

**Experiences of Spouses Caring  
for Aggressive Family Members  
Diagnosed with Alzheimer's Disease**

by

**Shelley Claralyn Keast**

A thesis submitted to  
the University of Manitoba  
in partial fulfillment of the  
requirements for the degree of  
Master of Nursing

**Winnipeg, Manitoba**

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**EXPERIENCES OF SPOUSES CARING FOR AGGRESSIVE FAMILY**

**MEMBERS DIAGNOSED WITH ALZHEIMER'S DISEASE**

**BY**

**SHELLEY CLARALYN KEAST**

**A Thesis/Practicum submitted to the Faculty of Graduate Studies of The University**

**of Manitoba in partial fulfillment of the requirements of the degree**

**of**

**MASTER OF NURSING**

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## ABSTRACT

### "Experiences of Spouses Caring for Aggressive Family Members Diagnosed with Alzheimer's Disease"

The number of Canadians affected with Alzheimer's disease and related dementias in 1991 was estimated at 250,000 half of whom live in the community. Demographers anticipate that the number of individuals with Alzheimer's disease and related dementia will double by the year 2021, and triple by the year 2031. It is widely accepted that aggressive behaviour with abrupt mood changes may occur during the course of the disease (20% to 86% prevalence) presenting major problems for both patients and caregivers.

There is a lack of research related to the experience of family caregivers and the interventions used by these informal caregivers. The purpose of the study was to explore the problems encountered by spousal caregivers living in the community with aggressive abusive care receivers. Case study design was used to identify the experiences of these informal caregivers. Ryden's (1988) Theoretical Model for Aggression in the Cognitively Impaired was used as a guide in understanding aggressive behaviours in this population. Two "couples" were followed for a three-month period. Repeated (N = 26) caregivers' interviews and observations of the caregiver/care recipient interactions, field notes, caregiver's journal of aggressive behaviour (N = 1), and the Mini-Mental State Exam were used to obtain detailed descriptions of the spouses' experiences. Care recipients were interviewed for insights into aggressive behaviour.

Content analysis of the data revealed that the impact of aggressive behaviour on the caregiver must be understood within the context of not only Alzheimer's disease but within the significant life events of the caregiver. Findings highlighted the caregiver's ability to identify the antecedents to the aggressive behaviour and successful intervention strategies. Of interest was the care receiver's ability to identify the antecedents to their aggressive behaviour and the feelings associated with their "uncontrollable" expression of aggression.

Implications for nursing practice, education, administration, and research are discussed in the concluding chapter.

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Finally, but most importantly, I wish to thank Brian for his unending love and unfailing support.

## DEDICATION

This thesis is dedicated to my best friend,  
my husband Brian  
for your love, encouragement, and strength

To my children, Taylor and Shenade,  
may your reach for the stars

To my parents, Don and Teri Taylor,  
for always believing in me

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## CHAPTER ONE: STATEMENT OF THE PROBLEM

### Statement of the Problem

Demographers estimate that by the millennium, 32 million individuals (12%) in the United States will be over 65 years of age. Of this number, 12 to 18 million people will be over the age of 75 (Williams, 1986). Demographic projections for Canada reveal that by the year 2011, 15% of the population will be 65 years and older. Following the year 2011, the baby boom generation will begin reaching their 65th birthday and impact the demographics such that by the year 2021 more than 20% of Canada's population will have reached their 65th year (Stone & Fletcher, 1986). The risk of dementia increases with advancing age with Alzheimer's disease (AD) being the most common form of dementia (Canadian Study on Health and Aging Working Group, 1991, as reported in Canadian Medical Association Journal, 1994; Carswell, Dulberg, Carson, & Zgola, 1995; Page, 1992; Williams, 1986).

In the 1991 Canadian Study of Health and Aging the number of Canadians affected with Alzheimer's disease and related dementias is estimated at 250,000, half of whom live in institutions and, the remainder in the community. The Canadian prevalence of dementia in those older than 65 years is 8% with the breakdown of prevalence of dementia associated with age at (a) 2.4% at 65-74 years (b) 11.1% at 75-84 years, and, (c) 34.5% in those over the age of 85 years. Although

diagnoses cannot be confirmed until post-mortem examination, the 1991 Canadian Study of Health and Aging indicates that 5.1% of individuals aged 65 or better have Alzheimer's disease. The breakdown of the prevalence of Alzheimer's disease and age is (a) 1.0% at 65 to 74 years (b) 6.9% at 75-84 years, and, (c) 26% at age 85 and older. These results indicate that AD is the most common form of dementia, responsible for approximately 60% of dementias up to age 84, and 75% prevalence in those 85 and older. The 1991 Canadian study also anticipates that by the year 2021 the number of people with Alzheimer's disease and related dementia will double, and triple by the year 2031. Estimates of the prevalence of AD in the United States is 4 million (Zayas & Grossberg, 1996). The U.S. spends at least \$100 billion a year on AD, and surprisingly, AD is identified as the third most expensive disease in the United States, with only heart disease and cancer costing more (American Alzheimer's Association, 1995). Estimated costs to Canada are unavailable.

Alzheimer's disease affects brain cells resulting in intellectual impairment, memory loss, disorientation, and behavioural changes (O'Leary, Haley, & Paul, 1993; Williams, 1986; Zayas & Grossberg, 1996). It is widely accepted that aggressive behaviour with abrupt mood changes may occur during

the course of the disease and that these behaviours are magnified in individuals with severe cognitive impairment (Page, 1992; Ryden 1988; Teri, Larson, Reifler, 1988; Simon, 1994; Ware, Fairburn & Hope, 1990; Williams, 1986). Research into the psychobiology of agitation, which includes aggression, has revealed that aggressive AD patients have lower levels of the neurotransmitter serotonin (5-HT) compared to those with AD who are non-aggressive (Zayas & Grossberg, 1996). The relationship between neurotransmitters and aggression is currently being researched (Zayas & Grossberg, 1996). The debate, however, centers on the definition of aggression and prevalence of aggression. Studies (mainly from institutional settings) on the prevalence of aggression in dementia and/or AD, report that the incidents of aggressive behaviours range from a conservative 20% (Burns, Jacoby, & Levy, 1990) to a more dramatic 86.3% (Ryden, Bossenmaier, & McLachlan, 1991). Unfortunately inconsistencies in defining aggression and the absence of consistently applied measurement tools make comparisons across studies difficult.

Alzheimer's disease strikes people of every ethnic and socioeconomic group. The number of new cases of AD is keeping up with the rapid growth of the aging population. Although it is a terrible disease, Alzheimer's disease may be even more devastating for families of the victims. Caregiving spouses,

usually elderly and often frail themselves, have limited emotional and physical resources to manage the behavioural changes that become manifest with AD. Caregivers often "drive themselves" to physical and emotional exhaustion while rendering continuous care (Simon, 1994). Despite cognitive impairment, the behavioural manifestations of Alzheimer's disease present major problems for both patients and carers and frequently result in the institutionalization of patients (Eastley & Mian, 1993; Serby, 1989; Ware et al., 1990). In addition to the devastating emotional burden, the personal, social, and economic impact of Alzheimer's disease and its associated behaviours threatens to overwhelm the health care system (Serby 1989; Simon, 1994). Aggressive behaviour encountered by family caregivers is certain to increase as our population ages (Ryden, 1988; Williams, 1986).

It is ironic, then, that research into the nature of aggressive behaviour in persons with dementia who are living in the community lags behind other areas of dementia research (Ryden, 1988; Ryden et al., 1991; Serby, 1989, Ware et al., 1990; Williams, 1986). Of the studies which focus on the community setting (Deutsch, Blysm, Rovner, Steele & Folstein., 1991; O'Leary, Haley & Paul, 1993; Hamel, Pushkar, Gold, Andres, Reiss, Dastoor et al., 1990; Rabins, Mace & Lucas, 1982; Rubin, Morris & Berg, 1987; Ryden, 1988) many do



not focus specifically on AD, but refer to any form of dementia or psychosis in the geriatric patient. These studies lack definition and/or consistency as to what behaviours constitute aggression.

There is a demand for clinical research in the area of caregivers managing aggressive behaviour. Health care professionals have been criticized as being of little help to families in the management of aggressive behaviour (Ryden, 1988). Ryden (1988), believes that health care professionals may not be aware of the extent of the problem or the devastating impact of aggressive interactions between caregiver and care receiver. "Better empirical information regarding the phenomenon [aggressive behaviour] is essential as a basis for development of strategies for prevention and management" (Ryden, 1988, p. 343).

There are limited intervention studies in the literature and most focus on the institutionalized agitated individuals (Weinrich, Egvert, Eleazer, & Haddock, 1996). Absent from the literature are studies on the interventions and their effectiveness used by family caregivers living with relatives whose AD contributes to aggressive behaviours. Early intervention is required before the brutalizing effects of this behaviour irrevocably damage the relationship with the family caregiver (Eastley & Mian, 1993; Ryden et al., 1991).

However, before we can assist caregivers in the community, we must first understand the nature of their experience and not generalize findings from institutional settings to the community and the spousal caregiver. Weinrich et al. (1996), identified the need for qualitative studies on "agitation" from the caregiver's perspective. The majority of research studies are quantitative in nature. Of the limited number of qualitative studies (Hamel et al., 1990; Rubin, Morris, & Berg, 1987; Ryden 1988), the focus is on the prevalence and types of behaviour and not related to the experience of family caregivers or the interventions used by community caregivers.

Case study research specific to aggression could not be found. The current research focus remains on behavioural problems of those with dementia. Rabins, Mace, and Lucas (1982) completed a qualitative study on the impact of dementia on the family caregiver, with the majority of the participants residing in the community. How the caregiver manages and responds to the aggressive behaviours were not explored in this study.

Caring for a spouse displaying aggressive behaviour because of Alzheimer's disease is a serious problem. Researchers need to acknowledge both the experiential knowledge and address the problems encountered by family caregivers living in the community with confused, aggressive,

abusive, care receivers. However, before nursing can address the caregiver's concerns about the management of aggressive behaviour, we must understand what it is that the spousal caregiver is experiencing and not apply the experiences of the health care provider to the spousal caregivers. A better understanding of aggressive behaviour in those living at home with Alzheimer's disease and the impact of these behaviours on the spousal caregiver is necessary as research in this area is very limited. This study will explore the following research questions:

1. What are the experiences of spousal caregivers living with a family member who displays aggressive behaviour as a consequence of Alzheimer's disease?
2. To what types of aggressive behaviour is the caregiver exposed?
3. What aggressive behaviours do the spousal community caregivers find most distressful?
4. What techniques do spouses use to manage the aggressive behaviour?
5. How do community spousal caregivers view the help/suggestions/advice they have received from health care professionals regarding the management of aggressive behaviour?

## CHAPTER TWO: CONCEPTUAL FRAMEWORK & REVIEW OF THE LITERATURE

### Conceptual Framework and Review of the Literature

#### Conceptual Framework

Conceptual frameworks are models that present concepts assembled because of their relevance to a common theme or phenomenon. They provide a boundary for questions to ask and provide direction as to which methods would be of benefit in the pursuit of answers to various research questions. Research guided by a conceptual framework is a valuable endeavour, contributing knowledge and understanding not only to the phenomena under study, but to the construction and support of more formal theories (Meleis, 1991; Polit & Hungler, 1991).

Despite the plethora of theories on aggression which range from innate to societal origins, no theorist or discipline has irrefutably determined the precise origin of aggression (Lanza, 1983). It is beyond the scope or the intentions of this research to delve into the suppositions and theories of aggression; however, a brief composite review is required in order to understand the conceptual framework proposed for this study.

Classifications of aggression have been developed based on the primary location of the perceived source of aggression.

The classifications of aggressive sources are (a) within the individual and (b) as a result of individual interaction with the environment (antecedents to the aggressive potential) (Lanza, 1983). These classifications assist in the understanding of aggression expressed by the individual living with AD. Causes for aggression within these categories include (a) the "biological altering" of the individual due to a disease process resulting in uncontrolled aggression, (b) the violation of personal space, and (c) the aggressive drive engendered largely by frustration (Lanza, 1983). Other theorists also acknowledge the influence of the environment in shaping the expression of aggression. The similarities in the theories of aggression are: (a) people have the potential and ability to be aggressive, (b) there are a variety of expressions and intensities of aggression, and (c) specific elements influence aggression (Lanza, 1983).

Lanza (1983) developed a model (Figure 1, p. 12) which associates the root of aggression with the manifestations of aggression. The model is derived from theories on aggression. The model addresses innate factors and those from human environment interaction as the contributors to an individual's potential for aggression. This model was later modified by Ryden (1988) to represent aggression in the cognitively

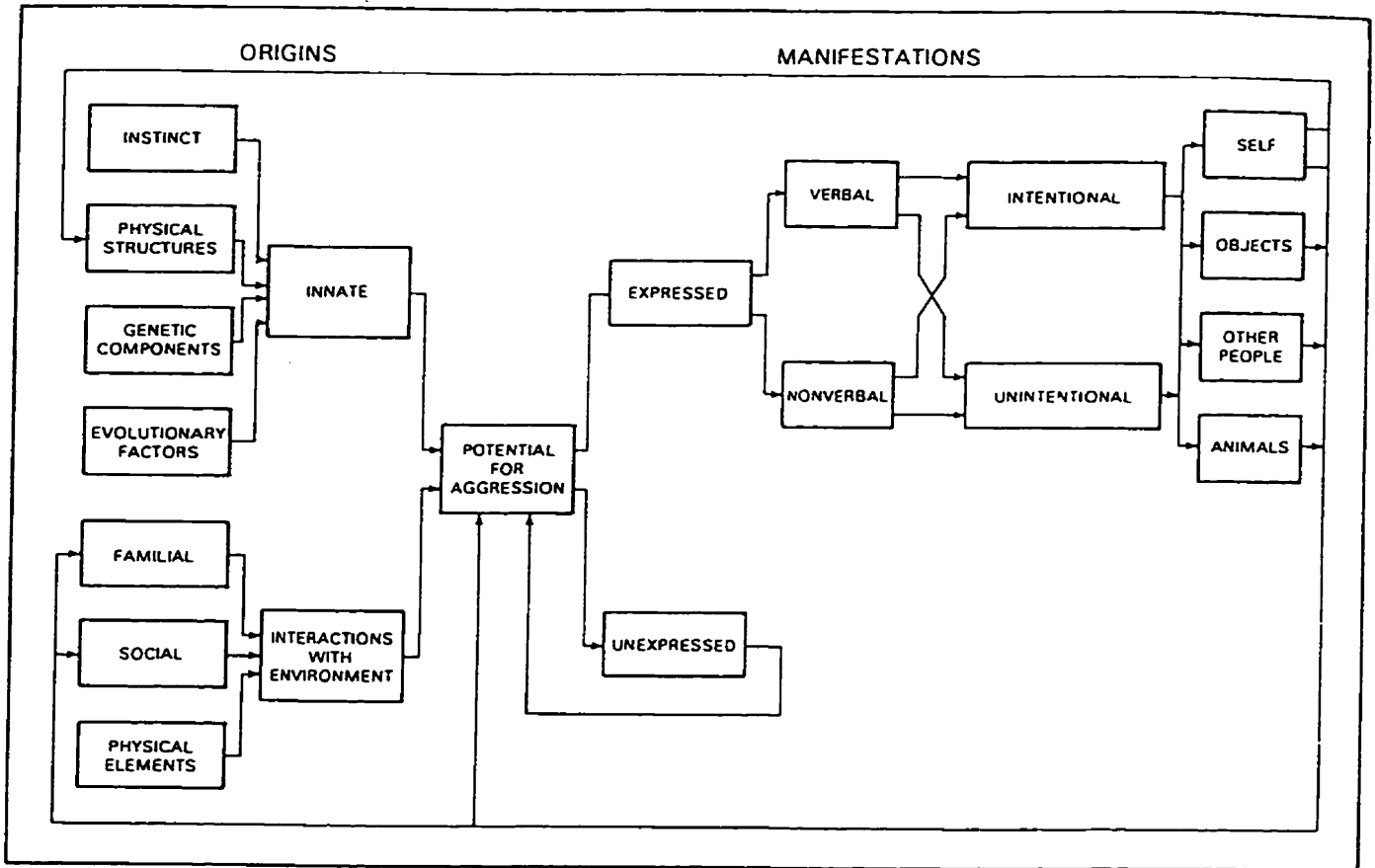
impaired, and provided the conceptual framework for this research (Appendix A).

Innate or internal origins of aggression include variables such as mental status, diagnosis of any disease, independence in self-care, and psychotropic medications. Origins related to human-environment interactions may include the variables of location, time of incidents, the antecedents of aggressive behaviour, the application of physical restraints, a prior modelling of aggression by others, and reinforcement for the behaviour, once the aggressive behaviour is expressed (Lanza, 1983; Ryden et al., 1991). Potential aggression may be expressed (physically, verbally or sexually), unexpressed (controlled), or defused and may occur with or without conscious awareness. Expressed aggression can be directed at self, objects, other people, or animals. If aggression is unexpressed for any reason, a feed-back loop occurs in which the unexpressed feelings of aggression build up and add to the potential for aggression. The presence of a feedback loop confronts the myth that "discouraging the expression necessarily decreases aggressive potential and expression of aggression always means the end of aggressive behaviour" (Lanza, 1983).

The environmental and internal origins of aggression identified in Ryden's conceptual framework guided this study.

Ryden's model accounts for the interaction between caregiver and care receiver as being a potential influence over both the incidents and types of aggressive behaviour. Ryden's Model for Aggression in the Cognitively Impaired provided a framework for understanding the experiences of the spousal caregiver. Evaluation of the framework, in relation to this study, is located in Chapter 5, "Discussion of the Findings."

Figure 1: A Theoretical Model for Aggression (Lanza, 1983, p. 15)





## Literature Review

### Alzheimer's Disease

#### Incidence and Prognosis

Alzheimer's disease (AD) is a progressive irreversible degenerative disease of the brain that occurs in middle or late life (Karlinsky, 1997; McKhann et al., 1984; Morris & Berg, 1987; Rubin et al., 1987; Simon, 1994; Williams, 1986). An estimated 5% to 7% of the population age 65 and older have AD, and more than 20% of those aged 80 and older will develop it (Canadian Study on Health and Aging, 1993; Simon, 1994). More than four million North Americans are afflicted with the disease, and in Canada estimates of occurrence range from 100,000 to 300,000 (Health and Welfare Canada, 1984; Zayas & Grossberg, 1996).

Although not always listed as the official cause of death, the resulting pneumonia and dehydration that often is associated with the later stages of AD is believed to be the fourth most common cause of death in Canada (Beck & Heacock, 1988; Health & Welfare, 1984; Simon, 1994). AD has affected the lives of such famous people as mystery writer Ross MacDonald, artist Norman Rockwell, (Health & Welfare Canada, 1984; Newsweek, 1988), and recently former President of the United States, Ronald Regan. What causes AD is still unknown as are methods of prevention or cure.

As stated the actual cause of AD remains unknown, however, it often occurs in several members of the same family. Recently abnormal genes on chromosomes 14, 19, and 21 have been associated with AD. Specifically, on chromosome 19, the gene ApoE4 has been identified as a major risk factor predisposing one to late onset AD. In individuals with one copy of the ApoE4 gene, the risk of developing AD increases to 60% (Simon, 1994; Whitehouse & Geldmacher, 1994). However, not everyone with AD has the ApoE4 gene, suggesting a combination of genetic predisposition and environmental influences such as socioeconomic forces, diet, and environmental toxins (Health & Welfare Canada, 1984; Serby, 1989; Simon, 1994). The influence of educational levels is speculated as a predisposing factor as some believe "that learning itself stimulates more neurons to grow and thus may create a larger reserve in the brain so that it takes longer for brain cells to be destroyed" (Simon, 1994, p. 1). It is also believed the future research will confirm the theory that there are several different types of AD with varying predisposing factors, behaviours, and treatments (Whitehouse & Geldmacher, 1994).

When the German neurologist Alois Alzheimer first described the disease in 1906, he documented hallucinations, delusions, and other behavioural changes that remain hallmarks

of the disease to date (Beck & Heacock, 1988; Health & Welfare Canada, 1984; Rabins et al. 1982; Ware et al., 1990). Diagnosis of the disease is always tentative (requires brain tissue biopsy) based on information obtained through patient history, physical examination, cognitive assessment, laboratory investigations and when able, diagnostic neuro-imaging (Karlinsky, 1997). Commonly used criteria specific to the diagnosis of AD from other types of dementia is that the individuals with AD or Dementia of the Alzheimer's Type must demonstrate (a) dementia that is characterized by gradual cognitive decline, and (b) significant decline in social or occupational functioning. This "combined" criteria serve as a useful tool in distinguishing AD from the cognitive changes associated with the normal aging process (Karlinsky 1997). As the individual with AD experiences pervasive cognitive decline, there is a change in his/her behaviour (Deutsch, Bylsma, Rovner, Steele, & Folstein, 1991; Ware et al., 1990). Unfortunately, behavioural changes may result in aggressive behaviour. Physical violence and hitting are reported as serious problems by family caregivers of individuals with AD (Rabins et al., 1982).

The devastating impact of AD, although individualized, can be divided into three stages which can progress over a period of four to twenty years. The initial or early stage

lasts approximately two to four years with the individual experiencing minor symptoms that are often attributed to other causes. Gradually, however, the person becomes more forgetful, has time-spatial disorientation, and relatives begin reporting behavioural or "personality" changes (Beck & Heacock, 1988; Health & Welfare Canada, 1984; Simon, 1994).

The second stage of AD has the longest duration which is marked by significant short-term memory loss, poor judgment, and a host of associated behaviours related to continued cognitive decline (Beck & Heacock, 1988). As the dementia progresses the individual's ability to comprehend lessens and disorientation begins. For the individual with AD, verbal communication becomes difficult resulting in frustration, hostility, and fear. Other manifestations such as confusion, irritability, restlessness, agitation, and aggression commonly appear and are associated with mood and behavioural changes. As speech becomes difficult for the Alzheimer's patient, his or her behaviour is frequently the only means of communication. Common behaviours include pacing, waving arms, raising the tone and volume of any speech, quick changes of mind and angry outbursts (Health & Welfare Canada, 1984; Williams, 1986).

Sensory deficits associated with aging in the non-demented individual such as diminished visual acuity are

compensated by accessing cues and memories of the environment. Unfortunately, the individual with AD may no longer have the memories, or the cognitive ability, to access cues from the environment. Perception or the conscious recognition of one's internal and external environment is affected. A partial or complete misrepresentation of the environment is commonly experienced by people living with AD (Beck & Heacock, 1988; Serby, 1989). Those without cognitive impairment experience the same environment; however, the frame of reference and perceptions may be completely different than individuals with AD. Difficulty in accurately perceiving the environment may cause the individual with AD to feel uncertain which may "lead to anxiety...and lead to panic" (Beck & Heacock, 1988, p. 110).

Agnosia, or the inability to recognize and attach meaning to familiar objects, sights, and sounds (in the absence of other sensory deficits) is an example of perceptual losses in the individual with dementia. The familiar no longer remains familiar and the individual begins to forget learned, socially acceptable behaviours. Apraxia, the inability to understand the sequence of actions or purpose of objects, is most readily evidenced during activities of daily living. As identified, agnosia and apraxia are specific to those with cognitive decline and either/or must be present along with memory loss

before Alzheimer's like dementia can be diagnosed (Karlinsky, 1997). AD may also affect an individual's ability to complete simple motor skills such as washing. Other motor deficits include unsteady gait and lack of coordination due to increased muscle tone (Beck & Heacock, 1988; Serby, 1989).

In the third and final stage of AD, which lasts about a year, symptoms progress to the point where the individual becomes bedridden. In this emaciated and helpless state, pneumonia and dehydration result which are often the cause of death (Beck & Heacock, 1988; Health & Welfare Canada, 1984; Simon, 1994).

Autopsies performed on the brain tissue of people with AD identify changes in the inter-neurons of the central nervous system as responsible for the observable changes in individuals' behaviour (Kolanowski, 1996; Simon, 1994). Changes to the proteins of the nerve cells in the cerebral cortex cause abnormal fibres to accumulate resulting in neurofibrillary "tangles." These scattered neurofibrillary tangles cause interneuron atrophy disrupting the passage of electrochemical messages between the cells. Senile or neuritic plaque formation resulting from deposits of the protein beta amyloid at the interneuronal junctions and granulovacuolar degeneration are other pathological findings (Health & Welfare Canada, 1984; Kolanowski, 1996; McKhann et

al., 1984; Page, 1992; Williams, 1986). Surrounding these plaques are the remains of dead neurons and it is questioned if the amyloid causes the destruction of nerve cells or if another process is responsible (Simon, 1994). What is known is that the degree of disturbance to cognitive function and memory is directly related to the number of these plaques and tangles (Health & Welfare Canada, 1984). Furthermore, the presence of these plaques appear to be associated with significantly diminished concentrations of choline acetyltransferase which is responsible for the manufacture of the neurotransmitter acetylcholine. Acetylcholine is part of the cholinergic system which affects memory and learning. People with AD have partially or significantly destroyed cholinergic systems, although other nearby nerve cells are unaffected (Simon, 1994). Page (1992) reports that aggressive behaviour in AD may be a result of this cell damage specifically to frontal or temporal lobes. Structural damage to these higher centres, which are believed to be responsible for behaviour, has been associated with disinhibition and potential aggression.

Confirmation of the diagnosis of Alzheimer's disease requires a post-mortem examination of the brain. Therefore, tentative diagnosis of Alzheimer's disease or senile dementia of the Alzheimer's type is dependent on clinical description

(often as reported by caregivers) which examines brain-behavioural relationships. Together with a physical exam to rule out other causes, cognitive functioning exams, and miscellaneous tests and scans of the brain, a diagnosis is made (Health & Welfare Canada, 1984; Rubin et al., 1987). The difficulty in differentiating dementia of the Alzheimer's type from other illnesses (depression, drug toxicity) stresses the need to strictly apply uniform diagnostic criteria. McKhann et al. (1984) report that in more than 20% of cases, individuals with a clinical diagnosis of AD are found during post-mortem examination to be erroneously diagnosed. Over the past several years there has been a great interest in the cause and treatment of AD. Research continues to examine the role of nutrition, metals such as aluminum (higher levels have been found in the brains of AD patients), viruses, drugs, immunological defects, neuropsychology, and the structural changes in the brain (Health & Welfare Canada, 1984; McKhann et al., 1984; Page 1992; Ramona, 1982; Williams, 1986). Recent research has focussed on acetylcholine, the cholinergic system, and the beta amyloid protein (McKhann et al., 1984; Page, 1992; Williams, 1986).

#### Pharmacological Management

Although the Federal Drug Administration identifies drugs



for AIDS, cancer and Alzheimer's disease as research priorities, there has been no major break-throughs in the pharmacological management of AD (Serby, 1989; Simon 1994). Pharmacological interventions primarily aimed at alleviating symptoms are being studied; however, the drugs appear to be of limited effect and only useful some of the time (Serby, 1989). Drugs holding the most promise, such as tacrine (Cognex), besipirdine, and physostigmine (Synaptin), affect acetylcholine and the cholinergic neurotransmitter system (Simon, 1994; Whitehouse & Geldmacher, 1994). Should one of these drugs be successful in delaying the onset of AD by even five years the financial impact alone would be staggering. It is estimated that the health care costs in the United States alone would be reduced by \$40 billion a year with such success (Simon, 1994). However, the effect of pharmacological interventions in the improvement of cognitive functioning and subsequent "behaviours" remains a guessing game as the elderly are often receiving multiple drugs which may be responsible for the varied responses or outcomes. Studies of effect are also clouded by the natural fluctuation in the patient's mental state and severity of the disease. Consequently, pharmacological clinical trials are always in need of replication before direct cause and effect can be substantiated (Serby, 1989; Simon, 1994).

Physostigmine and metritonate are two types of cholinesterase inhibitors that are currently being tested. There is also interest in the targeting of nicotinic cholinergic receptors as studies are showing that the incidence of AD is less frequent in smokers (Brenner, Kukall, & van Belle (1993) as cited in Whitehouse & Geldmacher, 1994) Nerve growth factors, channel blockers, and amino acid antagonists aimed at enhancing neuronal viability and decreasing cognitive decline are all in research and development stages (Whitehouse & Geldmacher, 1994).

Currently, low dose neuroleptics such as haloperidol (Haldol) and thioridazine are often the drug of choice when treating the range of behaviours associated with AD, including hallucinations, paranoia and agitation. Unfortunately, the side effects of these drugs are of concern. Haldol, because of its cholinergic properties, is associated with extra pyramidal side effects, and thioridazine has hypotensive and sedative effects which are not always desirable or safe (Serby, 1989; Whitehouse & Geldmacher, 1994). Benzodiazepines such as diazepam, lorazepam, and oxazepam have not been well studied, but show promise in the patient with mild dementia. Again, there is concern of the sedative qualities and the potential for a paradoxical reactions such as rage and insomnia (Whitehouse & Geldmacher, 1994). As with any

benzodiazepines, there is awareness of the potential for tolerance, dependency, and the complications of withdrawal (Serby, 1989).

In non-demented patients, carbamazepine, an anticonvulsant, has reduced violent behaviours in some individuals and has been proposed as a potential treatment for agitation in patients with organic brain diseases including AD. Mood stabilizers such as Lithium have been successful in managing agitation from other organic etiologies. Limited research regarding the effect of Lithium in the AD patient makes the potential benefit difficult to assess. Lithium is known to cause confusion in the elderly (Serby, 1989). Buspirone, a serotonin agonist and Beta adrenergic blockers such as Propranolol are also being used with some success in the treatment of agitation (Zayas & Grossberg, 1996).

Many pharmacological interventions have been tried at various times without much success. Even with the more promising treatments, confusion can be exacerbated which then creates additional behaviour problems. The risk of side effects, interaction with other medications, and the degree of compliancy in those taking the medication may result in some individuals faring better without pharmacological intervention (Serby, 1989).

Research into the relationship between pharmacology and aggression is limited. Research into violent behaviour and pharmacotherapeutic interventions aimed at decreasing incidents of violence is required (Shah, 1992). Ryden (1988) did address the relationship between the administration of psychotropic medications and aggression and found no relationship, but offers caution that her findings need to be replicated. Mendez, Martin, Smyth, and Whitehouse (1990) could not determine the outcome of pharmacological intervention in their research, although the majority of patients who had received medications gradually showed improvements in symptomology. Precisely which symptoms (insomnia versus aggression) were not identified. A positive relationship between improved behaviours and the administration of medications was also supported by Cohen et al., (1986), however, which medications for which behaviours are not detailed resulting in inconsequential findings.

### **Aggressive Behaviour and Alzheimer's Disease**

#### **Definition of Aggression**

The challenge in defining the concept aggression can be directly attributed to the inconsistencies in the literature as to what behaviours constitute aggression (Kolanowski, 1996; Ryden et al., 1991; Ware et al., 1990). Aggression is often

included as one of a cluster of behavioural problems and, when defined, is clouded by the use of additional concepts such as assaultive behaviour (Eastley & Liam, 1983), violence (Fagan-Pryor, Femea, & Haber, 1993; Kalunian, Binder, & McNiel, 1990; Lanza, 1987), and agitation (Cohen-Mansfield & Kerin, 1986, as cited in Ryden et al., 1991). Rabins et al., (1982) used the term behavioural problems. Examples of behavioural problems included, but were not limited to: catastrophic reactions, physical violence, demanding/critical behaviour, and hitting. Eastley and Liam (1993) in their study on "Physical Assaults by Psychogeriatric Patients" use the terms assaultive, aggressive, violent, and problematic behaviour without offering a definition. When definitions of aggression are included in the literature, examples of behaviours identified as aggressive are varied and range from withdrawn and/or wandering behaviours (O'Leary et al., 1993), destruction of property (Mesnikoff & Wilder, 1983), acting in an aggressive manner (Deutsch et al., 1991), to, verbal and physical violence (Ryden et al., 1991; Ware et al., 1990). Within the definitions and examples of behaviours that exist, one could create two gross generic categories of behaviours; verbal and physical.

