DAT, he responded,

JK: To me it doesn't matter. To me it doesn't matter as long as I know that if I have friends and if I want to phone somebody or something like that that they will talk to me.

(JK6, 409-413)

...

JK: I know what I am I I I sure I don't remember a lot you know but, so what I can't remember, I'll ask you. (JK6, 427-429)

So in a way, JK felt that the tragedy of cognitive impairment was the loss of cognition as an instrument for social involvement, friendships and intimacy. JK described himself as being more affected by the perceived treatment of others than by the perceived loss of cognitive ability per se.

Sense of Self

JK gave the impression his sense of self was in flux as he tried to hold onto treasured roles and competencies while accommodating his self to new realities.

Two personal characteristics embraced by JK were independence and being a valued member of a community. For JK a sense of independence had been kept alive by his ability to take his daily walk. Walking was very important for him and he often commented “I like to walk. I need to walk” however, it was difficult for him to articulate a reason for this favored activity.

Interestingly on the two occasions (JK5, 740-756; JK6, 12-38) when he referred to his independence, he did so in the context of his daily walks. For example in one instance he states,

Well I’m afraid a little bit you know. Is it too far for me? Should I go a little farther or not? So I go and then all of a sudden “I’d better come back” you know. And yet I walked I walk by myself yet but I was a little afraid this week. (JK6, 17-22)

In this and a previous conversation (JK5, 740-756), JK referred to obstacles he overcame in order to take his walk, an accomplishment to which he attached pride.

JK’s positive self also seemed to involve a sense of community or belonging. JK referred often to his desire to “help others” a reference perhaps to his long-standing association with Alcoholics Anonymous and helping others through talking. In one instance, he was referring to how he felt a responsibility to help others

JK: and now I have to help another guy.

CD: Uh huh

JK: You know, you know. Because I know what it is what's what how hard how it is hard for me and then I can help another guy. That's what I I I really like that (pause) to help people. (JK2, 318-325)

Interestingly, despite JK's assertion that he liked to help others, it appeared that he saw himself as dependent, a characteristic to which he often showed resentment.

JK's resentment to his disability and the effect it appeared to have on his self could be seen on one occasion in which he acknowledged the need for help by others. JK required help navigating within the community if he went anywhere other than his daily walking route. The idea of an adult needing someone to go everywhere with him was a humiliating one however for JK, this dependency might have been even more devastating because of the importance that traveling had for him in his career as a traveling salesman. The following excerpt indicates that JK's worth and identity had been attached to his career and, as such, found this limitation particularly difficult.

JK: And then, not only that you know, I was travelling so much and uh I had so much business and all of that.. and all of a sudden.. I have to have somebody with me.

CD: So now you have to have somebody with you?

JK: Yeah.

CD: Yeah. And (pause) what does that feel like?

JK: It's hard.

CD: Uh huh.

JK: You know I feel like uh (pause) I'm (pause) I'm not good for anything really now because you know (pause)

CD: So you used to be a man who went where you wanted when you wanted

JK: Yeah

CD:..and now you depend on others

JK: Yeah. Yeah.

CD: to get you there.

JK: yeah exactly. (pause)

CD: Did you expect that this might ever happen to you?

JK: No. (pause) No (pause) No (pause) No (pause) Never!

CD: Uh huh. (JK2, 623-646)

It may have been particularly difficult for JK to reconcile the independent self of a traveling salesman with the new self that required a chaperone.

But it was not just traveling by himself that JK could no longer accomplish. He was also unable to drive a car. To JK it appears the loss of driving ability carried with it the loss of self esteem. The importance of the loss of his license is expressed by JK when he was asked why he had stopped driving. Although his immediate answer was confusing, he ended the explanation with

JK: And uh it's, all of a sudden, you know, I'm not good for nothing you know

CD: From the perspective of others.

JK: Yes. Yes. (JK5, 498-501)

It appeared JK was struggling with a self that felt devalued, a self that felt little worth in the eyes of others.

It should be remembered JK had early onset dementia and was required to end an active career. It is possible this interruption in his career and the leapfrogging over age-appropriate activities into forced retirement made it even more difficult for him to accept the new roles he was required to play. For JK, his change in roles and the consequent change in the perception of self would have been telescoped into an age-inappropriate framework .

It might also have been that the premature role change accentuated how JK perceived himself as being different from others. There was little doubt JK was aware that he was different and connected this difference with his often repeated desire to escape his daily life

many times you know I wish that I'm not here, this kind of thing, or whatever it is you know and yet I would like to be like other people. (JK1, 732-735)

For JK, the changes that his 'self' were subjected to involved more than being different or adapting to different roles. JK appeared to have real difficulty coming to terms with what he perceived as a lack of power. JK openly expressed difficulty with the shifting of power or control to his spouse. JK expressed his distress with his wife's decision-making role in the following way:

like we say you know I'm not the boss at all. I have to ask and ask and ask and that is the hardest thing for me. (JK6, 332-334)

It might have been that the loss of a power was made more difficult by an underlying sense of lack of control that JK sometimes harbored. For example JK sometimes felt that his wife would keep plans from him and then spring them on him at the last minute. In describing his perception of being informed at the last minute of plans, JK referred to his weekly AA meetings

JK: You know because she says it it's lo lo lost already, you know, and because you know, and all of a sudden you know, I I'm going to AA.

CD: So just so that I understand you, at one point you thought you weren't going ?

JK: Yes.

CD: And then she changed her mind?

JK: Yes.

CD: And you were going?

JK: yeah. (JK5, 916-926)

This sense of powerlessness may have been fostered by his own memory loss, by his misunderstanding of the situation and/or by his spouse's strategy of informing him of events close to the time, rather than having him obsess about them in the interim. Regardless of the reason behind them, they left JK with the perception he had little control which in turn contributed to a sense of powerlessness.

Perceptions of Daily Life

JK gave the impression he perceived a large portion of his daily activities were out of his control.

The perception that his daily life was in the hands of others was expressed partly in his use of language and partly in the content of his statements. When referring to his position relative to others JK, constantly and consistently referred to the other as "allowing" him or "helping" him in his daily activities.

Those activities which he perceived to be within his control were highly valued. Walking by himself on the short route around his house was one of the few daily activities JK felt were within his control. JK often commented that he liked to walk, in fact, he suggested he not only liked to walk but needed to walk. On our first meeting together he talked a lot about walking, about when he had nothing to do or there was no-one around he could "at least walk". He repeated countless times "I like to walk" "I need to walk" (Fieldnotes, 18/4/95).

This need to walk was apparently influenced by several factors: boredom, desire to maintain a sense of independence and the pride provided by the accomplishment of a task. For JK the prospect of sitting around the house was arduous and the companionship down at Club 36 was something which he cherished.

Without them I'm lost because I'm at home all the time. ... By myself all the time. But Alzheimer's this is where I really enjoy it because at least I know where I am going. (JK4, p.24)

JK did not participate in any hobbies. Instead JK walked. Although JK often repeated that he walked it was very difficult to understand the exact reasons why he did so. One of the most lucid descriptions follows:

CD: Do you know what it is about walking that you like?

JK: Well yes you know because (sighs) uh out (pause) out of the house you know (pause) at least I can can walk (pause) you know (pause) and you don't have to work, dddon't have to be fffast or anything like that you know.

CD: So it's something you feel you can do (pause) and it gets you out?

JK: That's right you know. You know. Something to do you know. (JK 2, p.20)

In one statement he suggested that walking both relieved his boredom and allowed him to achieve success at an activity for which he still maintained skill

CD: Do you know what it is about walking that you like?

JK: Well yes you know because (sighs) uh out (pause) out of the house you know. (pause) At least I can walk you know (pause) and you don't have to work, ddddon't have to be fast or anything like that, you know.

CD: So it's something you feel you can do and it gets you out?

JK: That's right you know. You know. Something to do, you know. (JK2, 805-816)

The importance JK placed on the independence he maintained and the pride this independence gave is illustrated in the following excerpt:

CD: Since you were mentioning a couple of minutes ago that you don't like to go too far when you walk.

JK: Exactly.

CD: Can you tell me why that is?

JK: So I'm I'm afraid a little bit you know. Is it too far for me? Should I go a far farther or not? So I go and then all of a sudden well I gotta come back you know.

CD: Uh huh

KY: And yet I walked eh and yet I I by by myself, yeah. (JK4, 19-30)

Valued Activities

Walking was one activity which JK found enjoyable and appropriate for his skills. Another activity which he enjoyed and still wished to participate in was socialization. There is little doubt that JK was an individual who valued the company of others, and restrictions or limitations to social acceptance, resulted in his feeling lonely. During one interview, he became frustrated and tried to explain what his life was like. I suggested that he was very lonely and he began to cry. "Yes lonely" he said. He then said that just because people were "you know" didn't mean that they didn't need "you know". (Fieldnotes, 20/6/95). It appears for JK the need to be a valued member of a social group was very strong.

Concerns

JK did not voice any immediate concerns about the disease itself or indicate any pre-occupation with the future of the disease. There was considerable evidence, however, that he was concerned about the future of his quality of life.

Perhaps the instances of greatest vulnerability came when JK referred to his fears about the future. We had been discussing his perceptions of getting older when JK admitted that he feared the prospects of aging and the reasons were other than one might expect

CD: If I were to ask you (pause) what (pause) you used to think of (pause) like when you were a child or a young man (pause) when you thought about getting older (pause) What did you think it would be like? (JK4, 580-584)

...

JK: I don't really, it's hard to say.

CD: Uh huh

JK: (pause) Like to be uh old really, it will be hard.

CD: It will be hard ?

JK: Yeah.

CD: Uh huh

JK: Because (pause) you'll be (pause) in one place. Uh (pause) you'll you'll be like be by one (pause) by yourself, because you know if I'm old old (pause) uh no (pause) I would feel that nobody (voice cracks) would talk talk to me or that I could go or anyplace to go or things like this.

CD: Do you think when you're older you'll be lonely.

JK: I have a feeling you're right (voice cracks and he sniffles) because (pause) okay uh I can't drive a car, I can't do that, I can't do that, I can't do that (voice gets weaker). (JK2, 595-614)

Although JK worried about his future he also held concerns for his present. For example despite JK's apparent desire to maintain independence through his daily walk he was well aware of, and concerned about, the dangers of getting lost. The personal distress that this fear caused him has already been discussed (Awareness) however a separate comment of his during another

interview illustrated the concern that JK faces when he walks and the dilemma that he faces between giving into the fear and rescinding aspects of his freedom.

Summary of Results

As noted above, an analysis of each participant's experience led to the isolation of six common themes: personal significance of the cognitive impairment, sense of self, perception of daily activities, valued activities, and concerns. A summary of these findings across participants follows.

Awareness

As a first step toward understanding the perspective of the participants it was important to determine the individuals awareness of a) the presence of dementia-related symptoms and b) the implications of these symptoms. It was determined that this understanding would affect our understanding of a) the trustworthiness of the data, and b) the individuals judgments in making decisions.

Evidence indicates that an awareness of symptoms of DAT was present in all of the participants at least periodically. For some individuals such as AH, KY and JK the awareness of DAT symptoms was fairly stable and was spontaneously referred to during most conversations. Comments regarding symptoms from these participants were generally evoked by instances of memory loss, communication difficulties or being directly confronted with a task they could not complete.

For two other participants the awareness of symptoms of DAT appeared to be either transitory or indeterminate. There is evidence that RM's awareness of his memory problem was both transitory and task specific. While RM was periodically aware that he had a memory problem, he seemed unaware that other cognitive skills, such as his driving ability, were affected.

The extent to which JM was aware of his symptoms is unknown; however it is likely that he was more aware than he acknowledged.

There was variation in acknowledgment for different type of skills lost. The loss of certain abilities such a memory recall was generally described by all individuals while, other abilities such as having the skills necessary to drive a car were not. While impairment for driving a car was denied by three individuals (RM, JK and JM), all three individuals showed concern for their loss of their ability to find their way in the community.

Awareness of impairment should not be confused with ambivalence toward impairment. Awareness of symptoms is a measure of cognition whereas ambivalence is the affective response to awareness. The two could be confused because one's ambivalence toward the symptoms, or the implications of the disease, might be interpreted as lack of awareness. The issue of emotional reaction to awareness is discussed in Personal Significance of the Cognitive Impairment.