Researchers who categorize aggression as verbal or physical disagree on the behaviours that constitute a verbal

or physical act of aggression. For example, Deutsch et al., (1991) do not include threatening gestures such as the raising of a fist as if to strike as an act of physical aggression, yet others do. Ware et al., (1990) in their "Community-Based Study of Aggressive Behaviour in Dementia" defined aggression as hostile action directed toward other persons, objects or self. Aggression was further divided into verbal aggression, physical aggression, violence to objects, and violence to self. Examples of verbal aggression included refusal to speak or any verbal action which appeared to be intentional or uncooperative in nature. Examples of physical aggression included gestured threats of physical assault or actual physical contact. No definition or examples of violence to objects or violence to self were provided. Although similar, Ryden (1988) does not include refusal to speak as acts of verbal aggression, but does include threats of aggression and physical assault as acts of physical aggression. Ryden adds a third category of sexually aggressive behaviour. The differences in opinion amongst the researchers as to the behaviours to be included as examples of aggression are at the very core of the problem to define the concept.

For the purpose of this study, aggression was defined by the caregiver. It was the intent of the study to understand the experiences of the family caregiver both in relation to

the nature of aggressive behaviour and the impact of this behaviour on the spousal caregiver. Therefore, the definition of aggression was guided by the work of Ryden (1988) but was not limited to only those behaviours identified by Ryden. This "blended" approach to defining aggression provided caregivers with a "shopping list" of behaviours, but allowed for more items to be added as necessary. A list of what constitutes aggressive behaviours (Appendix B) was provided and it was stressed to the caregivers that this was only a guide. The caregivers were encouraged to move behaviours that were identified by Ryden as not being aggressive to the aggressive "list" if they felt that the behaviour should be identified as aggressive. Aggressive behaviour was further divided into verbally aggressive behaviour (VAB), physically aggressive behaviour (PAB), and sexually aggressive behaviour (SAB).

#### Incidents of Aggression

Examining aggressive behaviours that are specific to a disease entity such as Alzheimer's disease is difficult. Not only are there conceptual problems identified with aggression, but an accurate diagnosis of AD can only be made upon post mortem examination (Simon, 1994). This may explain why aggression in Alzheimer's disease is commonly researched under

such generic headings as dementia or Dementia of the Alzheimer's Type (Hamel et al., 1990; Knopman, Deinard, Kitto, & Hartman, 1985; Rabins et al., 1982; Ryden, 1988; Snyder, Egan & Burns, 1995), cognitive impairment and psychogeriatric problems (Fagan-Pryor et al., 1994; Petrie, Lawson, & Hollendar, 1982; Seltzer & Buswell, 1994).

A few studies do provide a breakdown of dementia etiology; however, findings are reported as a whole and incidents of aggression are not disease or etiology specific. Swearer, Drachman, O'Donnel and Mitchell (1988) compared disruptive behaviours within the disease categories of AD, multiple infarct dementia, and Mixed AD and multi infarct dementia, and found no significant differences in behaviours. However, the definition of disruptive behaviours was very broad-ranging from aggression and assaultiveness to sleep disorders and incontinence.

Rabins et al., (1982) interviewed family caregivers of 55 patients with dementia living either in institution or at home. The clinical diagnosis was broken down to 60% with AD, 18% with multi-infarct dementia, and 22% had dementia due to "other causes". Ryden's (1988) study recruited subjects that had "some form of dementia." Ryden provided the diagnosis for the majority of the subjects as follows: 69.4% diagnosed with AD, and stroke or multi-infarct dementia in 7.1% of the



subjects. Tardiff and Sweillam (1979) studied assaultive behaviour in individuals admitted to a mental hospital in which the primary diagnosis of the group 65 years and older was organic brain syndrome. Mesnikoff and Wilder (1983) in studying behaviour problems in adult homes provided no data as to diagnosis; however, half of the sample were identified as "mental" patients. In a Canadian study of aggressive behaviour in community dementia patients, Hamei et al., (1990), identified that of 213 subjects, 175 were diagnosed as having Senile Dementia of the Alzheimer's type, 12 with multi-infarct dementia, and 25 subjects had dementia of unknown etiology. The variety in diagnosis clearly identifies the difficulty in relating aggressive behaviours specific to those with the diagnosis of AD.

A literature review of problem behaviour in the cognitively impaired elderly suggest that although the extent of occurrence is not clear, the majority of researchers report that a significant proportion of those who are cognitively impaired display aggressive behaviour (Cohen-Mansfield & Billig, 1986; Ryden, 1988). Frequency of aggressive behaviour in those persons who have some form of cognitive impairment, is reported to occur in as few as 2% of the population (Mesnikoff & wilder, 1983), to an extreme of 87% (Cohen-Mansfield & Kerin, 1986, as cited in Ryden et al., 1991). The

extreme range in frequency of aggressive behaviour reported in the literature likely reflects differences in (a) methodology, (b) study design, (c) collection instruments, (d) types of samples including the disease/illness entity, and (e) the dependent variables used in the studies (Deutsch et al., 1991; Eastley & Mian, 1993; Hamel et al., 1990; Ryden et al., 1991; Swearer et al., 1988).

Furthermore, there is disagreement among researchers as to the accuracy of reported estimates of aggressive behaviour. Silver and Yudofsky (1991) found that incident reports and patient records are inadequate in recording both the number of incidents and the behaviours related to an aggressive episode. Lion, Snyder, and Merrill (1981) state that less than one-fifth of aggressive attacks on staff in a nursing home were formally reported on incident forms. These findings received support from Eastley and Mian (1993) who found that over 60% of assaults are not formally documented. Under reporting is attributed to (a) the frequent exposure of nurses, especially psychogeriatric nurses, to aggressive behaviour resulting in desensitizing and/or a "part of the job" perception especially when dealing with cognitively impaired patients, (b) the lack of serious injury from assaults by the elderly, (c) the time it takes to report the incident, (d) the perception that no action will be taken, (e) fear of recrimination by peers, (f)

lack of support from peers, and, (g) concern that they might be blamed for the incident (Lion, Snyder & Merrill, 1981; Conn & Lion, 1983; Patel & Hope, 1992; Shah, 1992). Eastley and Mian (1993) even go as far to say "Assault by a relatively frail, elderly patient will not be perceived as a frightening incident" (p. 519), and therefore not reported.

Ryden et al., (1991) report that a retrospective measure of incidents of aggression in nursing home residents (66%) was much lower than what Ryden refers to as the concurrent measure which is a recording of the behaviour as it actually occurs (86.2%). The concurrent measure is believed to be more accurate as distortion that may occur due to recall would not be present. Also, in this study the concurrent measure was completed by nursing assistants who best know the resident's behaviour and thus are likely in the best position to identify and record the behaviour.

Studies that rely on community caregiver's retrospective reporting of incidents of aggression are being challenged. Relying on the caregiver's willingness or ability to clearly recall incidents and types of aggression need to be considered when reviewing these research reports (Polit & Hungler, 1991). Literature assessing the accuracy of caregiver reports on care recipients physical and functional health is sparse (Kiyak, Teri, & Borson, 1994). To date, no studies have been found

that compare caregiver assessment of incidents of aggressive behaviour with actual behavioural observations (O'Leary et al., 1993). It is hypothesized that under reporting may be related to the stigma attached to aggressive behaviour and the belief that it is socially unacceptable to discuss such matters. Eventually, due to the caregiver burden, the family member finally seeks help and reports the behaviour (Hamel et al., 1990; O'Leary et al., 1993). Therefore, one must be cautious when relying on the accuracy of caregivers retrospective reports (Kiyak et al., 1994).

Although verbal and physical aggression are common to Alzheimer's disease, research identifying the incidence and types of behaviour is limited. Most studies are retrospective frequencies of the behaviour as reported by the caregiver. Accurate reporting of incidents in retrospective reports is questionable (O'Leary et al., 1993).

The majority of studies on aggression and Alzheimer's disease/cognitive impairment/dementia are conducted in institutions with a predominance of studies in psychogeriatric settings, and/or on pharmacological interventions (Ryden, 1988). It is obvious that institutional settings and community settings are very different. Consequently, studies on aggression in institutions and aggression in community settings are reviewed separately.

### **Aggression in Institutional Settings**

Besides differences in definitions, variations in methodology, study design, and reporting may account for some of the variability in findings as summarized in Appendix C. In some cases, the lack of information on the measurement tool, including reports on the validity and reliability of the instrument, make a critical assessment of the findings difficult.

Petrie et al., (1982) revealed that of the studies recruiting subjects from psychogeriatric in-patient units, 62% of admissions involved aggressive behaviour or violent behaviour. Aggressive behaviour was defined as acts or threats without a weapon and violent behaviour as acts or threats with weapons. Aggressive acts in individuals with some form of brain tissue damage with associated memory loss and confusion are reported as being less "violent" and more reflexive than premeditated. The violent acts were found in people who were not confused or disoriented, but were delusional. Mesnikoff and Wilder's (1983) American study on acting out behaviour in 1900 residents living in adult homes (providing 24 hour residential care for the chronically ill) throughout New York state, identified that 5% - 6% of those aged 65 or older displayed "acting out" behaviour problems (losing temper/self control, damaging property), and 2%

"antisocial" behaviour (causing complaints, "bizarre" and/or "unusual" behaviour). Data were collected using client assessment forms. The categories of behaviours were based on elements identified in the client assessment that were identified as having face validity and strongly related statistically. No further information on scoring methods was provided. Slightly less than half were identified as "mental patients," but no further data were given specific to diagnosis (Mesnikoff & Wilder, 1983).

Using the term "agitation," Cohen-Mansfield and Kerin, 1986, reported that of 107 nursing home residents, 87% exhibited one or more agitated behaviours weekly (as cited in Ryden, 1991). Later, in 1988, Cohen-Mansfield reported that agitated behaviours occurring at least once a week were present in 54.3% of the 165 nursing home residents. Using the Ryden Aggression Scale (RAS) to measure aggressive behaviour, Ryden et al., (1991) found that 86.3% of 124 cognitively impaired nursing home residents showed some form of aggressive behaviour. Of the 124 subjects, 50.8% displayed physical aggression (PAB), 47.6% verbal aggression (VAB), and only 4% of the subjects displayed sexual aggression (SAB). Despite the high incidents of verbal aggression found in this study, not all researchers include verbal aggression in their assessment of incidents of aggression.

Malone, Thompson, and Goodwin (1993) completed a 12 month retrospective study on the types and incidence of aggressive behaviour in a 350 bed long term care facility. In a one year period, there were 1592 incident reports completed of which 94 incidents described aggressive behaviour. Included in the 350 beds was a 60 bed Alzheimer's Unit which was identified as being responsible for 48% of the completed incident reports on aggression. As expected, this unit had a much higher incidence of aggressive behaviours (.75) than the reported facility average. Six residents on the AD unit accounted for 44% of all the documented incidence of aggression. Although no definition of aggression was offered, incidents of PAB were reported with hitting occurring most frequently at 57.4%, followed by grabs/shakes at 17%. Of the aggressive behaviours 50% occurred during the evening shift, 46.7% during the day, and only 3.3% at night. There were no differences in mean age or gender between those residents who exhibited aggressive behaviour and the resident population as a whole. Data were collected retrospectively from incident reports, with accuracy relying on the health care professionals commitment to the documenting of such behaviours and consistency in this documentation (Malone et al., 1993).

Bridges-Parlet, Knopman and Thompson (1994) directly observed physically aggressive behaviours (PAB) in 20 dementia

patients using the RAS1 and portable bar-code-readers to measure incidents and duration of PAB. The bar-code-readers scanned a variety of codes related to observed behaviours, tracking time of occurrence, order of occurrence, and length of occurrence in minute increments. Of the patients, 65% displayed PAB (28 incidents), and 82% of these behaviours were directed at staff, with 65% occurring during hands on care. The duration of incidents were as follows; 25% less than one minute, 43% one to five minutes, and 32% five to twenty minutes. In comparing incidents documented on the RAS1 with the incidents recorded with the bar codes, nursing staff were found to be negligent in the completion of the RAS1. The researchers acknowledged the problems associated with non-researchers collecting data.

### **Aggressive Behaviour in the Community**

As was the case with the literature on aggression in institutions, the research into aggressive behaviour in the community is also filled with variations that makes comparisons across studies difficult. Variations that make a critical assessment of the findings challenging include the population studied (disease entity), definitions, methodology, and study design. Appendix D summarizes the literature on aggressive behaviour in the community.



Ryden (1988) investigated the nature, prevalence, and context of aggressive behaviours in dementia patients using the Ryden Aggression Scale (RAS). The RAS has a test-retest reliability of .86 and an ability to differentiate between individuals living with dementia in the community and those residing in nursing homes (Hamel et al., 1990). Ryden found that 65% of 183 individuals living in the community who attend dementia clinics displayed some form of aggressive behaviour. Aggressive behaviour occurred at least once a week in 31% and daily in 16% of the 183 individuals in the study. Aggressive behaviour was operationally defined and included verbal aggression with a 50% incidence, physical aggression with a 46% incidence, and sexual aggression which occurred least often at 18%. Limitations to Ryden's research include a potential sample bias as it is possible that subjects were more likely to participate if they had a family member who was acting aggressively. Another sample bias concerns subjects who were recruited from dementia clinics and excluded those who did not access these resources. Ryden also relied on retrospective caregiver reports of aggressive incidents. Generalizability of the findings were also limited. Ryden acknowledges these limitations in her research and also adds that including a control group would have given strength to the study findings.

A Canadian study by Hamel et al., (1990) examined the predictors and consequences of aggressive behaviour in 213 community individuals with dementia. The study also measured incidents and types of aggressive behaviour using the RAS. Retrospectively, 57.2% of caregivers reported the presence of aggressive behaviour in the care recipient. Verbally aggressive behaviours (VAB), especially hostile and accusatory language, had the highest incidence occurring in 51% of cases. Physically aggressive behaviours (PAB) were displayed by 34.1% of care recipients. Threatening gestures was the most common behaviour, occurring in 21% of the subjects. Sexual aggression (SAB) was present in 7.2% of cases with inappropriate hugging and kissing identified as the most common form of SAB. Despite the majority of patients displaying aggressive behaviour, VAB, the most common form of aggression, only occurred daily in 10.6% of the subjects. Hamel's et al., study(1990) indicated a lower incidence of the physically harmful behaviours than Ryden's (1988) study. The reported high incidence of verbal aggression in Hamel's study are consistent with Ryden's findings. Similar to Ryden's study, the majority of caregivers reporting in Hamel's study were spouses (56%).

Ware et al., (1990) established that the Present Behavioural Examination (PBE) was a valid measurement tool

with high reliability evident in preliminary work. They used the PBE to document incidents of aggression in community-based dementia patients. VAB, which included refusal to speak, was found in only 11% of the 37 participants which is markedly lower than in other studies. Mild physical aggression (pushing away, threatening, resistance to care, or throwing of a soft object in anger) in the absence of severe aggression, was found in 46% of the population. Of the subjects, 43% had at least one occasion of physical aggression that was identified as severe and included hitting, kicking, and throwing a hard object. Although the definition of aggression is similar to that used by Ryden (1988), Ware et al., (1990) further break down aggression into mild and severe. Limitations to this study are similar to the limitations in Ryden's 1988 research including (a) a sample bias, (b) retrospective reporting, and, (c) generalizability of findings.

Researchers O'Leary et al., (1993) had 32 caregivers (50% spouses, 50% daughters) of individuals with Alzheimer's disease complete a concurrent 48-hour behavioural log of the patient's adaptive and ineffective behaviours. Using the Memory and Behaviour Problem Checklist (MBPC), behavioural problems were identified as occurring in 44% of the patients waking time with the problems occurring most commonly between

1600 and 2000 hours. Five percent of the care recipients awake time was spent in acts that were identified as harmful to self or others. Behaviour problems included not only aggressive behaviours, but other behaviours such as wandering, repeated questioning, repetitive behaviours (such as emptying and refilling of a purse), and memory difficulties. These findings were then compared to the caregivers concurrent behavioural assessment as recorded on the "24 hour behavioural log". Only the most frequent behaviours were collected even though other less frequent behaviours were of greater concern. Behaviours were recorded in half hour time frames resulting in any behaviour that lasted less than a half hour being rounded up to the nearest half hour duration. As a result, an exact measurement of behaviour was not collected. Data on the caregiver's assessment of the stressfulness of each behaviour were not collected.

Over a 50 month period, Rubin et al., (1987) followed the progression of behavioural changes in 44 individuals diagnosed with senile dementia of the Alzheimer's type (SDAT). Recruiting strategies resulted in a relatively homogeneous population including a comparable group of control subjects. Subjects were evaluated every 15-18 months using information obtained from both the subject and a spouse or child caregiver through structured interviews, the Clinical Dementia Rating

Scale, and the Blessed Dementia Scale. Of the 44 dementia subjects, 24 remained in the study over the course of 50 months. During this time, 17 of the subjects progressed from mild to severe dementia. As the severity of the dementia progressed, agitated behaviours increased from a frequency of 25% upon entry to 67% ( $P < .001$ ). In the control group agitated behaviours increased to 9% incidence from an entry incidence of 4%. Of the 58 control subjects, 46 remained in the experiment the entire 50 months, with one subject having a deterioration in his/her cognitive state. Although no detailed definition of agitation was provided, irritability, purposeless hyperactivity, and sexual misdemeanour were considered agitated behaviours. Factor analysis was used to categorize items which were then combined into four groups of behaviours including passive, agitated, self-centred, and suspicious. Limitations of the study related to the application of the concept agitation without further detail or definitions offered. The inability to generalize the findings was also a limitation of the study as individuals with SDAT, who also had other medical illnesses or who were receiving substantial psychotropic medications, were excluded from the study. The researchers also identified a potential weakness with the grouping of behaviours, feeling that other groupings could have been considered. In spite of these weaknesses, the

researchers believed that even with another statistical method the relationship between dementia and agitated behaviours would be reproduced.

Deutsch et al., (1991) examined the relationship between psychotic symptoms and aggressive behaviour in individuals with probable AD. Clinic charts were reviewed on 181 subjects who had been followed in the clinic every 6 months. Cognitive impairment was measured using the Mini-Mental State Exam (Folstein, 1985) with the level of cognitive impairment ranging from moderate to severe. Summary notes on each visit were completed by a research psychiatrist and/or a research psychiatric nurse and were recorded on all charts. Caregiver interviews using open-ended questions, Psychogeriatric Dependency Rating Scales, and Scale of Psychosis in Alzheimer's Disease were completed. Physical aggression was defined as any physical contact with a person or object in an aggressive fashion. Threats of aggression (verbal or physical) were not included as an incidence of aggression. Data regarding physical aggression were available on 169 subjects of which 29.6% were reported by their caregiver as having at least one episode of physical aggression since the onset of symptoms. Weapons such as a chair, knife, or scissors were used by "many" patients during physically aggressive acts. There were no demographic differences

between the non aggressive and the physically aggressive subjects. The majority of aggressive episodes, 68%, occurred while the patients were living at home. Applying chi-square analysis and stepwise binary multiple regression, delusions were found to be the best predictor of physical aggression with delusions and misidentifications significantly higher in the physically aggressive subjects. Limitations of this study included the inability to generalize the findings and the "lack of reliable and valid rating scales with which to assess the presence and severity of these symptoms" in the target population (Deutsch et al., 1991, p. 1163).

In a study on the impact of behavioural problems on family caregivers, Rabins et al., (1982) used structured interviews with 55 caregivers of both community (N=52) and institutional patients (N=3) with dementia. Catastrophic reactions (outbursts of anger or physical blows) and demanding/critical behavioural problems were reported as a problem by 87% of community caregivers and 71% of families whose family member was institutionalized. Specific behaviours cited as causing serious problems were (a) physical violence reported by 42% of families of which 75% identified this as a serious problem, (b) catastrophic reactions reported by 87% of families of which 56% identified it as a serious problem, and (c) hitting occurring in 29% of the families and

identified as a serious problem for 50% of those families. Limitations to this study include a sample bias as these families were seeking help and could possibly be perceived as experiencing more problems than families who have not sought help and the potential for a structured questionnaire (with problems listed) compared to an open-ended interview to elicit more complaints (the power of suggestion).

### **Relationship Between Aggression and Cognitive Impairment**

Studies examining the relationship between cognitive functioning and incidence of aggression are contradictory (Appendix E). The disagreement regarding the effect of impairment may be due to the lack of consistent definitions and tools to measure such behaviour. The variety of cognitive exams, varying methods for completion, and on occasion the subjective categorizing of the participant by the caregiver or researcher, contribute to the confusion.

Teri et al., (1988) studied behavioural disturbances in dementia of the Alzheimer's type in community based participants and measured cognitive functioning using two different mental status exams. The Folstein Mini Mental State Exam (MMSE) and the Blessed Dementia Scale (BDS) indicated that the frequency of most behavioural problems increased with increased cognitive impairment. Reliability and validity of



the MMSE and BDS were not reported. Absent in this study were definitions of behavioural problems, although it did include many examples that ranged from agitation and restlessness to falls and incontinence. Ryden (1988), in studying aggressive behaviour in persons living with dementia in the community, also found that increased cognitive impairment is associated with increased incidents of aggression. Ryden further broke down the types of aggression into physical, verbal, and sexual categories. Upon examination of mean scores for each specific category of aggression, the physically aggressive behaviour category was the only behaviour to be associated with cognitive impairment. What Ryden offered was a very specific and observable definition for the concept aggression. Ryden's definition was specific to aggression and did not include behaviours such as falls and incontinence which were included in the group of "behavioural disturbances" reported by Teri et al., (1988). Once again, inconsistencies in definitions makes comparisons across studies difficult. Unfortunately Ryden's (1988) study lacked the use of a standardized assessment tool to measure cognitive impairment. Rather, the degree of cognitive impairment was obtained from family members based on behaviours and then assigned to categories of mild, moderate, severe. Ware et al., (1990) used the MMSE to assess cognitive functioning but did not report on the relationship between

cognitive functioning, and aggression. O'Leary et al., (1993) assessed behavioural problems in Alzheimer's disease and also used the MMSE to measure cognitive impairment. Although they did not report on the relationship between degree of dementia and occurrence of harmful behaviours such as throwing objects, they did find that persons with lower scores on the MMSE (indicating more cognitive impairment) had lower levels of adaptive social behaviours. Ineffective social behaviours included yelling, "hollering," and putting clothes on in an unsuitable manner. The relationship between the MMSE and what O'Leary et al., defined as harmful behaviours, such as throwing objects, was not reported. This relationship between cognitive functioning and aggressive/assaultive/agitated/problematic behaviour is supported by a variety of other researchers (Burns et al., 1990; Cohen-Mansfield, 1988; Cohen-Mansfield, Marx, & Rosenthal 1989; Malone et al., 1993; Rubin et al., 1987; Sorrentino, 1992; Swearer et al., 1988).

In 1991, Ryden, Bossenmaier, and McLachlan researched aggression in cognitively impaired nursing home residents (as defined in Ryden's 1988 research). Using the Short Portable Mental Status Questionnaire (SPMSQ) they concluded that "mental status did not prove to be associated with aggressive behaviour in this sample, as the relationship between aggression scores and scores on the SPMSQ shown by Pearson

product moment correlations was not significant" (p. 90). Cohen-Mansfield (1986) studied agitation in nursing home residents. Using a t-test to compare agitated to non-agitated elderly individuals, this researcher established no significant differences between the groups cognitive level. Cohen-Mansfield does conclude, but not to the level of significance, that the highest level of agitation in patients was associated with moderate impairment, and lower levels of agitation occurred in those with mild and severe impairment. Cohen-Mansfield does caution about generalizing the findings as the study population consisted of only 66 subjects. Eastley and Mian (1993) in their research on physical assaults occurring in psychogeriatric wards did not measure cognitive functioning, but did find the assaultive female was older than those who were non-assaultive. The advanced age of the assaultive female was assumed to predispose the individual to cognitive decline. Therefore, hypothesizing that cognitive impairment was associated with aggression in this population. However, these researchers could offer no explanation why similar findings were not present in the male population with identical mean ages between the assaultive and non-assaultive male population.

A Canadian community based study by Hamel et al., (1990) measured the nature and frequency of aggression using the

Ryden Aggression Scale (RAS) applying the same operational definition as Ryden (1988). In addition, these researchers also assessed cognitive functioning using the Hierarchic Dementia Scale (HDS) which has high test-retest reliability (.84) and high interrater reliability (.89). Results indicated that levels of cognitive decline did not predict aggressive behaviour as aggression occurs at all levels of cognitive functioning. The above findings are also supported by other researchers (Bridges-Parlet et al., 1994; Rabins et al. 1982). As previously stated, the differences in the definition of aggression, and the variety of measurement tools available to study cognitive functioning make comparisons across studies arduous.

### **Predictors and Influencing Factors**

The influence of gender on physical assaults is an area of debate. Researchers report that incidents of physical aggression are higher in elderly female patients (Hodgkinson, McIvor, & Phillips, 1985), higher in elderly male patients (Burns et al., 1990; Eastley & Liam, 1993; Kalunian et al., 1990; Ryden, 1988), and similar between elderly male and female patients (Malone et al., 1993; Patel & Hope, 1992; Ryden et al., 1991; Shah, 1992; Tardiff & Sweillam, 1979). Ware et al., (1990) report that incidents of mild physical

aggression (pushing the caregiver away, resisting help with activities of daily living, threatening gestures, throwing a soft object at someone in anger) are more common in the female population than in the male population. Verbal aggression and severe physical aggression (hitting, kicking, and throwing a hard object) more prevalent in males.

The association of premorbid personality and acts of verbal and physical aggression is found in the literature (Deutsch et al., 1991; Hamel et al., 1990; Marrant & Ablog, 1983; Ryden, 1988). Ware et al., (1990) discovered that in 37 subjects known to be aggressive (34 living in community, 3 living in institutions), the aggressive behaviour seen in 58% of the subjects was identified as an exaggeration of previous behaviours. Ryden (1988) reported that 40% of subjects who showed some form of aggressive behaviour had demonstrated aggressive behaviour prior to the onset of the dementia. In another study of patients admitted to a psychogeriatric unit, Eastley and Mian (1993), revealed that men were significantly more likely to have been physically assaultive prior to and during their admission. Using multiple regression analysis Hamel et al., (1990) found similar results reporting that premorbid personality is a significant predictor of aggression in the dementia patient.

A history of difficult caregiver-care recipient relationships is identified by one group of researchers as a predictor of current patient aggression (Hamel et al., 1990). This positive association may be attributed to the perpetuation of ineffective communications and interactions, (identified as social origins in the conceptual framework). The opposite of the "rose coloured glasses" effect with the present experiences and situations discolouring the past relationship may also account for the above findings. Caregivers who manage more aggressive individuals may view the past with tainted vision and past relationships are now viewed as being poorer (Hamel et al., 1990).

It is widely agreed that the administering of care or providing instructions/directions is the catalyst to an aggressive incident. As those with AD become increasingly unsure of their surroundings and what is expected of them, fear and distress result. Failed attempts at completing simple tasks creates anxiety and agitation and commonly result when people with AD are pressured to assist in their own care. When environmental demands exceed one's functional capacities catastrophic reactions of anger and aggression may result. Rational approaches requesting reasonable behaviour aggravate the situation and may add to the cognitive overload accelerating the crisis. The confusion and disinhibition in

this population result in a susceptibility to violent outbursts and sudden acts of aggression. These outbursts are often in response to aggression directed towards the care receiver by another individual such as the caregiver (Beck & Heacock, 1988; Mace & Rabins, 1981). Cognitive change in those with AD is believed to be the source of the disinhibition. Although the cognitive decline may result in the individual behaving in a more aggressive fashion (disinhibited), the continual display of aggressive behaviour may be unintentionally reinforced by the caregiver. If the aggressive behaviour of the care recipient results in him/her having their needs met by the caregiver, the behaviour is more likely to be repeated (Beck & Heacock, 1988).

Although difficult to separate, the interplay between the cognitive impairment and the patient's distinctive individual emotional reaction to events also needs to be considered. The individual's normal response to an event may be one of anger, but once the event has passed, the anger also leaves. However, once cognitively impaired, the source or events related to the angry feelings may be forgotten, but the emotional tone of anger remains. The person with AD is unable to recognize his/her feelings and may then respond with an exaggerated emotional response such as rage. Once initiated, the escalation continues because of his/her impaired ability

to accurately assess and control the expression of emotion (Beck & Heacock, 1988; Mace & Rabins, 1981).

As previously stated, most of the assaults on nursing staff and caregivers occur during the delivery of routine care or while trying to prevent the individual from leaving an area (Deutsch et al., 1991; Eastley & Mian, 1993; Hamel et al., 1990; Ryden et al., 1991). Routine care included assisting the care recipients in meeting their activities of daily living such as bathing or dressing. In a mixed community and nursing home study, Ware et al., (1990) identified assistance with activities of daily living as the most common antecedent to aggression in 68% of all subjects, followed by aggression occurring in response to instructions or directions in 36% of subjects. Night-time aggression occurred in 14% of subjects and aggression in response to aggression initiated by others (usually the caregiver) occurred in 11% of the subjects. The remaining situations in which aggressive behaviour occurred were: irritability in the subject; paranoid beliefs that others were acting against them; being prevented from doing something inappropriate such as leaving a safe environment; arguments during which the subject would stick inappropriately to a point of view; and a miscellaneous category.

Ryden et al., (1991) identified nursing staff as the primary targets of aggressive behaviour in over 87% of all



aggressive episodes. Differing slightly from the above findings, Hamel et al., (1990) identified that community patient aggression was most often elicited by instructions being directed toward the care recipient, as when told to "do something." Ryden et al., (1991) summarized that a specific antecedent such as previously described was identified in 98% of aggressive incidents occurring in 124 cognitive impaired nursing home residents.

Psychotic symptoms are also viewed as predictors to aggressive behaviours in those with Senile Dementia of the Alzheimer's Type. Delusions, hallucinations, and misidentification are often found in those with Alzheimer's disease and are positively associated with incidence of physical aggression (Deutsch et al., 1991; Mayeux, Stern, & Sano, 1985; Patterson, Martin & Mendez, 1988).

### **Aggression and Caregiver Impact**

The gerontology and chronic illness literature is saturated with research on caregiver burden and the physical, emotional, social, and financial demands of caring for a family member with chronic illness. What is lacking in the literature, and hence the purpose of this research, is the family caregiver's feelings/perceptions specific to their exposure to aggressive behaviour in the family member with AD.

How do they feel, manage, or cope when exposed to this behaviour? There are anecdotal statements about feelings of strain, fear, and frustration, when caring for someone who is cognitively impaired, but research specific to aggressive behaviour is limited.

It is clear that aggressive behaviour is poorly tolerated by caregivers because of the associated strain and increased hardships experienced by the caregiver (Eastley & Mian, 1993; Hamel et al., 1990; Kalunian et al., 1990; Patel & Hope, 1992; Shah, 1992; Tardiff & Sweillan, 1979; Teri et al., 1988; Ware et al, 1990). The limited treatments available for cognitive deterioration and behavioural problems and the potential danger to both care recipient and caregiver are sources of frustration and fear to families (Health & Welfare Canada, 1984; O'Connor, Pollitt, Roth, Brook, & Reiss, 1990; Serby, 1989; Ware et al., 1990). Even when not physically dangerous, verbal aggression is a major burden for the caregiver. Anger and insults are often aimed directly at the caregiver and the caregiver in turn, is bewildered by the changes in their spouses character or disposition. The difficulty experienced in separating the behaviour resulting from cognitive decline from the person they know and love may result in family members misperception of the events. Anger and frustration simmer beneath the surface until the caregiver explodes with

frustration (Health & Welfare Canada, 1984; Teri et al., 1988; Ware et al., 1990).

The majority of studies focus on incidents and types of aggressive behaviour, not caregiver responses. Clearly, caring for anyone with a chronic illness is difficult. The additional challenge of caring for someone who is cognitively declined and aggressive due to his/her illness is an additional burden, making life for all involved extremely troublesome and exhausting.

Recent studies readily identify aggressive behaviour as a significant problem and point out the need for increased training and emotional support for health care personnel (Chase, 1996; Hagen & Sayers, 1995; Martin, 1995, Ryden et al., 1991; Weinrich et al., 1996; Zimmer, Watson, & Treat, 1984). Nurses identify physical and verbal abuse by the elderly patient during the provision of care as one of the most difficult, dangerous, and distressing elements in their work. Nurses in one western Canadian study unanimously identified physical aggression in the elderly as their "most frustrating" day to day nursing problem (Hagen & Sayer, 1995, p. 7). The stress that staff experience when exposed to verbal, physical, and sexual aggression is said to be amplified by the "demoralizing effect" that knowing the individual will not improve despite their care (Ryden et al.,

1991). In effort to reduce the emotional and physical toll that aggressive behaviour has on health care providers and the financial burden to institutions, staff education on the management of aggression is becoming a priority (Hagen & Sayers, 1995; Martin, 1995; National Crisis Prevention Institute, 1995).

Another study comparing family member and nursing staff reporting of behavioural problems, found there was frequent disagreements about the presence of behaviours between the two groups (Lukovits & McDaniel, 1992). The behavioural problems encompassed a multitude of behaviours such as agitation, depression, and incontinence. Agitation which included angry outbursts and physical threats, was rated the third highest in areas of disagreement. Caregivers were asked about their concern over different behaviours. Although verbal aggression was broadly grouped (verbal aggression was reported with agitation, restlessness, wandering, and repetitive questioning), family caregivers were reported as being more concerned over "verbal aggression" than the nurses. The difference between the two groups was attributed to the subjectivity of caregiver reports, the history with the patient, the nature of the relationship to the patient, and the emotional investment in the patient (Lukovits & McDaniel, 1992). Perhaps family caregivers are more concerned over the

verbal aggression than nurses because nurses have "finished their shift" at the end of the day and get a break from what can be at times, relentless verbal abuse. Family members do not experience an "end to their shift" and are continuously exposed to the verbal aggression. Similarly, researchers Eastley and Mian (1993) conclude that hospital personnel tolerate aggressive behaviour better than the informal caregivers in the community.

Researchers need to acknowledge and address the problems encountered by family caregivers living in the community with confused, aggressive, abusive, care receivers. However, before we can accomplish this, we must understand what it is that the spousal caregiver is experiencing and not blindly apply the experiences of the health care provider to spousal caregivers. Nursing research documenting the spousal caregiver's self appraisal of the impact of aggressive behaviour is very limited as the current research focus remains on behavioural problems of those with dementia.

In an eight week study audio taping support groups for families caring for individuals with AD, Barnes, Raskind, Scott, and Murphy (1981) found that caregivers removed potentially dangerous items such as guns and tools from the house. Although spontaneous physical abuse was not readily identified, many of the spouses found themselves in physical

battles with their partner while trying to prevent them from carrying out something personally dangerous. The fear caregivers had of both the potential and actual verbal and physical aggression created an "exhausting emotional background of anxiety and uncertainty (Barnes et al., 1981, p. 82)." This resulted in the caregiver's reluctance to impose limitations on unacceptable behaviours which is strongly encouraged for the management of aggressive behaviour (Martin, 1995; National Crisis Prevention Institute, 1995). Techniques are offered for the management of aggressive individuals; however, it is not known if these techniques are effective or relevant to those individuals living with AD. It is the purpose of this study to shed some light on the range of management techniques and approaches used in the community by caregivers of family members who have AD and behave aggressively.

The purpose of this literature review was not to examine caregiver burden, however a study by Hamel et al., (1990) that examined both burden and aggression is important. In their 1990 Canadian study, these researchers examined the relationship between aggression in the dementia patient and the burden reported by community caregivers. Enrolled in the study were 145 female and 68 male caregivers of family members with dementia. Of the 213 care recipients, 82.5% were

diagnosed with dementia of the Alzheimer's type. Health problems associated with caring for a relative with dementia were identified. Those caregivers who identified themselves as feeling burdened also described themselves as being less healthy, having a history of poorer quality social interactions with the family member, and spent less time in enjoyable activities with the family member. These "burdened" caregivers were caring for individuals who had a greater number of behaviour problems (including memory problems) than caregivers who did not identify themselves as feeling burdened. What is important in these findings is that aggression did not significantly predict caregiver burden once statistical analysis was conducted.

Although not specific to aggression, a review of the literature of informal caregivers of elderly individuals criticized the needs assessments of family caregivers. Ryan and Winslow (1991) reported that significant gaps exist between what the caregiver needs and what the caregiver receives. This gap is attributed to the focus of needs assessments on the care recipient and not the caregiver. These results are similar to earlier findings of researchers Bowers (1987) and Ryden (1988). The support of informal caregivers in the community must be seen as a greater priority and a rightful focus of nursing intervention. Nolan and Grant

(1989) also criticized the low priority and commitment that nurses give to informal caregivers, finding fault with the education of nurses which does not prepare them for their significant counselling role.

To group the experiences of health care workers and families together is inappropriate. Little is known if their experiences, reactions, resources, and needs are similar. Individuals providing care because of family ties have a very different bond than individuals who were hired to provide care. "The importance of this [the impact of aggression on the family caregiver] can be underestimated if only hospitalized patients are studied" (Ware et al., 1990, p.340).

#### Aggression in the Caregiver

Conflicts commonly arise between caregiver and care receiver. When the care receiver becomes confused and abusive, the caregiver becomes understandably impatient. The typical caregiver response to the display of aggressive behaviour is to "retreat, ignore or accept" the behaviour (Hamel et al., 1990, p. 208). Unfortunately this is not always the case. Ryden (1988) argued that there is a feedback loop in the care giving context in which patient aggression creates caregiver response aggression, and in a vicious



feedback loop (interactions with the environment) care recipient aggression.

In their 1990 research on aggressive behaviour in dementia Ware et al., identified that in 11% of cases, the aggressive behaviour of the subject was in response to the aggressive behaviour of someone else, usually the caregiver. According to Ryden (1988) 35.5% of caregivers reported that the aggression of the patient evoked feelings which made them want to respond aggressively. Twenty two percent of family members/caregivers admitted to having acted aggressively toward the care recipient. The types of response aggression reported by Ryden included nineteen caregivers admitting to verbal abuse, eight responding with physical abuse such as hitting, pushing, or shaking, and two individuals resorting to the use of restraints. Feelings and acts of aggression were positively associated with the aggressive scores of the family members as measured using the RAS. Those who admitted to and acted upon feelings of aggression, had family members with significantly higher scores as measured by the RAS.

Rabins et al., (1982) reported that 48 of 55 primary family caregivers reported feeling angry, sad, depressed, or tired most of the time. Unfortunately, no further breakdown (angry versus sad) was provided. Similarly, although to a much lesser degree, Hamel et al., (1990) found that 10.1% of

caregivers admitted to feelings of anger, but did not respond aggressively to the care recipients aggression. However, 10.6% of the caregivers reported responding to aggression with aggression. Because of the difference in findings between their study and a comparable American study by Ware et al., (1990), Hamel et al., (1990) identified a cultural difference between the two countries as a reason why there may be less actual aggression in the Canadian study. In fact, culture may impact one's willingness to admit that they have responded in a socially unacceptable manner. In all three of the above studies, the caregiver was the primary source of information and as such self reports of response-aggression may be conservative (Hamel et al., 1990; Ryden, 1988; Ware et al., 1990). At the very least, the possibility of under reporting of caregiver response aggression indicates that the study results must be viewed cautiously. Interestingly, and not found elsewhere in the literature, was the finding that caregiver aggression had no relationship to burden (Hamel et al., 1990).

Aggressive behaviour by the caregiver in response to the aggressive behaviour in the care recipient underscores the need to understand the experiences of the caregiver so that we may intervene through education and support to break this cycle, improving the safety and health of all involved. "The

potential for the punitive use of both physical and chemical restraints by both professional and family caregivers must be acknowledged and guarded against" (Ryden, 1988).

#### The Decision to Seek Placement

Aggressive behaviour is implicated as a cause of prolonged hospitalization and a common reason for caregivers to refuse accepting individuals once discharged from hospital. The result is the placement of the individual into a nursing home (Chenoweth & Spencer, 1986; Eastley & Mian, 1993; Handy, Chithiramohan, Ballard, Bannister, & Rusca, 1991; Lam, Sewell, Bell, & Katona, 1991; Shah, 1992). Understandably individuals who were less healthy and/or taking care of someone who was often aggressive were more likely to identify a care plan which involved placing the individual in a nursing home.

Of interest is the finding by Hamel et al., (1990) that non-spousal caregivers were more likely to institutionalize the individual with dementia than the spousal caregiver. These researchers attributed this to the context of long-term marriages which reflect a high level of involvement and fewer competing demands on the spouse as child care and employment outside of the home are behind them. While there may be fewer competing demands, there is decreased involvement in community

activities which usually affords the spouse much needed support. The common link appears to be life-long commitment.

Obviously, relationship to the care recipient is only one predictor of institutionalization. Unpredictable aspects of the care giving situation such as health and the availability of supports must be factored in to the caregiver's decision to seek placement for his/her family member (Hamel et al., 1990).

### **Interventions and Management Strategies**

The need for education and support of health care staff who work with the aggressive patient with AD is well documented. Institutional techniques recommended to manage aggressive behaviour such as medications and physical restraints, leaving the room, physical distancing from the patient, venting to someone, taking a break (Crisis Prevention Institute, 1995), may be very effective, but not realistic for many spousal caregivers. Only 38% of 183 family caregivers of aggressive relatives with dementia reported that health care professionals' suggestions on how to deal with difficult dementia-related behaviours were of any help (Ryden, 1988). Even though more family members with an aggressive care recipient attend support groups (54.8% of participants had an aggressive family member, compared with 35% who did not have an aggressive family member), no significant differences in

the amount of help received from family and friends was identified (Ryden, 1988).

The one consistent finding in the research on aggressive behaviour is that the most common cause or antecedent to aggression is the direct hands-on care required to assist the individual with his/her activities of daily living. This "social" origin of aggression based on interaction between a patient who is cognitively impaired and his/her caregiver is unlikely to be easily amenable to pharmacological intervention. Energies directed at modifying the precise interaction between the patient and caregiver is thought to be of greater value than pharmacological intervention in the effort to decrease the incidents of aggression in this population (Ware et al., 1990).

### **Summary of the Literature**

Alzheimer's disease is a devastating disease with a prevalence that is expected to triple in Canada by the year 2031. Half of the population afflicted with AD continue to live in the community with the majority of caregiving being administered by family members (Canadian Study of Health and Aging, 1991). The studies examining cognitive functioning and incidence of aggression are contradictory. Of those that do report a relationship between increased aggression and

cognitive deterioration, estimates of occurrence are reported in as few as 2% (Mesnikoff & Wilder, 1983) of the population to an extreme of 87% (Cohen-Mansfield & Kerin, 1986, as cited in Ryden et al., 1991). The extreme range in frequency is directly attributed to the lack of consistent definition of what constitutes aggressive behaviour, the lack of reliable and valid measurement tools, differing study designs, methodology and disease/illness entities. The accuracy in the reporting of assaults is also questioned, in that under reporting occurs in institutions as staff become "accustomed" to the behaviours (Eastley & Mian, 1993; Lion et al, 1981; Patel & Hope, 1991; Ryden et al., 1991; Shah, 1992). Although studies of incidents of aggressive behaviour in the community are limited, under reporting is thought to occur because of the stigma attached to aggressive behaviour and the social unacceptability of such behaviour (Hamel et al, 1990; Kiyak et al., 1994).

The literature on the experiences of family caregivers of the aggressive Alzheimer's relative is limited. The majority of research studies are quantitative in nature, with a focus on the types and incidents of the aggressive behaviour (Bridges-Parlet et al, 1994; Cohen-Mansfield, 1988; Petrie et al., 1982; Malone et al, 1993; Rubins et al, 1987). Similarly, the few qualitative studies (Hamel et al., 1990;

Rubin, Morris, & Berg, 1987; Ryden 1988) focus on the prevalence and types of behaviour and are not related to the experience of family caregivers (as shared by the caregiver) or the interventions used by community caregivers. Weinrich et al. (1996), identified the need for qualitative studies on "agitation" from the caregiver's perspective. Although Rabins, Mace, and Lucas (1982) completed a qualitative study on the impact of dementia on the family caregiver, with the majority of the participants residing in the community, caregiver management and response to the aggressive behaviours was not identified.

What is understood is that providing care to an aggressive individual places caregivers at emotional and physical risk. Aggressive behaviour in the care recipient is reported as occurring in 11% of cases in response to aggression in someone else, usually the caregiver (Ware et al., 1990). Aggression in caregivers in response to care recipient aggression has been admitted to by 10.1% (Hamel et al., 1990) to 22% (Ryden, 1988) of caregivers. Aggression in the care recipient is identified as being of significant influence in the caregiver's decision to seek long term placement for the relative (Chenoweth & Spencer, 1986; Eastley & Mian, 1993; Handy et al, 1991; Lam et al. 1991; Shah, 1992). Only 38.3% of caregivers report that advice from

health care personnel was helpful in managing the aggression in their family member (Ryden, 1988).

In summary, the lack of qualitative studies on the experiences of the spousal caregiver of the aggressive AD patient support the need for this study. Beyond the caregiver burden scales very little is known about the impact aggressive behaviours have on the life of the family caregiver. Treatment approaches tend to be pharmacological in nature or focus on approaches that are specific to institutional settings. There is no available data on the techniques used by the family caregiver in managing or coping with aggressive behaviours as they occur. The future of health care places more and more previously institutionalized individuals in the community with family caregivers directly responsible for care. Nurses are in the ideal position to positively impact those affected by this trend. However, before nurses can be of benefit, they must increase their understanding of the experiences of the spousal caregiver so that interventions are tailored to their individual needs. It is inappropriate to apply the experiences of the health care workers and institutional interventions to the community. This "force fit" is potentially detrimental to those in need who turn to nurses for understanding and guidance.



## CHAPTER THREE: METHODOLOGY

### Methodology

Chapter three outlines the research methodology that was chosen for this study. Using a case study design, the experiences of spousal caregivers living with a family member who displays aggressive behaviour related to Alzheimer's disease was explored. The Winnipeg branch of the Manitoba Alzheimer's Society and their support groups was the agency used to assist with participant recruitment. Informal, semi-structured interviews, participant observations, and field notes served as primary source of data collection. Supplemental sources of information included the results from the Mini-Mental Status Exam, (MMSE) on the care receiver. Incidents of aggression reported on the RAS aggression scale by the caregiver were initially planned to be another source of data. Each caregiver consented to collecting this data using the RAS provided, however this did not happen. Jane, the caregiver in Case Study One, opted to record her behaviours in a journal which offered additional information beyond the log and was a valuable source for data. Bill, the caregiver in Case Study Two, declined recording incidents of aggression as he felt he had nothing to record. The rights of the human subjects were protected throughout this study.

## Design

### Case Study

The science of nursing requires that "any phenomenon first be explored at the qualitative level" (Brink & Wood, 1989, p. 123). The impossibility of gaining knowledge about others without describing the individuals circumstances as they live, experience, and interpret them in his/her own words is an underlying premise of qualitative research (Polit & Hungler, 1991). Quantitative research contributes to the scientific body of knowledge by supporting or providing a theoretical framework or theory to be tested and by identifying variables, hypothesis, or patterns to be examined. The results of qualitative research contribute to what is known, challenge the status quo, and affect the direction of future research (Morse, 1989).

Case studies are an effective way to explore phenomena that are not well understood. This research design is a thorough, in-depth analysis that focuses on "determining the dynamics of why the subject of the investigation thinks, behaves, or develops in a particular manner" (Polit & Hungler, 1991, p. 208). Case study research allows for the "idiosyncratic, unique, and non fungible features of cases that give them their integrity and make them so valuable for study" (Sandelowski, 1996, p. 525). This is accomplished by

the collection of data that accounts for the interaction of the participant's present state, past experiences, and situational and environmental variables that give meaning to their experiences (Polit & Hungler, 1991). The interactions of the participants and his/her influence on the phenomena under study serve to clarify concepts and variables, adding insight and greater understanding to the subject matter (Polit & Hungler, 1991; Streubert & Carpenter, 1995). Case study design allows for a depth of understanding required when a larger sample was not available (see Population) (Polit & Hungler, 1991).

Informal caregivers whose loved ones behave aggressively because of AD have large stores of experiences. These experiences are rich with implications for understanding how they live, manage and cope with their loved one's aggression and for the understanding of aggression. The lack of research and understanding of the spousal caregiver's experiences, perceptions and impact of aggression from the at home patient with Alzheimer's disease warranted a case study design. Previous research on the concept of aggression and cognitive impairment and its impact on other populations provided the rationale and conceptual framework (A Theoretical Model for Aggression by Ryden, 1988) for this study.

Understanding of the caregiver's experience was arrived at through frequent, repeat interviews, multiple participant observations, field notes, a caregiver's journal of the care recipients aggressive behaviour, and a measurement of the care recipients level of cognitive functioning. Moreover, this data collection strategy facilitated clarification and confirmation of categories and themes that emerged from the ongoing data analysis. "The repetitive nature of the interviews and observations, over time, and on the same subjects, lends strength and credence to the design" (Brink & Wood, 1989; p. 147).

Data analysis for this case study research was ongoing throughout the collection period. This process provided increased opportunity for the researcher to gain valuable insight allowing the researcher to direct his/her inquiry so that categories and themes could be clarified or confirmed by the participant. This in turn lead to more questions whose answers were sought and clarified in the same manner (Guba & Lincoln, 1989; Polit & Hungler, 1991; Struebert & Carpenter, 1995).

## Measurement Instruments

### Aggression Scales

There are few quantitative assessment instruments measuring aggressive behaviour. Of those that are available, the difficulties in using the tool are numerous. Difficulties included: lack of definition of the concept aggression; inconsistencies in using similar concepts in each measuring tool; aggression being merely mentioned as one of many items in the assessment of more global concepts such as general health; and measuring the concept of aggression primarily in those individuals who are institutionalized (Cohen-Mansfield & Billig, 1986; Ryden, 1988; Ryden et al., 1991). Furthermore, the majority of the instruments are retrospective assessments of the frequency of the aggressive behaviour completed by the caregivers. Unfortunately, frequency instruments alone may miss significant elements of aggression such as duration of the behaviour. The absence of studies comparing caregiver retrospective reports of incidents of aggression with actual behavioural observations of such problems can cause one to question if these measurement tools are valid measurements of actual behaviour (O'Leary et al., 1993).

In 1988 an instrument appropriate to measure aggressive behaviour in persons living with dementia in the community was

developed. The Ryden Aggression Scale (RAS) was based on a modification of Lanza's (1983) conceptual framework which integrates the internal and environmental theoretical perspectives of aggression. The Ryden Aggression Scale (RAS2/Form 2, 1991, Appendix F), is 25 item Likert-like scale consisting of 3 subscales which measure verbal, physical, and sexual aggression. The items in each of the subscales represent manifestations of aggression based on Ryden's literature review (Ryden, 1988; Ryden et al., 1991).

Content validity of the RAS was confirmed by a panel of expert nurses. The 16 item physical aggression scale (PAB) had an alpha coefficient of 0.84; four item verbal aggression scale (VAB) had an alpha of 0.90; and, the five item sexual aggression scale (SAB) an alpha coefficient of 0.74. Pre-test reliability analysis of the RAS as a whole showed an alpha coefficient of 0.91, with a pilot sample analysis of 0.88. An 8-12 week test-retest of the RAS, showed a reliability of 0.86. Inter-rater agreement of the RAS2 was 0.88 (Ryden, 1988; Ryden et al., 1991).

The initial RAS, referred to as RAS 1 (Form 1), is a retrospective measurement of the nature and frequency of aggressive behaviour. A comparison of the RAS 1 with the RAS2 being applied on the same sample revealed a correlation of 0.65 ( $p < 0.001$ ), indicative of a substantial degree of

convergent validity (Ryden et al., 1991). For the purpose of this research, the RAS 1 will not be used. The RAS2 (Form 2) (Appendix F) which had the behaviour of pulling hair added to the PAB subscale, measures aggressive behaviours concurrently using a tally or checklist system. By marking each behaviour observed within a predetermined time frame over a number of days, a mean daily aggression score can be determined. The RAS2 can also be supplemented with a description sheet on which the observer documents antecedents to the aggression, duration of aggression, and the consequence of the behaviour. Although they would have yielded informative data, for the purposes of this study and with respect to the time demands on the caregiver in completing the description sheets, these were not included as a component of the RAS2.

The participants in this study consented to the collection of data on the RAS2 behaviour log. However, one of the caregivers opted to keep a written record of her experiences as she wanted to "tell her story" which she was unable to do on the log. The other participant continuously reported that he had no aggressive behaviours to report and therefore did not document aggressive behaviours in any form (see Chapter Five for further information). I believe the RAS remains an appropriate tool for collecting information

surrounding aggressive incidents. The willingness of caregivers to use the instrument must be carefully evaluated.

### Cognitive Exams

Although there are a variety of cognitive exams available, many researchers studying cognition and aggression in the community have used the Folstein Mini Mental State Exam (MMSE) (Deutsch et al., 1991; Mendez et al., 1990; O'Leary et al., 1993; Teri et al., 1988; Ware et al., 1990). Further support for the use of the MMSE in measuring cognitive functioning is the 1986 recommendation by the Medical Research Council Working Group on Dementia that the MMSE be "included in any future data set collected for research into Alzheimer's disease, to enable comparisons across studies" (Jagger, Clarke, Anderson, & Battcock, 1992). The MMSE instrument was chosen for this study.

The MMSE (Appendix G) is a general global cognitive screening test that has been widely used to assess the cognitive abilities of the elderly due to its ease of administration (less than 15 minutes), objective scoring, and ability to be interpreted without formal training (Nelson, Fogel & Faust, 1986; Teng & Chui, 1987; Teri et al., 1988). The MMSE consists of 11 items, tapping a wide range of cognitive functions including orientation, registration,



attention, visual skills, and recall. The score is the sum of the items with the range being 0 to 30. A score of 27-30 is considered normal cognitive functioning, with the score below 24 considered a cutoff for organic impairment. Consistent with the application in the studies completed by Teri, et al. 1988, and for the purpose of this study levels of cognitive impairment were considered mild if the MMSE score ranged from 26-23, moderate if 11-23, and severe if 10 or less.

Criticisms of the MMSE are directed at the tool's inability to take into account cultural differences affecting the person's ability to successfully complete the test and it's inability to differentiate the very advanced stages of dementia (Teng & Chui, 1987). (Note: Cultural differences were not an issue in this study). Education and social factors must be taken into account as they are associated with lower scores (Jagger et al., 1992; Nelson et al., 1986). Since no perfect brief dementia screening assessment tool yet exists, it is important that the MMSE is used as it was designed to be, that of a screening measurement tool and not a diagnostic determinator.

My familiarity with the MMSE was an asset in the proper administration of this cognitive exam. The MMSE provided information regarding the level of dementia in the care

recipients and the aggressive behaviours that were associated with the level of cognitive impairment.

### Population

The target population for this study was identified as spousal caregivers living in Winnipeg with a partner who displayed aggressive behaviour attributed to Alzheimer's disease. The population was limited to spousal caregivers, married or living common law prior to the onset of the partner's (care recipient's) diagnosis of Alzheimer's disease. Care recipients were identified as having dementia of the Alzheimer's type or a probable diagnosis of Alzheimer's disease by the family physician or gerontologist. Behaviour which was deemed aggressive in nature included verbal, physical, or sexual interactions as identified by the spousal caregiver.

### Setting

The Winnipeg branch of the Manitoba Alzheimer's Society and their support groups were of assistance in participant recruitment. The setting for the visits/observations was not to take place in the homes, but in a mutually agreeable location, away from the care recipient. The interviews were of a sensitive nature which could be uncomfortable for the

caregiver or insensitive to both the caregiver and the care recipient if discussed where the care recipient could hear the conversation. For both of these case studies, however, the caregivers elected to have the interviews conducted in their own homes. This was unrelated to difficulties with leaving the care recipient alone as both care recipients were fairly independent. The decision to have the interviews in their own homes was also not related to difficulties with travel arrangements as I offered transportation. The caregivers in this study believed that they would feel comfortable at home, and could ensure "privacy" for interviewing. For the Summer Family (Case Study One), interviews were scheduled while the care recipient was out for his regular "coffee date." For the Winter Family (Case Study Two), the care recipient remained at home in her room with the door closed. The caregiver identified that this was where she spent the majority of her evening and this would impose no change in routine for her. The kitchen, where the interviews took place, also had doors that were closed. Visits/observations took place in the caregiver's home. The initial recruitment meeting for both participants took place in a local restaurant during the restaurant's "slow period."

### Sample Selection

Sample selection directly affects the quality of research. The type of sample used in qualitative research, including purposeful and volunteer, are chosen so as to respect the "qualitative principles of sampling" (Morse, 1989, p. 117). The best participant is someone who is experiencing or has experienced the phenomena under study, and by virtue of this lived experience has knowledge, a desire to share this knowledge, and an ability to do so (Germain, 1993; Morse, 1989; Polit & Hungler, 1991).

A convenience sample of volunteers was used to recruit participants for this research project. In non-probability sampling technique, the researcher relies on potential participants who are presently experiencing the phenomena under study to identify themselves. This type of sampling provides informants that are "knowledgeable about the topic and experts by virtue of involvement in specific life events" (Morse, 1989, p. 121).

### Inclusion Criteria

The following criteria was applied to the recruitment of participants for this study. Spouses (caregiver's) were:

1. Self selected (volunteered).
2. Willing to be in the study for 8 to 12 weeks.

3. Willing to be interviewed 4-6 times and have 8-12 home visits/observations over an 8 to 12 week period.
4. Living with a partner who had been diagnosed (by the family physician or gerontologist) as having dementia of the Alzheimer's type or as having Alzheimer's disease.
5. Able to identify aggressive behaviours in the individual with dementia of the Alzheimer's type or Alzheimer's disease.
6. Living with their partner for five years prior to the onset of symptoms.
6. Able to read, write, and understand English.
7. Able and willing to sign a consent on behalf of the individual with Alzheimer's disease.
8. Willing to have the researcher complete the Folstein Mini-Mental State Exam on the partner with Alzheimer's disease.
9. Residing in the city of Winnipeg or within twenty minutes of the city.
10. Willing to have the interviews audiotaped.
11. Willing to complete the Ryden Aggression Scale for the duration of the study.

### **Procedure**

The Winnipeg branch of the Manitoba Alzheimer's Society was selected as the organization to assist with sample selection. Because of difficulties experienced with the recruitment of participants, significant changes to the study procedure occurred. To assist fellow researchers who are considering research of a similar type, a brief review of the efforts made to recruit participants will be included.

The Director of the Alzheimer's Society met with Support Group Facilitators and informed them of the study purpose. Facilitators received written information about the study which they read out loud at their next support group meeting. Facilitators were also provided with a sufficient quantity of these written statements which introduced the research project which were distributed during the support group meeting. The Director of the Alzheimer's Society also posted the information letters in the main public office of the Alzheimer's Society. Additional copies were also kept at the main desk to respond to any inquiries. This recruitment process was initiated in the beginning of June 1997.

By August 1997, no participants had come forward. The Director of the Alzheimer's Society contacted all facilitators by phone to ask that they again discuss the need for participants during their next support group meeting. According to the Director, most of the support groups continued meeting over the summer months. At the end of August, the Director was again contacted as this recruitment strategy was completely unsuccessful. The Director recommended a random mail out which was the recruitment strategy used for this study.

Prior to the implementation of any procedural changes, ethical approval was sought. A revised design was submitted

to the Ethical Review Committee, Faculty of Nursing, and was subject to an expedited review.

### Recruitment

The Winnipeg branch of the Manitoba Alzheimer's Society was the organization which assisted with sample selection (Appendix J). Using a computerized program, the Alzheimer's Society randomly selected the names and addresses of 160 spousal caregivers that were registered with the Alzheimer's Society. (Note: This random selection could not be limited to only those caregiver's who attended support groups or to those who had aggressive family members.)

The letter that was supplied to support group facilitators in the original recruitment efforts (Appendix K), was then mailed to the 160 caregivers by the Alzheimer's Society, at the researchers expense. Official Alzheimer's Society letterhead was used so that potential participants would know that the research was sanctioned by the Society.

After two and a half months, only two participants who fitted the study criteria volunteered. After consultation with the Director of the Alzheimer's Society and my thesis committee members, it was decided because of recruitment difficulties, that case study research would be acceptable. Both participants agreed to be in the study despite the

increased time frame and demands the case study method would place on them.

Note: This recruitment strategy results in a sample bias as these participants volunteered. Also, sample selection from an organization that provides education and support to those affected by Alzheimer's disease will obviously be restrictive. It is most probable that individuals accessing external agencies are able to mobilize their resources and may not be representative of the total population. This is recognized as a limitation of the study.

### Data Collection

The participant interview is a most significant data collection tool available to the researcher and as such the respondents must believe that their participation in the interview is important (Fetterman, 1989). As suggested by Spradley (1980) the principles of language identification (identifying who said what) and the verbatim principle (using the exact words of the speaker) was adhered to during data collection.

Although questioning through interview generates a substantial amount of rich and lavish descriptions, qualitative data methods can be augmented by a blend of qualitative and quantitative approaches (Brink & wood, 1989). The research objective was to elucidate the caregiver's perceptions of his/her world. Data collection therefore relied on a qualitative perspective. However, quantitative data collection methods were also used. Caregiver's were requested



to complete the RAS2 which was designed to assist the caregiver to record the incidents and duration of aggressive behaviour in the care recipient. This information was to be used as a guide in questioning the caregiver and asking them to elaborate on their experience. As already stated, neither caregiver completed the RAS2. The MMSE was administered and provided information of the level of dementia in the care recipient. The relationship of dementia, types/duration of aggressive behaviours, and the caregivers experience was examined.

Data collection took place over a three month period (January to April) and consisted of caregiver interviews and caregiver/care recipient visits and observations.

A. Interviews/Visits/Phone calls

1. Interviews

Interviews (N=8 Case Study One - The Summer Family; N=6 Case Study Two - The Winter Family) occurred in the home and were of one to two hours in duration. The initial interview was an "icebreaker" during which the purpose of the study was reviewed and my phone number given. The initial interview also consisted of (a) obtaining informed consent (Appendix M), (b) initial collection of demographic data (Appendix N), and (c) instructions to the caregiver on the completion of the

RAS2 (Appendix O). Prior to every interview, verbal consent for audio taping (which allowed for accurate recording of data) was received. Dates and times for subsequent interviews and visits/observations were also set. Caregivers received a phone call before each interview or visit/observation for confirmation and to clarify any problems.

Obtaining such delicate information as aggression in one's partner is certainly sensitive and personal. Before trust between interviewer and participant can be established, time must be allocated for building this rapport (Sorrell & Redmond, 1995). The initial interview provided "time" for both the caregiver and myself to become familiar with each other while collecting data that was less threatening in nature. This was especially important as the subsequent interviews placed the caregiver in a more vulnerable position as they were asked to disclose very tender and private feelings and experiences.

If at any time during any interviews the caregiver had become distressed, the taperecorder and the interview would have been stopped. This would provide the caregiver time to regain his/her composure without concern over the "progress" of the interview. At all times the needs of the care recipient were a priority. The need to turn off the tape

recorder as described above, was not required during this study.

Subsequent interviews served to build on, clarify, and confirm categories or themes emerging out of the data. Answers to the questions on the interview guide were also sought. The interview schedule was organized so that the more sensitive questions were asked in later interviews, after an atmosphere of trust was established. A variety of question designs was used ranging from general questions to contrast or comparative questions, all directed to get open, free flowing, unstructured answers (Spradley, 1979). Incidents of aggression which were recorded in journal format in Case Study One were reviewed. Upon conclusion of each interview, time was spent in "social conversation" allowing for the interview to end on a lighter subject.

## 2. Visits/Observations

The visits/observations consisted of five to seven visits with the caregiver and the care recipient occurring both in the day and evening time. Differing times of day provided the opportunity for observation when different activities and stimulations were present in the home. The families were encouraged to continue with their daily routine, but often chose to visit over coffee. The MMSE was completed on the

care recipients after two to three visits when familiarity between the care recipient and the researcher was established. Upon completion of each visit, the participants were thanked for their time and subsequent visits were scheduled.

Data collection concluded with the option of a follow-up phone call. The option of a follow-up phone call is a common provision used by experienced researchers as additional questions may arise from data analysis or clarification and validation of data may be needed (Morse, 1989; Sorrell & Redmond, 1995).

### 3. Field Notes

Upon completion of each interview and visit/observation, field notes were made after leaving the participant's home. Field notes included my observations of the events and behaviours that occurred during the course the interview and visit/observation. Field notes provide the researcher a system for remembering observations and recording ideas, concerns, confusions, insights, and problems so that they can be later retrieved and analysed. This contributed to a richer description of the caregiver's experience (Polit & Hungler, 1991; Streubert & Carpenter, 1995; Wilson, 1985). No comment, observation, or interaction is to be viewed as insignificant

or incidental as these may offer important insights as the study continues (Streubert & Carpenter, 1995).