Despite the fact that all five participants were able to indicate they had been diagnosed with DAT, it was unlikely they consistently made the connection between their symptoms, DAT and the consequences of impairment. For example, AH readily admitted difficulties in language ability, perseveration and writing skills, but did not attribute any of these impairments directly to DAT. JK was well aware of his amnesic syndrome, spatial disorientation, and aphasia, but, like AH, never attributed the loss of these skills directly to DAT. This does not mean, however, they were unaware of the connection. It is possible they weren't able to articulate the connection.

Also, while all five individuals spontaneously acknowledged having been diagnosed with DAT, and four of the five were able to comment on the potential consequences of the disease, they were not consistently aware of the connection between DAT and impairment. For example JK, RM and AH spontaneously articulated concerns for their future, and KY mused about the potential behaviors caused by the disease; but not one of the four was able to suggest effects, other than

memory loss that were consequences of DAT. As for JM, it is difficult to assess his awareness since his descriptions of awareness were almost exclusively characterized in terms of minimization or denial.

Connected to the individuals' awareness of DAT symptoms was the tendency for all individuals to minimize their impairment. Such minimization of abilities was achieved in four ways: focus on remaining strengths; normalization of the experience; belief in fluctuation of symptoms; and comparison of ones present abilities with the expected disabilities.

i) Two individuals, RM and JM, took comfort in listing their remaining abilities. For RM, it was remembering his mother's birthday; for JM, it was his ability to build Mechano.

ii) Another strategy was the comparison of one's deficits to one's expectations of deficits. JM, JK and RM all engaged in this form of coping strategy: JM and RM bragged that they never got lost and JK boasted that he could still walk independently. AH's method of minimizing was to compare herself with others at Club 36 who experienced a dementia. It was, as if, the knowledge that others experienced a similar problem normalized the experience for her.

iii) Another form of minimization was normalization, or the placing of one's behavior or attributes in the context of what is 'normal'. The most common form of normalization was excusing memory loss as a normal consequence of aging. This form was engaged in by KY, RM and JM.

iv) The final form of minimization was the tendency to dismiss a deficit with the statement that the effects of the disease fluctuated and the memory or word would come back later. There was a tendency by AH, RM and KY to interpret their perception of periodic memory loss as a positive sign which allowed them to dismiss the incidents as inconveniences. Individuals used this perception of fluctuation as an opportunity to minimize the effects of the cognitive impairment.

They invariably referred to the perception of inconsistency in ability as evidence for optimism; either that their memory was not all that bad, or that if they only waited the lost skill would return.

It is interesting to note that JK did not minimize his impairments (although he did minimize the significance of his impairment). Not once did JK indicate that he did not believe his impairments were as severe as others thought they were. It might be that JK was constantly reminded of his impairment because of the serious communication problems that he was experiencing.

In summary there are five points which can be made regarding the participants cognitive awareness:

i) Awareness was task specific. Individuals consistently detailed more awareness of the loss of basic abilities but showed less insight into deficits of more complex tasks. For example, loss of writing ability was readily acknowledged whereas loss of judgment was not.

ii) The connection between symptoms and DAT was not usually made except in the case of memory.

iii) Awareness of the consequences of DAT, or at least that there was something amiss, was present in four of the five participants.

iv) Lack of apparent insight might be a case of minimization or denial.

v) Awareness, a cognitive ability, should not be confused with ambivalence, an emotional reaction.

Personal Significance of the Cognitive Impairment

Although it is likely the participants had gaps in their cognitive awareness, it should not be assumed that they were unaware of emotional nuances or that the symptoms and/or consequences of the disease, when recognized, did not have personal significance for them.

Although all individuals, including JM, acknowledged a memory loss, not one of the individuals indicated the loss of memory per se was the most significant loss. For example, despite the fact that during the research process KY showed agitation on two occasions, and on each of these occasions agitation followed an incident of memory loss, it does not necessarily follow that memory loss caused the reaction. KY had reacted passively to memory loss on numerous occasions thereby indicating that these two occasions, involving agitation, were different; they differed in the meaning the loss of memory had for him. In the first incident, KY forgot the name of one of his children, and in the second, he seemed to have experienced his wife's repeated questioning of a forgotten message as a public reprimand or a humiliation. JK and RM also appeared to react negatively (JK more so than RM) when they were quizzed about specific memory lapses. In effect, the meaning attributed to the memory, or the emotional significance of being quizzed about a memory, apparently was related to the consequence that a lapse in memory had for the individual, and personal meaning would be a more meaningful indicator of personal significance than memory loss per se.

The greatest personal significance of impairment appeared to come from each individual's perception of the reaction of their "other" to their impairment. For example, the most significant effects of the disease for JK seemed to be those which caused him; a) social and emotional isolation; b) feelings of devaluation; and c) loss of memories from his personal past. In the case of AH, the significance of the impairment came from her perception of feeling: a) discredited because she was not allowed to own her own thoughts and feelings; b) devalued because she believed herself to be treated as invisible; and c) shamed that she could not remember and be accountable for her behaviors. RM, like JK, appeared to take the greatest personal offense to what he perceived as the threat of being scorned and devalued as a consequence of his impairment. In addition to feelings of humiliation, it appeared that RM attempted to dampen feelings of shame by minimizing

and normalizing the effects of loss. For JM the personal significance appeared to be found in the value and care that he was shown by his family.¹ Finally, for KY the significance was dependent on the context in which the memory loss occurred. The loss of memory for personal history was of particular significance to him.

Although the significance of memory impairment was unique for each individual, all participants shared a tendency to resign themselves to acceptance of the disability. This resignation created a somewhat ambivalent attitude. The degree to which there was acceptance differed between the individuals, however. JM apparently resigned himself to the diagnosis of DAT, but did not acknowledge the subjective experience. AH, RM, and KY not only acknowledged their diagnosis, but resigned themselves to it, and reflected upon, their subjective experience of both the present and the future. Perhaps the most surprising form of resignation came from JK who simply stated that it didn't matter to him if he couldn't remember something, he'd ask someone else.

Sense of Self

The sense of self for all five participants can be described in terms of strength, vulnerability, dependency and social membership. These characteristics are best thought of as being found along a continuum.

For the purposes of this paper, the concept of 'strength' refers to an internal core, that part of one's sense of self that is built up over a lifetime and that enables our coping patterns. Three individuals indicated a strong sense of self. AH described herself in terms of someone who wanted to be mistress of her behavior, someone who could choose "not to give in to" what she would perceive as unseemly reactions. Comments such as, "I know what I know", indicated a woman who retained an intact sense of herself as being capable. Similarly, KY retained his belief that he had choices about what he could or could not, would or would not do. His feelings were so strong in

¹ It should not be assumed that because JM focused on the positive attention received from his family he was the only one treated in such a way. All families in the study were caring in their treatment of the participants.

this regard that he commented that the only barrier to his behavior would be his lack of desire. In other words, he believed himself to be master of his own destiny. RM also gave the impression of having a sense of himself as a man bound to maintain a sense of control. One way in which RM indicated this inner resolve was in his indication of appreciation for having been informed of the diagnosis of DAT. RM suggested that by being informed of the diagnosis, he was given something to think about. This suggests that RM, in a way, was still in the process of building his character, that his sense of self was still in the process of “becoming”. In addition, RM’s tendency to ‘cover-up’ suggested a mechanism to maintain his strength and control. On the other hand, JK seemed to feel he had little strength. It was as if his strength had come from support that he received in his relationships with others. In addition to the strength he apparently received from others, it appears that JK had derived a sense of strength throughout his adult life from being in a position of power. The belief that he was no longer the “boss” seemed to affect this sense of strength as if, by giving up the “boss” position, he had been rendered powerless. As for JM, it can be assumed that his constant references to support indicated he felt very little inner strength and needed to be supported externally to compensate for this lack of strength.

The second characteristic describing participants sense of self of participants was that of vulnerability. ‘Vulnerability’, in this thesis, differs from ‘strength’ in that vulnerability refers to the evaluation of one’s relationship with others, rather than an evaluation of one’s inner resolve or character. Since vulnerability seemed independent of strength, it cannot be assumed that an individual who felt inner strength did not feel vulnerable. A sense of vulnerability was found in many of the participants.² The most obvious display of vulnerability was feeling powerless against the whims of others. Two participants indicated such a sense of vulnerability. One stated that there was a need to be careful of what was said for fear of creating problems. The other individual was

² Out of respect for the participants concerns of confidentiality no specifically identified references will be given in this section.

very concerned about the degree of confidentiality in this research and asked numerous times who would know what had been said.³ The issue here is the potential effect a perceived power differential had on the individuals. It can be assumed that the increased dependence brought on by progression of the disease would affect one's sense of vulnerability.

The third characteristic useful in describing the participants sense of self is dependency. Dependency can be defined as the inability to carry out the necessities of daily life, and consequently being reliant on others (Oliver, 1990. p. 83). Once again it is necessary to distinguish between two concepts: the concept of vulnerability and the concept of dependence. Vulnerability, as described above, was reflected in the individuals' awareness of and concern for power differentials. Dependency might best be described in terms of one's awareness of the need for support. It might be argued that the same variables could elicit either a sense of vulnerability or a sense of dependency, depending on the interpretation of the individual.

All five participants acknowledged a level of dependency; however, it was interesting how the concept of dependency was incorporated into the 'self'. For JM the element of dependency appeared to take over his life as he viewed his family and social relationships in terms of the support they could provide for him. JK also appeared to perceive his 'self' in great need of support, and often talked of individuals who would be of a help to him. RM appeared to vacillate between dependence and independence. Although he apparently maintained a sense of self that wanted to participate in decision-making, he hinted at the strong role that his wife played in his well-being and his need for her help. AH, while appearing to cherish and maintain a sense of intrinsic control, was quite frank in her admission that she was dependent on her daughter for instrumental support and on Club 36 for emotional support. Even KY, arguably the individual with the most intact sense of internal strength, unabashedly admitted the role that his family played in supporting him.

³A priority in the reporting of this research was the omission of any interview material that would have placed the participant in a more vulnerable position.

While there can be no doubt that all individuals were aware of their dependent self, dependency appeared to have differential effects on the individual and this effect was likely mediated by the state of 'self'. For example, becoming dependent for JK appeared to mean giving up of power which might have threatened a beleaguered sense of self. On the other hand, KY joked about the fact that his wife left him instructions, and did not appear affected by this gesture. Whereas JK felt that his power was threatened, KY gave the impression that he still felt himself to be in power and that an act of that power was to allow his wife to leave instructions.

Finally, the sense of self appeared to exist in relationship to others. All five participants referred to themselves as members of a community, and all five indicated the value this membership had for them. Although some individuals such as KY and JK referred to the idea of being contributing members of the larger community, the theme common to all five was being a valued member of a smaller social group. This theme of desire and longing to *belong* was undeniably strong, although individually expressed.

For AH, the social self was realized chiefly through her involvement with the Alzheimer Society's social and recreational club. Although appreciative of the help received from her daughter, AH felt that Club 36 provided emotional support that was not available to her anywhere else, partly because the club gave her the opportunity to be with individuals who experienced the same problems as she was experiencing and understood what she was going through. In addition to the more general idea of belonging to a social group, AH also expressed the need for intimacy or a close friendship.

For RM, of importance was the opportunity to talk with others and participate in friendships. KY, despite his rather quiet nature, also indicated his desire for mutual friendships and indicated the value he placed upon being a respected member of his family. JM also appeared to maintain a part of himself in relation to his family in particular. JK was the strongest in his

comments about needing others, and about feeling worthless because of the devalued position he felt he had amongst many of his peers. Regardless of how they attained it, each of the five individuals indicated a 'self' that needed to be part of a social group, and each indicated the need to belong and to be valued.

Perception of Daily Activities

Three of the participants (JK, JM, and KY) described their lives in believable terms. They tended to refer to their lives in terms of "things to do" such as walking, building Mechano, or puttering. In contrast, AH seemed fairly oblivious to her daily life, and could only describe it in terms of doing the things 'she'd always done', and taking her daily walk. On the one occasion when she was asked specifically who she spent her time with, she suggested that she went out fairly often with her daughter's friend (a fairly accurate statement according to her daughter). The only individual who was inaccurate in describing his daily activities was RM who talked in terms of weekly card games with a couple who lived hundreds of miles away. It would seem the reason RM might be more inclined to confabulate friendships is that he had recently moved to the city of Calgary leaving behind established friendships.

Two other brief points should be made. First, three of the participants (JK, JM and RM) described themselves as capable of driving a car. Although JK and JM described themselves as capable of driving, they did not profess to drive daily as did RM (all three had not driven for some time). Second, two individuals (JK, and JM) indicated feelings of boredom. JK indicated that he enjoyed walking because it was something to do, and JM admitted that he got bored sitting around all day.