#### B. Ryden Aggression Scale (RAS)

Researchers using measurement tools which are completed by the caregiver need to give consideration to the willingness of the participants commitment to use the recording device. Researchers must balance the complexity of the instrument and time period of data collection against the problems of poor compliance (O'Leary et al., 1993). The most valid measurement tool may be of little value if not properly completed by the participants. The additional work that each caregiver was faced with in completing the RAS2 with time dimension (Appendix N) was recognized. O'Leary et al., (1990) had caregivers complete 24 hour behaviour logs for seven consecutive days and this was found to be an excess burden for the caregivers. The collection of data was then reduced to two consecutive 24 hour periods and found that caregivers were diligent in recording behaviours even at night, as they were always in the "monitoring mode." O'Leary et al., (1993) suggested that although they found consistency in the behaviours over the 2 day collection, "the correlations across days are not high enough to suggest invariance across days" (p. 143) and suggest that the monitoring of behaviour over a

greater number of days is important. For this study, the caregivers were requested to complete the RAS2 for as many consecutive days as they could.

The RAS was instrumental in the development of Ryden's (1988) Theoretical Model for Aggression used for this study, and is applicable to the community setting. The modified RAS2 with time dimension (Appendix P) was the aggression measurement tool to be used in this research (approval granted, Appendix Q). To assist in recording, each RAS2 form had a pencil attached for ease in recording. The caregiver was encouraged to place the RAS2 log in a convenient, easily accessible location at their discretion.

#### RAS2 (Modified with Time Dimension)

The RAS2 was designed to be completed concurrently on individuals residing in institutions. As such, the instructions refer to "institutional words" such as "resident" and "shift." For the purpose of research in the community, the instructional wording in the RAS2 (Appendix F) was changed to reflect that the spousal caregiver will be collecting the data, not a nurse. Words such as resident were changed to partner and the word "shift" was eliminated. The times of recording on the RAS were set to accommodate shift changes. Although there is no "shift change" for the spousal caregiver,

the times albeit unusual for those at home remained the same. This would allow for basic comparisons of the times of day aggression occurs with the 1988 Ryden study. The signing off of the daily log sheet was deleted to protect informant confidentiality. The above minor changes to the RAS2 could have affected the collection instruments validity or reliability. However, I still wanted to use the instrument with these changes as the changes made it "user friendly" for the caregiver. (Dr. M. Ryden was advised of these wording changes via telephone conversation). The RAS2 was further modified to incorporate a temporal dimension as there was no provision to capture duration of aggressive episodes (Appendix P).

Behavioural definitions of aggression, physical (PAB), verbal (VAB), and sexual (SAB) used in the RAS were consistent with the behaviours under examination in this research. A list defining what behaviours do and do not constitute aggression (Appendix B) was reviewed as a guide only as caregiver's were encouraged to record any behaviour that they felt was aggressive. If the caregiver was going to be away from the partner, the caregiver was to record on the log that there was no data collected.

### C. Mini-Mental State Exam (MMSE)

The administration of the MMSE (Appendix G) takes 10-15 minutes to complete, and can be applied by individuals with only limited familiarity with the tool, as long as the individual adheres to the instructions for administration (Nelson et al, 1986). The MMSE was completed in a room away from the caregiver (the kitchen or living room) to minimize care recipient distractions. Completing the MMSE away from the caregiver also served to eliminate any uncomfortable feelings in the caregiver related to the partner's ability to correctly answer the questions. If this was going to be upsetting for either individual, then both partners could have been present during the exam.

The MMSE was administered after two to three visits when it was mutually agreeable and I sensed that a comfortable relationship had been established with the care receiver. {For complete MMSE results, see Appendices H (Tom's) and I (Mary's).} Although the care receivers may have been cognitively impaired, they still had the right to refuse the test. Confidentiality was protected at all times and only the code number assigned to the informant was recorded on the MMSE. If I would not have been able to administer the MMSE, the participants still would have remained in the study unless



they specifically requested to discontinue their participation in the entire study. Incomplete MMSE results or withdrawing from the study would not in any way affect the care these individuals received from the community or private agencies. Unless informed by the caregiver, external care agencies did not know that the caregiver was a participant.

The MMSE was used as a screening tool (based on the scores) for determining degree of cognitive impairment.

### **Data Analysis**

Note: The diagnosis of AD cannot be confirmed until post mortem examination. For the purpose of this study it is "assumed" that the tentative diagnosis of AD is correct, and that the aggressive behaviours (as reported by the caregivers) and their antecedents are attributable to the care recipient having AD. Although some of the caregiver/care recipient interactions are not unique to those living with AD, they are reviewed if identified as of concern to the caregiver.

Data analysis, or the systematic organization and interpretation of data can be achieved through the rewriting and coding of data using content analysis (Polit & Hungler, 1991; Streubert & Carpenter, 1995). Data for this study were analysed using content analysis. The interviews were transcribed verbatim to the Word Perfect program. Aggressive behaviours documented by the caregiver in Case One fit the existing categories of verbal, physical, and sexual. One could not forecast what information would be obtained from the

open ended questions, observations, and field notes, and as such data analysis was ongoing. The end point of data analysis was the "identification of conceptual categories, that is concepts linked together logically" (Streubert & Carpenter, 1995, p. 133). Please see Chapter Five, Research Design and Data Analysis for further discussion specific to the data analysis procedure.

To facilitate understanding of the caregiver's experience, a variety of data collection methods were used, specifically, (a) multiple interviews, (b) multiple participant observation, (c) field notes, (d) the MMSE, and (e) a journal of aggressive behaviours maintained by one caregiver. Triangulation of the data in case studies is achieved by using multiple sources of data as listed above (Tellis, 1997). Triangulation of the data provided for the accurate representation of reality giving strength to the truthfulness of the study findings (Polit & Hungler, 1991).

### **Rigor**

The measure of rigor refers to the credibility and thus the trustworthiness of the research findings (Streubert & Carpenter, 1995). Guba and Lincoln (1989) report that credibility can be established through (a) prolonged engagement, (b) persistent observation, (c) peer debriefing, (d) progressive subjectivity, and (e) member checks. Efforts aimed at ensuring credibility for this study included (a) following the participants over a three month period, (b) multiple caregiver interviews and observations of the caregiver/care recipient interactions N = 26, (c) discussing my perceptions, concerns, and questions with peers (who had no investment in the study), (d) recording of my thoughts or hunches in field notes and reviewing the field notes at regular intervals clarifying or modifying my thoughts in subsequent field notes, and (e) confirming, clarifying, or correcting my interpretation and understanding of data with the caregivers. This occurred within each case study and between the two case studies using a compare and contrast format.

Efforts aimed at establishing rigor of this study included multiple interviews and observations which provided an opportunity for clarification. The order of the interview questions had the more "sensitive" questions being raised in

later interviews. This allowed for trust and rapport to be built during previous interviews and visits, during which discussions were not so emotionally invasive. Although prolonged engagement in the field does not ensure that the caregiver's experiences have been shared with complete sincerity (Guba & Lincoln, 1989) the opportunity for immediate (during the interview) clarification by requesting that the caregiver elaborate or expand on findings gave strength to the study findings. Recognizing that "the stories that members tell in interviews are themselves constantly changing,...what (was) said and meant in the interview and how the interview itself was made" (Sandelowski, 1993, p. 5) was carefully considered. "It is the immediate and continuing interplay of information that militates against the possibility of non-credible outcomes" (Guba & Lincoln, 1989, p. 244).

### **Protection of Human Subjects**

Throughout the study the protection of the participants was paramount. Consent was obtained from the caregiver for participation in the study, and for the administration of the MMSE on the care recipient. Participant confidentiality was upheld throughout the study. A list of resources to contact (Appendix S) was available to any caregiver who felt a need to make contact with other agencies/individuals. Case study

allows for flexibility in the timing of data collection. I was sensitive to the emotional response of the caregivers when they were sharing their experiences and was prepared to stop the interview as required. At no time during the data collection was there a need to stop the interview. Both care receivers were willing to complete the MMSE. The physical safety of either the caregivers or care recipients in this study were not of concern. Therefore, interventions aimed at assisting the caregiver in their role were not required.

#### **Study Strengths and Limitations**

The strengths of this qualitative research lie in the strength of case study design that being the flexibility in data collection. This flexibility assisted in the collection of rich data resulting in greater insights into the phenomena under study (Polit & Hungler, 1991). As identified earlier in the literature review, relying on caregiver reports may result in answers offered due to courtesy, impatience, political, moral, personal, and other social constraints over answers given with regard and desire for accuracy in the findings. Repeated interviews over the three month study allowed for clarification of information that was appearing inconsistent. Participant non-compliance in completing the RAS 2 limited the data available, however the documenting of aggressive

behaviours in a journal by one participant provided valuable information on the aggressive behaviours caregivers may be exposed to. Participant's were self selected (via their contact with the Alzheimer's Society) and a potential sample bias must be noted. Please refer to Chapter Five for further discussion on the study strengths and limitations.

## CHAPTER FOUR: THE WORLD IN WHICH THEY LIVED

### Interviews and Observations

The purpose of this research was to describe the experiences of spouses caring for aggressive family members diagnosed with Alzheimer's Disease. In particular, I was interested in answering the following questions:

1. What are the experiences of spousal caregivers living with a family member who displays aggressive behaviour as a consequence of AD?
2. To what types of aggressive behaviour is the caregiver exposed?
3. What aggressive behaviours do the spousal community caregivers find the most distressful?
4. What techniques do spouses use to manage the aggressive behaviour?
5. How do community spousal caregivers view the help/suggestions/advice they have received from health care professionals regarding the management of the aggressive behaviour?

It was through case study design that these questions were answered. Through prolonged and sustained contact with the participants, I realized that aggression can only be understood by becoming familiar with the families understanding and acceptance of AD itself, and within in the context of two very different lives, two very different families.

Tools used for data collection included the research questions, the interview guide, recorded behaviours, frequent

visits and observations, field notes, and the MMSE. Data analysis began with the very first interview. After each interview the data were transcribed verbatim and reviewed so that concepts and themes emerging could be confirmed or clarified at the next interview. Field notes after each visit and interview were also analyzed. Comparisons and contrasts between the two Case Study's was also an approach for generating and clarifying data, giving strength to the emerging concepts. Upon completion of the data collection I examined all the data as a whole by once again listening to the taped interviews and reviewing interview transcriptions and field notes. This immersion into the data assisted me in categorizing the data into meaningful information.

The Theoretical Model for Aggression (1988) (Appendix A) was also used throughout data analysis. The model provided direction and focus to the understanding of aggressive behaviour. Specifically, the model clearly served to focus in on the caregiver - care recipient interaction (environmental source of aggressive behaviour). The findings of this study are presented by first understanding the local worlds of these two very different couples. The experience cannot be fully understood unless the participants understanding of AD and the impact of AD on their life is known. The individual and collective experiences of the couples prior to the onset of



the disease is also important. Familiarity with the lives of the participants helps to understand how they interpret the AD which helps to understand how they then interpret and perceive the aggressive behaviour of their spouse. How we interpret and make sense of our world is very much dependent on who we are as individuals. Our experiences whether positive or negative set up our expectations for future events. How these caregivers come to terms with AD will certainly affect how they understand, manage, and cope with the aggressive behaviour resulting from AD. The impact of Alzheimer's disease and specifically the incidents and impact of aggression are then examined, including the identification of management techniques and coping methods. The participants in this study are distinct from one another. Tom and Jane (Case Study One - The Summer Family) and Bill and Mary (Case Study Two - The Winter Family) are at different ages and stages in their lives and are from different social and economic backgrounds. Although the dichotomy between the two cases is profound, the impact and the outcomes associated with aggressive behaviour are similar. A schemata of the dimensions generated from the data which make up the participants local worlds is presented in Table 1 (p. 112). Findings from each case study are compared and contrasted to each other and are also presented in the schemata.

## Overview

Through a brief review of their life, each of the case study participants are introduced to the reader. A general familiarity with their lives is presented prior to a more detailed examination of their local worlds.

## Introduction

### Case Study One: The Summer Family Tom and Jane

Tom and Jane are in their early 50's. They have been married for more than twenty years, have five children still in school, and live in their own home. They have been residing in the Province of Manitoba for two years. Tom began having difficulty concentrating which caused significant concern for both Tom and Jane as early as 1987 and was finally diagnosed by a psychiatrist in 1992. Tom is in the very early stages of AD and is lucid at all times. AD has reduced Tom's ability to complete complex and, at times, even simple tasks and has slightly diminished memory recall. Tom is also easily overstimulated by such things as time pressures and family interactions. As a result of the frustration this causes, and perhaps the disease itself, Tom is both verbally and physically aggressive. Tom depends on the antipsychotic medication Resperidol .5 mg twice daily to help him to control

his physical aggression, although every couple of months is known to throw plastic dishes against a wall or groceries into a cart. In 1992 shortly after diagnosis, Tom had frequent episodes of moderate to severe aggression which consisted of him forcefully pushing the children around. Since 1991, Tom has been unable to work because of the effects of his disease. Tom is home full time and receives pension and disability insurance income. Jane is a full time mother and is responsible for the household. Tom and Jane are very open with each other about AD and Tom's verbal aggression.

#### Life Before AD

The years prior to any noticeable symptoms of AD were very different for Tom and Jane than the life they have now. They resided in Ontario where Tom worked outside the home full time as a labourer. Tom was the main decision maker in the home and was actively involved with the children. Tom's spare time was spent focusing on his dream to become a full-time gospel singer. With an obvious talent for music, Tom spent both money and time pursuing his desired career. Jane divided her time between her infants and toddlers and supporting Tom's pursuit of singing. Despite a tight financial situation, the family enjoyed going to the lake at the family cottage or camping out together. Tom and Jane were

very active in their church. Tom displayed no signs of verbal or physical aggression during these years.

#### Life With AD

Very early in the disease progression, Tom was unable to maintain employment outside of the home. As a result, the family now lives below the poverty level. They no longer have the cottage at the lake and because of Tom's poor coping ability, family camping trips no longer occur. The family moved to Manitoba in 1996 and reside in their own home which is in obvious need of repair. Tom is minimally involved with the children and no longer is instrumental in decisions regarding the family. Tom's responsibilities around the house have been reduced to emptying the dishwasher and doing laundry. Tom states that anything he does takes concentrated effort. "Even to do the simplest of tasks...I realize I am using more concentration than the normal individual." Jane's responsibilities have increased dramatically to the point that anything that needs to be done is orchestrated, if not completed, by her. For a significant number of years, the family attended numerous support groups in Ontario but discontinued their participation upon moving to Manitoba. The Summer's felt the support groups were of limited benefit. Tom no longer sings publicly or participates in gospel shows. Tom

regularly goes out for coffee during the day with friends. However, Jane has minimal time for social activities external to managing the house and meeting Tom's and the children's needs.

The routine activities of daily living with the children cause stress and often frustrate Tom. As a result Tom becomes verbally aggressive which then sets the tone in the house. When the children come home from school the stimulation in the house increases with their play, watching television, talking on the phone, and general conversation with each other. Overwhelmed and "frustrated" Tom inappropriately yells at the children telling them to "shut-up" or "go to hell." In response, the children begin shouting back at their father and at each other. When made aware of this, Tom isolates and withdraws temporarily (for minutes to hours) from the family until Jane has things under control.

Although no longer physically aggressive toward the children, Tom admits to thoughts of wanting to be physically aggressive, but states that he controls them. "There is no temptation to really be physically aggressive. I mean the idea crosses your mind, but there is no danger." Tom does, however, become easily frustrated especially when shopping and it is during these times that he is verbally aggressive and

prone to express physical aggression both of which are mild in nature.

Tom does have his "coffee buddies". However, Tom and Jane do not socialize beyond their church activities. The children have numerous friends and are able to have friends over to the house. Tom states that he does everything he can to be on his best behaviour when the children's friends are over, isolating himself when possible. Jane does not complain of the extraordinary demands placed on her, but does admit to feeling lonely.

#### The Future

Tom and Jane do not worry about the future and choose to live one day at a time. They deny having made plans for their future and/or retirement as they trust that God will guide them. As a result, Tom and Jane state that AD and aggression have not changed their future as they had not discussed or made plans specific to their future. Tom and Jane believe their future is in God's hands and will be revealed to them one day at a time.

#### Case Study Two: The Winter Family Bill and Mary

Bill and Mary are in their early 80's. They have been married for more than 55 years, have a grown family, and live

in their own home. In the early 1990's, Mary became forgetful and began misplacing items as well began having difficulty remembering recent conversations with Bill. The memory impairment continued until it became a significant problem in 1995 and in that year a geriatrician and a psychiatrist offered the diagnosis of AD. Shortly after this diagnosis, verbally and physically aggressive behaviours appeared and although they have increased in incidents, they remain of a mild nature. Verbally aggressive behaviours are usually personal attacks on Bill telling him to "go to hell" or that she doesn't love him anymore and that their marriage was a mistake. Bill states that he feels that the aggression is in response to Mary's frustration with her memory loss, but is uncertain as to what specific antecedents might be responsible for them.

Mary is moderately cognitively impaired with significant memory loss. Mary is dependent on Bill to do the shopping, prepare meals, complete housework, and manage the financial affairs. Mary is independent with her personal needs including bathing, toileting, and dressing.

Bill's physical ability and mental acuity definitely do not reflect his advanced age. Bill thrives on an intellectual challenge and fills his day reading scholastic journals or autobiographies of famous people. Bill independently manages

the household including shovelling snow and mowing the lawn. They enjoy a comfortable standard of living and are financially sound. Mary is unaware of the diagnosis of AD, but is aware that she is being treated and monitored by a physician for her memory loss. Bill is very protective of Mary and does not want her informed of the tentative diagnosis. Mary is on the trial drug Aricept (donepezil) 5 mg per day, in effort in attempt to slow down memory deterioration and to possibly improve her memory.

#### Life Before AD

Given the stage in life of this couple and the fairly recent cognitive deterioration caused by AD, life prior to the disease was not significantly different in regards to their day-to-day activities. Bill has been retired for more than twenty years and they are essentially home bodies, entertaining minimally. They did, however, enjoy dining out at various restaurants and on occasion, would attend the symphony, opera, or ballet. Despite the gradual deterioration in her memory since the early 1990's, Bill and Mary would spend their days reading and discussing local events or intellectually challenging each other in spirited debates. Both Bill and Mary spent a great deal of time reading biographies, poetry, or, in Bill's case, scholastic journals.



Bill and Mary did enjoy an overseas vacation, but travel was unusual for them. They were each other's best friend spending all their time together. The roles were very traditional with Mary responsible for such things as house cleaning and meal preparation, and Bill responsible for the yard work and financial affairs.

#### Life With AD

Bill describes his life as lonely. Bill does not have many friends apart from his wife and a long-term neighbour and as a result, misses his wife's company terribly. Meals are still enjoyed together in the kitchen, however, they now have separate rooms in which each of them spend most of their days. Conversation is no longer an interactive affair, but mainly consists of requests "What do you want to eat today?" and commands "It is time to have your snack." The only outings they have together is when Bill takes Mary to the physician or dentist. He is now responsible for such things as the grocery shopping and paying the bills, which he does on his own. Mary is able to stay safely in the house alone for short periods. Mary is able to manage activities of daily living such as bathing and dressing, but it is up to Bill to ensure that she is appropriately dressed and eats her meals. Mary is extremely forgetful and at times confused. Bill is organized

and orderly and is very frustrated when items go missing from their location only to be found in an inappropriate location days later (for example, drinking glasses hidden in boots). The search for missing items by Bill is a source of frustration for both Bill and Mary. Bill admits that he loses his patience with Mary and demands an answer from Mary as to why she would do such a thing, which usually results in a verbally or physically aggressive incident. Mary directs her physical aggression toward inanimate objects (for example she will bang her coffee mug on the table or slam doors).

#### The Future

The future is of concern for Bill. He realizes that if he should die first, Mary would not be able to live on her own and would most likely require placement in a personal care home. If a "live in" could be found, he then worries about neglect or abuse. He is concerned that even with placement in a nursing home, Mary's "fits of rage" would subject her to mistreatment by others. Bill and Mary have one adult child living in another province and one child residing in the city who has a full time profession which requires a great deal of travel. Bill expects that the children would look after Mary's financial affairs, but he has no expectations of them providing direct care. If Mary was to die first, Bill states

that he would miss her, but would have more freedom to travel to visit family.

### **Local Worlds: The Summer Family**

Before understanding and interpretation can be given to life events, it is pivotal that the events are situated within the individual's local worlds. "Local Worlds" is a concept developed by Kleinman (1988, 1992) that refer to the various elements in a persons life (as listed below). The life trajectory of the participants is presented in relation to each of the dimensions that compose their local world. Where appropriate, dimensions unique to each individual within the case are highlighted. This approach is vital as one must be immersed in the local world of the individual, before understanding of their story and experiences are possible. The local worlds consist of the following dimensions:

- Health and Progression of AD
- Social and Relational
- Health Care and Resources
- Economic
- Religion
- Moral/Ethical

**Table 1: Schemata of Local Worlds, Alzheimer's Disease and Aggression Comparison and Contrasts**

Dimension		Case 1: The Summer Family	Case 2: The Winter Family
D E M O G R A P H I C	Age of:	CR Early 50's	Mid 80's
		CG Mid 40's	Late 80's
	Gender of:	CR Male	Female
		CG Female	Male
	# yrs married	20+	50+
	Housing	<ul style="list-style-type: none"> <li>• War-time 2-story in need of repair</li> <li>• Cluttered and in need of cleaning</li> <li>• Nice neighbourhood</li> </ul>	<ul style="list-style-type: none"> <li>• Bungalow, recently renovated</li> <li>• Clean and tidy</li> <li>• Nice neighbourhood</li> </ul>
	Education:	CR Grade 12 as an adult	Grade 12 and Teaching School
		CG Grade 12	PhD
	Occupation:	CR <ul style="list-style-type: none"> <li>• On disability since 1991.</li> <li>• Previously building custodian.</li> </ul>	Housewife (taught school in 1930's)
		CG Housewife	Mathematician
L O C A L  W O R L D S	Health of:	CR <ul style="list-style-type: none"> <li>• AD diagnosed in 1992.</li> <li>• Borderline mild cognitive impairment.</li> <li>• Elevated cholesterol.</li> <li>• Healthy.</li> <li>• Independent, but depends on CG to organize and manage everything.</li> </ul>	<ul style="list-style-type: none"> <li>• AD diagnosed in 1995.</li> <li>• Mod cognitive impairment.</li> <li>• Healthy.</li> <li>• Able to do own ADL but dependent on CG for meals etc.</li> </ul>
		CG Severe back pain due to MVA's.	Healthy
	Social:	CR <ul style="list-style-type: none"> <li>• Coffee with buddies.</li> <li>• Church Activities.</li> <li>• Converses freely.</li> </ul>	<ul style="list-style-type: none"> <li>• Husband &amp; family.</li> <li>• Ability to participate in conversations limited due to AD.</li> </ul>

	Dimension	Case 1: The Summer Family	Case 2: The Winter Family
L O C A L  W O R L D S	Social:	CG • Hard Life full of difficult challenges. • Church activities. • Too busy with demands and responsibilities of running the entire household. • ++ demands placed on her.	• Fairly "typical" life with few obstacles. • Weekly visits with the neighbour. • Prefers Isolation.
	Health Care	Attended support groups of minimal use (in Ontario).	Has few expectations.
	Economic	Live well below the poverty level.	Financially well off.
	Religion	Encompasses everything they do.	Non-believer.
	Moral/Ethical	• Love. • Life on this earth with AD is temporary. • Swearing is unacceptable.	• Love • Protector of CR • Pride
A G G R E S S I O N	Types	Verbal and Physical (mild)	Verbal and Physical (mild)
	Frequency	96 incidents in 2 months	As often as daily
	Antecedents	• Frustration • Time pressures • Over stimulation • Complex tasks	• Frustration • Confrontation
	Impact	• Significant • Has to orchestrate everything to avert aggressive behaviour. • Very accepting as God's way.	• Moderate • Orchestrates activities but to a lesser degree. • Frustrated as he cannot rationalize the behaviour.
	Management	• Give them space. • Patience. • Avoid antecedents. • Remain calm.	• Give them space. • Patience. • Avoid antecedents. • Remain calm.

Dimension	Case 1: The Summer Family	Case 2: The Winter Family
A G G R E S S I O N  Coping	<ul style="list-style-type: none"> <li>• Gives it up the Lord.</li> <li>• Accepts behaviours as they happen.</li> <li>• Does not look for reason.</li> <li>• Separates the disease from the person.</li> </ul>	<ul style="list-style-type: none"> <li>• Frustrated with not knowing why she acts the way she does.</li> <li>• Keeps it private, tries to forget about it.</li> <li>• Has difficulty separating the disease from the person.</li> </ul>
Life in General	A life of hardship	Relative fortune and comfort

**KEY:** CR - care recipient  
CG - caregiver  
MVA - motor vehicle accident

Case Study One: The Summer Family

## Health and Disease Progression of Tom - Care Recipient

Tom was born in the 1950's, a healthy child with the exception that he was born blind in the left eye and early in his life required glasses to correct the vision in the right eye. Tom denies that his vision has been a problem in life. Tom is a large man, significantly overweight and although he talks about losing weight, is not actively doing so. Tom is being treated by his physician for high cholesterol with mega-doses of niacin. Tom's cholesterol levels have been significantly lowered on this medical regime. Tom experiences difficulty with his bowels, having weekly episodes of diarrhea as well as occasional incontinence due to the urgency. In the 1980's, Tom was diagnosed with diverticulosis. Tom's parents died in the mid 1980's. Tom's father died of natural causes. In the last few years of her life (when approximately 80 years old), Tom's mother was diagnosed with AD and was cared for in personal care home. Tom's parents (Tom is an only child) were otherwise healthy.

In 1987, while residing in Eastern Canada, concerns were raised by both Jane and Tom to their family physician that Tom was experiencing great difficulty completing tasks, especially his work as a custodian. Jane became concerned over Tom's unusual hand, facial, and body gestures such as grimacing,

clenching fists and waving his arms in the air. Jane reported that these "gestures" were present years before she brought them to the attention of a physician. The family physician completed numerous diagnostic tests including a CT scan for a differential diagnosis, but all tests were negative. In the meantime, Tom was finding it more and more difficult to complete tasks and was becoming increasingly frustrated. Things that he once was able to complete within a day's work, were now requiring overtime. He also found that even though his work was physical and not mental, it was requiring more and more concentration and, as a result, he was coming home exhausted.

With his work performance drastically deteriorating, Tom found he could no longer manage and stopped working in 1991. Tom was aware of his poor work performance and when he left work he requested that the people remember him for "how I was, not how I am now." Despite not able to manage work " he was able to cope within a reasonable level" with the demands at home with a young family. Tom was then referred to a psychiatrist who after several interviews and examinations offered a tentative diagnosis of Alzheimer's disease. Tom is monitored by the psychiatrist every three months. (Tom was also monitored every three months prior to his move to Manitoba). When given the diagnosis of "probable AD," Tom



stated that he felt like "I should be measured for a coffin...I wanted to die." However, shortly after, with reflection and prayer, Tom stated that he realized "that I have a lot of living to do." Jane also felt the same way, but stated "There was a certain amount of relief...yet I just wanted to lay down and die. The ironical thing is that Tom actually (suspected) a certain amount." Jane stated that she suspected the diagnosis because of his family history of AD as by this time "he was already living a disabled lifestyle."

In hind-sight, Jane states that signs and symptoms of behaviour changes signifying Tom's declining health were apparent as early as 1983 when Tom's personality began to change. Tom began making "the motions of aggression, but not carrying it out, but his body language was gestures like this (demonstrates clenched fists and jaw and waves her fists in the air)." It was after a verbally aggressive incident directed at his mother in 1983 that his mother chose to remove Tom from the the responsibility of assisting her with her financial affairs and engaged a public trustee. In the spring of 1993 after a moderate to severe incident of physically aggressive behaviour (see Aggression p. 160) and repeated incidents of mild verbal aggression, Tom was prescribed the antipsychotic medication Haldol.

Haldol is commonly prescribed for the control of agitated and aggressive behaviours. Haldol is known to have potentially severe side effects such as depression and Parkinsonism. Within a very short time Tom became incapacitated because of the severe side effects of the medication. Haldol "put me in a chemical pit. I felt like I was in prison." Tom would sleep 20 hours a day and was not able to be involved or responsible for anything in the home. Tom did attend a day program twice a week, but that was his only outing (see Health Care and Resources p. 135). After almost four years and persistent complaints by Jane to the psychiatrist (in Ontario) of the drastic sedative effects of Haldol, it was discontinued. Tom was then without medication for three months before requiring further intervention because of escalating verbal aggression. During this three month period, Tom and his family moved to Manitoba to reside in a home they had inherited. Early in 1997, under the care of a Manitoba psychiatrist, Tom was prescribed a different anti-psychotic, Risperdal (risperidone). Risperdal has been successful in decreasing the incidents and severity of aggressive behaviours without significant side effects. Even with the Risperdal, Tom admits to having thoughts of physically aggressive acts; however, he is able to control them. As a result, incidents of physical aggression remain

uncommon; however, incidents of verbal aggression of a mild to moderate nature are still occurring frequently.

For purposes of this research Tom was requested to complete the Folstein Mini Mental Status Exam and scored 24 out of 30, indicating border line mild impairment (Appendix H). Tom lost all the "points" because of his inability to remember three words for more than a minute or inability to spell the word "world" backwards. Tom was, however, able to remember three objects that were placed in front of him and then removed after 5 and even 10 minutes. Tom was lucid and had no difficulty with the rest of the examination and in fact he was able to count back from 100 in increments of 7 with great ease. During conversation, Tom's memory impairment is not obvious; however at times, recalling specifics takes concentrated effort. For example, when Jane would drive Tom to the store, he would "run in" for a single item such as soap. He knows and remembers being with Jane the last time to pick up the item and can remember the unusual name of the soap. However, he cannot remember where in the store the item was located, but knows enough to ask for assistance. Tom states that his memory is still relatively good although definitely declining, but that his main problem is his verbal aggression.

As stated, Tom's cognition is only mildly affected by the disease and he has great insight into the disease and its impact. When describing what it felt like before being placed on the Haldol, Tom stated that he felt he was going 100 miles an hour when cruising speed is 55 miles per hour. With the Haldol he could only go 20 miles per hour at best. Tom states that his memory of events prior to taking the Haldol as well as while "on" the Haldol, is poor. He does, however, remember being physically aggressive in 1993 and verbally aggressive prior to that. When asked if he had insight enough to know during that time that the physical aggression was a problem, he stated that "he doesn't know as he cannot remember". When describing what it is like living with AD and the concentration it takes to complete tasks which often results in frustration, he states:

It is almost running with an obsession towards a goal. That goal could be a task that you want to accomplish and don't get in the way...because I am using every ounce of energy mentally and physically, well maybe not physically but mentally to concentrate on doing this task, and you get exhausted very quickly.

Despite the desire to be physically aggressive when extremely frustrated, acting on these feelings has for the most part disappeared. Tom states that the verbal aggression is much more difficult to control than the physical aggression and

equates the controlling of it's expression to "trying to hold on to a dog that wants to run down the street on a leash."

Even though he states that he does not always agree with them, Tom trusts his family, especially Jane, to monitor his behaviour and the need for medication as they are more "observant and astute." He gained this insight from interacting with his mother who lived with AD stating that "The person with the illness is aware that something is wrong, but they don't usually have, they are not aware that they are as bad as they actually are." The initial Risperdal dosage of .5 mg taken two times a day had been increased to three times a day at the family's request. At certain times, Tom also takes an additional .5 mg if he or the family feel that his behaviour warrants it. Without the medication, both Tom and Jane believe that there is good probability that the physical aggression would return. Tom and Jane state that even though the psychiatrist sees evidence that the disease is progressing, he is "amazed" that it has not shown significant advancement.

Dimension: Health of Jane - Caregiver

Jane was born in the 1950's with multiple older and younger siblings. Jane was raised on a farm by a foster family. She was born healthy and described herself at birth

as physically and mentally strong. She reports that at five months of age, Jane was in the local news because she could already walk and talk. Jane has had several healthy and successful pregnancies from the mid 70's to early 90's. Recently, Jane states that she experiences laboured breathing and has had investigations, results of which are inconsequential. Jane states that she has always been exceptionally healthy until recent years in which she has been in multiple car accidents (mainly rear-endings).