Valued Activities

Some kinds of activities were valued by most of the participants in the study, while others were specific to the individual. For AH the favored activities were: socializing, talking with others,

having fun, walking and reminiscing. JM preferred his hobby of building with Mechano and reminiscing. For RM the favored activities were socializing, playing cards and reminiscing. KY enjoyed gardening, golfing, listening to his classical music, and tinkering in his workshop. For JK the most valued activities were socializing and walking.

The two activities common to most of the participants were socializing and reminiscing about the past. Socializing is the activity of interacting with other individuals in an informal manner. Reminiscing is the activity of recalling past experiences. The desire to reminisce was common, but the specific 'past' was of course unique to each of them. All participants took pleasure in returning, via thought and conversation, to their past. For JM, the favored era was World War II; for RM his days in the oil industry; JK constantly referred to his favorite sales territory and the people he knew there; and, AH reminisced about her childhood and a couple who had treated her as a child of their own. KY did not openly reminisce about the past, but he did show unusual enthusiasm for conversations that had to do with his cultural heritage and the suffering he endured because of that heritage.

Although it is likely that this return to the past instills a degree of comfort because long-term memories are relatively intact, it also is quite possible that this kind of activity serves a more functional purpose. Reminiscing appeared to provide two individual with a means of escaping stressful or distressing situations. Both RM and AH actually stated when they need to escape stress they "returned to the past".

Just as reminiscing might be a coping mechanism, it is possible that other activities such as walking or wandering are also coping mechanisms. For example, JK suggested that he needed to walk and that walking was an activity which he was able to do. Similarly, RM described his nocturnal wanderings as a behavior that got his mind off of his concerns. Furthermore, wandering

as an apparent function of stress relief, was apparent with KY on the two occasions in which he showed agitation with his memory loss.

All participants indicated their enjoyment for activity. In talking about Club 36, JM boasted it was a place where they “did things”. To JM, ‘doing things’ encompassed a variety of activities including, going for an ice-cream cone or building a bird house. The specific activity didn’t appear to be as important as the sense of pride that participation in an activity gave him. For AH, activity and “fun” went together. AH delighted in describing how they did “crazy” things at Club 36, like indoor golfing. RM’s preferred activities were playing cards, a skill which he still managed to do well, and ‘socializing’. JK loved to walk but the also enjoyed other activities such as dancing and bowling. Finally, KY enjoyed more solitary activities such as ‘puttering’, golfing, gardening and listening to music.

Concerns

Five of the six participants indicated concern for the future. Concern for the future was shown by AH in her references to the possible closure of Club 36. JM indicated that he had no concerns for the future, nor, according to JM did he have any concerns in the present. One must question the validity of these statements however since JM was the individual who seemed most beset by the idea of others giving him support. RM openly spoke of his concern for his future. It was unclear whether RM was always referring to his ‘DAT future’; however, there was an underlying anxiety on his part as evidenced by his descriptions of worry. JK appeared to most concerned about being abandoned and lonely. Finally, for KY, the only real concern expressed was not being as close to his daughter as he would like.

Chapter V

Discussion

The objective of this study was to gain an understanding of the experience of individuals with a Dementia of the Alzheimer Type. Inherent in this objective were questions such as: How did individuals interpret what was happening to them; and how did they interpret the reactions of others? The objective was addressed by asking two specific questions. First, how do individuals with DAT describe their experience? Second, how does the decision to inform individuals of the diagnosis contribute to their experience with dementia? A discussion of findings follows.

Common Issues of Living With a Dementia

Thematic analysis resulted in the identification of five issues common to the participants: cognitive awareness; emotional appraisal; dependency versus autonomy; community participation; and need for personal meaning. These are discussed below in relation to previous research.

Cognitive Awareness

One of the most significant findings of this study is the extent to which individuals with a dementia can contribute to our understanding of the experience. Participants were able to articulate their experience of awareness, personal significance, concerns, valued activities, daily activities and sense of self. Not only were they able to articulate these experiences, but their description of their experience was found to be trustworthy as indicated by: a) the agreement between participants descriptions and observations made by observer-as-participant, b) the reliability of participants statements as tested by repeated interviews and triangulation, c) the commonality of experience shared by the participants; and, d) the agreement between what they described and what was reported in the literature.

As described in the Results section, the extent to which individuals indicated an awareness of cognitive impairment was influenced by fluctuations in their abilities and the specific ability being described. The first influence on the described loss of cognitive ability was the perceived fluctuation in clarity of thinking. Two participants referred specifically to their impression that there were times when they could think more clearly than at other times. Another alluded to the impression of variability when she said she'd be able to recall information at a later time. Three participants referred to their impression of fluctuation in positive terms since it apparently allowed them to minimize the effects of cognitive impairment. The literature consistently reports a fluctuation in ability associated with DAT. Hiatt (1990) discusses the extent to which awareness fluctuates within short periods of time; and Weaverdyck (1990) discusses the need for flexibility in assessing the severity of impairment of DAT due to fluctuation in ability according to day of the week, time of day, and environmental factors.

Differences in awareness, dependent upon the skill being described, were also present. These differences can be illustrated by contrasting deficits that were generally acknowledged by participants, (e.g. memory loss), with deficits that were not generally acknowledged, (e.g. inability to drive a car). These differences in awareness could be the result of the immediacy of feedback with different tasks. For example, if someone were to forget why they put on a coat, the deficit in short term memory would be apparent to them, at least in the earlier stages of the disease. Such a deficit in short-term memory would result in concrete feedback, since the individual would be confused as to why he or she had put on a coat. Thinking about one's driving ability, on the other hand, requires that the individual imagines him or herself performing certain abstract functions such as using good judgment. Imagining oneself performing a task provides no immediate feedback concerning ability.

While it is reasonable that immediacy of feedback effects awareness of impairment, this is an insufficient explanation. Evidence gathered in the study indicated awareness of two tasks which are similar in immediacy of feedback, yet did not yield the same degree of awareness. The task of imagining oneself driving a car is similar to the task of imagining oneself navigating one's way about one's neighborhood, in that neither provide immediate feedback on the performance of tasks. One task, but not the other, was associated with awareness of loss in three individuals. The same three individuals who denied loss of skills required for driving a car acknowledged an awareness of the potential for getting lost. While we cannot be certain why there is a difference in the awareness of impairment for these two skills, it is possible that lack of awareness for deficits of car driving skills came from an emotional reaction to the loss of driving ability rather than from a lack of cognitive awareness. Driving might be so representative of adulthood and independence that it is difficult to admit impairment in that area.

An interesting observation concerning awareness was that level of cognitive functioning, as measured by the DRS, was not a good predictor for awareness of symptoms. The individuals who had the three lowest scores on the DRS described more awareness of their symptoms than the individual with the second highest score. It is likely this discrepancy indicates the role personality and coping styles have in admission of awareness. For example although RM admitted more awareness of symptoms than JM, there is no evidence that he was, in fact, any more aware. While RM admitted certain impairments such as memory loss he was unaware of other symptoms such as temporal confusion. On the other hand, JM denied awareness of symptoms but described some that he may not have connected to DAT, such as being bothered by noise and crowds. In the end it can be concluded that a) admission of awareness is not the same as experience of awareness and b) personality and coping skills may be more indicative of 'awareness' than is cognitive level of impairment.

Emotional Appraisal

A distinction can be made between cognitive awareness and emotional appraisal. While cognitive awareness of deficits involves the judgment of one's abilities, emotional appraisal reflects an evaluation of the subjective experience of living with DAT. Emotional appraisals were influenced by both the negative and positive self evaluation of individuals in relation to their cognitive impairments and their sense of self. Self descriptions by participants such as 'stupid' and 'dumb' were indications of negative self-evaluation, whereas comments such as "I know what I know" and "Just because...doesn't mean " were indicative of positive self-evaluation.

One might expect that the progressive loss of skills associated with DAT would bring with it intrinsic feelings of negative self-worth, however, this was not usually the case. Except for one individual, participants generally described themselves in positive terms. Statements of deficit were often made as statements of fact, and only occasionally suggested feelings of recrimination. When negative comments reflected an underlying sense of negative self-evaluation, they seemed to stem not from the loss of memory per se, but from the significance of the loss for the individual.

In addition to intrinsic factors of self evaluation, there also are extrinsic factors such the perceived evaluation of the opinion of others. Based on findings, it is suggested that perceptions of negative evaluation are more often associated with the reactions and attitudes of others than intrinsic feelings of worthlessness. For example, individuals either commented on feeling, or were observed to be, slighted, left out, discredited, shamed, devalued, or belittled by others. Instances of humiliation and belittlement led individuals to describe feelings of devaluation, react with anger, show signs of agitation, or emotionally withdraw. This awareness of the evaluation of others by individuals with DAT has been noted by other researchers (Harrison, 1993; Kelley & Lakin 1988).

The importance of drawing attention to the relationship between the effects of the negative appraisals of others and consequent behaviors relates to the tendency of researchers to use a term such as depression to describe such behaviors. While it is true that signs, such as withdrawal, and symptoms such as feelings of devaluation, are commonly associated with depression, this association is descriptive and lacks causal utility. To illustrate, describing an individual as withdrawn does nothing to tell us why he or she has withdrawn. Has the individual withdrawn because he or she feels unwanted or ridiculed, or has he or she withdrawn as a retreat from stimulation that is too intense? Weaverdyck and Coons (1988) suggest that individuals with DAT have difficulty coping with large spaces and more than a few individuals and Mace (1990) suggests that the individual with DAT requires an environment where the level of stimuli is felt to be manageable. One way of achieving this need for a manageable level of 'stress', if not provided by others, is to close oneself off from over stimulation of the environment. This, in fact, was the description given by one of the participants for his preference in not attending certain functions.

In addition to withdrawal from stimulation, there can also be the withdrawal from emotional hurt. An individual who experiences moderate or severe aphasia would constantly be reminded of his impairment which in turn contributes to exclusion from many conversations. He or she would have few options, unless provided by others, to break down the barriers to communication and may be tempted to retreat into silence.

Similarly, noting that an individual feels devalued tells us nothing about the reason for these feelings. Are the feelings of being devalued a product of a "depression", or are they realistic assessments of how the individual is viewed by others? While it is possible to interpret withdrawal or feelings of devaluation as pathological, it might be worthwhile to regard these actions as normal responses to the negative evaluations of others.

Another common indicator of depression is apathy. Apathy, like withdrawal, is a descriptor for observed behavior and, like the term withdrawal, does nothing for our understanding of the experience. Could the individual who appears apathetic be quietly struggling with the acceptance of cognitive impairment? Could the person's apparent resignation reflect life-long coping skills rather than something inherent in DAT? It can be assumed that individuals, at least in the early phases of dementia, face the dilemma of their own mortality. Is it possible that this apparent resignation reflects a deeper conflict related to one's realization of mortality and the desire to come to terms with the meaning of life? Tobin (1991) studied a group of elders who were facing death and found that their tendency was to withdraw as they approached the time of death. This raises several questions. Could this kind of withdrawal be the apathy that researchers attribute to depression? Is it 'depression' or is it 'appropriate resignation'? It is likely that for some individuals it is a depression, and for others it may be a resignation to their expected mortality.

The use of descriptors for persons with DAT, such as depressed, is unfortunate for two reasons. First, the negative connotation of such terms makes it more likely that adaptive properties of certain behaviors are ignored. Second, the use of the term implies an intrapersonal problem, and downplays the importance of interpersonal and social factors on the behavior and affect of the individual with DAT.

In order to distinguish between adaptive response and inappropriate reactions, we must look beyond symptoms and signs to the meaning attributed to these characteristics. The only way to understand the responses and reactions of persons with DAT is to ask the individuals who experience it. This, however, is not common practice. Only two (Lazarus et al., 1987; Teri & Gallagher-Thompson, 1991) out of six studies on 'depression' and DAT (Lazarus et al., 1987; Merriam et al., 1988; Reifler et al., 1982; Reifler et al. 1986; Teri et al., 1989; Teri & Gallagher-Thompson, 1991) considered the perspective of the individual with DAT. This study took the

viewpoint of correcting a pathology rather than determining the meaning behind the person's response. This is not to deny that some instances of negative outlook can result from a chemical imbalance brought about by neurological pathology, but it is meant as a caution to look beyond symptoms and signs and ask the meaning behind these characteristics. This research indicated that the individuals with DAT are able to tell us a great deal about how they feel and why they respond. For example feeling "invisible" and lonely because they are not included in conversations.