It is the result of these multiple car accidents from 1987 through 1996 (three in the span of one year) which cause Jane to experience muscle aches and fatigue from initial whip lash-like injuries to her neck and back. The impact of these car accidents in Jane's life is significant enough that she copied her entire autopac file for me to read. Jane describes her life since the accidents as the most painful and difficult thing she has ever had to deal with both physically and mentally and admitted to crying a lot in the initial years. "I don't call myself healthy...I was born strong...and I have lost everything I once had." Jane is in a dispute with the automobile insurance agency (Manitoba and Ontario) trying to receive additional compensation for her injuries which she desperately needs to offset the cost of her chiropractic treatments. Even though there is no visible signs of injury,

it is obvious during Jane's conversation that she experiences a great deal of pain.

Albeit, recovering from the injuries and identifying that this is the best year she has had, her face reddens, her eyes brim with tears and her voice fills with sadness. The pain she experiences limits the amount of housework she is able to complete. Jane apologized for the condition of the house (which was in need of cleaning) immediately upon my first visit and for the next couple of visits. The house was unkempt, floors needed to be swept and cleaned and there was clutter everywhere.

Coping with the pain from the injuries is made even more difficult because Jane is also dealing with the effects of Tom's AD. "What I suffered in my body and (living with Tom's illness) for that one year, I didn't talk (to anyone)." When asked if Tom could be helpful or supportive she said that he simply expressed "his own helplessness in the situation" saying things like "you can't turn the clock back."

When Tom's aggression (both physical and verbal) were at their worst (prior to medication) 1992-1993, Jane stated that her injuries from her car accidents were also the most painful. "My pain in my body constantly reminded me of his anger" and as a result of the association between the two, pain:

Is always a reminder of..not to push him. I had this constant reminder of where his temper could take him. My pain in my body constantly reminded me of his anger.

When asked how the physical pain from the accident has affected her, she replied "It has impacted me more than T's illness...That is the message I would like to be sent."

### Synopsis

Prior to the onset of symptoms associated with AD, Tom was a fairly healthy man. AD was not diagnosed until 1992, although he began experiencing personality changes (verbal aggression, difficulty concentrating) as early as 1983. Tom has not been employed since 1992 when he quit his custodial work because of his inability to "get the job done." In 1993 after an episode of mild to moderate physically aggressive behaviour, Tom was prescribed Haldol, which was discontinued after four years due to severe side effects which put Tom in a "vegetative state." Shortly after the discontinuation of Haldol, Tom and his family moved to Manitoba. Following discontinuation of the Haldol, Tom was prescribed Risperdal which has been successful in controlling Tom's physically aggressive behaviours with minimal side effects. Tom is identified as having borderline mild cognitive dementia. Although his memory is slightly affected, Tom's biggest concern is his verbal aggression. Tom has great insight into



his disease, specifically the specifics surrounding his expression of aggression. He admits to the "idea" of physically aggressive behaviours, but identifies that it is the verbally aggressive behaviours (cursing, hostile language) that are the most difficult to control. Tom is very accepting of his disease, and talks openly about it with his family.

Jane has always been exceptionally healthy until she experienced multiple whip lash-like injuries as a result of multiple MVA's from 1987 to 1996. The pain and anguish she experiences as a result of these car accidents is significantly tied to the aggressive behaviour in Tom. When Tom's physical aggression was at it's worse, so was Jane's back pain. As a result, Jane identifies her back pain as a constant reminder of how severely physically aggressive Tom can be. Jane's life and losses associated with the motor vehicle accidents are a shadow of the losses associated with the effects of AD on Tom. Jane is an emotionally strong and independent individual which came at a cost. Jane was raised in a foster home environment, had few friends and now feels she can rely on and trust no one. Currently, Jane has an immense amount of pressures in her life as they have a large fairly young family (including twin boys age six) which depend completely on Jane.

Dimension: Social/Relational - Tom - Care Recipient

Tom describes his childhood as relatively uneventful, although states that he and his dad were not exceptionally close as his father never shared Tom's passion for music. Tom dropped out of high-school as a teen, but did return as an adult to complete his grade 12. Although Tom grew up in a church-going family, he states that it was not until early adulthood that he truly "accepted Christ as his saviour." The church is paramount in Tom's life and until the early 1990's when AD affected his ability to perform, Tom spent all of his spare time and energy focussing on a gospel singing career. All of Tom's socializing was done in association with the church and that remains the same to date with the exception that his involvement is now reduced. Tom was well liked and although very "chatty," Jane found him to be soft spoken and a gentle man. Tom denies a premorbid personality for aggression as the desire to act physically even if really mad was "very unusual for me, I couldn't swing, I couldn't throw a fist even if my life depended on it...I just don't do that sort of thing." The same holds true for the verbal cursing, "I have been a Christian for many years, and one of the things that you don't want to do is you don't want to start swearing all the time. That just isn't a good idea". Tom is an honest

and humble man, who despite his challenges is also positive about life.

Once diagnosed with AD, Tom began attending a variety of support groups both with his family and individually. Tom stated that although the support groups were of limited value in helping him understand what he was experiencing, he did find the social element most rewarding as he was missing the social interaction that the intense involvement with the church previously provided. Tom stopped attending the Alzheimer's support groups two years ago just prior to moving to Manitoba (see Health Care System and Resources). Tom was raised in Manitoba and had established friends and family in Manitoba prior to his move to the province. Tom now meets his social needs by having biweekly coffee with his brother in law, or a friend from the church. Tom is either "picked up" or takes a bus to get to his coffee engagements and Jane usually picks him up when they are finished.

Tom has great insight into his behaviour not only because of his high level of functioning, but because of his interaction with his mother who died with AD. Tom is aware of his behaviour and when in public makes every effort to remain in control. Tom is humble yet proud. When Tom and Jane were discussing whether or not they wanted to participate in the study, Tom stated that I was free to visit, but that I would

not see anything as "I will be on my best behaviour." Jane informed me that Tom took an additional pill prior to my arrival for our first meeting. During the initial recruitment meeting, before even talking to Tom about the study, Jane predicted Tom's response stating that he "will be on his best behaviour." Tom has also on occasion reminded Jane that I did not have to see "all their dirty laundry," yet seemed surprisingly open and willing to share his story upon being interviewed.

Dimension: Social/Relational - Jane - Caregiver

As a consequence of her father's alcoholism and his physical abuse of her mother, Jane, (age 4) and her brothers and sisters were placed in foster homes. Even though all the siblings still kept in touch with each other, they were physically separated growing up in three individual foster homes. Jane describes her childhood as unhappy. Jane's foster parents were exceptionally strict and Jane and her sister were not encouraged to have friends. "We were raised in isolation..we were not allowed to play with the town (children)." Jane states that she and her sister were raised like twins and that she did not view herself as a separate person until her late teens. Soon after their placement in foster homes, two of Jane's younger siblings (and their foster

family) died in a fire. Jane states that when she and her sister were informed of the tragedy their only response was "we laughed" because of their immaturity to understand the situation. It is obvious that Jane has a lot of issues surrounding her foster home, "at age ten I was declared Ward of the Province. So nobody owned me, I belonged to a thing called the province." "Impersonal" is also how Jane describes her return to live with her mother.

We came to the city, my foster parents dropped me off on her door step, and my sister was spending the summer by choice with my mother. I was never even given a choice. I didn't even have my 18th birthday yet. They brought me as soon as school was out to be with my sister, which meant being with my biological mother. So even though legally they were paid to take care of me for the month of July, they never did.

Jane grew to have a friendly relationship with her mother (who died in the mid 1980's), although she did not confide in her. Jane never confided in anyone stating that being raised in a foster home, she learned that she could not trust or depend on anyone. You "can't trust...that was the basic thing because if you had a problem and you presented it nobody wanted to hear what you had to say."

Jane did not have any "friends" throughout childhood and as a young adult was very private. "People who knew me did not know a whole lot about my life." Jane and her sister keep in close contact, but Jane's relationship with her sister is

superficial as they share different values, mainly surrounding the church. Jane did have one close girlfriend whom she could talk to. Although "she didn't understand anything that I talked to in relation to Tom," she found her to be a great confidant. Unfortunately, the girlfriend died a few years ago. It is obvious Jane misses her terribly as evident in the poem she wrote about her friends' death titled "Does Jesus need you more than I do?" Jane states that although she never really gets time off and certainly does not get out for coffee, she on occasion has a few minutes for herself during the day when the children are at school. Jane was also raised in Manitoba and had friends/acquaintances and family in the province prior to their move to Manitoba.

Jane also attended various support groups (in Ontario) related to AD from 1991 to 1996, but did not find them of significant value. Discussed in greater detail in a later section, Jane is very private about the support group experience, referring to them as an "invasion of territory." It was initially very difficult for Jane to talk about her experience, "I think aggression is not something that you talk about period," yet she was willing to share a great deal. Upon conclusion of my visits, she admitted to finding it easier to talk about her experience than she had initially anticipated. It was however, obvious when she felt she had

said enough or did not want to discuss something and this did happen on occasion.

Jane is also active in her church attending prayer groups and Bible study. Even though she does not "connect" with any one person, she feels that she is beginning to feel supported. "People are becoming a little bit more open (in the church) and in our circle (of friends)...some are better listeners than others." Jane appears lonely and despite her family, is alone. She admits to feeling alone, but states that it is getting better. "Before the only support I really got is when outsiders (church guest speakers) came to town." Now, "people are listening better...they have changed their attitude. It's just a different atmosphere (referring to the Christian community)."

Despite the tremendous demands placed on her and all her trials and tribulations, Jane appears as a positive, humble, honest, and sincere individual. She appears to be emotionally strong and a practical person, who does not dwell on the negative or feel sorry for herself.

Dimension: Social/Relational - Tom and Jane - As A Couple

Tom and Jane met in the early 1970's and were married shortly there after. Their love for each other is obvious not because of any physical contact, but by the way they speak to

and about each other. Even though much of what they have to say is not positive, it is done in a sincere and understanding manner. The ease and honesty in which they share even the most difficult situations within each other's presence is noteworthy. For example, Jane and Tom attend Tom's appointments with the psychiatrist together (as they had done prior to moving to Manitoba) and Tom states he prefers that so that the physician understands the real picture. When asked about the honesty that Jane brings to these appointments surrounding his aggressive behaviour, Tom says:

My flesh has a tough time every once in a while. You kick and scream...you may not outwardly, but I mean inside you go "Oh gosh, did you have to bring that up (laughter)"...I realize that the doctor cares and Jane cares and so, so I am able to go through with this thing. But it is kind of unnerving sometimes.

Additional examples of their honesty with each other are revealed in these comments by Tom:

Jane said she was getting the cards on the table that she was being quite honest with you.

Jane is always honest enough and open enough to tell me "you know I don't think you can handle this situation. I don't think you should touch it." And, ah, I've learned to respect her decisions because she is more observant than I am.

Both Tom and Jane believe in traditional roles for husband and wife. Given Tom's illness, however, this no longer applies. Jane admits to giving in to selected situations "because of his masculinity, I let him overrule automatically."



I was the quiet one, he use to be my mouth piece, I did not ever express myself, partly he never encouraged me to.

He could talk..the hind leg off a horse (laughter).  
It use to be you couldn't turn him off.

Jane's role has changed "immensely" as she is now the one that is expected to do the talking and be the "communicator" both at home and in social settings.

Jane states that their relationship is very different because of Tom's illness. "There is still a bond there with Tom...but to communicate on a certain level (silence)." Socially, Tom and Jane attend numerous church events and always do so as a couple. However, anything they do is always completed with consideration given to Tom's potential to be aggressive, "I usually have to plan any activity with Tom apart from the children. That is one of the ways to deal with Tom." Jane states that she cannot rely on Tom to take care of her and frequently mentions how he cannot "protect" her from some of the difficult situations she experiences such as the chiropractor's "torment" or her sister's "venom." Jane admits to carefully selecting what she says around Tom so as not to escalate him, "he cannot respond the way I would like him to." Jane gets forgotten in the picture at times as the focus is usually on Tom and how things are going for him.

He gets all the attention and what I have to live with as Jane is far worse on me because I still have to do the doing. I still have to be

responsible. If I can't do it then my family doesn't get it and then they suffer too. If I didn't put food on the table it didn't get on the table.

Tom is very dependent on Jane not only to manage the house and the children but emotionally as well. Despite his illness, Tom and Jane are still each others' best friend.

Dimension: Social/Relational - As a Family

The love within this family is visible and strong. The open honesty and sincerity that is evident between Tom and Jane is also evident in the interactions with and between the children. While Tom talked of the physical aggression (past) the children's actions and expression appeared to be unchanged by this discussion. (Perhaps they chose to ignore or not to react.) Some remained at the table, others were only feet away playing. The oldest two seemed to simply listen to what he was saying. However, when talking about the verbal aggression the children would nervously laugh and animate a very sarcastic expression of surprise when Tom relayed how his verbal aggression often sets the tone for the family. Despite the aggression, the children appear relaxed around their father and interact and joke with him. However, Jane states that they know when to stay clear of "his territory." Tom relies on his family's feedback as to his behaviour. The family often draws to Tom's attention that he appears tense.

The children state that they can see rising tension in their father's face immediately and will say to him "Daddy you're making faces again." Tom states that although he does not necessarily believe them he responds to their assessment and tries to remove himself from the situation.

The activities around the house do not reflect that a family member has AD, the children often have friends over and participate on numerous outings. However, because of a combination of financial restraints and the increased stimulation that would precipitate an aggressive episode, family vacations have become a thing of the past. Jane states that she feels badly when her youngest will ask why they cannot go camping as a family like the neighbours do. The children do attend bible camp and camping outings with their friends. They are also involved in numerous school-based extra curricular activities. The Summer family are very pleased with their move back to Manitoba as it was always their preference to live in the province.

Dimension: Health Care System and Resources: Tom - Care Recipient

Initially upon diagnosis, the family attended support groups for individuals with head injuries. It was from this group that they were directed to the Alzheimer's Support

Groups and Day Programs of which Tom and Jane (and some of the children) participated in from 1991 to 1996 (in Ontario). Specifically, Tom attended a weekly program for the early stages of AD which was discontinued because of limited numbers. He also attended a general program on a weekly basis which included individuals with more advanced AD. Jane stated that the general program was somewhat of a "vacation" for Tom because he was catered to and in fact after each meeting Tom usually returned home angry "because he had to come home to responsibilities." Eventually Tom left this program as the only people he could talk to was the staff because of the deterioration of participants.

Tom feels that the health care system could do more for individuals with aggression. He feels that the support groups did not really understand what was going on with his feelings of aggression and that they were mainly equipped to deal with memory loss. "Aggression is not a pretty situation and they have a tendency to ignore it or sweep it under the carpet." As a result, Tom states that he feels let him down by the Ontario Alzheimer's Society. He does state that the Society is a wonderful organization and a good social network and was pleased with the social element of the group which was why he attended. Both Tom and Jane felt the day programs and support groups were "superficial". They perceived the facilitator and

other members to be reluctant to talk about anything that was "unpleasant" such as aggressive behaviour.

Dimension: Health Care System and Resources: Jane - Caregiver

For the last number of years Jane has been receiving chiropractic treatments for her neck and back and describes the treatments as abusive although beneficial. She feels the previous chiropractors were negative about her ability to recover from her injuries, but is pleased with the chiropractor she is seeing currently.

While Tom attended his day program during the years of 1991 to 1996, Jane attended monthly support group meetings and became distressed by them. Unwilling to specifically disclose what happened, she eluded to the fact that she did not feel supported. The group did not understand what she was going through related to Tom's aggression especially the "impact on the family and the interrelationship and the stimulation of family life" and that "Tom requires stimulation in order to get him triggered off." Jane suggested that the group did not acknowledge her physical pain (from the motor vehicle accidents) as an added dimension that made her situation more difficult. "They just didn't want to support me...I was the one that got the least support (within the family)." She felt

that Tom and the children did receive help, but that "it was a bit of a play on emotions...and it actually increased frustrations."

I think the Association of Head Injuries was the most helpful because they treated us as a family unit. Whereas, the Alzheimer's Society support was more trying to tear us apart as a family rather than pulling us together as a family.

Jane was not willing to discuss the support groups any further stating that it was too painful to talk about and I was invading her privacy; "invasion of territory" were her words. She did, however, conclude that "there was a certain amount of help just being in the Alzheimer's Society, but it ended on a bad note." Prior to moving to Manitoba, Jane did contact the Director of the Ontario Alzheimer's Society to express her concerns and felt somewhat better after doing this. Shortly after arriving in Manitoba, Jane did contact the Manitoba Alzheimer's Society for information about support groups, but declined to attend.

Both Tom and Jane like their current psychiatrist and feel they can trust him. When asked if he has been helpful in giving suggestions, Jane stated "Well he isn't a psychologist," and learning to manage and cope with the aggressive behaviours has been learned "just within the household" by trial and error. Tom "appreciates what he has

to say" but doesn't always find it easy to hear. He describes one of his recent appointments this way:

Somebody had picked me up and put me through the ringer. Jane was rubbing her hands and was totally delighted while I was booted from one end of the room to the other...but he usually calls a spade the way he sees it...basically my family shouldn't have to put up with my obnoxious behaviour. Just go off and cool your heels someplace.

In relation to the care received in Ontario, Tom and Jane do however question why the Ontario psychiatrist did not discontinue the Haldol sooner or at least warn them of the side effects. Jane states that she had to prove everything when talking to the psychiatrist. Despite numerous complaints about how non-functional and slowed down Tom was while on the Haldol, it was not until Jane presented his annual "report card" (from the day program) to the physician that changes to the medication regime were made. As a component of the day program, participants walk around a track for an hour each week with a volunteer recording their mileage. Tom had only walked a total of 8 kms in a year. Another time Jane did not believe the physician fully understood the impact that Tom's behaviour had on the children until she showed one of the children's report cards. In one semester this child went from "average" to "above average" marks to "failing" in all but one subject. Overall, they do have confidence and trust in the present psychiatrist and as Tom states "trust in (not) only

God, but the medical profession to put me on the necessary drugs to keep this aggression under control if it does increase."

Dimension: Economic: The Summer Family

Prior to 1991, Tom had been employed in a variety of different settings, but mainly in caretaking/custodial work for a minimal salary. In 1991, Tom was no longer able to complete his work at a satisfactory level and resigned. Since this time, Tom and Jane have been living on Tom's disability insurance and a small pension. To date they have managed on a limited budget, but they state that in the recent years making ends meet has been especially tough. Disclosing their income tax submissions for the last ten years reveals on how little the family lives as their income is substantially below the poverty level. In fact, this family of more than six often lives on less than \$20,000 annually. Tom (being an only child) and Jane have relied on inheritance from Tom's parents (to meet financial obligations) and are expecting a small inheritance in the near future from another relative.

Tom inherited the home they live in which was why they moved back to Manitoba. Tom sold their lake property (in Ontario) for needed income and upon moving to Manitoba, took a mortgage out on their home to help put their oldest daughter



through college. The home is a two-story war-time bungalow in a respectable neighbourhood. The home is in desperate need of repair (broken windows, cracked walls) and the yard is also in need of attention. The home is equipped with modern conveniences such as a microwave, dishwasher, VCR, and cordless phone. The eldest daughter living at home has her own bedroom, the rest of the children share rooms. The family owns a van which is less than eight years old. They purchased the van with proceeds from the sale of the lake property. Jane has remained at home full time. Pursuing employment outside of the home is not an option, as they strongly believe that the mother must be home for her children. Jane states that financial worries are a great source of concern and frustration for both her and Tom, especially Tom. She states she is worried that Tom will not be able to cope with the additional expenses of the upcoming wedding of their oldest child and expects incidents of verbally aggressive behaviour in Tom to increase.

Despite what appears to be a difficult economic situation, the children are involved in multiple extra-curricular activities including hockey for the twin boys. The children have ice skates, roller blades, and the newest backpacks. The family has always appeared well groomed and wear the current style of clothes. Jane states that she does

accept hand-me-downs for the family from the church but also sews their "good" clothes for church and special occasions. Jane is an accomplished seamstress (self taught) and often makes matching outfits for the girls' dolls. Jane states that she will not cheat the family on nutritional meals and there is always a bowl full of fresh fruit on the table. The family cannot afford to eat out very often, but they do on occasion, especially if time is tight because of the children's activities. The times that they do eat out, however, are either "drive through" or picked up and brought home as the noise in restaurants is too stimulating for Tom and dining out often causes Tom to feel over-stimulated resulting in a verbally aggressive episode.

Drinking water is purchased because of the aged water pipes they have in their home. Like some other children, Tom's and Jane's children often have friends over to eat. Tom and Jane have numerous pets, some of which were strays. The pets are well taken care of and see a veterinarian regularly. As earlier stated, Jane is in a dispute with Autopac and another insurance company in Ontario to secure increased financial coverage for her injuries suffered in the series of car accidents.

Dimension: Religion

"We try to put the Lord first in our lives." This quote by Tom is what this family is all about. They have an strong faith that structures everything they do and guides the interpretation of anything that happens. When completing the Mini-Mental Status Exam, Tom was asked to write a complete sentence. The sentence he wrote was "I love Jesus." As children, both Tom and Jane attended church regularly, but it was not until late adolescence/early adulthood that they each committed their lives to God. Tom and Jane devote a great deal of their time to their church, attending various prayer groups and Bible classes. The church is essentially the only social activity outside of the children's activities and Tom's coffee dates in which Tom and Jane participate. Tom and Jane try to read the bible an hour a day. Although their religious teaching is that their devotions should be shared together, Jane states that they could never do that as it did not work. Tom would become easily frustrated with the schedule and the expectations that went with reading together. Instead, they each do their readings alone "feeding ourselves" and if needing to see if they were both "sensing the same direction" they would then share their readings. Church and its' activities are very much a family event and all the children are equally active in the church activities.

It is because of their strong religious position that the family find the swearing element of Tom's verbally aggressive episodes to be most distressing. In a society where swearing is common place, this couple is deeply disturbed by this language. Turning to their faith, Tom and Jane accept what has happened to them without question. They accept disappointments as "the arm of flesh will fail you" and believe that their life on earth should not and will not be any easier than the life of Jesus while he was on earth.

Jesus endured the cross for the joy that was set before him. It was not the death on the cross that was Jesus' focus point. And he went through pain and he was not medicated and he refused the bitter gall/vinegar whatever...and he did say Father if you're willing let this cup pass from me but it didn't pass from him.

It is not surprising then that this couple finds strength in their beliefs. Jane believes that because of what they are going through "Tom's and (my) walk with the Lord has deepened. Both his and my own." Tom finds both comfort and guidance:

I have a faith that keeps me on the road. If I didn't have that...(sighs)...I don't know what would be happening...the bible says that if any man lacks wisdom let him ask of God. So I am constantly praying and asking Lord, how do I handle this situation.

Dimension: Moral/Ethical

The life of this couple is rooted in Christian values. Honesty and love prevail in this home. For example, Jane

admitted that their elaborate Saturday morning brunch which I attended (5 or 6 courses including a variety of toppings for pancakes and crepes) usually consists of toast and cereal, but she wanted to "impress me." The patience and tolerance each child has for the other and their parents, and the resounding laughter that is always present, also reflects these values. Impossible to capture on tape was the overwhelming feeling of love that is evident in the home. Despite all the trials and tribulations these people have had as individuals and as a couple, their financial hardships and the impact of AD disease, this family celebrates and enjoys the gift of life and does not dwell on the hardships. However, there are times that Jane is not so proud of her feelings. Since Tom has been diagnosed with AD she feels the spotlight is always on him. People question how his health is, how he is feeling emotionally, and praise him for his courage to manage day to day. This competition for love is additionally frustrating especially when she is living with not only the pain of Tom's illness but the pains from her car accidents. Yet, always having a positive comment, Jane does believe the disease has deepened their love.

Profanities have been identified by this couple as unacceptable and in fact insufferable. This language is so offensive to Jane that in the journal of aggressive behaviours

that Jane maintained during the study, words such as "hell" or "ass" are often identified only by blank lines for each letter eg: ---- for hell as Jane later identified. Explanation of the specific behaviours would often be revealed this way; "and so by the time the first onslaught of kids were out the door by 0810 he would have had three swears...and um, two more swears from here to (street name)." The swearing appears to be associated with the manifestations of the AD as Jane doesn't "remember Tom swearing before 1983...it was never a problem." Tom refers to his swearing this way:

Swearing is very unusual for a Christian...It just doesn't jive. This guy is a gospel singer singing about the Lord and he is swearing at home if he gets into...if the situation is right. It just doesn't jive!

When asked how AD fits within their Christian beliefs, Jane refers to the teachings of the Bible. "The Lord created the dumb and created the deaf, that He created everybody. God has a plan. He does work everything out for good. He knew the beginning from the end even before we did." Seeing the good in life, Jane identifies ways in which their lives have been blessed such as the eldest child falling in love. Off tape she states that she is grateful that the Lord has spared them of other difficulties that another family is having with a child who is fighting at school. When asked how she makes sense of aggression as a result of AD, since there is no good

to be found in aggression, her response was "suffering." Aggression is simply a part of suffering. She identified numerous times in the life of Christ that he was alone despite requesting that someone be with him.

When Jesus went to the mountain to pray his disciples fell asleep on him...So in that hour of need...there isn't necessarily somebody there standing by you...Paul said that might know Him and the power of His resurrection, and the fellowship of his suffering.

Tom identified that AD and aggression fit easily into their Christian beliefs referring also to the bible that the Lord never promised an easy life on earth.

Jesus was a man acquainted with sufferings and grief. He suffered and the pupil is no higher than the master. So if the master suffered the pupils going to...Why do bad things happen to good people? I don't know. Life is a painful experience here on earth. It doesn't matter...You just learn that whatever life throws at you, you just give it to the Lord and you keep going...I just learn to live with it. I don't ask the Lord why..because he knows what is best. And if I can glorify Him with AD and go through this ugly process of coming apart at the seams piece by piece and over a slow period of time, well.

## Local Worlds: The Winter Family

### Case Study Two: Bill and Mary

The participants in Case Study Two have a less complex life than the Case Study One participants. This, which is obvious when the dimensions of the local world are explored, can be attributed to their advanced age and the fairly recent onset of Alzheimer's disease.

Dimension: Health and Progression of Alzheimer's disease:  
Mary - Care Recipient

Mary was born in the early 1900's and until recently has been exceptionally healthy with minor complaints of constipation, earaches, and "always feeling cold." Two years ago she was diagnosed with Type II diabetes and is well controlled on insulin administered twice daily, the dosage based upon a sliding scale. Bill is responsible for the management of Mary's diabetes and takes this responsibility very seriously. Mary's blood sugars are monitored and recorded three times daily and snacks and meals are prepared within a very strict time line. Mary has suffered no apparent consequences as a result of her diabetes. She is always cooperative with the three daily "finger prick" bloodsugar testing and twice daily insulin injections.

In the early 1990's, Mary began complaining that she was having difficulty with her short term memory. Bill also



noticed this and after repeated physician visits to rule out organic causes, Mary was admitted to the psychiatric unit of a community hospital for assessment in 1995. After an admission lasting one month, the geriatrician and psychiatrist offered the tentative diagnosis of AD. Mary was not verbally or physically aggressive during this time, but was very argumentative. Within months, episodes of yelling at Bill and at times mild physical aggression followed the argumentative behaviour. Mary's memory continued to decline and she now has difficulty carrying on a conversation.

Mary is oriented to person, place and time yet at times can misinterpret her environment, has difficulty following conversations, gets the stories she is telling mixed up, and often repeats herself. She does, however, have moments to hours of complete lucidity. Mary scored 14 out of a possible 30 "points" on the Mini-Mental Status Exam indicating moderate to severe cognitive impairment (Appendix I). Even though she could not draw the pentagons, she lost the majority of her points in the memory section, scoring only 2 out of 11. In January of 1998, Mary was started on the trial drug Aricept which, as earlier described, is aimed at improving memory loss. According to Bill there have been no improvements in her memory. Mary regularly removes items from their rightful location and places them in most unusual locations. Bill has

found coffee mugs in her boots and dishcloths in her bedroom. Mary cannot remember seeing the items and becomes angry when Bill "accuses" her of taking them. Even when the items are found, Mary cannot remember her involvement in their disappearance and accuses Bill of lying. During visits, Mary would often repeat herself, confuse her deceased brothers with her children, and forget why I came to visit. Surprisingly enough, she did not forget my name and on occasion would remember that I said I would be back for another visit. Mary is able to bath and dress herself. She does keep her own bedroom neat and tidy and on occasion will dust the house, although she usually gets side tracked. Bill identifies the disease as having progressed fairly slowly despite how significantly impaired Mary has become in three years.

Dimension: Health: Bill - Caregiver

Despite his age, Bill states that aside from the odd cold or flu he has always been healthy. He does not suffer from any of the more common ailments associated with aging such as arthritis or loss of hearing. Bill appears to have above average intelligence. He is physically strong and still does his own snow removal and that of a neighbour.

Dimension: Social/Relational: Mary - Care Recipient

Mary does not socialize with anyone other than her family and one neighbour. This neighbour has been a friend of Mary's for more than thirty years and during those years has always had coffee with Mary on a weekly basis. In the last few years, with Mary's declining cognition, they no longer alternate homes for coffee, but rather the neighbour always goes to the home of Bill and Mary. Even though for the past year Mary's part in the conversation has been declining, she would always sit and "visit" while Bill carried the conversation. Recently however, Mary has begun excusing herself from the occasional visit stating that she was tired and would resign to her room.

During her younger years, Mary stayed home full time raising their two children. Bill states that Mary has always had a temper, but was never abusive. Bill describes Mary as a happy person. Mary is often smiling and appropriately laughs at her husbands jokes. Mary has a sister (only immediate family member alive) to whom she is very close and who lives in another country. She makes daily entries in a letter which is then mailed to her sister at the end of every month. Unfortunately, Bill states that the majority of the letters do not get mailed as Mary ends up misplacing them or once sealed in the envelopes throws them out in confusion. Mary does call her sister each evening to share what her day

was like. Mary no longer has outings (for groceries, for dinner), but does enjoy walking up and down the side walk in front of the house. Mary presents more typically as someone with a cognitive impairment.

Dimension: Social/Relational: Bill - Caregiver

Bill is a highly educated man, holding a PhD in mathematics. His friends consist of his children and the neighbour who now visits with him instead of Mary. Bill does have an older brother who lives in Eastern Canada, but who is deaf and confused. Bill appears in need of opportunity to converse in depth with others and frequently would engage me in extended "sololiques" about mathematics, physics, history, inventions, and especially his family. Bill is very proud of his family, pulling out pictures or their childhood keepsakes (poems and cards) at almost every visit. Bill describes himself as not very social and states that even as a child he preferred to be alone. Bill is very protective of Mary and if asked a general question such as "What did you do today?" Bill would quickly answer for her. Mary seemed fine with this "arrangement" and eagerly smiled at me when he answered on her behalf, admiring how easy it was for him to remember things. Despite this protective nature, it was Bill's idea that I

spend time with Mary alone so that I could get to know her better.

With a mathematician's background, Bill describes himself as "quantitative" in nature. He is not afraid to challenge either the definition of aggression and most certainly the lack of a tool that could record specifics (such as changes in brain waves) that would accurately measure the occurrence of aggressive behaviour. Repeatedly he would tell me that he is not certain if I was going to have any valuable data from my visits. He would then quote the writings of Lord Kelvin stating that without an exact measurement and something to compare it to you will have knowledge that is "rudimentary and not very useful." When I would review my study design he would make comments such as "oh yes, of course, this isn't hard science."

Mary was recently started on the experimental AD drug Aricept aimed at improving memory. With the drug administration, the caregiver is to keep a daily log grading a variety of behaviours. Bill is extremely frustrated and insulted with such a "coarse" and "useless" tool as there is no way to measure if "something is more or less of anything without a yard stick." He therefore refused to complete the daily log unless he had something to report. By his own admission he is extremely frustrated by things that are not

concretely and objectively measured. Bill initially agreed to keep track of Mary's aggressive behaviours on the behaviour log, however, he never made a single entry, telling me each visit that he had nothing to report. Bill is a proud man and even though he originally stated he was willing to discuss the aggressive episodes with me, he was most reluctant. He would deny that there were any acts of aggression and would only share them if pushed and only then for brief moments repeating each time that:

I don't want to mislead you.  
These don't happen all the time.  
I am afraid I am giving you the wrong impression.

Dimension: Social/Relational: As a Couple

Bill and Mary had three children, but at age six one child died from osteosarcoma. To this day, Bill finds the loss of this child unbearable and would often bring the child's death up in conversation, stating how painful the loss is and how he will never "get over it." It is obvious that Bill and Mary do not discuss this loss, as Bill was surprised when I told him that Mary mentioned the death of their child. He commented that he did not think she would even remember as they do not talk about it. The two remaining adult children are married and like their father have also attained their PhD's. One child lives in the city and visits biweekly to

monthly. The other child lives in another province and despite not being able to visit with his parents frequently, they are in contact via telephone on a regular basis.

Mary has nothing but praise for her husband on each and every visit. She talks about how much she loves him, how well he takes care of her, and how amazing he is because not only can he cook, he can bake as well! Bill (although not to the same degree) speaks fondly of Mary sharing with me some of the love letters and poems he wrote for her. It is obvious that their relationship is rooted deeply in love. They are not afraid to talk about the love they have for each other, are often winking at each other, and it is common to see them hug, or reach out and touch the others arm or leg. It is this love that Bill has for Mary that makes her verbal aggression painful as she will often state things like "I hate you" and "I should have never married you."

In the past Bill and Mary would spend their hours in stimulating intellectual conversation. Unfortunately, that has come to an end. Although Bill and Mary do "discuss" the children, the majority of conversations are lacking substance and usually aimed at meeting a need. Bill has turned to more reading (which he has always enjoyed) for intellectual stimulation and Mary watches television and writes letters to her sister. With the progression of the disease Bill felt it

best if they each had their own bedrooms. This way he was not always questioning her as to the whereabouts of his personal items which usually resulted in verbal aggression or "fits of rage" as he prefers to call them.

Dimension: Health Care System and Resources

Fortunately, Bill and Mary have had only limited experience with the health care system. In 1995 when Mary was admitted to hospital for assessment, Bill was pleased with her care but he was upset with the diagnosis. In 1996, Bill left the province for a week to attend a family wedding. With guidance and direction from their geriatrician, Mary was placed in an respite bed at one of the personal care homes. Concerned over how she would manage and how much she would miss him, Bill was pleasantly surprised upon his return to see how well Mary managed in respite care. Mary was in good health and had positive things to say about her stay. He found the staff to be very capable and pleasant. Although things went well, he does caution that it was only for a week and still worries about how Mary would manage if she required long term placement.

Bill is aware of the Alzheimer Support Groups, but states that he has no real use for them. He believes that they are in no position to assist him in managing his wife's aggression



as they do not know her or the dynamics of their relationship. He would have to be a "buffoon" not to know how to communicate with his wife, and to know what approaches are useful. He states that he has no desire to participate in the social aspect of the groups either, as he does not find his life "very traumatic." "You don't need to worry about my social life. It is what I want it to be...It's not that I have a lack that I can't fill." Bill and Mary like their geriatrician, but again Bill has little expectations of her in the management of Alzheimer's disease. He does not believe there is much the physician can do for the aggression and admits to only mentioning his wife's behaviours once in passing. He is pleased that the physician has placed her on the trial drug in an attempt of improving her memory, but feels nothing more can be done. Bill is pleased with the management of Mary's diabetes, although he was frustrated with his referral to the dietician. During the educational sessions, the dieticians display the size of servings that constitute a serving of fat or carbohydrates instead of reporting the size in grams.

No quantitative remarks at all about food. It is as though somebody in the system has said that dirty unwashed public out there, they don't know anything about numbers!...I find this quite insulting.

Dimension: Economics

Bill has been retired for more than twenty years from a well paying profession. He receives an employment pension and both he and his wife receive a senior's pension. Bill and Mary have separate bank accounts, but both have significant amount of investments which they can access at any time. They have recently sent a money draft to Mary's sister for \$16,000 for first class airfare for the sister and a grandchild (so the sister wouldn't have to travel alone) so that they could come and visit. Bill and Mary live in an older bungalow in a pleasant neighbourhood. Both the kitchen and the bathroom have been recently renovated. Bill drives an older luxury vehicle. In their younger years the couple did travel abroad, but generally preferred to stay home. Prior to 1995 - 1996, Bill and Mary enjoyed fine dining and the occasional art/cultural outing.

Dimension: Religion

Even though Mary was the daughter of a minister, Bill and Mary have seldom attended church. In fact, Bill states that he is an atheist and will remain an atheist until someone can give him concrete evidence that the Bible is a book of facts, not beliefs. When asked how Alzheimer's disease and aggression fit into his view of life, he very scientifically

referred to the fact that it is a disease and diseases happen especially as we age.

Dimension: Moral/Ethical

A deep love, a traditional role of protector, and pride are the components of the moral/ethical dimension. It was obvious on every interview and visit, including the initial recruitment interview, that Bill and Mary are deeply in love. With such love comes the need to protect. His protection of her is evident in keeping her unaware of the diagnosis of Alzheimer's disease and answering questions for her even when she was beginning to answer. According to Bill the children are unaware of Mary's potential to be aggressive and he does not discuss it with the physician either. Bill is a proud man and with precision manages Mary's diabetes.

### Synopsis

Even though both families are living with aggressive or potentially aggressive behaviours, all the elements that surround their lives give meaning to their stories and their experiences with aggression. Table 1 (p. 112) is a Schemata comparing the dimensions between the two cases, which in summary appear to be one journey on a very rough road full of barriers versus a smooth and steady journey.

## **Understanding Aggression**

### Case Study One: The Summer Family

With insight into Tom's and Jane's local worlds one can now review the incidents of aggression within the context of this couple's life. This study focuses primarily on events surrounding recent aggressive episodes. Tom's past behaviours, prior to being placed on medication, are significant and as such will also be reviewed. Declining to use the behaviour log, Jane opted to keep a written record of the aggressive episodes from January 6, 1998 to and including March 10, 1998. In this two month period, Jane recorded 96 incidents of aggression, averaging 1.5 incidents per day with the majority of the incidents occurring during the evening which Tom and Jane attribute to the increased stimulation when the children are home (social/relational dimension). A large number of the incidents occur in the privacy of their own home, yet, a significant number occur in public, which Jane finds to be the most disconcerting. All but two of the incidents were verbal of a mild nature ranging from cursing and the use of vulgar or hostile language to name calling. The two physically aggressive incidents were also of a mild nature. The majority of the incidents, both physical and verbal, were less than five minutes in duration. Although Jane states that there is an "unpredictable element involved," she can readily identify

several triggers that commonly cause Tom to feel frustrated resulting in verbal aggression. The antecedents were identified by Tom and Jane during separate interviews and also during concurrent interviews. The antecedents are:

- Overstimulation (increased noise and activity in the home especially when the children are home).
- Time Pressures (trying to get somewhere on time or complete a task within a given time frame).
- Multiple Tasks (Shopping and unloading groceries).
- Waiting (Usually in the vehicle while the children are completing extracurricular activities).
- Miscellaneous Pressures (Financial worries).
- Changes or deviation from a plan.
- Interruptions (while completing a task).

Note: The antecedents in this study (for both the Summer and Winter Family) were revealed to me by individuals who were experiencing cognitive impairment and individuals who were managing the behaviours. These could also be identified as triggers for feelings of frustration and/or aggression in individuals who are not cognitively impaired. This potential "overlap" must be recognized, but within the context of this study, they will be identified as antecedents for the participants with AD.

Serendipitous to the study is the insight Tom has into his feelings and expression of aggression. For increased understanding of how or why the episodes might have occurred Tom's perceptions will first be presented. To illustrate the type of aggression demonstrated by Tom, a few of the significant escalations will be discussed in this section. Please refer to Appendix T, page 330 for a larger sampling of Tom's aggressive incidents as recorded in Jane's journal. Incidents of abrupt behaviour were not recorded by Jane as

aggressive. Tom and Jane deny (past or present) incidents of sexually aggressive behaviour.

Note: The aggressive feelings and behaviours in the care recipients, identified by both the Summer and Winter Families, are not unique to only those with AD. These feelings and behaviours may in fact be present in individuals who are not cognitively impaired. However, for the purpose of this study, and because these feelings and behaviours were identified as occurring within a reasonable time frame of the tentative diagnosis of AD, they will be identified as behaviours associated with AD in these participants.

Insights offered by Tom: Living with AD and Aggression

Identifying his cursing and name calling as unacceptable, Tom states the aggression is fuelled by frustration. "My biggest problem right now is verbal aggression...it's much harder to control the verbal than the physical." Events in life that are minor irritants to others become almost "catastrophic" to him. Tom says that he has to concentrate so hard to get things done or carry out a request. He tells of an incident while on his way to return something to a room in his church, a fellow member asked him to buy a raffle ticket. Tom responded by being very rude and "telling the guy off." Tom stated when "I was programmed to do that (task)" and there was "interference...I can't deal with it...I cannot have any deviations." Explaining the frustration which is antecedent to his aggressive behaviour Tom observes:

What is happening is your frustration level is increasing because your brain is being destroyed. You're trying to act normal and you're trying to

function properly but you're losing it and you can't...You're trying to hang on to everything but your world is getting smaller and you can't hang on to everything. So you're losing stuff and it is very frustrating trying to...you're losing coping mechanisms. Your coping mechanism is breaking down. That is exactly what's happening...You're trying to work with what you've got and your still trying to function as if you have 40 bags of tricks and you don't have 40 bags of tricks so you're going wild.

Tom describes living with aggression as a sudden tenseness and tightening in his body. Specifically:

I don't know if I can tell you how I actually felt...agitated that's about the only way...sometimes I do things physically like clench my fists or do something like that, and I am not even aware of it...I probably would have looked pretty ridiculous. You act a certain way but you don't want to act a certain way. It is very frustrating. Extremely frustrating. I wish I could handle every situation perfectly and be calm, cool, and collective. But it just doesn't work that way...it just happens.

Tom denies expressing physical aggression since the 1993 incident, but does admit to the occasional urge to swipe at something, sweep everything off a table, throw things, slam his fists, or "anything." The difference is that with medication he recognizes the urges, but does not act on them. The medication helps him stay in control until he can remove himself from the situation.

Fortunately for me the physical aggression isn't there. Although I must admit the idea of punching somebody out if you get frustrated does enter your mind, but fortunately you don't put it into practice...I don't consider myself a danger to anybody.

## Incidents

Tom's behaviour began changing as early as 1983, but concerns over verbal aggression did not present until the early 1990's when Tom became very short tempered and began using profanities. Shortly after this, Tom became physical, shoving the two oldest children around. The physical aggression increased to a severe level in 1993 at which time he was placed on Haldol. Although Tom openly admits to shoving the children around, he did not reveal any other acts of physical aggression. Little about this time period (prior to the administration of Haldol) was shared by Tom. Jane stated that there were a number of verbally and physically aggressive incidents in 1993 that she identified as severe in nature. (Jane was reluctant to discuss the incidents). Following the Haldol Tom's behaviours changed almost immediately.

Jane stated that it took approximately a year after the incidents in 1993 to trust Tom again. "After I was injured (referring a physical incident that occurred in 1993 which she would not discuss) it took a year..of keeping my space before I could um..it took (the daughter) the whole year too. She had to have that space." Jane states that her daughter (who was witness to and/or involved in) has put the incident behind her. Jane admitted to being frightened of Tom when he was "in



that state" but denies it now and upon observation does not appear to be frightened of Tom. "He seems to be on a different level for the most part. Like, you know, there is still evidence of agitation, being upset and that. But it seems to be less and less." Prior to Tom being prescribed Haldol,

He got extremely wound up...and that emotional buildup in him was looking for a place to explode. And (psychiatrist) told him more than once if he wasn't on medication he would end up in jail...That was his option to go to jail or to be on medication.

Since 1993 Tom has remained on medication and the incidents of aggression have greatly reduced Jane discloses:

His aggression is less now than what it was. It use to be like walking through a mine field. You had to be careful where you stepped. It's much better now. We didn't know Haldol was going to be such a relief. I felt like going to support group meetings and say how could you say this drug was no good! It saved our family!

It did not take long before the labile nature of Tom's moods was evident. During the very first visit one, of the children called home to inform her parents that she had been chosen/honoured to do an eight-week art class at the art gallery, but this now conflicts with an advanced swimming class. As Jane (who answered the phone) relayed the conflict and the need for a decision you could see Tom get more anxious. He started rubbing his hands together, his facial expression changed and became tense looking, his voice got

slightly louder, he pushed away from the table and very firmly said that he wanted swimming to be the priority. A brief discussion followed in which Jane took control identifying all the various ways their daughter could achieve both, and what plans Jane had to set in motion for this to occur. The discussion was dropped by Jane being silent and letting Tom vent. Tom's concerns in this situation could be viewed as appropriate, however, his actions were more escalated than would be expected in this situation. The immediate escalation was obvious. Later, Tom identified that any deviation from a plan "throws him." "I can't deal with it." "This is crazy, she had a plan, why suddenly the change?" He was able to identify what an honour it was for his daughter, but stated that changes in plans "drive him crazy" and he lets "Jane deal with it". He is very aware that his behaviour sets the tone. He admits to being the "cause" of a lot of problems in the home.

Tom admitted to increasing his medication (by a half a pill) recently at his family's request. Tom states that the family confronted him that he was yelling more and for no apparent reason, and was becoming more difficult to be around. Tom states that he thought his family was "full of it" as he saw no difference in his behaviour, but did agree to augment his medication. Tom said that he suddenly found that he could

identify with his mother who had AD who also resisted when the family would encourage an increase in her medication because of deteriorating and aggressive behaviour. "So, maybe the family is right". After a few days of the increased medication Tom commented on how the family appeared happier and calmer to which Jane informed him that it was because of improvements in his behaviour with the increased medication. Again, Tom admitted that he was responsible for much of the "frustrated" tone around the family.

On the second visit during brunch, Tom was very withdrawn and seemed overwhelmed by the brunch. Tom later admitted that he was concentrating on tolerating and getting through the brunch. Tom stated that he had to work at maintaining his "calm" as he found the event to be overstimulating. Despite their father's behaviour, the children were very animated and friendly. Each did their own thing and brunch conversation covered everything from nudity to diarrhea. After brunch things became very hectic. One child was playing the recorder, the other the piano, and a third had the TV on top volume. Another was running around with the chicken pox, the birds were chirping, the dogs were barking, the cat was demanding attention, and one of the rabbits was running loose about our feet. Surprisingly enough, this was when Tom began to participate in the conversation at the table and no longer

appeared to be having the difficulty managing the situation as he did when things were somewhat quieter. Jane seemed so in control and used to all the demands placed on her.

The next visit took place as the children were getting home from school, the preparation of supper, and the actual meal. The fact that it takes a great deal of effort and concentration for Tom to get through the day's events was more visible. At the supper table, his facial expression was grimacing, he would push back from the table as if to physically distance himself from the goings on of mealtime and he would just quietly stare at the bowl of cheese. Interestingly enough, Jane assembled his taco's for him. I believe this was significant because the ingredients of the taco would not be handed to him in order and he would have to organize his thoughts about how to "stuff" the taco. It was obvious from his behaviour that this would be more than he could manage and would definitely frustrate him.

Tom describes frustration as being the antecedent to his verbal aggression. Later, when alone with Jane and I, Tom identified that he was getting frustrated with the regular on goings of mealtimes. Tom states that even though there are still numerous incidents of verbal aggression, the medication is providing better control of the expression of aggression. The example he cited took place during mealtime when the

youngest child was playing under the dining table. He stated that all of a sudden he wanted "just to yell" and that it "took everything in my power not to do that." He states that the feelings emerged because he was suddenly feeling "frustrated" with the situation. With insight, he explained how the desire to yell (not specifically at his son) was so inappropriate especially because he had no reason, as his son was "just being a six year old". Explaining the incident now, he says he cannot see why it felt like such a big issue or why he felt so "frustrated." Despite the work of mealtime, Jane seemed very animated and obviously enjoying the antics of the children and was not focussing on Tom's behaviour.

During the middle of March, nearing the end of the study, Jane tells of a verbally aggressive incident in which her sharing of information with me was the antecedent. Tom felt that Jane was airing too much of their "dirty laundry" and that she should not tell me anything more. Jane describes the incident as follows:

Well it came out very much like a machine gun. I didn't interrupt him..and I said well I am sorry um (silence). I said "it's been nine years and I have really not said very much (laughter). So after nine years I am entitled to say something (laughter).

There are times Jane picks the children up after school so that they do not have to take the bus home. On one occasion, Tom was going to meet her at the school as he was having

coffee with a friend near by. Jane was not yet due to arrive for another five minutes, but Tom who arrived early "became anxious and confused" and went into the school office informing the principal that the children will indeed be taking the bus home. When Tom left the building Jane was in the parking lot waiting. Tom became very upset, yelling at Jane for being late and told her that he informed the school that the children will have to take the bus home because their mother has not shown up. Jane then went into the office to correct the situation. Jane stated that she was glad that the school got to see what her world is really like "Oh, you go to see what my life is really like. It's about time!"

There was also an incident when Jane was in the drugstore photocopying and Tom was waiting in the van. Tom came into the store yelling at Jane that she was taking too long and he had to go to the bathroom. When asked how she felt she replied "Well I saw the cashier lady staring at him, and so I used that (laughing) to say do you know where a bathroom might be?" Jane said that she felt she had to respond, "I mean he was chewing me out, he was very much chewing me out."

The psychiatrist has had Tom's driving privileges revoked due to aggressive tendencies. Tom states that he cannot drive because "I don't trust what I would do if I became frustrated." Both Tom and Jane state that Tom gets very angry

when in the van resulting in the majority of verbal outbursts occurring in the van. Tom states that he often asks to be dropped off at a bus stop so that he can be removed from the situation which he identifies as an antecedent to aggression because "at times I just want to drive the car into anyone or anything."

Upon my final interview and with great humour, Tom and Jane shared their most recent "event" which involved physical aggression of a mild nature in a public place. As they were going through the check-out at Superstore, Tom suddenly began throwing groceries from the check-out counter into the cart, which meant the individual items were not bagged and had to be thrown over Jane's head. Tom states that the whole process of unloading your cart, watching prices, and bagging your own groceries was too much (even though he was only responsible for unloading the cart) and a source of frustration which was the antecedent to the situation. "Suddenly I just lost it at the check out counter. I could not have been better, and I knew I was doing terrific when we were going around the store, but I fell apart at the check out counter." A customer two aisles over was watching and offered to help them with their groceries and even gave up her own bags (which she had paid for)... "because she is afraid I am going to throw the eggs (laughter) into the cart and so far all I pitched was a box

(of cereal)." Jane stated that she could not help but laugh at the situation even though "he chucked a few more smaller items, and maybe a tin can or two but (laughter) he didn't chuck the glass bottle." When asked how Jane could find humour in the situation she replied:

It wasn't directed at me personally. I just happened to be in his line of fire (laughter). What to me was the funniest part was he had an audience that he wasn't aware of. And so looking at their faces was what I was more laughing at than him trying to ah...

Both Tom and Jane deny being embarrassed by the situation even though Tom commented "I don't even realize how stupid I must look."

Now that we have a picture of the local worlds of the Summer Family, and familiarity with the types of aggressive incidents with which they live, an understanding of aggression is emerging. For ease of explanation, what we now know about aggression is presented in a table format (Table 2, p. 173).



**Table 2 - Understanding Aggression: The Summer Family**

<b>DIMENSIONS</b>	<b>WHAT IT TELLS US ABOUT AGGRESSION</b>
Health and Progression of AD	<ul style="list-style-type: none"> <li>▶ May be first sign and symptom of disease.</li> <li>▶ Catalyst in having caregivers and care recipients seek health care professionals for cause.</li> <li>▶ May be present even if only borderline cognitive impairment is present.</li> <li>▶ Although physically healthy, it can disable the individual from being an active participant in the home as sensitivity to stimulation sets off incidence.</li> </ul>
Social/Relational	<ul style="list-style-type: none"> <li>▶ Caregivers find it difficult to talk about.</li> <li>▶ Caregivers are often the target.</li> <li>▶ Can isolate both the caregiver and care receiver.</li> <li>▶ Places increased demands on caregiver related to the "delicate dance" of pre-planning events so as to have control over stimulation.</li> </ul>
Health Care/ Health Resources	<ul style="list-style-type: none"> <li>▶ May be amenable to pharmacological management.</li> <li>▶ Support groups not identified as helpful in the management.</li> <li>▶ Management technique offered by physician (confront) not able to be implement by caregiver for fear of further escalation.</li> </ul>
Economics	<ul style="list-style-type: none"> <li>▶ Affects ones ability to maintain employment.</li> </ul>
Religion	<ul style="list-style-type: none"> <li>▶ Is easier to accept if the presence of aggression can fit within your belief system.</li> <li>▶ Definition is affected by one's belief system - swearing unacceptable for this family.</li> </ul>
Moral/Ethical	<ul style="list-style-type: none"> <li>▶ Unconditional love for care receiver, helps the caregiver cope with the behaviours.</li> </ul>

### Case Study Two: The Winter Family

As previously stated, Bill was very reluctant to discuss aggressive episodes and refused to track their occurrences. "Oh, I don't try to remember these thing." As such, we only have a glimpse of what some of the incidents were like. However few, one can still get an sense of what it was like for him. Unlike the complexities in the first case study, the data I collected from the Winter Family was limited. This is attributable to the reluctance or inability of Bill to disclose his personal experience. Unable to specifically identify the antecedents to Mary's aggression, the antecedents that Bill is aware of can be categorized into two broad categories:

- Frustration (with memory loss)
- Confrontation or questioning about behaviour or missing items.

As with the Summer Family, we have opportunity to learn about aggression with the aggressor's insight. Despite her cognitive impairment, Mary has times of lucidity. It was during one of these periods that she shared what she experiences.

#### Insights Offered by Mary: Living with Alzheimer's Disease

Mary has not been told that she has AD and attributes changes in her behaviour to her memory loss. She states that

she can tell me everything I want to know if I let her tell me, but if I ask her to retrieve something on demand "it just isn't there." Mary states that the memory loss makes her "so angry" and clenches her jaw and waves her fists in the air. She describes frustration with her memory loss as steam building up inside as if "my brain will explode." Physically she says it feels like she cannot breathe which "feels like it is the end of the world" and finds these feelings very frightening. Mary admits that when angry, she screams, pounds her pillow, throws things, slams things to make a noise, or anything physical that would "vent my steam." She says she "flares up fast and calms down quickly." "Sometimes my husband wants to argue me back to a good mood which confounds the situation." Aware that sometimes her behaviours "scare and annoy" her husband and he "yells" at her from time to time, she tries to control her actions; but when unable to, she gives her husband space. When Bill does "yell" at her, Mary states that "I just scream and rush out of the way." Bill does admit to losing his temper from time to time, but both Bill and Mary (in independent interviews) state that Bill would never act physically.

## Incidents

As previously stated, there are inconsistencies in the details relating to aggression or "dust ups" or "fits of rage" as Bill prefers to call them. He has stated that behaviours occur as often as daily, a few times weekly, once monthly and then other times as "rarely". When questioned about the variance in the reported frequencies he states that he is "guessing" and once more agreed to record them on the behaviour log, but never carried this through. As a result, only a limited number of incidents were reported. The shared incidents and the general descriptors of the behaviours exhibited during a "dust up" were both verbal and physical and mild in nature. The verbal behaviours occurred more frequently and often followed, what can best be described as, an argumentative mood. If de-escalation did not occur during the verbally aggressive phase, the aggression then became physical in nature. According to Bill, it does not require very much for the aggression to advance to a physical outburst. The duration of the verbal aggression is usually less than five minutes, and when combined with the physical aggression can range from five to thirty minutes. The verbally aggressive behaviour is always directed at Bill. His wife tells him to shut up, or that their marriage was a mistake, or that she never should have married him. "The

things she says to me when she gets into a real rage are absolutely horrendous. Go to hell is the mildest thing." Physical aggression is always directed at inanimate objects and mainly consists of slamming or banging drawers, doors, and one object against another such as a mug on the table. "When I see her going out of the room when she is in a rage, I go and I grab the door so it shuts gently. I know in advance she is going to slam the door." Mary then retreats to her room, or Bill leaves the room and resolution occurs. Bill reports that within ten to thirty minutes after the incident is over the incident is usually forgotten by both Bill and Mary.

Even though the incidents are described as unpredictable, they do reflect a pattern as they always follow when she "does something very Alzheimer's like" such as misplacing things. He readily admits that on occasion he is responsible for her aggressive incidents because he has called her attention to what she has done or "scolds" her for misplacing items. He shows the indent on the kitchen table from when Mary "in a rage," banged her coffee mug on the table. He says that he drew her attention to it and challenged her as to why she would do something so "destructive" to their furniture and that now she has ruined the table. Bill stated that he was very angry and his response escalated Mary even further. When Bill is trying to give Mary direction or guidance such as

putting on a jacket and/or boots before she goes out for a walk in the winter, "she will want to argue with me...so there is a potential "dust up" over that kind of thing." He then quickly adds after each shared incident "Lets not overdo it. They don't occur very often."

In assessing the incidents, Bill says that there is no pattern to the aggression. To get a "pattern it must happen sufficiently often to see how it develops. But if it happens every two weeks, there is no pattern that you can identify." Bill states that the specific antecedent is difficult to identify, but believes they occur because she forgets something and wants to "attack something" and "I am the one here." "I can tell by the inflection in her voice" that she is going to be verbally aggressive. She says things like "I think we should get a divorce." "You don't love me anymore." "You have broken my heart." With his voice raised and a stern look on his face revealing his frustration, Bill then adds "and I didn't do anything! I haven't said anything yet!"

Only on one occasion did I witness an interaction between Bill and Mary that was argumentative in nature and had the potential to escalate. While Bill and I were interviewing in the kitchen, Mary came in to say that she was going to go her room and Bill very quickly told her that she cannot go to sleep because she had not had her evening snack. Mary very

sharply and quickly stated that she did not say that she was going to go to sleep, but that she was going to her room. Bill did not drop this right away and instead reinforced that she cannot go to sleep, and once more with clenched fists and a firm jaw, Mary loudly stated that she was not going to sleep! The discussion between the two of them continued back and forth for a few more minutes with Mary's voice and non-verbal behaviour escalating. Then, as Bill went to reinforce his message once more he stopped part way through and very lovingly said "all right dear, I will see you at nine for your snack." Although this interaction could easily have occurred between a couple that are not dealing with AD, this scenario does demonstrate how quickly Mary's voice could rise, and how Bill chose to manage the situation.

On another visit, Mary was very sharp and quick with her words. She was muttering under her breath most of which I could not discern except for "oh hell." When Bill commented about some crumbs on the floor, Mary very quickly and in a defensive tone said something to the effect that the floors are never dirty. Bill asked if she wanted more water (empty water glass in front of her) she snapped back "well I don't have any water!" In past visits she would usually laugh or simply say "yes." Also there was something different in her eyes on this day. They were not clear and "sparkling" which

was most notable about Mary. When alone, I addressed the potentially aggressive behaviour I observed, and Bill seemed most surprised. He said he did not find her that way.

Now that we have some insight into the local worlds of the Winter Family, and a cursory familiarity with the types of aggressive incidents to which they are exposed, an understanding of aggression is emerging. For ease of explanation, what we now know about aggression is presented in a table format (Table 3, p. 181).



**Table 3 - Understanding Aggression: The Winter Family**

<b>DIMENSIONS</b>	<b>WHAT THEY TELL US ABOUT AGGRESSION</b>
Health and Progression of AD	<ul style="list-style-type: none"> <li>▶ Behaviours were present after diagnosis and cognitive decline.</li> <li>▶ Present in individuals with moderate cognitive impairment.</li> <li>▶ Care recipients have insights into his/her aggressive experience.</li> </ul>
Social/Relational	<ul style="list-style-type: none"> <li>▪ Difficult for caregiver to talk about.</li> <li>▪ Caregiver's may not even discuss behaviours with family or physician.</li> <li>▶ Caregiver often the target.</li> <li>▶ Causes anger and frustration in caregiver.</li> <li>▶ Aggression in the caregiver increases aggression in care recipient.</li> </ul>
Health Care/ Health Resources	<ul style="list-style-type: none"> <li>▶ Not discussed with physician.</li> <li>▶ Caregivers may not seek help as they do not believe anything can be done or that somebody outside the immediate family (support group member) would have anything to offer as they do not have individualized knowledge of the care recipient.</li> </ul>
Economic	<ul style="list-style-type: none"> <li>▶ May not be affected if aggression occurs in later years when employment is not the source of income.</li> </ul>
Religious	<ul style="list-style-type: none"> <li>▶ Caregivers who challenge the existence of God, turn to a scientific explanation for AD.</li> </ul>
Moral/Ethical	<ul style="list-style-type: none"> <li>▶ The bond between husband and wife causes the recipient of the aggression to be "hurt" by what is said.</li> <li>▶ Resolution of the incident (hugging, making conversation, declaring their love for each other) is seen as an important component.</li> </ul>

## **Impact of Alzheimer's Disease and Aggressive Behaviour**

### Case Study One: The Summer Family

The impact of AD and the associated aggressive behaviours have been alluded to throughout this chapter. However, the personal impact of the disease and behaviours on Tom and Jane, and to a small extent the children (study focused on the spouse) needs to be specifically addressed. "I cannot imagine physical pain before, prior to experiencing it." These, Jane's words, were used to describe the impact of Tom's aggression as a result of his AD and that no one could know what she is going through unless they too have experienced it. This is partially why she wanted to participate in the study as the interactions in the physician's offices and support groups is "superficial" making her feel at times that she is not understood.

I think that your letter (Participant recruitment letter) initially zeroed in on something. The dynamics of Tom going to support group, just interviewing Tom, talking about pleasantries and denying issues is a completely different life than interaction with a family, being overstimulated, having your circuit overcharged, and, it is just a totally different setting. It...they would think we are talking about two different people (laughter) but it is always the same person.

When asked if she ever wants to cry or scream, feels frustrated, or disappointed, the response was "it depends on which pain is the loudest" admitting that she feels all of these things at any one time.

Initially I was angry. It didn't seem fair that I was the one that was suffering and I had to do all the work. What work I did do was the only work that got done. Angry because I was dragging myself through the day. Some days I couldn't walk, some days I couldn't talk..It didn't seem fair I had this load. It made it obvious to me that he definitely had an illness because he could not take care of his wife when she needed help.

Jane feels positive that overall Tom's behaviour, with the help of the medication, is improving and has not had a nightmare surrounding Tom's aggression since 1993 when Tom was most physically aggressive. She describes the her life during the early 1990's when Tom's verbally and physically abusive behaviour was at it's most extreme this way:

It was like going through a holocaust. Survival was really the only thing that was (nervous laughter followed by silence). The fact that the family was dependent on me and if I didn't do it, it didn't get done. Their needs were not being met and in essence Tom's needs were not being met either...that would increase his frustrations. It wasn't a win situation.

The changes in the medications have also had an impact on the family. During the three years that Tom was taking Haldol not only did the physical behaviours stop but "so did everything else." Unaware of the side effects of the medication or that there was alternative medications the family lived with Tom essentially incapacitated. He slept twenty out of twenty four hours and when awake was slowed down, uninterested, uninvolved, and incapable of interacting with Jane or the family. With the change in medication from Haldol to

Risperdal, Tom now empties the dishwasher and does the laundry. Six months ago he also was responsible for cleaning the bathrooms and the floors throughout the house, but is no longer able to complete these things stating that they take too much energy for him to carry out. While Tom was taking the Haldol, everything, including caring for Tom fell on Jane's shoulders yet, she describes life as somewhat easier as he was out of the way and not setting the emotional tone. "Things weren't as tense and angry. That way it was easier." Without side effects from the Risperdal, Tom has increased his interaction with the family. Jane states that this in some way has even been harder as the stress level in the house has increased because of the tone that Tom's verbal aggression sets. Jane "wouldn't even leave him alone (with the children) for half an hour" until recently as the children are getting older and there is less stimulation.

Emotionally it wasn't easier...there was more stress at home if I was to leave him at home with the children. And they're more stressed themselves so they have their own explosions. That is what increased. Their own explosions. The tone in the house.

It was also during the early 1990's that the school called Jane with the concerns over the dramatic drop in grades in one of their children. "It was very evident to the school that something was happening at home." When trying to encourage this daughter to do better in school Jane would say "You have

a future, you don't have to stay in this environment. Doesn't that inspire you? And it doesn't." Jane handled the situation by decreasing her activities because "the strain on the home was greater" and she needed to be there to intervene.