Community Participation

Cox (1985) described a research unit, in the United States, for individuals experiencing DAT. The unit was based on principles of increasing the individual's sense of personal control and feelings of dignity, promotion of community, sense of belonging, and acceptance. Individuals on the unit engaged in peer support activities which encouraged acceptance of each others limitations and the sharing of concerns. The belief that individuals with DAT are in the best position to understand the experience of others with DAT was paramount to the principles of the unit. Staff had the crucial role of facilitating and supporting remaining strengths while, at the same time, saving individuals from embarrassment because of their failure at specific tasks. This unit provided a sense of 'community' by accepting the individual as he or she was, supporting individual weakness, and valuing remaining strengths. The movement toward membership in a community is not specific to dementia. Tobin (1991) found that elderly people who faced death also moved away from being assertive and affiliating more closely with others.

In the study not only were the individuals emotionally aware, they had a desire to be emotionally connected. The emotional connection came not from the desire to be cared for, but from the longing to be valued and accepted. All participants valued membership in a community where they felt needed, were accepted as 'individuals', had fun, shared intimacy, and were respected for their remaining strengths. Many of these characteristics were found by the individuals

in membership in a social and recreation club run by the local Alzheimer Society. The idea of belonging to a community where one is supported by others experiencing similar difficulties, was expressed by AH in her comment about appreciating Club 36 where people were the “same”. AH was particularly strong in her emphasis that it “helped” to be there with others who had been through the same thing. The idea of being valued was expressed by JM who indicated everyone was treated well there and it was just like family. It appeared that the function of the club may have come from allowing the individuals to gain strength from one another and be valued for who they were, not as stereotypes or caricatures.

Dependence Versus Autonomy

One of the consequences of dementia is that, with the passage of time, a person progresses into greater states of dependency. Dependency, as previously defined, is an inability to carry out the necessities of daily life and, consequently contributes toward reliance on others (Oliver, 1990, p.83). While all participants in this study acknowledged dependency, it was not necessarily associated with a negative attitude. In general, statements regarding dependency were positive. It can be concluded, therefore, that dependency per se was not necessarily a negative consequence of DAT.

While dependency itself was not necessarily regarded as negative, the same cannot be said for the loss of control. Whereas dependency involved a reliance on others for the basic necessities of life, loss of control involved the loss of power to make decisions. Descriptions of incidents involving a loss of control were almost invariably accompanied by reactions of anger or withdrawal.

Loss of control took many forms and involved the negation of sovereignty over one's thoughts, feelings and actions. The loss of control of thoughts and feelings refers to the tendency of others to interpret or, in the worst case, negate the expressed feelings or thoughts of the individual

with DAT. This tendency was shown by caregivers as they ‘corrected’ the memories or feelings of individuals with DAT; for example, telling them they could remember things when they could not, or feel things they did not. By not allowing the individuals to experience control for what their thoughts “should be”. Reaction to this loss of control was seen to result in apparent humiliation and anger. Despite the potential humiliation it caused, this behavior is reported in the literature to be common amongst caregivers (Kelley & Lakin, 1988). In its more obvious form, loss of control could be found in the perceived loss of power to make decision. The individuals perceptions that others were making decisions for them, or the hypothetical thought of others making decisions for them, usually was met with anger and resentment.

Autonomy, as defined by Brechling & Schneider (1993) involves independence, and self-determination through the ability to make decisions. Autonomy is an issue for individuals with DAT because of the conflict between reality and idealism. In reality, the ability to make sound judgments progressively declines, while the ideal of dignity that accompanies the decision-making power remains (Brechling & Schneider, 1993). The dilemma was clearly described by JK as he spoke of wanting to take walks independently while knowing that he was losing his ability to find his way home.

The dilemma of autonomy associated with DAT is raised as an issue by Gilleard (1992) who suggests one of the essential features of ‘adulthood’ is the ability to make decisions that reflect our values and attitudes. Despite the ideal of autonomy, there is real concern for the extent to which individuals with DAT are capable of autonomous thought (Harrison, 1993). If we accept that decision-making will be adversely affected by the degree of cognitive impairment, and that decision making is a characteristic of adulthood, it follows that the progression of dementia will bring with it problems of autonomy, and insults to the individual’s sense of adulthood.

One way of addressing the issue of control is to determine the individual's perspective on the subject. By determining what elements of 'control' are either offensive or beneficial, a sense of autonomy might be maintained by offering choices that have no significant risk of harm. For example, both JK and AH were pleased that they were allowed to take walks independently but both did not go beyond a small known circuit. Although the parameters were defined, a sense of control was provided.

All participants made statements indicating their resentment, or hypothesized resentment, toward attempts by others to take control away from them. There was a distinction however between having control taken away and conceding control. In those instances in which there were no statements of resentment toward the loss of control, participants described the matter in terms of relinquishing control rather than having control taken away. In other words, the key to retaining autonomy seems to be in the attribution of control. For example, when one individual described how he allowed his spouse to have more decision making power, it was described as if the decision to allow her more power would not diminish his own strength. In his perception, control was not taken away; rather, he allowed control to be given to his spouse. When one individual allows another to have decision making power it is the one who 'does the allowing' who maintains control.

The preceding example is an illustration of how loss of control is subjectively, rather than objectively, defined. Control is an issue of power and is affected by several factors including role rigidity, stage in the life cycle and the extent of brain pathology. Males who have had a traditional view of their roles believe that it is a male's role to have the power and control in the family (Simon, 1989, p.114). Men who have rigidly adhered to roles based on gender likely find it more difficult to concede control than those who adhered to a more egalitarian view of power. The difficulty that some males have in conceding control seems dependent on the stage in one's life-cycle that the change occurs. Walsh (1989, p. 326) indicates that individuals become more flexible

in gender-associated roles as they age. Citing previous research by Gutmann (1977) and Sinnott (1977), she suggested the tendency of the male to become more nurturing, and the female more assertive as they age. This move toward less rigid gender roles makes the transitions in roles easier for individuals in the later years. The two characteristics of rigidity in role and being of a younger age, were possessed by the participant who had the most difficulty with the issue of control. JK was quite open in expressing the difficulty he had with his wife being “the boss” and, according to his wife, he had always wanted to follow traditional roles such as her not working outside the home. JK was also the youngest participant (62 years of age) and had been required to retire from an active career because of DAT. This might have made control more of an issue for him than for other participants.

In addition to personal variables that affected a sense of control there are some choices caregivers could make in encouraging a sense of autonomy. For example, all individuals indicated they appreciated having been informed of their diagnosis. It was as if having been informed of the diagnosis allowed them to be included in the concern for their own well-being. Cox (1985) commented in a similar vein regarding individuals with DAT who had participated in several months of milieu therapy. She indicated that individuals had been allowed to retain a sense of responsibility which had made them

perhaps more aware of their pain but less afraid of it. Alzheimer’s disease has taken options from them, but they have gained a different kind of control by facing their dilemma through shared grief and empathy. (Cox, 1985, p. 154)

This issue of control is not unique to individuals with a dementia. Tobin (1991) reports in his study of personhood in old age, one of the most common concerns of the elderly in regards to death was concern over loss of control.

The Need for Personal Meaning

The search for personal meaning in the face of physical decline has been addressed by several authors. Wong (1989) defines personal meaning as “the individually constructed cognitive system that is grounded in values and is capable of endowing life with personal significance and satisfaction” (p. 517). This definition suggests that personal meaning contains cognitive, motivational and affective aspects. The cognitive aspect involves how we make sense of the world around us, the motivational aspect gives importance to the search for meaning, and the affective aspect effects how we use the meaning we have created to foster and support a sense that one’s life has been worthwhile. This section of the theses will address the affective aspect of personal meaning.

Personal meaning, as a theme, has been explored in relation to life threatening illnesses, the aging process and in terms of dementia. A life threatening crisis was described by Frank (1989) as an opportunity to develop meaning in one’s life. Specifically, Frank suggested the experience of a serious illness prompted individuals to respond to the situation in two ways: One could either react to the crisis as a threat to personal identity or respond to it as an opportunity to bring meaning to his or her life. Butler and Lewis (1974) also talk of personal meaning but from the perspective of aging. They suggest that aging brings with it a loss of control, and individuals can compensate for this loss by focusing on the search for personal meaning.

Tobin (1988) also addressed the issue of purpose from the perspective of loss. Tobin found that individuals who faced the accumulation of personal losses associated with aging, in particular an impending loss of life, sought meaning from the life they had lived. He further suggested one way of creating meaning was to create a ‘self’ who’s past justified one’s life. According to Tobin, the need to create a solid self that justifies one’s life is so important, the individual will often

‘mythesize’ his or her life and create a “self” that exonerates one’s existence. In a sense, the emphasis on ‘I am who I have become’ focuses the attention to one’s past.

There is evidence that two individuals, AH and JM, engaged in a mythesizing. AH reminisced more than any of the other participants and her memories were about her childhood, her mother, her father, and a couple who had been very close to her. According to AH’s stories these individuals were the epitome of good. Her father adored her mother, her mother was the kindest woman ever and the couple who had been a surrogate aunt and uncle were community ‘saviors’. Although it was comforting to think that such people could exist, the likelihood of them having been as perfect as described was small. Every once in awhile the picture of perfection would crack and AH would get confused as she recounted her ‘myth’. During these short lived periods of confusion, which perhaps indicated conflicting memories, she would comment in a way suggestive that something was wrong with her story, but she couldn’t be sure what it was. Usually however the interruption was momentary and she would quickly resume her happy childhood memories.

JM also seemed to be creating a myth, but in his case, it was a myth concerning his family, his children in particular. During the course of the interviews, the descriptions of his family seemed to take on unusual characteristics of caring and at one point, in the fieldnotes, a comment was written concerning the suspicion that JM was embellishing the goodness of his family. Unfortunately since most exchanges had not been recorded it is difficult to go back and investigate the accuracy of this query.

Harrison (1993) referred to similar concepts in her work on dementia and personhood. Harrison defined personhood as that essential quality that makes an individual the same ‘person’ over time and the essential element is the continuity of thoughts, beliefs and memories. Harrison suggests that the experience of dementia threatens the sense of self. This in turn creates the necessity to protect personhood through distortion of their history thereby maintaining an

identifiable, strong 'self'. She suggested that the maintenance of personhood is vital to the individual and suggests that maintenance of characteristics that were integral to an individual's identity be encouraged, even if that means supporting activities which are no longer easily accomplished by the individual. JM's desire to build his Mechano sets, even though it caused him difficulty, was an example of the individual trying to maintain his or her self through activity.

A frequent behavior of participants in this study was reminiscing, the "vocal or silent recall of events in a person's life, either alone, or with another person or group of people" (Woods, Portnoy, Head & Jones, 1992, p.138). At one time reminiscing was viewed as a negative consequence of senility, but has more recently been viewed as having positive benefits for the creation of meaning and making sense of one's existence (Butler & Lewis, 1974; Woods et al., 1992). The sense making of reminiscing was particularly evident in RM and AH. Both used memories from the past, personal difficulties for AH and professional problems for RM, in relation to dealing with the problems associated with DAT. For example, AH in talking about her concern about ending up in a nursing home quickly changed topic to how she had coped with having her appendix removed. RM was able to use his life experience to help him cope with the confusion he sometimes experienced. Upon commenting on the confusion, he then recalled how he had been able to stop worrying about professional problems when he worked in the field. He then reminisced about the past and the problems he had encountered. Reminiscing was a tool, in these cases, which allowed the individuals to keep in touch with their accomplishments and bolster their sense of self which continued to face challenges. At these moments, the thread of personhood was strengthened and the meaning of their hardships given significance in light of the present and the future.

Not only is it possibly a strategy to maintain a sense of self, but evidence from this study suggests that reminiscing can represent a conscious effort on the part of the individual to reduce

stress. Two individuals (AH and RM) described clearly the strategy reminiscing in times of distress (See Reminiscing in Atypical Behaviors as Coping Strategies).

People with dementia often reminisce, but not always with the permission of others. Recalling the past is often seen as a deficit by others (Woods et al., 1992) however, if we accept that reminiscence is a strategy individuals engage in to maintain a dwindling sense of personhood (Harrison, 1993), to place their life within a meaningful context (Butler & Lewis, 1974) and to minimize moments of distress, then it can be viewed as a positive adaptation.

Summary of Common Issues of Living with Dementia

The phenomenological approach of this study, has allowed the researcher to gain an in-depth understanding of the experience of five individuals with DAT. A number of issues presented by participants are similar to those reported in the research literature on DAT and illness. The experience of interviewing highlighted a) the participants awareness of DAT, b) their ability to reflect upon their perceptions and, c) factors which influenced these perceptions. Of particular interest to the researcher were the internal and external influence of control, and the positive influence of a sense of community. Professionals and researchers need to see beyond the label of dementia and create ways in which individuals can maintain a sense of control and belonging, given their remaining strengths. The DAT unit described by Cox (1985) offers promise of this type of approach.

Disclosure of the Diagnosis of Dementia to the Affected Individual

The second research question raised the issue of the effects of diagnosis disclosure on the affected individual. Based on this study, where all five participants were appreciative of being told of the diagnosis, it may be assumed that disclosure can be beneficial. Disclosure of the diagnosis potentially has three significant benefits which will be discussed below.

The decision not to inform an individual of the diagnosis of DAT is usually based on assumption that the individual is not aware that he or she is aware has a cognitive impairment. This assumption is likely erroneous, especially in the earlier stages of the disease as indicated by the present research. Two of the five participants indicated they had known, previous to diagnosis, there was 'a problem' with their cognitive functioning. Both individuals were appreciative of being informed of the diagnosis since it allowed them to stop worrying about potential problems and to deal with the real issue of adjusting to a progressive dementia. There was no evidence of prior knowledge for the other three participants but that does not mean they had been unaware of their symptoms: two were unable to recall the early stages of the disease, and the third likely minimized or denied any symptoms. Furthermore all individuals, even those in the moderate to moderate-severe range of dementia were able to describe their symptoms of cognitive impairment suggesting a greater awareness than might be expected.

Autonomy was one principle that was espoused by most of the participants. If autonomy is viewed as independence of thoughts and emotions, and self-determination through decision making, these two elements can be satisfied by the disclosure of the diagnosis of DAT. If it can be assumed that individuals with DAT are aware they are experiencing some form of cognitive impairment, it might also be assumed that they are concerned about the future of the disease. One of their concerns might be the loss of decision-making power and the fear that they would lose control. By informing the individual of the diagnosis it allows them to maintain a sense of autonomy of their future since they can actively participate in decisions regarding that future (Brechling & Schneider, 1993). This would hopefully have the benefit of allaying some of their fears about the future.

The most hurtful loss of independence for the participants was having sovereignty of their thoughts and feelings taken away. This lack of sovereignty tended to bring with it feelings of devaluation and discreditation. By discussing the issue of diagnosis with the individual there would

be an acknowledgment that those with cognitive impairment still ‘owned their own minds’, had the right to use this faculty to consider their lives, and respond to the situation with the wisdom of coping strategies that they had gained over a lifetime. By denying the rights of the individual to know what is happening to his or her life, the negation of the potential for the wisdom, or accumulation of decades of personal knowledge is denied.

Furthermore, the disclosure of the diagnosis can provide the knowledge that is necessary to build a framework from which individuals could both understand and discuss their behaviors and emotions openly. For example AH indicated that it helped to know what the problem was. Although it is not likely that AH was always reminding herself she had DAT, she did report spontaneously that having this knowledge allowed her to interpret her behavior differently. On those occasions when an individual with DAT is not cognizant of his or her behavior, or is confused about an emotional reaction that seems out of character, the prior disclosure of the disease would allow greater flexibility in discussing the issue. Even if the individuals cannot totally appreciate the content of the conversation they would benefit from being respected enough to be allowed to participate in their lives.

Atypical Behaviors as Coping Strategies

Many of the behaviors associated with DAT can either be viewed as deficits passively incorporated by the individual, or as coping mechanisms actively engaged in by the individual. Coping mechanisms can be defined as the resources available to an individual which assist in the accommodation of distressing life events. These mechanism can include both conscious and sub-conscious behavior. For example, withdrawal, a behavior commonly attributed to personality change, could be viewed as a deficit in behavior, or as a conscious or sub-conscious strategy used by the individual to escape bothersome stimuli. It is also possible that withdrawal could be used by the individual to reminisce and mentally create a life that could be thought of as having been worth

living. In essence, by either mentally or physically withdrawing, the individuals maintained a sense of autonomy.

One of the most interesting aspects of this study was the identification of coping mechanisms, seven in all: a) community participation; b) acceptance of impairment; c) acknowledgment of the need for support; d) maintaining a sense of autonomy; e) reminiscing; f) minimization of impairment; and g) engaging in activities.

Community Participation

Describing themselves as valued members of a community, often the ‘community’ provided by the social and recreational club of the local Alzheimer Society, brought pride to all participants. An understanding of the pride experienced is obtained if we consider the properties of the club in relation to those activities which enhance quality of life through the maintenance of self-esteem. Zgola (1990) suggests that certain activities are beneficial to the maintenance of psychosocial needs including: an identity; positive esteem of oneself and others that comes from an activity valued by others; ‘meaningful’ relationships; and membership in an accepting group. Through membership in Club 36, individuals experiencing DAT were able to have all of these needs met because they felt like ‘individuals’; were encouraged to engage in recreational activities; were able to feel equal to the other members rather than inferior; and shared experience with other individuals who experienced and understood the difficulties of living with DAT.

Acceptance of Impairment

Four individuals (AH, KY, JK and JM) accepted their diagnosis as a part of life. None of these individuals celebrated the impairment, but all resigned themselves to the realization that DAT, and/or the impairment it brought, was a part of life that could not change. It is possible to interpret this resignation as apathy, but we should look more deeply and ask if, in some individuals

at least, this resignation is not wisdom. This coping strategy might be considered an integral part of life review therapy.

Acknowledgment of the Need for Support

All participants believed themselves to be supported by others. The level of support varied both intra- and interpersonally, but the core feeling of 'being supported' was described by all individuals. The most commonly acknowledged form of assistance was instrumental support for activities of daily living. Participants described themselves as being aware of the need for support in the management of their daily activities. By allowing themselves to feel supported, the individuals, who all experienced awareness of impairment were relieved of the responsibility of caring for themselves, a task they apparently believed to be beyond their capabilities.

Maintaining a Sense of Autonomy

Support should not be considered the same as autonomy. Autonomy is described as having two essential elements: a) self-determination through decision-making and b) independence. Individuals who valued support often indicated a desire to maintain autonomy. In many instances autonomy became an issue between the individual with DAT and the caregiver. One of the most frequently mentioned ways of having a sense of autonomy was by being included in the process of dealing with their disease. This sense of ownership of one's life, a feeling that accompanies autonomy, was often achieved by being actively involved in decisions regarding daily activities. All five participants acknowledged their appreciation of being informed of the diagnosis and most spontaneously spoke of wanting to play an active role in decision-making that affected their lives.

Reminiscing

Perhaps the most unexpected coping mechanism was a control over emotional stress. Evidence for this control came from two individuals who indicated they used a return to the past as a way of escaping stressful situations. This strategy was described by them as a conscious effort to

escape from a negative situation into a positive one, from a distressing situation to a comforting one. It is doubtful that this mental and emotional return to the past, or reminiscing, is always a conscious effort to manage one's level of strain. However, the fact that it was described by two of the five participants indicates an active search for coping strategies by individuals with DAT. This strategy, of reminiscing, along with acceptance of impairment would be considered a vital component of life review therapy.

Minimizing of Impairment

Minimization of deficits might best be seen as a coping strategy that allows the individual to focusing on remaining skills. Zgola (1990) has stressed the need to minimize the negative effects on self-esteem by focusing on remaining skills. Although minimization might be a positive coping strategy, when it is taken to an extreme, such as in denial, it might present interpersonal problems.

Engaging in Activities

Engagement in activities was positively regarded by all participants. Individuals appeared to use activity as a strategy to deal with two problems: boredom and distress. Several individuals commented that they experienced boredom and enjoyed the opportunity to be involved in appropriate activities. Activity as a strategy against distress was also described by one individual.

Summary of Coping Skills

It appears, then, that individuals with DAT actively seek, and intuitively know, what a coping strategy is for them. Not all individuals chose the same strategy, and those identified above are not meant to be all-inclusive. The description of such mechanisms should be taken, however, as an indication that individuals with dementia should be included in their care and treatment.

Limitations of the Study

Three limitations to the present study should be noted: a) selection bias, b) communication difficulties, and c) the lack of rigor for determining the diagnosis of the individual.

At the onset it was noted that individuals in this study were not randomly selected, rather they were chosen on the basis of certain characteristics including: a definite diagnosis of DAT; a positive work and vocational history; and a minimum of communication ability. Individuals who chose to participate in this study were likely to be: a) inherently sociable, b) aware of their diagnosis, c) viewed by the Alzheimer Society as relatively articulate, d) members of families that would be open to the views of others, and e) represent individuals at particular stages of the disease. There was no intent to imply that people with these characteristics are representative of the population of persons with DAT. On the other hand, there is no reason to suspect these individuals were anymore sociable, insightful or articulate than many other individuals with DAT. Furthermore, although these characteristics can all be seen as limitations, they can also be seen as strengths in that they reveal the potential of the individual with DAT.

The second limitation was that of communication difficulties of some of the participants. There can be no doubt that the severe aphasic-like behavior of one individual, and the severe memory problems of two others, hampered the interviews and gave rise to concerns over the interpretation of the results. This was taken as a serious consideration; however, these same factors can also be looked at in terms of helping to create a degree of rigor in one methodology that would not have been found if such limitations had not been present. For example, the difficulties in communication required extensive bracketing in the interpretation of some narratives and extreme attention to trustworthiness. Struggles with language occasionally forced questions to be re-framed, answers to be bracketed and new insights to be gained.

Finally, one caution must be added about the use of DAT in describing the diagnosis of the individuals. All individuals referred to themselves as having Alzheimer Disease, all caregivers referred to the individuals as having Alzheimer Disease and the Alzheimer Society of Calgary suggested them for the study based on the assumption they had Alzheimer Disease; however, there

was no confirmation of these diagnoses with medical records. On the other hand, there is no reason to suspect that these individuals were not experiencing DAT.

Conclusions

Based on the findings of this research six conclusions can be drawn.

1. Individuals with dementia of the Alzheimer Type can offer trustworthy insight into the experience of the disease. It is true that individuals who experience a dementia are not necessarily good historians, but there was no evidence to indicate they were unable to be faithful describers of their experience. To the contrary, their descriptions, although sometimes rambling, rang true of their inner experience.

2. Cognitive awareness and emotional appraisal are two different issues. Individuals with DAT might not always be aware of specific symptoms, nor were they always aware of the implications of the disease, however, they were quite aware and sensitive to the reactions and appraisals others as well as being subject to their own self-appraisals.

3. A distinction must be made between dependency and control. Whereas the individuals with dementia might realize and accept their need for instrumental support, they were not quite as willing to give up their sense of control.

4. Disclosure of the disease to individuals with DAT can have positive effects. These positive effects included: allowing the individuals to feel that they were included in the decision-making and control processes that governed their lives; provided a framework from which to understand their behavior; and allowed the open discussion of effect and behavior between the individual with DAT and significant others in their relationship.

5. Symptoms and signs associated with DAT may provide a shorthand for professionals, but does little for us to understand the meaning behind the symptoms and signs. By dismissing behavior as depressive, or withdrawn, and not determining the meaning behind such

behavior there is a disservice in two ways: a) potential for appropriate interventions is reduced, and b) the possibility that the behavior or affect is adaptive is denied.

6. It would be beneficial to view some of the problematic behaviors of the individuals with DAT as coping mechanisms. Many strategies now advocated by professionals, such as life-review or focusing on remaining strengths, had previously been denigrated as 'maladaptive behaviors'. Rather than condemn given behaviors as inappropriate, it would seem appropriate to seek an understanding of what the purpose of such behaviours is from the perspective of the individual who is experiencing DAT and devise personal support strategies in the light of such alternate understanding.

Future Research

The description of the experience of the five participants suggests four topics for future research: the effect of a) autonomy, b) community membership, c) disclosure of the diagnosis and d) inherent coping mechanisms on the behaviors and affective response of individuals with DAT.