The children have also been embarrassed by their father's behaviour and yet are "amused" when he is verbally aggressive in front of a friend. They feel supported when their friends see how their life can be and also hope that their father will be embarrassed by his own behaviours. Jane reports that one of the children, when observing her father walk down the street grimacing and clenching fists, stated "if I didn't know that was my dad making all those faces I would be scared of him." As previously identified, Jane feels that in the recent years the children are managing and interacting pretty normally. Jane denies being concerned that the aggression may escalate as the stimulation in the home (main antecedent) is decreasing. She believes that his behaviour will actually improve when the children leave home. Even now as the children are becoming more independent:

His stress load is being reduced. If he had to relive the last nine years where he is at now (laughter) it would have been impossible. Completely impossible. It was the fact that we had a really young family that played havoc with him.

When asked if she ever feels sad about the whole situation Jane admits that "there is a certain amount...there is not end

in sight." Jane states that she really does not have time to worry about things in her life but "I do feel sorry for myself sometimes. I am not allowed to make mistakes..when a person is tired they do error but I am not supposed to." Jane denies being embarrassed by Tom's behaviour, but is most stressed by the aggressive episodes that happen in public. She states that "the biggest part of his illness...affecting my life is what people expected...of the disease...a disease implies such and such." Jane does expect a certain amount of "intolerance," but states the "frustrating part is chronic illness and that people are not understanding...not patient by nature." Chronic illness "brings out the worst and the best in others as well."

Jesus took it upon himself the sins of the whole world. I got to see a lot of sins of the whole world that I didn't know didn't exist before..I got to see the ugly side of people that I didn't know existed to the extent that it does.

When in the final interview Tom and Jane were asked to identify what would they describe as the toughest part of their life, Jane without hesitation answered "the loss of my health." She adds that Tom's illness has affected her health. "I would say I would be more tense at the times of the car accidents which would compound (the situation)." She also identified that the residual pain is also affected by tension in the home. In addition to the difficulties Jane has had in

living with her back pain, she describes that Tom's aggressive behaviour is the toughest element in her life. She states that, behaviourally, the situations she finds "really out of control" are when Tom is in the van where he cannot escape the stimulation and the frustration. These are the times that he is the most verbally aggressive. Jane also identified "the silence between Tom and me" since his illness as having a great impact on her life. She tells of a luncheon she went to and everyone at the table was having "everyday conversations, but not one of them I could relate to. My life wasn't like that." When asked if this made her feel sad, she replied "A little yes. Alone yes...I'm not as lonely now as what I was when the kids were so little and I didn't get out." While sharing this experience, Jane appeared to have a "sad" expression on her face. Jane's voice was very soft, head was somewhat lowered, and her eyes were becoming tear filled. Of equal importance was the expression on Tom's face as he listened and observed her sharing of the story. Tom's expression appeared to communicate empathy. Tom, leaning forward in his chair, looked only at Jane, and was slowly nodding his head up and down. It was as if I was not even in the room. It was moving to watch something so sad yet so beautiful. Jane summarizes what she has been through this way:

In the fiery furnace (referring to a bible passage) there was only one person who volunteered to jump in. Nobody else could take the heat, and that was Jesus. And that is the advice I gave my children. Was that there comes a time in life that nobody else can stand the heat, except the Lord. Now they didn't spend all their life in the fiery furnace, okay, that's not the impression I want to leave. But there is a time when there is too much heat in a persons life and nobody else can identify or step into that situation. And, I have to say that I have been there, and I know that I am coming out of that place.

Jane stated that coming out of the fiery furnace is partly because she has less physical pain as the children no longer need to be carried and that Tom's behaviour is improved. "We are having a better quality of life...because it's normal."

Tom and Jane deny that this disease has significantly affected their plans and dreams for the future, although they are concerned about finances both short and long term. Jane states "My life before was in raising my family and that hasn't changed. I can't give you an answer about the future."

For Tom:

The future was just unfolding one page at a time. My goal in life is to walk as closely with the Lord as I can. That has always been my goal...So I can't say the disease really super interfered with, well it did (dreams of becoming a full time gospel singer) but it didn't throw me for a loop because, well it's one day at a time anyway.

Tom finds the "spontaneous" and "immediate" need to "act out" as the most difficult to deal with. Tom stated that he finds it very humbling that his wife trusts a young child with the



children more than himself and how humbling it is that he cannot be relied upon. He says that Jane tells him:

The way the kids react is because their father hasn't set a very good example through no fault of my own. That is a humbling experience...it can be kind of embarrassing...kind of frustrating seeing a six year old kid using some of the words you do...it's really frustrating. I have to say Lord if I am the reason the kids are doing this sort of thing then please forgive me and you straighten out her little heart.

Tom talks about the potential to be incontinent as the disease progresses and says that:

Cruxifixion isn't a glamorous form of death and neither is AD. So if the Lord can die on the cross for me and endure that kind of death, I guess I can endure the death of AD as slow as it takes.

When challenged that on a good day fine, but on a bad day, his response again was "we only operate one day at a time remember?" For Tom the toughest part of the disease and aggression is "the fact that you're sick always" but generally does not feel that things for him have been overly tough.

It's harder on Jane than it is on me. A lot harder on her. Me, I can pick myself up and go to bed if I want to. If I can't cope with a situation I can just walk out. But she has to sit there and run this place, and battle in the arena with the kids...I turn off what is going on in the house like a light switch, but she can't. It's a lot harder on the caregiver. If I had a choice, I would rather be a victim than a caregiver."

Case Study Two: The Winter Family

After the month assessment in hospital, and upon discharge when Bill was told by the geriatrician and the psychiatrist that the diagnosis was probable AD Bill had questions. Bill verbally challenged the physicians diagnosis, identifying that AD cannot be diagnosed until post mortem examination and that they were simply guessing. Bill states that he cannot remember much more of what was said identifying that "they were the purveyor of bad news" and he choses not to remember those things. He admits that it was not until recently that he has truly accepted that it is most likely that his wife does have AD. He talks about how years ago he would try to improve her memory by playing memory games. He would place all different kinds of objects on the table trying to have his wife remember them. He would then hide them and challenge her recall. He said after a while that just caused frustration and he gave up on it. He also sought information on how memory is stored in the brain and tried to challenge those parts of the brain by playing bridging games and such. When she acts normally "it's not at the front of my mind that she's an Alzheimer's patient. I forget that, and then another one of these things (aggressive incidents) comes along and suddenly reminds me that this is in fact the case."

The impact of this disease on this man is not found in his words, but rather his non verbal behaviour. The majority of the time he is in full control of the story he is sharing and shares it with a humorous tone. However, there were times when asked specifically about his feelings, and when he was willing to disclose, that his body language would change. He would at times put his hand over his face, shield his eyes and look down at the floor. His face would redden and the volume and cadence of his speech would change. He would then pause for a moment, look up and say, "well enough of that," adding that he did not want me to get the wrong impression that things were a problem.

The most difficult element to deal with for Bill is watching his wife "slowly slipping away" and having a "slow death." He also desperately misses her as a companion and a friend with whom he used to enjoy challenging conversations and debates. The words she uses hurt more than the fact that she is angry, as the verbal escalation consists of statements surrounding their relationship and love for each other "she breaks my heart." After a verbal incident in which she has said "horrendous things," Bill experiences a "sort of a low because I think, God, it is lonely here, and I can't really talk to her." Relating to a recent incident he sat in the kitchen "feeling quite horrible about the whole affair" asking

"What is it that I did wrong?" Yet, it is important to Bill that we understand that he does not view his life as traumatic, but it is indeed lonely. With almost every visit, Bill would conclude how nice it was to have someone to talk to and would state how he misses that in his wife. When sharing how they use to debate and converse together his expression is always sad and distant looking. However, when loneliness was specifically discussed and how he does not have anyone to talk to his statement is succinct. "You don't need to worry about my social life. It is what I want it to be...I don't have to unburden my soul to somebody from time to time." Bill freely admits that Mary's behaviour, especially when she loses or misplaces items frustrates him a great deal.

I mean you don't know which drawer the spatula is in, then you spend 20 seconds looking for the damn spatula every time you want to cook something. That's intolerable. Let everything have it's place...and leave it precisely there.

Given their age, Bill is understandably concerned about the future especially if he died first. Knowing that she would then need to be cared for in a Personal Care Home, he asks questions which again confirm his protective love for his wife. "Would they think that they are being put in the hands of strangers? Is this a problem for them?" Bill prefers that Mary live out the rest of her life in the house, which means that she would die before him. With mixed feelings, Bill

identifies that if Mary should die, the decreased responsibilities would allow him to travel more to visit family, and even take another trip overseas.

It would to some extent be a release, as though I have been set free. But then it occurred to me that in spite of it all, there would be a big hole because most of the time she is very much the way she was.

### **Management of Aggression**

As previously stated, it is assumed that the care recipients have AD and that the aggressive behaviours are as a result of AD. The management strategies used by the caregivers may also be used by others in situations different than described in this study. The strategies are however identified by the caregivers as strategies they use to manage the aggressive behaviours in their spouses who have been diagnosed with probable AD.

#### Case Study One: The Summer Family Strategies Implemented by Jane: Caregiver

Jane is effective in decreasing not only the frequency of aggressive incidents, but the severity as well. Jane describes the incidents as having on occasion an "unpredictable element" yet for the most part she can readily identify the antecedents. Jane spends a great deal of time and energy manipulating the environment so that the triggers

are eliminated or reduced. Outings with Tom are planned alone, daily routines are honoured and conversations/discussions are well timed. When asked about venting her own frustrations to Tom over his behaviour or about anything else in life she says "If I have to express myself with him, I have to do it when he is calm. So I have to pick and choose the times. Generally I have to wait when he is calm."

Other examples of Jane constructing the day/event with Tom in mind avoiding situations which would cause him to become verbally aggressive include: Tom not being left alone with the children if possible, helping Tom reorganize his day if his coffee buddy has cancelled, and completing many household tasks after Tom has gone to bed. Jane structures everything for him so that he is not faced with situations that he cannot handle.

Other examples of how Jane controls the environment and Tom's involvement with the children, based on what his day has been like, is that she "sometimes does not let him" meet their youngest child at the bus stop. Jane says the mission in Tom's mind is to get home and of course young children dawdle. This dawdling would be enough if Tom was having a bad day to cause Tom to be verbally aggressive. The one thing Jane states that she does not do is ask that the children behave differently or quiet down because of their father.

Jane was advised by the psychiatrist to "scold or call him on it" when Tom's behaviour is inappropriate. However, Jane feels she could never do it for fear that it would escalate Tom. It is through trial and error that Jane has learned to manage Tom's behaviour. Jane states that if the incident is in public "I down play it. I usually do not respond...wait for him to stop." In fact, remaining calm and letting Tom vent is the approach that Jane uses with the majority of the interventions. Also leaving Tom alone (both verbally and physically) is very successful. When Tom is cursing at the children or calling them names, Jane says that for the majority of times she just lets it go, unless they specifically call for help.

For the most part Jane is very successful in decreasing the incidents and the degree of escalation. There are times, however when Jane states the intervention does not work especially "when I don't think for myself" and agrees that there are times that she just gives up. When asked what she would tell someone who asked for her advice in managing aggressive behaviours in their spouse she stated that she would not be quick to give out advice because "different situations trigger a person off. It depends on the disease, it presents itself differently."

### Strategies Implemented by Tom: Care Reciever

Both Tom and Jane identified that time pressures to go somewhere and be there on time as being the most difficult for Tom to manage. To avoid acting out, Tom will isolate himself either in the van or in the bedroom. Tom states that although Jane has everyone to get ready (for a family outing) and he just has himself, he cannot help her as this usually results in a verbal outburst. Jane says that it is better if he just leaves during these times so that things remain calm. Tom states that prior to the Haldol when he was physically aggressive, he did not know when or where the physical aggression came from. Now Tom states that he can recognize definite situations which set him off and he tries to avoid them, walking away from situations. He says he can see the tensions coming, as they don't always "sneak up" although there is always a "surprise element."

If you see situations coming at you that are going to be potential problems, don't stand there waiting for them to run them over. Get out of the way of them...so that you're not part of the problem.

### Strategies Implemented by Family and Tom Concurrently

Identifying early changes in Tom that are indicators of his frustration is another way the family as a whole try to prevent incidents. They will alert Tom to the fact that he seems "edgy" or "tense" and Tom then (although not always agreeing with their assessment) will usually have a "time out"



isolating himself in another room or location. Tom does say, however, that there is still a number of times where he has no idea why he behaved the way he did. With the absence of physical aggression Tom states how much better he feels about himself. However, he states that even though he feels more controlled with the medication, the verbal aggression occurs before he has even realized or recognized how he is feeling. Tom is complimentary towards Jane and her ability to manage his behaviours, giving him "space" and always remaining "calm, cool and collected." Tom states that the children do not remain calm and he tries desperately to have Jane's calm and collected behaviour influence him, and not let the children's obvious frustration with him escalate him even further. "Two people falling apart doesn't make it twice as good as one. No way. You have to be calm, cool, and collective." Jane says that the children know when to move "out of his territory." See Table 4 (p. 198) for a summary of the Management Strategies used by the Summer Family.

**Table 4 - Management Strategies: The Summer Family**

<b>Family Member</b>	<b>Strategy</b>
Jane (Caregiver)	<ul style="list-style-type: none"> <li>▶ Manipulate environment so that aggression triggers are eliminated or reduced.</li> <li>▶ Carefully choose times for conversation and interaction.</li> <li>▶ Assist Tom with the planning of his day so that interruptions and changes to schedules are minimized.</li> <li>▶ Accept or ignore the behaviour.</li> <li>▶ Allow Tom to vent.</li> <li>▶ Leaving Tom alone (verbally and physically) when potential to act aggressively is present or after aggressive incident.</li> <li>▶ Remaining calm.</li> </ul>
Tom (Care recipient)	<ul style="list-style-type: none"> <li>▶ Isolates himself when he identifies feelings of frustration building.</li> <li>▶ Avoids know situations that cause him to feel frustrated.</li> <li>▶ Draws on spouse's ability to create calm.</li> </ul>
Family as a whole	<ul style="list-style-type: none"> <li>▶ Drawing to Tom's attention that he appears "edgy."</li> <li>▶ Give Tom space. Move out of his territory.</li> </ul>

Case Study Two: The Winter Family

Bill believes that there is "nothing very magical...nothing very profound" in the management of Mary's aggressive behaviours, adding that "it's not rocket science... It is just ordinary human behaviour." Years ago he would challenge and argue with her out of frustration and precipitate her telling him "to go to hell." He says he has now adjusted to her behaviour and realizes that the confrontational approach does not work and instead finds that he plans an approach that would not be threatening or frustrating to her. He now tries to appease her and says something to the effect, "Oh now Mary, you can't let a little thing like that bother you. Here, come and have some tea." He says that this has been working fairly well lately, but he has to change his approach to keep up with the changes in her behaviour. "I am rather pragmatic type in many ways...I don't keep trying to do something which I know won't work." He has also made some modifications to the home such as bi-fold doors in the kitchen. This way when Mary is having a very confused day and removing everything from the kitchen he can keep her out if necessary. In efforts to decrease her frustration (frustration is an antecedent) with her memory loss, he has also taped notes to the wall to remind Mary that she should not do something, and has taped the phone number of Mary's

sister along the back of the phone handset. Calendars and clocks are also clearly displayed in most rooms. If he is concerned that the behaviour is going to become physical in nature, which often involves throwing objects, he removes all heavy objects around her. Specifically Bill states that he can often avoid or decrease the severity of aggressive incidents by:

- Approaching in a cartoon character eg; as a butler in the morning.
- Changing the subject that appears to be causing the escalation.
- "Biting his tongue" when she "tells him off."
- Physically leaving the scene.
- Not asking or expecting an explanation for her behaviour.

After he has let Mary be alone for a while he will approach her to see if she is okay and describes his follow-up approach this way:

If I go in too soon, and she has not forgotten she will say "my heart is broken...so I leave it a little longer...I can tell when it is forgotten and she responds in a reasonable way. I will lean over her bed and put my arm around her and (she) will put her arm around me and she will say something like you are so huggable.

Bill admits that especially when the verbal incidents were first happening, "I wasn't shining too much" he would often react by scolding her or arguing with her, especially if she had "pushed his buttons." "When somebody starts attacking you, in a way your defence mechanism kicks in almost automatically. So that is what I have to be on guard

against." He says that she is not in any danger, but he does not handle all the situations like he should and reviews the situation to see how he could have handled it differently.

#### Strategies Implemented by Mary: Care Receiver

When asked what people should do to help her de-escalate, her advice was to "just be quiet...Let them be left to themselves and they will calm down." Taking "slow deep breaths" is a technique that she uses herself when trying to regain control. Also being left alone helps her to "settle" alone.

**Table 5 - Management Strategies: The Winter Family**

<b>Family Member</b>	<b>Strategy</b>
Bill (Caregiver)	<ul style="list-style-type: none"> <li>▶ Manipulate environment so that aggression triggers are eliminated or reduced (tapes notes to wall, bifold doors in kitchen).</li> <li>▶ Leaving Mary alone (verbally and physically) when potential to act aggressively is present or after aggressive incident.</li> <li>▶ Anticipatory actions to minimize harm and to decrease severity of the physically aggressive incidents (removing all heavy or dangerous objects).</li> <li>▶ Trial and error. Changes approach when it no longer is effective.</li> <li>▶ Very sensitive to "timing" of his approach so that Mary does not escalate.</li> <li>▶ Retrospective account/reflection of what worked and what didn't work.</li> <li>▶ Demonstrates physical affection once Mary is calm as a resolution strategy.</li> </ul>
Mary (Care recipient)	<ul style="list-style-type: none"> <li>▶ Takes slow, deep breaths.</li> <li>▶ Isolates herself in her room after an incident.</li> </ul>

### **Coping Methods**

Coping refers to the actions taken regarding a situation that is identified as a problem (Zimbardo, 1985). Coping strategies are traditionally identified as (a) positive or effective (aimed at solving the problem) or (b) negative or ineffective (aimed at self protection, not addressing the problem) (Zimbardo, 1985). The majority of coping strategies are acquired through experience and role modelling of others (Zimbardo, 1985). The caregiver's in this study (for the most part) displayed positive coping techniques. Coping strategies that have a potential ineffective element will be identified as such.

#### Case Study One: The Summer Family

How Tom and Jane cope with the disease and all it's components may be attributed to the following: 1) an ability to separate the disease from the person, 2) a strong desire to live life, and 3) a strong faith. Together with a great sense of humour, patience, tolerance, and love, this family and especially Jane, cope very well. As Jane states how you cope "depends on your makeup." Jane identifies that the aggressive behaviours are caused by a disease that one has no control over and compares it to an alcoholic who does have choices in controlling the disease that may cause his or her aggressive

behaviour. This, she says, places the behaviours in a different perspective. When asked if the relationship with Tom and all the aggression feels abusive she replied "not once I recognized where it was coming from...putting it in perspective." Both Tom and Jane have an ability, perhaps as a result of their faith, to simply accept things the way they are. Ironically, it is well known that the slow progression of the disease is what caregivers find the toughest, yet both Tom and Jane identify the slow progress as an asset as it gives them time to adjust to each new behaviour. Both Tom and Jane are very much committed to living one day at a time and to it's fullest. As for the future, Jane says "it's an unknown" with Tom adding that they will "deal with it" when it arrives.

Jane has had a challenging life and thinks that it "has helped prepare me for what I am going through now." Although exhausted by the end of each day, "The momentum of a family has also kept me going because...they depend on me so much." She describes the aggression as "painful" and has learned to "focus and endure."

I took Lamaze classes four or five times...You learn to focus not on your pain. You learn that you have to have a focal point...It was not the death on the cross that was Jesus' focus point.



She also advises that one must not expect too much of the individual with AD or you will be let down. One should not be overly sensitive and not expect to be appreciated as "that's life." Jane does not believe that AD and aggression have made her life seem unfair:

It is a way of life at this point. AD cannot destroy the spirit, it might be able to destroy the mind of the person but it cannot destroy the spirit. Even mentally retarded people have a spirit.

Despite how many different times or ways she was asked how she gets through each day she constantly returns to her faith for the answer.

How do I do it? The joy in the Lord is my strength...If it wasn't for my walk with the Lord I couldn't do it.

AD cannot destroy the spirit. Even though there may be deficits in one area, the increase in the spirit area is a binding factor that the world does not experience.

#### Case Study Two: The Winter Family

Despite numerous discussions about how Bill copes with the day to day behaviours and the aggressive behaviours of his wife, Bill stated that it was the love he has for his wife that helps him cope with the challenges that her illness brings. He also identified his flexibility in approach (such as an animated cartoon character) and his trial and error management strategy as assisting him to cope with Mary's

behaviour. Bill's need to re-establish positive contact with Mary after an aggressive incident (offering her a hug, saying something positive to her) is also identified as a coping strategy.

A potential ineffective coping strategy of Bill's is the fact that he does not discuss his wife's aggression with anyone. The children are unaware of Mary's aggressive behaviour, and he has only mentioned it in passing on one occasion to his physician. This coping strategy could be identified as negative as it might serve to protect Bill from getting in touch with his feelings or admitting to others the impact that Mary's illness and behaviour has on him. Bill also has difficulty separating the disease from the person. The following quote clearly captures this:

If I were a professional nurse, my cool would be maintained because it is part of my professional behaviour and this is a stranger...all of the professional stuff flows out automatically. But I am not. I have more than fifty nine years of association with Mary...and this has a weight which is hard to counterbalance. So when she does things that are clearly unjust to me I find it difficult not to become a bit annoyed sometimes.

Bill admits that because of the personal nature of the verbally aggressive behaviours, he finds these most difficult to cope with. He states that "when she gets into a rage, I don't pay much attention to the things she says. I don't expect her to be rational," yet he is always looking for a

logical explanation to her behaviours, expecting her to be functioning at a consistent level. This is a source of his frustration and is clearly seen in the conversation that occurred during one of the interviews when Bill was telling of the incident when Mary put the cups on the floor:

Bill: I have no idea why she would put them on the floor. There must have been some kind of logic in her mind at the time. Wanted to get rid of them perhaps?

Interviewer: Perhaps they were something different to her, not cups.

Bill: No! She knows they were cups. She knows these are things she uses. She has no problem going to get a mug for putting milk in. That is not a problem.

A positive coping technique identified by Bill, aimed at changing his reaction to the problem, is his viewing incidents with a very light-hearted approach.

"I think if you don't take things too seriously it often helps. It is when we think of things so seriously, that we think of nothing else that we are in psychological trouble."

Whether it is denial, or protection of Mary, Bill throughout the entire three months of interviews repeated, "I don't give much thought to it." "They all blend into each other then they disappear from my mind. I take no special pleasure in recalling these things." Is Bill's lack of cooperation in completing the behavioural log and his limited discussion of actual aggressive incidents truly because he forgets them?

Or, is his limited discussion and/or recollection of Mary's aggressive behaviour a consequence of his respect and need to protect her reputation? Perhaps this truly is the case. I saw no evidence that he harboured a grudge with Mary for her behaviour, and in fact I saw exactly the opposite. A man so very in love with his wife.

### **Chapter Summary**

The couples in this study had a large store of individual experiences which predated the aggressive abusive behaviours. Data for this study were collected about the caregiver's present situation, their history, past experiences, and situational factors. The examination of their "local worlds" gave insight and understanding to: 1) The concept of aggression, and 2) the experiences of spousal caregivers caring for partners who because of AD behave aggressively. The insights gained are discussed in detail in Chapter Five.

## CHAPTER FIVE: DISCUSSION OF THE FINDINGS

### Summary

Note: As previously identified, findings must be viewed with caution as the diagnosis of AD is only tentative. Behaviours although identified as being attributable to AD, and not as a result of a pre-morbid personality, may have other organic causes, or, may also be present in those without any illness. The antecedents to the feelings and/or acts of aggression could possibly be identified as triggers for those who are not afflicted with AD. As well, the coping and management strategies of the caregivers may not be unique to caring for spouses with AD. AD is only one explanation for the findings of this study.

This research identified the experience of spouses caring for partner's who because of Alzheimer's disease, behaved aggressively. Specifically the purpose of this study was to answer the following research questions:

1. What are the experiences of spousal caregivers living with a family member who displays aggressive behaviour as a consequence of Alzheimer's disease?
2. To what types of aggressive behaviour is the caregiver exposed?
3. What aggressive behaviours do the community spousal caregivers find most distressful?
4. What techniques do spouses use to manage the aggressive behaviour?
5. How do community spousal caregivers view the help/suggestions/advice they have received from Health Care Professionals regarding the management of aggressive behaviour?

A brief presentation of the main methodological issues of the study, followed by discussion of the research findings is presented in the first section of this chapter. Research

findings are compared and contrasted with existing studies. As identified in Chapter Two, the absence in the literature of a consistent definition of what constitutes aggressive behaviour, makes comparisons across studies difficult. Therefore, as it was relevant, studies with like definitions were critically chosen for comparison. The implications for nursing practice, education, and administration follow the discussion of the findings. Future research considerations conclude the chapter.

#### Statement of the Problem

The number of Canadians affected with Alzheimer's disease and related dementias in 1991 was estimated at 250,000, half of whom live in the community. Demographers anticipate that the number of individuals with Alzheimer's disease and related dementia will double by the year 2021, and triple by the year 2031 (Canadian Study on Health and Aging Working Group, 1991, as reported in Canadian Medical Association Journal, 1994). It is widely accepted that aggressive behaviour with abrupt mood changes may occur during the course of the disease (20% to 86.3% prevalence) presenting major problems for both patients and caregivers.

The types and management of aggressive behaviours in institutional settings is well described in the literature,

however, few studies focus on the community setting. The impact of aggressive behaviours on professional health care providers is also well researched (Chase, 1996; Hagen & Sayers, 1995; Martin, 1995; Ryden et al., 1991; Weinrich et al., 1996); however, research studying the effect of aggressive behaviour on the community spousal caregiver is limited. Of the studies available, the majority are quantitative in nature focussing on prevalence and types of behaviour, and not related to the experience of family caregiver or the interventions used by these community caregivers.

The purpose of this study was to identify and acknowledge the problems encountered by family caregivers living in the community with aggressive abusive care receivers. This portrait of community caregiver's experiences will enrich our understanding of this serious problem, and assist the nursing profession in identifying ways to support and educate this challenged group of caregivers.

#### Conceptual Framework

The conceptual framework which guided this study was derived from theories on aggression aimed at identifying contributing factors to an individual's potential for aggression. The framework was initially developed by Lanza

(1983) and later modified by Ryden (1988) to represent aggression in the cognitively impaired. The internal origins of aggression account for the variables of instinct, physical or chemical influence including the presence of disease, genetic influence, and learned response. The environmental variables of the framework include familial, social, and physical elements as most significant in examining an individual's potential for aggression, and the types of aggressive behaviour displayed. The performance of the conceptual framework, in relation to this study, is discussed on page 270.

### Literature Review

The literature to date on the experiences of family caregivers of the aggressive Alzheimer's relative is lacking in breadth and depth. The majority of research studies and current research trends are quantitative in nature (Bridges-Parlet et al., 1994; Cohen-Mansfield, 1988; Petrie et al., 1982; Malone et al., 1993; Rubins et al., 1987) with a limited number of qualitative studies generated (Hamel et al., 1990; Rubin, Morris, & Berg, 1987; Ryden 1988). These studies quantify the prevalence and types of behaviour and are not related to the experience of family caregivers (as shared by the caregiver) or the interventions used by this group of



community caregivers to manage aggressive outbursts displayed by their loved ones.

Institutional techniques recommended to manage the aggressive behaviour may be very effective, but unrealistic for many spousal caregivers (Ryden, 1988). Beyond the caregiver burden scales, very little is known about the impact aggressive behaviours have on the life of the family caregiver. Treatment approaches to the management of aggression tend to be pharmacological in nature, mainly low dose neuroleptics or anti-psychotics such as haloperidol or thioridazine (Serby, 1989; Whitehouse & Geldmacher, 1994), or, focus on approaches that are specific to the institutional settings. The application of physical restraints, physically distancing oneself from the patient or allowing the patient to "work off" the aggression walking in a secured ward are the more common institutional management approaches to aggressive behaviour in patients (Ryden, 1988; Crisis Prevention Institute, 1995). Providing care to an aggressive individual within the home context places caregivers at emotional and physical risk, and is of significant influence in the caregiver's decision to seek long term placement for the relative (Chenoweth & Spencer, 1986; Eastley & Mian, 1993; Handy et al., 1991; Lam et al., 1991; Shah, 1992). Aggression in the caregiver in response to care recipient's aggression is

also of concern and is reported to occur in 10% (Hamel et al., 1990) to 22% (Ryden, 1988) of caregivers.

Beyond statistics and "quantitative knowing", there is no available data on the techniques used by the family caregiver in managing or coping with aggressive behaviours as they occur. There are no case studies specific to aggression in Alzheimer's disease. Weinrich et al., (1996) identified the need for qualitative studies on "agitation" from the caregiver's perspective. Health care reform is placing more and more previously institutionalized individuals in the community with family caregivers directly responsible for care. Nurses are in the ideal position to understand the experience of family members who are providing care to persons living with AD and exhibiting aggressive behaviour. Moreover, such understanding can serve as a foundation to providing appropriate support and education for these family care providers.

#### Research Design and Data Analysis

The experiences of spouses caring for aggressive family members diagnosed with AD was absent in the literature. Case study was used to research the experiences of two couples; Tom and Jane Summer (Case Study One), and Bill and Mary Winter (Case Study Two). As identified in Chapter Three," Case

studies are a useful way to explore phenomena that have not been rigorously researched (Polit & Hungler, 1991, p. 208). The strength of the Case study is the depth of information possible, providing the researcher with intimate knowledge of his/her participants. Clarifying concepts or gaining insights into relationships previously unidentified are additional advantages to the design. Repeated informal caregiver interviews using an interview schedule (Appendix P) as a guide and "family" visits observations were carried out over a period of three months. Together with field notes; a journal of aggressive behaviour (Tom and Jane) (Note: Specific "logging" or "journaling" of Mary's aggressive behaviour was not completed by Bill, as he felt he had nothing to report); and examination of the caregiver's cognitive functioning, a depth of understanding of this social phenomena was achieved.

Data was analysed using content analysis. Content analysis is an appropriate method for handling qualitative narrative data. Words or themes (such as frustration, giving space) were identified in the data. Narrations supporting the theme (frustration, giving space) were then sought out. The themes were then categorized (such as incidents of aggression, antecedents to aggression, management strategies) in effort to make the analysis "objective and systematic" (Polit & Hungler, 1991, p. 511). In addition, the categories relating to types

of aggression and management techniques originated from the research questions, and data was examined in attempt to find themes relating to these categories. Analysis of the data also occurred during and not separate from the ongoing data collection. Behaviours, observations, and interview findings were examined, and the initial analysis for content occurred. As categories or themes surfaced, gaps or missing information was then sought on the next visit and/or interview. This allowed for clarification of the data so that behaviours and responses became meaningful. Transcriptions, field notes, the journal of aggressive behaviours, and taped interviews were re-examined upon completion of the data collection. As necessary additional categories or regrouping of categories occurred. This "immersion" into the data assisted in the identification of "higher-order" categories, which were examined and reworked as necessary (Burnard, 1991). Attention was also given to the case "as a whole" so that messages were not presented out of context or as pieces not related to the whole. The relationship between the data and the context is an important component of analysis (Sandelowski, 1996).