Participants indicated an acceptance of dependency but not an acceptance of lack of autonomy. Interventions aimed at the encouragement of autonomy have been shown to have positive effects. Arendt and Jones (1992), citing pilot studies by Annerstedt et al . (1987) and Karlsson et al. (1988), indicate that experimental groups which had received interventions aimed primarily at "psychological integrity and autonomy" showed significantly less cognitive, emotional and psychomotor deterioration than control groups. Furthermore, the experimental groups showed detectable biochemical change in their cerebrospinal fluid. The challenge with individuals with a progressive dementia is to provide genuine opportunities for decision-making within a safe environment so moments of poor judgment will not endanger their well-being.

Community membership was another area identified as important to the individual. The disabilities, created by DAT, make an individual's involvement in the community challenging for

both himself or herself as well as for others. Social and recreational needs have been recognized as therapeutic for individuals with dementia (Zgola, 1990), however, there has not been a similar recognition of the benefits of being a valued member of a community. A common misperception of the disabled is they somehow do not have the same need for intimacy and interpersonal relationships as the rest of the population. Mace (1990) reminds us that the DAT individual does have a need for those human qualities. Gilleard (1992) further suggests that one's identity is maintained within a social network and it is through social interaction that one maintains one's place in the world. It is unknown to what extent the sense of self of individuals with DAT is preserved by interactions with others and having a sense of belonging, however, the concept of community membership and DAT would be worth investigation.

The present research indicated four benefits of disclosure of the diagnosis of DAT: a) individuals are likely already aware of cognitive impairment and might experience disclosure as a relief from unknown and unstated possibilities; b) autonomy is encouraged since the individual can be included in decision making discussions; c) involvement in discussion is a confirmation of remaining abilities and; d) it provides an open framework for future discussion of problem behaviors. Considering the lack of previous literature on disclosure, and the selection bias of this sample, systematic research into the benefits of disclosure should be encouraged.

Finally, reminiscence, a process that commonly accompanies DAT, has been considered by some researchers (Lewis & Butler, 1974; Woods et al, 1992) to be therapeutic. It has been suggested that engagement in life review, or reminiscence, allows the individual to create meaning out of the life he or she has lived. It is also possible that reminiscence serves as a coping strategy against stress. At times of stress, the individual might engage in reminiscence in order to either recall successful handling of similar situations, thus instilling a sense of confidence, or remembering instances of 'comfort' therefore attaining a sense of solace. The effects of reminiscing, an easily

accomplished intervention for individuals with DAT, should be researched systematically with the intent of determining effects on well-being and/or behavioral adaptation.

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APPENDICES

Appendix A

Guided Interview Topics and Sample Questions

Underlying Assumptions and Beliefs.

Can you explain to me the kind of memory problems that you have?

Do you have any idea what causes this kind of problem?

How do you think that this memory problem effects you?

If I were to ask _____(caregiver) how the memory problem affects you what do you think she would say?

Do you think that the problems with your memory also affect _____(caregiver)?

How?

Can you remember back to when this problem began?

What do you remember about it?

Even if you can't remember can you guess how the problem would have began?

Can you tell me what it's like having (or living with) a memory problem?

What do think your future will be like?

Root Metaphors

Do you think that younger people know what it is like being older?

Now that you are older is it anything like you expected?

Is there anything good about being older that young people don't realize?

Is there anything bad about being older that young people don't realize?

Do you think that most older people feel needed (useful)?

Do you think that it's important to feel needed (useful)?

Do you feel needed (useful)?

yes\

-what kinds of things make you feel needed?

-is this important to you?

-do you think that other people realize that it is important for you to feel needed (useful)?

no\

-would you like to feel needed?

-why?

What do you think other people your age do with their time?

-Is this different from what you do with your time?

Social Relationships

I'd like to make a list of the people that you spend time with. Could you help me by telling me who you spend time with?

(Begin completing a sociogram)

Is there anyone else that you spend time with?
Who would that be?

What is it that you like about being with these people?
Individually name each person named by participant.

What is it that you don't like about being with these people?
Name each individual separately again.

Is there anyone that you used to see often that you no longer see.
Who was that?
Do you miss _____?
Do you know why you don't see them as much as you used to?

Is there anyone else that you would like to see?
-probe for old friends

Do you feel close to any one person, someone that you could talk to about everything.

(yes) What kinds of things do you talk about with _____?

Do you talk to this person about your memory problem?

(no) Would you like to be able to talk to someone about personal things?

What kinds of things would you talk about if you had someone you felt comfortable with?

Do you enjoy being with people?
Who do you spend the most time with?

Do you still see your old friends?

Would you like to see more of them?

Do you enjoy going to club 36?

Why?

Do you feel really close to any one person, someone you could tell anything to?

Do you talk this person about your memory problem?

Power Relationships

Have you always made most of your own decisions?

Who do you think makes most of the decisions for you now?

Do you feel comfortable with this?

Would you like to change this in anyway?

Why do you think this has happened?

What decisions are you able to make for yourself?

Is this important to you?

Are there any decisions that you no longer feel comfortable making?

What kinds of things are you able to do on your own?

How do you feel being able to do this on your own?

What kinds of things are you no longer able to do on your own?

How does that make you feel?

Do you feel that you are able to trust others as much as you once did?

Do you think that others understand your need to do things on your own?

Do you feel comfortable talking to _____ (caregiver) about your needs?

You know you have Alzheimer's Disease. You know that Alzheimer's Disease affects your memory. Do you think Alzheimer's Disease affects you in other ways?

Probe: decision making, confusion, independence.

How do you feel about this?

Decision Making

How are decisions made in your family?

Who decides. (Name at least 4 common decisions that must be made in an average day that an individual usually makes for him or herself)

i) through iv) _____

a) If it were up to you, would you make the same decision (If caregiver decides)

b) Would you like to be more involved in _____ (name each of the decisions attributed to the caregiver individually).

Do you like it when _____ makes decisions for you.

Would you describe yourself as a very independent person. Why?

Adult Status

Do you think that (caregiver) _____ worries about you?

(If answer is yes) What kinds of things does she worry about?

Why do you think she worries about that ?

Do you think that she worries about you too much?
Why do you say that?

Does she tell you why she worries about you?

Do you think she's honest about why she worries?

Do you wish she didn't worry so much about you?

Do you ever worry about yourself?

Disclosure of the Disease

Do you think that someone with Alzheimer's Disease should be told the truth about having the disease?

:

Why?

Are you glad that you were told the truth?

How does knowing that you Alzheimer's Disease affect you?

Appendix B

Cover Letter to the Family/Caregiver of the Potential Participant

Address:

Date:

Dear Family:

My name is Clare Dupuis and I am a Master's student in Rehabilitation Studies at the University of Calgary. As part of my graduate studies I will be completing a thesis on the effects of living with a cognitive impairment. To complete this study, which is being conducted in cooperation with the Alzheimer Society of Calgary, I require the participation of at least three individuals who are considered to have a significant memory impairment. It has been suggested to me by the Alzheimer Society that you might be interested in having your family member participate in such a study.

The proposed research is a formative study into the experience of living with a cognitive impairment: the perspective explored will be that of the diagnosed individual. The primary intent of the research is to explore the day-to-day experience of living with a memory problem. It is hoped that by exploring the perspective of the individual who directly experiences the effects of the disability I might gain insight i) into the emotional impact of such a disorder and ii) how this emotional response might effect the daily functioning of the individual. It is expected that gaining knowledge about the personal reactions and adjustments will enhance our ability to create effective intervention. It is also hoped that the opportunity to talk with your family member about the experience will be personally helpful to the individual experiencing the cognitive impairment.

The study has been designed in such a way as to minimize the risk of emotional strain on the participants. Research will take place over a 12 to 14 week period in an environment which is familiar to your family member: I will spend approximately two to three hours a week with each individual, participating in activities that he or she enjoys (e.g. walking, bowling, looking at photographs, watching TV etc.). During this time I will try to get a sense of their daily life through participant observation and conversational interviewing. It is expected that these two activities will allow insight into the i) practical problems faced by an individual with a cognitive impairment ii) allow me to become familiar with the individual's particular coping pattern and iii) be aware of his or her strengths. During the participant-observation and conversational interviewing I will be keeping detailed written notes.

During eight of these twelve weeks I will be asking open-ended guided questions which will be focused on several specific topics. These questions will be different than the conversational interview and participant observation in that the questions will be focused on a specific theme of importance to the research. The questions will be few in number and worded in such a way that the depth and direction of the interview will be determined by the participant. In this way it is expected that the questions and the subsequent response will not be unduly upsetting to your family member. Before each focused interview I will ask permission to tape-record that part of our time together. He or she will be free at anytime to deny me the right to tape-record our interviews.

Although precautions are being taken to minimize any emotional impact to the participant it is possible that the research might be upsetting to the individual. My experience as a co-facilitator for a brain injury and stroke group indicates that while individuals with a cognitive impairment do not always openly acknowledge the extent of their awareness and suffering, when asked directly they reveal a much deeper understanding and show deeper emotion than might be expected. Although the opportunity to discuss the experience has the potential to be beneficial it also has the potential to cause some discomfort. During the course of the research, in the event that either you or your family member feel uncomfortable you are encouraged to call Linda McKenzie, a social worker at the Kerby Centre during office hours 9am to 5pm at 265-0661. If the need arises after regular working hours you can contact the Seniors Helpline at (264-7700).

If you agree to participate in this study you will be asked to choose between being having your family member identified by his or her first name only or by a pseudonym. In addition you should be aware that all collected data will be kept in a locked drawer and will be destroyed at the end of the research process. If the results of this study are published or reported to other scientific groups the individual's name you will not be identified in any recognizable way.

I would like to thank you for taking the time to consider participating in this research. I feel that research into the experience of those individuals most directly effected by a memory impairment is invaluable. It is my hope that a more complete understanding of the phenomenon from the perspective of the individual directly experiencing its effects will benefit the rehabilitation profession as we try to create more appropriate intervention techniques.

Attached is a letter which will explain the research process to the individual who will participate in the study. Please review this letter with your family member. If you have any questions please do not hesitate to call me at the number below. Margo Johnson at the Alzheimer Society would also be more than willing to answer any of your questions. In addition to these individuals, you may contact the project director, Dr. A. Neufeldt at 220-7347, the Office of the Associate Dean (Research and Resources), Faculty of Education at 220-5626 or the Office of the Vice President in Research at 220-3381.

Yours truly

Clare Dupuis
220-5669

Appendix C

Letter to the Participant

Dear (participant's name) :

My name is Clare Dupuis and I am a Master's student in Rehabilitation at the University of Calgary. As part of my learning I am writing a report on the effects of living with a memory problem. To complete this work I would like to spend some time with individuals who are presently experiencing memory difficulties.

If you agree to participate I would like to spend about 2 to 3 hours a week, for approximately 3 months, with you. During this time I would join you in activities that you enjoy; for example, walking, talking, bowling, watching TV, looking at family photographs etc. I am hoping that by talking with you and spending some time with you I will gain some understanding of the difficulties faced daily by individuals with a memory problem.

I am also expecting that the opportunity for you to talk about your experience will be personally useful to you. Although the opportunity to discuss your experience has the potential to benefit you it also has the potential to cause some discomfort. I would not in any way expect you to talk to me about anything that you felt was private or upsetting unless you wished to do so. If you find the conversation upsetting or intrusive I would appreciate it if you let me know. If something that we have talked about bothers you and I am unavailable to talk to you, you would be welcome to call Linda MacKenzie at the Kerby Centre (265--0661) during office hours or the Seniors Helpline (264-7700) after hours to discuss the issue.

During our time together, if you agree to meet with me, I would want to record some of our conversations and take notes. Before each session I would ask your permission to record our conversation. You would be free at any time to refuse me that right.

When writing up the results of the project I will use information that I obtained through our conversations. Although information that we discussed will be used in the project you will not be identified by your full name.

I would be happy to talk with you about any questions that you might have in regard to this project. You would be able to reach me at either 220-5660 or 282-0054.

Thank you for your consideration.

Yours sincerely,

Clare Dupuis

Appendix D

Sample Consent for Research Participation

I hereby consent to participate as a subject in the research project, entitled "*A Formative Study into the Experience of Living with Dementia of the Alzheimer Type*" conducted by Clare Dupuis under the supervision of Dr. A. H. Neufeldt, of the department of Educational Psychology at the University of Calgary. I understand that the study will involve the following procedures: spending two to three hours a week, for a period of twelve to fourteen weeks, with Clare Dupuis and participating in interviews which will be audio-taped. In addition to audiotaping it is realized that C. Dupuis will make extensive notes of the participant-observation and conversational interviewing.

- It is my understanding that the research is expected to:
 - 1) give me an opportunity to talk about my experiences with dementia
 - 2) add to the theoretical knowledge about the influence of dementia on affective and behavior response and
 - 3) provide insight into the experiences of living with dementia.
- I understand that my participation is completely voluntary, and I am free to withdraw from the study at any time without penalty.
- The general plan of this study has been outlined to me, including any possible known risks. I understand that this project is not expected to involve risks of harm any greater than those ordinarily encountered in daily life however it is possible that the types of questions raised have the potential to cause emotional stress. I also understand that it is not possible to identify all possible risks in any procedure, but that all reasonable safeguards have been taken to minimize the potential risks.
- I understand that the type of questions asked during this research may cause me to focus on sensitive issues. This may cause some emotional distress. I realize that I am free to call Linda McKenzie of the Kerby Centre at 265-0661 during office hours. After office hours I will be able to contact the Seniors Helpline at 264-7700.
- I understand that the results of this project will be coded in such a way that my identity will not be physically attached to the data that is produced. The identity of the individuals will be kept separate from the data in a locked file accessible only to the project director and the researcher, and it will be physically destroyed at the conclusion of the project.
- I understand that the results of this research may be published or reported to government agencies, funding agencies, or scientific groups, but my name will not be associated in anyway with any published results.

I understand that if at any time I have questions I may contact the project director, Dr. A. Neufeldt at 220-7347, the Office of the Associate Dean (Research and Resources), Faculty of Education (220-5626), the Office of the Vice President in Research (220-3381), or the experimenter Clare Dupuis at 220-5669 (office).

Dated this ____ day of _____ 1995

Signature

Participant's Printed name

Appendix E

Personal Biases

One of the criteria of good qualitative research is the acknowledgment by the researcher of pre-existing assumptions concerning the research findings. The rationale behind this criterion is the realization that the perception of reality is clouded by one's assumptions. The "truth" we uncover is only a part of an evolving complexity of truths. If one accepts the assumption that truth is both evolving and complex, it would follow that one's perception of this truth will be imperfect. A further assumption might be that this imperfect truth will be influenced by our pre-existing tendency to focus on those features that we are expecting to find. By admitting these limitations and acknowledging one's biases two advantages are served: the first advantage is to sensitize the researcher to those prejudices which might subtly influence both observations and interpretations; the second is to provide a context in which the reader might evaluate the findings of the investigator. In honoring qualitative research tradition of disclosure, the following chapter is an outline of the personal world views which might be expected to influence this work.

Personal Background

The statement of my biases are perhaps best begun with personal experiences of aging and dementia. As a very young child my maternal grandmother spent several weeks a year living in our home. She taught me how to drink tea rather than milk and she was never too busy to be kind. I have a sister who remembers her as a coldly religious woman. I remember her as a quiet woman who bore sadness with dignity and honor. This warm experience with an aging, burdened grandmother may prejudice me to see dignity and honor where others see coldness.

As a child my experience with other elderly individuals was limited. I have only one other memory of a grandparent, a moment of humor shared with my paternal grandfather. I was a very shy quiet child and tended to watch strangers from a distance. I remember meeting him only once. On this occasion I sat watching him from across the table as he tried to pour milk from a bottle. He was having no luck so he checked the top of the bottle. The cap had not been removed. He looked over at me, the only individual in the room, and he laughed gently. It was only a moment of his time but it has remained with me as a memory of his generosity, the generosity of sharing his humor with a child. This experience may also prejudice me: I may be inclined to see the gift of humor where others might see the shame of embarrassment.

Both my maternal grandmother and my paternal grandfather died in their 90's and neither were considered to be senile, a fact that made both my parents quite proud. My experiences with dementia therefore were provided by strangers. The nursing home where my grandmother eventually moved provided the first observations of senility. One day two women were dressed up and leaving by the front door. I didn't hear their conversation myself but someone generously provided the details to my parents. The two women were doting and believed themselves to be teenagers again and going out on a date. I can still remember being quite interested in this idea of "doting". How was it possible that someone so old could think she was young. It didn't make any sense to me and I kept thinking about how this was possible. I knew nothing of the brain at this time and probably didn't even consider it a major player in the phenomenon. This experience may have been one of the first to awaken me to the wonders and the tricks of the human mind.

Several years later, in my late teens, I got one of my first experiences with "sun downing". My mother had asked me to take a week-end job looking after an elderly woman. The position would only be for a few weeks and the requirements seemed fairly easy. Make meals, help her bathe and keep her company. The day times were delightful "Celia" reminded me of a mole: her

white hair was tied back in a bun, she wore some sort of glasses on a very large nose and her less than five foot stature was diminished even more by what I would suspect was osteoporosis. But Celia, mole or not, was a delightful conversationalist. She was well educated, inquisitive and thoughtful. We had long chats which made me feel very important: Celia did not treat me as college kid but talked to me as a peer. I remember one specific conversation with Celia. She was telling me all about children who had problems at school and the difficulties it made in their lives. She then looked at me quite intently and said that I should become a teacher for these children for she felt I had tremendous patience. I remember this clearly because it may have been the first time in my life that I felt someone saw me having any useful ability. My parents acknowledged that I was intelligent and my teachers harped on my lack of interest but Celia saw not intelligence nor potential but value. Celia may have prejudiced me to see wisdom in the elderly.

But Celia's wisdom faded at nighttime. Before bedtime Celia became paranoid. She insisted that money had been taken during the day and that we needed to protect ourselves at night so that the thief couldn't take more. Knives were used to secure the doors and her money was hidden. I thought that Celia was peculiar but didn't feel that it really did any harm to follow her wishes. At night the apartment was sealed up tightly. These precautions, along with a good massage of Antiphlogistine, calmed Celia and allowed her the rest that was required for her to regain the wisdom she would display again the following day. After a few week-ends with Celia her regular caregiver returned and my job was finished. I never saw Celia again but I understand she was eventually placed in a home due to her "senility". I regret never having gone back to visit with Celia but I thank her for allowing me to experience and value the daytime wisdom of the individual while accommodating the nighttime senility. This experience may have prejudiced me to look for and see wisdom even in the presence of a dementia.

Strangers also heavily influenced me when I volunteered with the Alzheimer's Society of Calgary. I had read about Alzheimer's Disease before volunteering with the agency. Memory impairment, confusion, apathy and death "due to pneumonia" were the only features that I really remembered. Other information had been derived from my mother's stories of friends and neighbors who had Alzheimer's Disease. I believe that at this point I had forgotten about Celia and only thought of Alzheimer's as a disease and not as a phenomenon that happens to people. My expectations were to find people who were unable to function properly, individuals who were confined and irrational, vacuous souls who needed others to 'fill them up', individuals devoid of interest in either people or activities. It came as a surprise then to find individuals like Bob and Anna: Bob had a severe memory deficit but retained charm, grace and an encyclopedia of interesting information; Anna quietly thrived as she chatted with others, she appeared to sparkle when brought into a conversation. Somehow this did not jive with what I learned about Alzheimer's Disease as an undergraduate. It seemed that part of the puzzle was missing, perhaps the human part.

Both my experience with Celia and the individuals at the Alzheimer's Society suggested to me that it might be more useful to view the individual with a dementia as someone with pockets of impairment. Although Alzheimer's Disease is commonly thought of as uniformly affecting the individual this description might be more accurate of the later stages of the disease. Contact with Celia, Bob and Anna had suggested that pockets of ability remained. These pockets might be dwindling and not always easily accessible but that does not invalidate them.

As a graduate student I took part in a practicum that involved a family who's father had recently been diagnosed with Alzheimer's Disease. This experience had a tremendous affect on my desire to understand the influence of disclosure on the behaviors of the diagnosed individual. In this particular case the family chose not to disclosure the diagnosis of Alzheimer's Disease to their

father. Instead they engaged in clandestine behaviors meant to protect the father. Although the actions of the family were intended to protect the father they may have, in the end, had the opposite effect. Within a few months of diagnosis the father had engaged a lawyer to protect his interests against his children, who he saw as trying to control his life. The father died two days before the case was to go to court and the cost of the legal bill for both families was 10's of thousands of dollars. Unfortunately it was not only a financial cost that the family paid: the father went for months without seeing or speaking to his children. The children are now left with a legal bill and perhaps regret that their father died estranged from them. This experience is one of the strongest influences on my decision to do this research. I felt at the time and still feel that keeping the truth about a diagnosis of Alzheimer's Disease has the potential to do more harm than good. Consequently one of the primary intents of this research is to investigate the consequences of disclosure for the diagnosed individual.

Finally, an uncle has recently died after several years of living with a dementia. Although I was fond of my uncle, it was the effects of his dementia on my aunt that has prejudiced me the most. She died three years before he did, perhaps from the exhaustion of caring for him. The process of living with a dementia had been a painful one for them. When he was first showing symptoms of cognitive impairment she looked for help but found none. A long list of specialists were consulted in two provinces but a specific diagnosis could not be made. It seemed that without a diagnosis they lived in confusion. The doctors didn't know what was wrong and her family didn't know what was wrong, therefore she was on her own to cope. In the end I don't if a final diagnosis was made. My uncle died in a large institution in Brockville, Ontario where he had been placed after my aunt's death. How does this prejudice my research? Probably only to remind me that diagnoses are only a very small part of the struggle that takes place in those who try to cope with a dementia. The professionals may struggle with a diagnosis but the affected individual struggles

with the meaning that illness brings to his or her life. Diagnoses aside, the individual must live with the horror or the acceptance, and the stages in between. It is this understanding of everyday life that I feel is overlooked in the understanding of disease. I am thereof prejudiced in trying to understand the individual's perspective rather than only observing the phenomenon from the outside although, ideally, I will have done both.

Theoretical Background

I have always been in awe of the tremendous capabilities and complexities of the human brain. I believe the literature which suggests that the brain is a complex machine with great elasticity and the potential to compensate for many types of system failure. I also believe that compensation can only occur under certain conditions and up to certain limits. I have no reason to doubt the volumes of literature which suggests that Alzheimer Disease is a progressive disease and as such it will effect the behavior of the affected individual in a progressive and global manner.

Where I may differ from some researchers is in my questioning of the extent to which the expression of DAT is biologically determined and to what extent it is intrapersonally, interpersonally and culturally determined. That is, I question how the symptom presentation is effected by the personality traits of the diagnosed individual, his or her caregiver, the pre-diagnosis relationship between the two, and the extent to which our institutions, both formal and informal, restrict the acceptance of "odd" behavior.

I also fear that the labeling of an individual with a dementia may have broad ranging affects. One such effect that I would expect to find is the belief by caregivers, family and professionals that the label of dementia brings with it uniform dysfunction. This does not mean that I disagree with the literature that suggests that DAT results in a global impairment but I do suspect that this aspect of DAT may result in individuals closing there eyes to the possibilities to

the remaining abilities. If this were true I would expect to find a patronizing behavior on the part of the others toward the diagnosed individual.

I also expect to find that the individual experiencing a dementia is more aware of the disease and the affects that it has on him or her than is commonly reported in the literature. It is a personal belief that awareness is not dependent upon cognitive abilities and a decline in cognitive abilities does not necessarily bring with it a 1:1 decline in awareness.

Finally I would suspect that the individual comes to terms with the diagnosis either by redefining the meaning of life or by becoming more ensconced in his or her spiritual beliefs. I would further believe that those who do not redefine their life meaning may be subject to depression.

Appendix F

DRS Consent FormCommunity Rehabilitation Studies Programme

It is my understanding that Clare Dupuis will be performing a cognitive assessment on the undersigned during the last week of June 1995. This assessment, the Mattis Dementia Rating Scale, is to be performed as a part of the research that she is carrying out on the perspective of the individual who has been diagnosed with a dementia. The purpose of the test and its procedure has been explained to me and it is understood that the results of the test are confidential and will be used only in the context of the research.

Participant _____

Caregiver's Signature _____

Date _____

2500 University Drive N.W., Calgary, Alberta, Canada T2N 1 N4
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Appendix G

DRS Scoring Form

DRS Scoring Form

Steven Mattis, Ph.D.

Name _____ Age ____ Sex ____ Date _____

Occupation _____ Education _____

Diagnosis _____

Scale	Raw Score	Cutoff	SDAT Sample:	
		+ or -	% ile	T Score
▲ Attention	_____	_____	_____	_____
● Initiation/Perseveration	_____	_____	_____	_____
★ Construction	_____	_____	_____	_____
◆ Conceptualization	_____	_____	_____	_____
■ Memory	_____	_____	_____	_____
DRS TOTAL SCORE	_____	_____	_____	_____

Attention

A. Digit Span

I'm going to say some numbers and when I'm through I want you to repeat the numbers in the same order . . . Say them just the way I did . . . Say what I say.

- A1. Forward 25
 316
 4792
 (0, 2, 3, 4) _____

Now when I say some numbers I want you to say them backward . . . For example, if I said 1-2, you would say 2-1 . . . Understand? . . . Ready?

- A2. Backward 14
 539
 8593
 (0, 2, 3, 4) _____

Score A _____▲
 (0-8)

B. Two Successive Commands

I'm going to give you some commands . . . Do what I say and then relax.

- B1. "Open your mouth and close your eyes" (1pt) _____
 B2. "Stick out your tongue and raise your hand" (1pt) _____

Score B _____▲
 (0-2)

IF SCORE B = 2, GO TO E
 ENTER MAX SCORE FOR C-D

C. Single Command

I'm going to give you some commands . . . Do what I say and then relax.

- C1. "Open your mouth" (1pt) _____
 C2. "Stick out your tongue" (1pt) _____
 C3. "Close your eyes" (1pt) _____
 C4. "Raise your hand" (1pt) _____

Score C _____▲
 (0-4)

D. Imitation

Watch me . . . Do what I do . . . Imitate what I'm doing . . . Do this.

- D1. Open mouth (1pt) _____
 D2. Stick out tongue (1pt) _____
 D3. Close eyes (1pt) _____
 D4. Raise your hand (1pt) _____

Score D _____▲
 (0-4)

Initiation and Perseveration

E. Complex Verbal Initiation/Perseveration

**I'd like you to name all the things you can find or buy in a supermarket
... You have 1 minute to name as many different items as fast as you
can. (60-second time limit, 1 point for each different item)**

- | | |
|----------|----------|
| 1 _____ | 11 _____ |
| 2 _____ | 12 _____ |
| 3 _____ | 13 _____ |
| 4 _____ | 14 _____ |
| 5 _____ | 15 _____ |
| 6 _____ | 16 _____ |
| 7 _____ | 17 _____ |
| 8 _____ | 18 _____ |
| 9 _____ | 19 _____ |
| 10 _____ | 20 _____ |

Score E _____
(0-20)

IF SCORE E > 13, GO TO I
ENTER MAX SCORE FOR F-H

F. Simple Verbal Initiation/Perseveration

**Look at me ... Look at what I'm wearing ... I'd like you to name all of
the things I'm wearing. (60-second time limit, 1 point for each different
item)**

- | | |
|---------|---------|
| 1 _____ | 5 _____ |
| 2 _____ | 6 _____ |
| 3 _____ | 7 _____ |
| 4 _____ | 8 _____ |

Score F _____
(0-8)

G. Consonant Perseveration

**Say "bee" ... Say "key" ... Say "gee" ... Now say "bee-key-gee" four
times.**

"bee-key-gee"—four repetitions (1pt) _____

Score G _____
(0-1)

H. Vowel Perseveration

**Say "bee" ... Say "bah" ... Say "boli" ... Now say "bee-bah-boh" four
times.**

"bee-bah-boh"—four repetitions (1pt) _____

Score H _____
(0-1)

I. Double Alternating Movements

Watch me . . . Do what I'm doing . . . Do this . . . Palm up, palm down, now switch . . . Keep doing it until I tell you to stop.

palm up/palm down—five repetitions (1pt) _____

Score I _____ ●
(0-1)

IF SCORE I = 1, GO TO L
ENTER MAX SCORE FOR J-K

J. Double Alternating Movements

Now do this . . . Fist, fingers out, switch . . . Keep doing it until I tell you to stop.

clenched/extended—five repetitions (1pt) _____

Score J _____ ●
(0-1)

K. Alternate Tapping

Now do this . . . Tap left, then right, then left, then right . . . Just like this . . . Keep doing it until I tell you to stop.

tap left/tap right—ten repetitions (1pt) _____

Score K _____ ●
(0-1)

L. Graphomotor Design 1

Present Card 1 in stimulus booklet. Give sheet of paper to subject. **Copy this entire design** (point to entire "ramparts" design from left to right). **Start right here** (point to paper).

reproduction of "ramparts" (1pt) _____

Score L _____ ●
(0-1)

IF SCORE L = 1, GO TO P
ENTER MAX SCORE FOR M-O

M. Graphomotor Design 2

Present Card 2 in stimulus booklet. **Copy this** (point to the circle). **Put it here** (point to paper).

reproduction of "circle" (1pt) _____

Score M _____ ●
(0-1)

N. Graphomotor Design 3

Present Card 3 in stimulus booklet. **Copy this** (point to the "X"). **Put it here** (point to paper).

reproduction of "X" (1pt) _____

Score N _____ ●
(0-1)

O. Graphomotor Design 4

Present Card 4 in stimulus booklet. **Copy these** (point to alternating XOXO). **Put them here** (point to paper).

reproduction of "alternating XOXO" (1pt) _____

Score O _____ ●
(0-1)

Construction

P. Construction Design 1

Present Card 5 in stimulus booklet. Turn paper over. **Copy this** (point to vertical lines). **Put it here** (point to paper).

reproduction of "vertical lines" (1pt) _____

Score P _____★
(0-1)

Q. Construction Design 2

Present Card 6 in stimulus booklet. **Copy this** (point to diamond in box). **Put it here** (point to paper).

reproduction of "diamond in box" (1pt) _____

Score Q _____★
(0-1)

IF SCORE Q = 1, GO TO V
ENTER MAX SCORE FOR R-U

R. Construction Design 3

Present Card 7 in stimulus booklet. **Copy this** (point to square and diamond). **Put it here** (point to paper).

reproduction of "square and diamond" (1pt) _____

Score R _____★
(0-1)

S. Construction Design 4

Present Card 8 in stimulus booklet. **Copy this** (point to diamond). **Put it here** (point to paper).

reproduction of "diamond" (1pt) _____

Score S _____★
(0-1)

T. Construction Design 5

Present Card 9 in stimulus booklet. **Copy this** (point to square). **Put it here** (point to paper).

reproduction of "square" (1pt) _____

Score T _____★
(0-1)

U. Construction Design 6

Write your full name here (point to paper).

produces signature (1pt) _____

Score U _____★
(0-1)

Conceptualization

V. Identities and Oddities

Present Cards 10-17 in sequence. **Look at these three designs . . . Which two are the same? . . . Which are the most alike?** Return to Card 10 and present Cards 10-17 again. **Look at these three designs . . . Tell me which one is different from the others . . . Which one doesn't belong with the others?**

- V1. Card 10 Same (1pt) _____ Different (1pt) _____
 V2. Card 11 Same (1pt) _____ Different (1pt) _____
 V3. Card 12 Same (1pt) _____ Different (1pt) _____
 V4. Card 13 Same (1pt) _____ Different (1pt) _____
 V5. Card 14 Same (1pt) _____ Different (1pt) _____
 V6. Card 15 Same (1pt) _____ Different (1pt) _____
 V7. Card 16 Same (1pt) _____ Different (1pt) _____
 V8. Card 17 Same (1pt) _____ Different (1pt) _____

Score V _____ ◆
(0-16)

W. Similarities

In what way are a _____ and a _____ alike? . . . How are they the same? Record responses.

- W1. apple - banana _____ (0-2pt) _____
 W2. coat - shirt _____ (0-2pt) _____
 W3. boat - car _____ (0-2pt) _____
 W4. table - chair _____ (0-2pt) _____

Score W _____ ◆
(0-8)

IF SCORE W > 5, GO TO AA
ENTER MAX SCORE FOR X-Z

X. Priming Inductive Reasoning

Name three things that people _____ . How are a _____ , _____ , and a _____ alike, the same? Record subject's responses.

- X1. eat _____
 response _____ (1pt) _____
 X2. wear _____
 response _____ (1pt) _____
 X3. ride _____
 response _____ (1pt) _____

Score X _____ ◆
(0-3)

Y. Differences

I'm going to name three things . . . You tell me which one doesn't belong with the others, which one is different.

- Y1. dog-cat-car (1pt) _____
 Y2. boy-door-man (1pt) _____
 Y3. fish-car-train (1pt) _____

Score Y _____ ◆
(0-3)

_____ and _____. . . . Are they both _____, both _____, or both _____?

- Z1. apple-banana
 both fruit (2pt) _____
 both green (1pt) _____
 both animals (0pt) _____
- Z2. coat-shirt
 both clothing (2pt) _____
 both wool (1pt) _____
 both fruit (0pt) _____
- Z3. boat-car
 both means of transportation (2pt) _____
 both move (1pt) _____
 both clothing (0pt) _____
- Z4. desk-chair
 both furniture (2pt) _____
 both wood (1pt) _____
 both means of transportation (0pt) _____

Score Z _____ ◆
 (0-8)

AA. Verbal Recall—Sentence Reading

Present Card 18 in stimulus booklet. **Read this sentence aloud . . . Remember the sentence because I'm going to ask you to repeat it later.**

(Not scored)

AB. Verbal Recall—Sentence Initiation

Make up a sentence using the words "man" and "car" . . . Remember this sentence also because I'm going to ask you to repeat it later.
 Record sentence.

_____ (1pt)

Score AB _____ ◆
 (0-1)

Memory

AC. Orientation

- | | |
|------------------------|--|
| AC1. Day (1pt) _____ | AC5. ^{Prime Minister} President (1pt) _____ |
| AC2. Date (1pt) _____ | AC6. ^{Prime Minister} Governor (1pt) _____ |
| AC3. Month (1pt) _____ | AC7. Mayor (1pt) _____ |
| AC4. Year (1pt) _____ | AC8. Hospital (1pt) _____ |
| | AC9. City (1pt) _____ |

Score AC _____ ■
 (0-9)

AD. Counting Distraction 1

Present Card 19 in stimulus booklet. (Turn card lengthwise). **Point out and count all of the A's.**

Score AD _____ ▲
 (0-6)

AE. Counting Distraction 2

Present Card 20 in stimulus booklet. **Point out and count all of the A's.**

Score AE _____ ▲
 (0-5)

AF. Verbal Recall—Reading

Remember the sentence that you read? . . . Tell it to me. Record sentence.

complete sentence (4pt) _____ brown (1pt) _____
 boy (1pt) _____ dog (1pt) _____

Score AF _____ ■
 (0-4)

AG. Verbal Recall—Initiation

Remember the sentence you made up? . . . Tell it to me.

complete sentence (3pt) _____
 man (1pt) _____
 car (1pt) _____

Score AG _____ ■
 (0-3)

AH. Verbal Recognition—Presentation

Present Card 21 in stimulus booklet. Read this list of words aloud four times so that you will remember each word.

AH1. 1st correct reading (1pt) _____
 AH2. 2nd correct reading (1pt) _____
 AH3. 3rd correct reading (1pt) _____
 AH4. 4th correct reading (1pt) _____

Score AH _____ ▲
 (0-4)

AI. Verbal Recognition

I'm going to show you some words, two at a time . . . For each pair of words, you pick the one that was on the list you just read. Present Cards 22-26 in stimulus booklet, one at a time.

AI1. *evening-head* (1pt) _____ AI4. *machine-night* (1pt) _____
 AI2. *inch-plant* (1pt) _____ AI5. *fire-milk* (1pt) _____
 AI3. *land-open* (1pt) _____

Score AI _____ ■
 (0-5)

AJ. Visual Matching

Present Cards 27 and 28 in stimulus booklet. The designs on this card (point to Card 28) are exactly the same as the designs on this card (point to Card 27) . . . When I point to a design on my card, you point to the same one on your card . . . Now, which design is the same as this one (point to top left design, from subject's point of view, on Card 27)? Match to three remaining designs in any order. Repeat three times.

AJ1. 1st presentation of designs (1pt) _____
 AJ2. 2nd presentation of designs (1pt) _____
 AJ3. 3rd presentation of designs (1pt) _____
 AJ4. 4th presentation of designs (1pt) _____

Score AJ _____ ▲
 (0-4)

AK. Visual Memory

I'm going to show you some designs, two at a time . . . For each pair of designs choose the one we have just been working with . . . Point to the one you have just seen. Present Cards 29-32 in stimulus booklet, one at a time.

AK1. left (1pt) _____ AK3. right (1pt) _____
 AK2. right (1pt) _____ AK4. left (1pt) _____

Score AK _____ ■
 (0-4)