### **Discussion**

The case study design, which allowed for multiple interviews and site visits over a three month period, produced

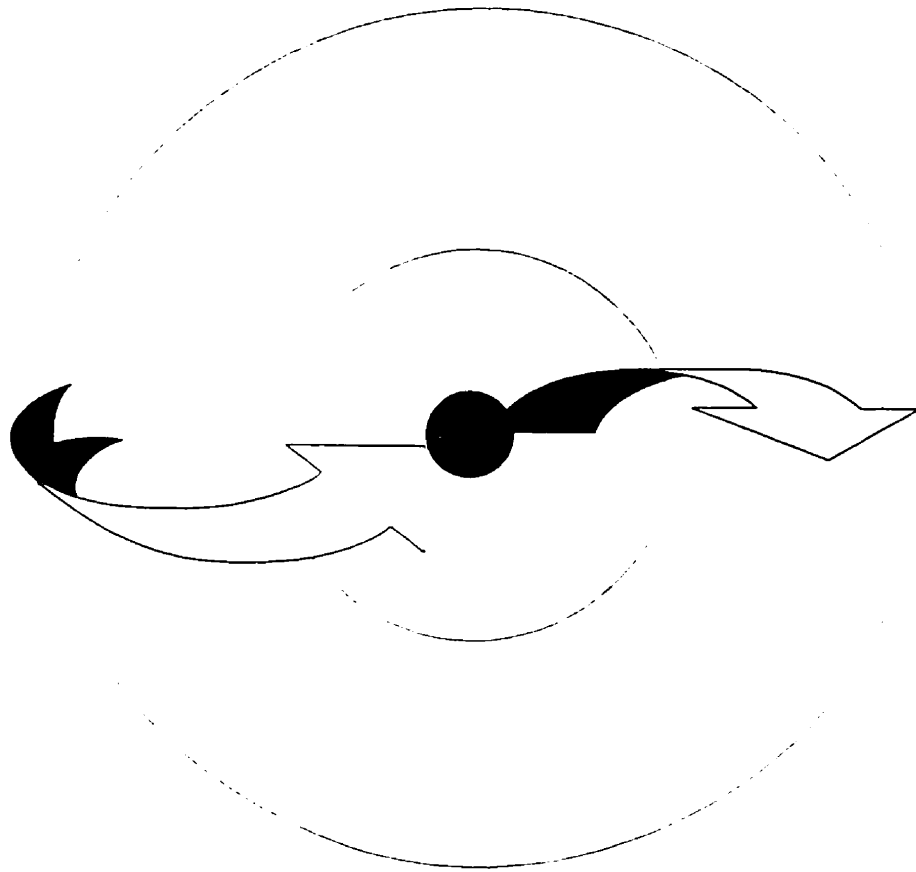
extensive qualitative data. With every interview or visit, data were analysed (content analysis), which together with the interview schedule, were then used in subsequent interviews or visits for the generation of additional data and/or clarification and confirmation of emerging categories and/or themes. Flexibility in the study design allowed for the uniqueness of each case study, and accommodated the differing number of interviews (8 in Case Study One, 6 in Case Study Two) and site visits/observations (5 in Case Study One, 7 in Case Study Two). Combined interviews and site visits totalled 13 for each case study or 26 for the thesis project as a whole. The Summer Family (Case Study One) was very open and able to verbalize their experiences, and a greater number of interviews were required. The Winter Family (Case Study Two) were less willing to disclose, requiring a greater number of visits/observations than interviews. Also, very often the visits/observations concluded as interviews in the Winter Family as Mary would excuse herself from the visit and retire to her bedroom. What became apparent was that you cannot understand aggression and AD without exploring aggression within the context of not only the disease, but framed within the lives or local worlds (Kleiman, 1988) of these individuals and family members. I have chosen to illustrate this using "The Circle of Life" (see Figure 2, p. 220). Aggression is a

behaviour which was at the "core" of this research. Caregivers identified the aggressive behaviours as resulting from the effects of AD on the care recipients. Or, as illustrated, occurring within AD. AD, is situated within the circle of life. Each of us has large stores of unique experiences (experiential knowledge). It is not only the participant's current circumstance, but also the past experiences and situational factors that have implications for the problem being examined. It is this "living" that makes each caregiver unique in how they interpret, understand, manage, and adapt to AD in their spouse. In turn, how the caregiver perceives AD directly impacts how they interpret, understand, manage, and adapt to the resulting aggression. As illustrated, the influence is "circular". The impact of the aggressive behaviours, colors the caregiver's views on AD, which obviously add to their life experiences. These experiences which "season" the caregiver must be understood as they apply to their world in order to appreciate the depths of their ordeal (Polit & Hungler, 1991). The case study approach facilitated such an understanding. The importance of this study is clearly supported in the literature.

Nursing can succeed only when it recognizes that the person is not summarized by the immediate present but is burdened by a lifetime of experienced-recorded not only on the tissues of the body, but on the spirit and mind as well.

Levine, M. 1990, p.197

The dichotomy of the two case studies was significant (age, socioeconomic status, stage of the disease), yet there were striking similarities to both the impact and management of the disease among the spousal caregivers (removing environmental stimuli, giving them space and opportunity to vent, remaining calm).



**Figure 2** - Understanding Aggression & Alzheimer's Disease within the Circle of Life

- Aggression
- Alzheimer's Disease
- Life/Living



### Types and Incidents of Aggressive Behaviour

The caregivers in each case study agreed to record the incidence of aggression on a behaviour log, however, neither carried through. The caregiver in Case Study One (the Summer Family) opted to record behaviours in a journal format, which resulted in much more meaningful data. The journal was maintained for two of the three months that the Summer's were enrolled in the study. Recording in the journal required a great deal of commitment and time, as a result Jane discontinued the journal four weeks before the study concluded. The Case Study Two caregiver (the Winter Family) continually reported that there were no incidents to record, yet with perseverance on my part, he revealed and identified aggressive situations he was experiencing. In both case studies, the aggressive acts were mild in nature. Verbal aggression was reported to occur more frequently than physical aggression which is consistent with the literature (Ryden 1988; Hamel et al., 1990).

As earlier identified (Incidents of Aggression, p. 164) the Summer Family (Case Study One) maintained a journal of aggressive behaviours for two months, or 61 consecutive days of the three month study. They reported 94 incidents of verbal aggression and two incidents of physical aggression in 61 days, averaging 1.5 incidents per day. Ryden (1988)

reported that aggressive behaviour occurred at least daily in 16% and once a week in 31% of dementia patients living in the community. The high incidents of verbal aggression is in keeping with the literature on aggression in the community. Hamel et al., (1990) and Ryden (1988) reported the verbally aggressive behaviours occurred in 50% to 51% of all cases. The verbal aggression consisted of cursing and hostile language directed at the caregiver, another family member, or occurring in general conversation. This type of verbally aggressive behaviour is identified by Hamel et al., (1990) as the most common form of verbal aggression. Contrary to my findings, these researchers identify the incidence of physically aggressive behaviour ranging from 34% to 36% frequency. There were only two incidents of physically aggressive behaviour documented by the Summer Family. Both of the incidents involved the throwing of an object (not directed at an individual). Threatening gestures was identified by Hamel et al., as the most common type of physical aggression. It is important to note that both Hamel et al., (1990) and Ryden (1988) had similar definitions of aggression which were consistent with the definitions of aggression used in this study.

Even though the care receiver in Case Study One (Tom) had a history of moderately severe physically aggressive

behaviours, both Jane and Tom deny any recent occurrence (within the last five years). The two occurrences of physical aggression were not escalations of verbally aggressive incidents, and occurred in and of themselves. The lower incidents of physically aggressive behaviours found in Case Study One, may be attributed to the control that the medication Risperdal has afforded Tom, and/or it may be because he was borderline mildly cognitively impaired. Increased cognitive impairment is reported by Ryden (1988) as being associated with increased incidents of physical aggression. In Case Study One, both the verbally and physically aggressive behaviours occurred in private and in public arenas, with the behaviours much more common in the privacy of the home. The majority of the behaviours occurred in the early evening when the children were home from school. Their presence increased overall stimulation in the home. Of aggressive incidents, 50% are reported as occurring during the evening (Malone et al., 1993).

As identified, trying to obtain specifics related to the occurrence of aggressive behaviours in Case Study Two was difficult. Bill estimated that Mary's aggressive behaviour occurred as seldom as once monthly to as frequently as once daily. Verbally aggressive behaviours were always directed at the caregiver and were of a more personal nature than in Tom

and Jane's situation. Verbally aggressive behaviours were the most frequent. Physically aggressive behaviours were reported as quickly following a verbally aggressive incident if de-escalation did not occur. This continuum of escalation from verbal to physical aggression is consistent with the literature (Beck & Heacock, 1988; Crisis Prevention Institute, 1995; Mace & Rabins, 1981).

Mary had experienced relatively more cognitive decline than Tom. If applying Ryden's (1988) findings that increased physical aggression occurs with increased cognitive impairment, one would expect increased incidents of physically aggressive behaviours. Without the recording of the physical incidents of aggression, we cannot tell if their frequency would be more in keeping with the findings of Hamel et al., (1990) and Ryden (1988). The reported number of physically aggressive behaviours, which consisted mainly of slamming inanimate objects, were greater in Case Study Two than Case Study One. The aggressive behaviours expressed by Mary occurred in the home as she seldom left home. Bill did not identify a time of day during which aggressive behaviours occurred.

In both case studies the aggressive behaviours were reported as lasting less than five minutes. This is consistent with the findings reported in the literature, as

the majority (43%) of aggressive episodes have a duration of one to five minutes (Bridges-Parlet et al., 1994). If a physically aggressive episode followed a verbal incident, as was usually the situation with Mary, the duration of the incident was then increased to a reported 30 minutes. The longest duration of aggressive incidents identified in the literature was five to twenty minutes, which accounted for 32% of aggressive incidents (Bridges-Parlet et al., 1994). There were no accounts of sexually aggressive behaviours reported by spousal caregivers.

#### Antecedents to Aggressive Behaviour

The association of a premorbid personality and acts of verbal and physical aggression identified in the literature (Deutsch et al., 1991; Hamel et al., 1990; Marrant & Ablog, 1983; Ryden 1988; Ware et al., 1990) were only evident to a small degree in the case of Bill and Mary. Mary was described by Bill as "always being somewhat quick to temper," but never verbally or physically aggressive. Both Jane and Bill report that Tom's aggressive behaviour was a dramatic change from his premorbid personality. My insight into the couple's "history" is limited by the horizons of this study/research design. However, a history of difficult relationships between the couple (Hamel, 1990) as a predictor of aggressive behaviour

could not substantiated in this study. In fact, what was most notable with both couples was a love for each other that was grounded in open communication. Reinforcement for the aggressive behaviour as an influencing factor for further aggressive behaviours (Beck & Heacock, 1988) was not evident in either of the case studies. Both care providers (Jane and Bill) withdrew from Tom and Mary after an incident. As a result, the care recipient's were not given any extra attention during this time. The incidents were then forgotten and it was unusual for them to be discussed again.

Perhaps because of the invasion of one's personal space, the administration of care that requires "hands-on" by the caregiver has been frequently identified as the main antecedent to aggressive behaviour (Eastley & Mian, 1993; Deutsch et al., 1991; Ryden et al., 1991; Hamel et al., 1990; Ware et al., 1990). Hands-on care was not pertinent to this study as Tom and Mary were still independent in meeting their personal needs, and therefore was not a predictor of aggression. It is probable that as the disease progresses, both Tom and Mary will require increased care to complete their activities of daily living. Most research has been conducted in institutions where the individual does require hands-on care, and therefore hands-on care is identified as an antecedent to aggressive behaviour. Bill also identified that

Mary was prone to aggressive behaviour when instructions were given that were in direct conflict to what she was doing at the time such as trying to go outside when inappropriately dressed. Researchers have identified that trying to prevent an individual from leaving an area as a predictor of aggression, but whether the prevention was a verbal cue or a physical approach is not identified (Deutsch et al., 1991; Eastley & Mian, 1993; Hamel et al., 1990; Ryden et al., 1991).

Challenging or scolding the individual for his/her inappropriate behaviour was identified as a trigger for aggressive behaviour in both of the care recipients and is also identified in the literature as a source for aggressive behaviour (Beck & Heacock, 1988; Mace & Rabins, 1981). Aggressive behaviour in the care receiver is reported in 11% of cases as a direct response to aggression in someone else, usually the caregiver (Ware et al., 1990). Cognitive deterioration is identified by Ryden (1988) as having a direct relationship to physically aggressive behaviours, and a direct relationship to "disinhibition" (Beck & Heacock). The result is the greater the cognitive deterioration, the greater the physical aggression. Both care recipient's (Tom and Jane) completed the Mini-Mental State Exam (MMSE) for the purpose of this study. Mild impairment on the MMSE is recognized if the individuals score ranges between 26-23, moderate impairment if

the score ranges from 23 to 11 (Folstein, 1985). Scores on the MMSE for Tom and Mary identified them as being borderline mildly (score of 24) to moderately (score of 14) cognitively impaired. It is possible then, that cognitive changes resulting in disinhibition only partly contributed to the displays of aggressive behaviour.

Specifically, the antecedents for aggressive behaviour in this study, as identified by the aggressor themselves, were rooted in feelings of frustration. Frustration with her memory loss was a definite trigger for Mary. Frustration as a result of trying to cope with multiple demands or stimuli was the main trigger for Tom. The word "frustration" is not clearly identified in the literature as an antecedent to aggression, however this may be a matter of semantics. Frustration is defined as being thwarted from achieving one's desires, feeling defeated or disappointed (Webster, 1989). Fear and distress resulting from being uncertain of one's surroundings and what is expected of them is identified in the literature as an antecedent to aggression, as is anxiety due to failed attempts at completing simple tasks (Beck & Heacock, 1988; Rabins, 1981). The antecedents listed in the literature are a result of observational studies and caregiver reports. This may explain why the term "frustration" is not identified as an antecedent, yet both care recipients in this study



consistently describe the internal feelings immediately prior to an aggressive episode as a "build up of frustration."

An inability to recognize their feelings is also identified as a cause for an exaggerated emotional response in this population (Beck & Heacock, 1988; Mace & Rabins, 1981). Both Tom and Mary (care recipients) were able to identify the physical (difficulty breathing, tension in muscles) and emotional (frustration) feelings they experienced which would predispose them to an aggressive episode. The consensus between the study findings and what is reported in the literature is that despite the original "source" of the antecedent, the result is that environmental demands exceed ones functional capacities.

#### Care Recipients Insight into Aggressive Behaviour

The verbal abilities of persons with AD remain intact and even though they may have mild to moderate dementia, they are still, with relative ease, able to tell us about their experiences (Happ, Williams, Strumpf & Burger, 1996; Russell, 1996). Unfortunately, this "experiential world" of individuals with dementia is not researched. As a result we have very little "first hand" information about the dementia experience (Russell, 1996).

A unique aspect of this study was the opportunity to interview the care recipient. Their insight into why they behaved aggressively, and the sensations experienced surrounding their expression of aggression, gave further explanation for their behaviours. Both Mary and Tom consistently identified "frustration" as the antecedent to their aggressive behaviour. Mary identified her frustration as originating from the inability to remember things. This was supported by Bill's assessment that Mary was most prone to aggressive episodes after she had misplaced an item or could not remember what she was doing. Mary denied being unsure of her surroundings which the literature site as antecedents to aggression (Beck & Heacock, 1988; Mace & Rabbins 1981). Mary denied being fearful, but did admit to being distressed with her memory loss and her difficulty in recalling events.

Tom's main source of frustration was over-stimulation. Both Tom and Mary identified the aggression as a build up of "steam" or energy which has to be expressed or vented. They both admitted to feeling this "energy" build up inside them, but often they did not know where it came from. Both individuals identified physical sensations that occur just prior to an aggressive outburst. Mary stated that "it was as if she could not breathe," and Tom "felt everything in his body tightening." Both Mary and Tom admitted to being

surprised at the spontaneity of their aggressive behaviours and wished they could stop their expression.

Both care recipients, Tom and Mary, strongly identified with the need to be alone in order to regain control when feeling frustrated and when recovering from an aggressive episode. The Crisis Prevention Institute (1995) stresses the importance of allowing the aggressor time for "tension reduction" in a quiet location with stimuli to a minimum. Respecting the need for "tension reduction," and not interrupting the individuals "quiet time" is essential for complete de-escalation of the individual to occur (Crisis Prevention Institute, 1995). Tom was able to recognize the feelings of frustration within himself and remove himself from the situation. Mary's ability to recognize her feelings of frustration before actually becoming verbally or physically aggressive was not as keen, although after an aggressive episode she too isolated herself.

Tom felt that Jane managed his episodes with calm collectiveness and identified that Jane's calm approach has on occasion been successful, resulting in immediate de-escalation of his aggression. However, Mary identified that her behaviour at times made her husband angry, which in turn made her angrier. The influence of the caregiver's aggressive behaviour during an aggressive episode by the care recipient

is identified in the literature. Care recipient aggression in response to aggression in another (mainly caregiver) is reported to occur in 11% of care receivers (Ware et al., 1990). The influence of "positive" behaviours in the caregiver is an important management technique. Caregiver aggression and implications related to caregiver aggression is discussed in the following section, Impact of Behaviours.

The care recipient's insights surrounding their aggressive behaviours are significant findings and worthy of further exploration. Sensitivity to their particular experiences will challenge us to tailor individualized approaches specific to the circumstances surrounding their "aggressive experience." Improvement in quality of care for the "patient" may result.

#### Impact of Alzheimer's Disease and Aggressive Behaviours

The impact of behaviours must be understood within the context of individual lives. The physical and mental anguish that Jane experienced because of the multiple motor vehicle accidents can be viewed as "shadows" of her experiences with Tom's aggressive behaviours. The significance of this cannot be dismissed. The pain Jane experienced is identified (by Jane) as a constant reminder of Tom's potential for physical aggression. In the early 1990's when Jane's pain in her back

was at it's worst, so too, was Tom's physically aggressive behaviour. Jane states that as a result, she has an "emotional" association between her back pain and Tom's physical aggression.

For the Winter Family, Bill has chosen not to discuss Mary's aggression with friends/family or their physician. His behaviours aimed at protecting his wife and intervening on her behalf illustrated his need to control situations. The result of this "privacy" is that Bill is becoming emotionally isolated and not able to share his day to day encounters with others. As previously identified, this could be identified as a negative coping strategy aimed at self protection.

The social/relational dimension of the caregiver's life is also affected. Jane was rarely if ever alone. Bill was frequently alone and enjoyed being alone. Yet despite the contrasts, both caregivers (Jane and Bill) identified the toughest part of the disease for them was being "lonely." Cognitive deterioration, the hallmark of AD, caused irrevocable change in Jane's and Bill's partners commonly identified as "loss" of a loved one (Albert, Castillo-Castaneda, Sano, Jacobs, Marder et al., 1996). The disease itself has robbed each of them of their confidant and partner in life. Tom's involvement in parenting and his church activities have been greatly reduced. Responsibilities and

decision making that Tom and Jane once shared as a "couple" are now Jane's responsibility. Jane now chooses carefully what she discusses with Tom and when the discussion will take place. The loss of a "partner" was most significant for Bill. He frequently commented that Mary was his "intellectual mate" and he what he missed the most was their stimulation conversations and debates. As nurses, we must recognize the feelings of loneliness in this group of caregivers. We must exercise caution in assuming that because the caregiver has numerous friends and family, they are not lonely.

For each of the caregivers, the most difficult element of the aggression to deal with was the verbal behaviour, but for very different reasons. Jane found Tom's cursing intolerable and offensive even when it was not directed at her. In a society where swearing is common, Jane was most disturbed by this language. Again, this supports the need to have aggression defined not by observers, but by those who were the subject of the aggressive behaviour.

Mary's aggression consisted more of personal attacks on Bill and as a result she really "hurt Bill" or as Bill stated, it "breaks his heart." Researchers report that verbal aggression, in particular the "personal attacks" filled with angry insults are a major burden for the caregiver (Health & Welfare Canada, 1984; Teri et al., 1988; Ware et al., 1990).

Bill was bewildered by Mary's "attacks" on their marriage and his love for her and wondered why she would say such a thing.

Physically aggressive behaviours are identified by nurses as the most "frustrating" problems they deal with (Hagen & Sayer, 1995). Verbal aggression is identified as more of a concern to family caregivers than it is to nurses (Lukovits & McDaniel, 1992), and certainly for the caregivers in this study, verbally aggressive behaviours were the most distressing. Techniques and supportive intervention aimed at diminishing the impact of physically aggressive behaviours are important. However, of prime importance are techniques and supportive interventions related to the informal community caregivers' management of the verbally aggressive behaviours. These findings once more stress the need to understand aggressive behaviours from the caregiver's experience. Informal caregivers must be asked what behaviours they would identify as aggressive and what behaviours do they find the most difficult, and why.

Aggressive behaviour is said to be poorly tolerated by the caregiver because of the strain, fear and increased hardships (Health and Welfare Canada, 1984; O'Connor et al., 1990; Ware et al., 1990; Shah, 1992). Feelings of strain, fear and hardship, were not clearly identified by either Jane or Bill. Despite Tom's history of physically aggressive

behaviours, Jane only admitted to feeling fear years ago when the physical aggression was at it's peak. The fear she experienced was significant enough to cause a nightmare.

Sadness, and at times frustration, were the more common feelings that these caregivers identified. Perhaps feelings such as sadness or frustration were viewed by the caregiver as socially more acceptable and thus easier to admit to. Jane became frustrated with the constant cursing that has become part of Tom's vocabulary. Bill identified the need to have order and precision in his life. AD has represented loss of order; loss of cognitive precision. Bill became frustrated with the frequent misplacing of items by Mary. Feelings of frustration in this informal group of caregivers is well documented in the literature (Health & Welfare Canada, 1984; Russell, 1996; Teri et al., 1998; Ware et al., 1990). Is caregiver frustration a result of our "inexplicable sense that we are missing some of "their" meaning" (Russell, 1996, p. 1400), or is it "their inability to understand "our" meaning" (Russell, 1996, p. 1400) that is the root source? We know very little about the "experiential world" of those with cognitive deficits (Albert et al., 1996). Research into the world of those with cognitive impairment, as viewed by those afflicted, may provide valuable insight into our understanding of cognitive impairment. Much of which is "assumed" and taken



at face value surrounding the world of dementia would either be confirmed or challenged by the findings. Nurse researchers should be encouraged to take leadership in this area of research.

It was clearly evident that AD and the associated aggressive behaviours were responsible for the increased demands and responsibilities in the lives of Jane and Bill. Perhaps it is "semantics", or that the caregivers both viewed their caregiving role as their responsibility and duty, but neither Jane or Bill would admit (when specifically asked) that the aggressive behaviours were a hardship. Tom and Jane viewed the AD and aggressive behaviours as human "suffering," but not as a hardship. This appears contradictory in nature, but when understood within the frame of reference of their faith, "suffering" is accepted as Jesus suffered. The word "hardship" does not fit with how the Summer Family viewed living with AD and resulting aggression. Bill admitted to being frustrated when Mary misplaced items and slammed doors and drawers and hurt by what she said when verbally aggressive, but denied that his life was a hardship. Bill was exhibited a pained expression while talking about the "horrendous things" Mary would say when verbally aggressive. Yet, Bill continuously stressed that overall, these things really did not bother him but for a moment. Bill's reluctance

in admitting to the impact of Mary's behaviours is not consistent with his non-verbal behaviour. Bill would state that the behaviours did not cause him much "worry or hardship" but sometimes while stating this he would pause, lower his head, put his hand to his forehead and shake his head. After a few moments of silence, he would then sit upright and change the subject. When this behaviour was brought to Bill's attention, he would again state that the behaviours really are not of great concern. This may be associated with the concern over the stigma associated with aggressive behaviours and the belief that it is socially unacceptable to discuss such matters (Hamel et al., 1990; O'Leary et al., 1993). The Summer Family stated that they believed that the aggressive behaviours should not be shared with others. This stresses the importance of protecting and preserving the pride and dignity of the caregiver as nurses try to elicit information of such a sensitive and personal nature.

Jane admitted feeling sorry for herself, as Tom was always the centre of concern. She admitted to feelings of self pity related to what can best be described as the "competition for love" that exists between Jane and Tom. All the attention from physicians and well meaning friends and family members was focussed on Bill and how he was managing. Bill also admitted to "feeling sorry for myself" on occasion,

but identified loneliness (as previously discussed) as the most difficult consequence of Mary's AD. Although not specific to aggression, a general review of informal caregivers of elderly individuals criticized the needs assessments of family caregivers. Ryan and Winslow (1991) reported that significant gaps exist between what the caregiver needs and what the caregiver receives. This gap is attributed to the focus of needs assessments on the care recipient and not the caregiver. These results are similar to earlier findings of Bowers (1987) and Ryden (1988). The support of informal caregivers must be seen as a greater priority and a rightful focus of nursing intervention. Nolan and Grant (1989) also criticize the low priority and commitment that nurses give to informal caregivers. Nolan and Grant (1989) find fault with the education of nurses which does not prepare them for their significant counselling role.

Aggression in the care receiver is known to cause aggressive behaviour in the caregiver. Researchers Hamel et al., (1990) and Ryden (1988) reported that aggression in the care recipient evoked anger and feelings in the care giver which made them want to respond aggressively. Of these caregivers 10% (Hamel et al., 1990) to 22% (Ryden, 1988) admitted to responding to aggression with aggression. The Summer Family deny that this has ever been the situation for

them. However, for the Winter Family, verbally aggressive responses in Bill were acknowledged. It is the personal nature of the attacks and the "unjust accusations" that Bill found the most difficult to deal with and as a result on occasion (more so in the past) often raised his voice and argued with Mary. He identified this behaviour as both inappropriate and most ineffective as a management technique as it often caused Mary to escalate even further. Of interest, is that Mary also identified that her behaviour would on occasion make Bill angry and he would "yell" at her. Mary said that this would cause her to scream at Bill, and then "turn and run" as his behaviour frightened her. Feelings and acts of aggression in the caregiver are positively associated with care receivers who have increased incidents of aggressive behaviour (Ryden, 1988). (Interactions or "fights" as described above by Mary may also be an element of "normal" relationships.) As previously identified, specific numbers of aggressive incidents in Mary were not recorded.

It is believed that self reports of response-aggression may be conservative as the willingness of one to admit that they have responded in a socially unacceptable manner needs to be considered. Therefore, nurses must be very aware that response-aggression does occur. The vulnerable position that the elderly, not to mention cognitively impaired elderly are

in, puts them at risk for abuse by a well meaning but frustrated caregiver. When interviewing caregivers, this subject must be broached. A non-judgemental, empathic, and sensitive approach may create an atmosphere where caregivers feel it is "safe" to admit to the difficulties they are having in controlling their own behaviour. Again, the care recipient, despite having cognitive impairment, may also be able to provide information about management techniques and response-aggression of their caregiver.

Safety for both the caregiver and care recipient is of concern. Supportive interventions and education for the caregiver, specific to coping with and managing the aggressive behaviour can then be implemented. As a result, caregiver's "guilt" may be reduced and their ability to positively care for the individual enhanced, allowing the care receiver to remain safely in his/her own home.

The impact of the aggressive behaviours permeated everything the caregivers did or planned to do. Although the caregivers tried to minimize the changes that AD and aggression had on their lives, the impact was substantial. Each caregiver had experiences external to AD and it was these experiences (Jane's physical and mental anguish from the MVA's and Bill's stoic, private, "matter of fact" nature) that shaped and coloured how they viewed the aggressive behaviours

(Figure 2, p. 220). The impact of AD and aggression, although highlighted separately, cannot be understood in isolation and must be viewed in concert with the caregiver's management of the disease and coping methods.

### Management of Aggressive Behaviours

Management of the aggressive behaviours by Mary and Bill (as illustrated in Tables 4 and 5 p. 198 & 202) reveal their experiential knowledge. The sum of their life experiences and their successful and not so successful management attempts of their spouse's aggressive behaviours, served to mould the management approach they use today. Bill and Mary taking advantage of the slow progression of the disease learned to manage the aggressive behaviours through trial and error. Their experiential knowledge gave them the needed understanding of the significance of specific subtle changes in their spouses' which were indicators of Tom's or Mary's potential to be aggressive. Bill and June were then able to modify their actions in an anticipatory fashion. This often resulted in the potential for aggression in the care recipient to be decreased.

From my perspective as a researcher, I suggest a dance metaphor to help us understand the management strategies of these care providers. Everything they did was carefully

choreographed. Music was carefully chosen so as not to escalate (the environment was manipulated so that the antecedents to the aggressive behaviours were eliminated or reduced), steps were simple so as not to frustrate (days activities were structured with minimal demands placed on the care recipient), space was given to avoid stepping on toes (care recipients were allowed to vent and left alone when the potential to escalate was present), and timing was everything (carefully chosen times for conversation and interaction). Whenever possible, every event was pre-planned so that maximum control over each situation could be maintained. Management was aimed at prevention and protection. Neither caregiver expect that they prevent all aggressive episodes, but they know that they are instrumental in decreasing the incidence and the severity of the aggressive behaviours. Energies directed at modifying the precise interaction between the patient and caregiver is thought to be of greatest value in the effort to decrease the incidents of aggression in this population (Crisis Prevention Institute, 1995; Ware et al., 1990). The ability of caregivers of the cognitively impaired to recognize the diverse behaviours in the care recipient and adapt their approaches so that they are tailored and individualized at that particular moment is noted in the

literature (Albert et al., 1996; Evans, 1996; Hap et al., 1996; Russell, 1996).

Both Jane and Bill were able to identify the antecedents to aggressive behaviour. They could identify what would escalate the behaviour, and strategies/actions effective in de-escalating their partner. Allowing the person to vent, giving them physical space, and not challenging them were the specific management techniques used. In the case of Tom and Jane, the addition of an anti-psychotic medication was instrumental in controlling physically aggressive behaviours. Both caregivers recognized that confronting the individual about their aggressive behaviour typically lead to another aggressive incident. As a result, the majority of the aggressive incidents are accepted as they occur, and not reviewed with the care recipient.

"Retreating, ignoring, or accepting" the behaviour are identified by Hamel et al., (1990) as typical caregiver responses to aggressive behaviour (p. 208). However, Ryden's (1988) argument that a feedback loop exists in which the expression of aggression in the care recipient creates caregiver response-aggression, which then creates further care recipient aggression was also supported in this study. The different responses to aggression is evident in the behaviours of Jane and Bill. Both Jane and Bill have responded to the



aggressive behaviours in their partner as Hamel et al., (1990) reports. Jane is consistent with this approach, but for Bill, ignoring or accepting the behaviours is sometimes difficult. On occasion, (see Impact) in response to Mary's aggression, Bill became frustrated and verbally aggressive (shouting) which in turn resulted in Mary's aggressive behaviours escalating to a physical level. Bill admitted that he was trying to control his own frustration and verbal aggression as a response to Mary's aggression.

It was difficult for both Mary and Bill to specifically identify what management techniques they used. The management techniques had become so common for them that were implemented somewhat reflexively and at times at an almost unconscious level. The number of potential incidents for aggressive behaviour that Mary and Bill thwarted will never be known.

It is well accepted in the "Alzheimer's Community" that difficulties regarding the slow progression of the disease and the constant demands on the caregiver is most taxing for the caregivers. Perhaps in time, Jane and Bill will also identify that the slow progression of the disease presents difficulties. For now however, they report that the slow progression is advantageous to them in managing aggression. Behavioural changes were identified as occurring gradually over time. This "tender mercy", in turn, gave Jane and Bill

time to not only adjust to the behaviours, but to observe antecedents and trial management techniques. Key to the management of the aggressive behaviour was a flexible approach which was specific to the event, the type of aggressive behaviour, and the individual.

While residing in Ontario, Tom and Jane initially attended a variety of support groups (example: Head Injury Support Group, Church Support Group for those who are ill) until they linked up with the Alzheimer's support groups. Tom and Jane attended for five years and denied that there was ever any discussion about aggression. It is Tom and Jane's perspective that if the subject of aggression was brought up it in the support group, it was not given serious consideration by group members and/or the facilitator.

Although the Summer's experiences originated out of their association with the Ontario Alzheimer's Society, I consulted the Director of Manitoba Alzheimer's Society (Personal communication with W. Schettler, February 1998) for information about the Support Groups. W. Schettler (Director) reported that support group facilitators for Manitoba were also caregivers with a variety of experiences surrounding caring for individuals with AD. Facilitators receive training from the Alzheimer's Society of which aggressive behaviour is one component. Complaints specific to attitudes and support

surrounding participants experiences with aggression had not been received. In 1995, as part of my course work, I attended weekly Alzheimer Support Group meetings. I recall a caregiver expressing her frustration with the aggressive behaviours in her husband. The facilitator and the group were very understanding and offered coping strategies including the need to discuss the behaviours with their physician. Ryden (1988) identified that half of those who attend Alzheimer Support groups (54.8%) had care recipients who were aggressive. Barnes et al., (1981) audio taped Alzheimer Support Groups, and during these meeting the topic of aggressive behaviour was discussed.

The Summer's evaluation of the Alzheimer's Support Groups is just one perspective. It is possible that they may have a mis-understanding or a mis-representation of what occurred in the support group meetings. Tom enjoyed the socialization that the groups provided, but felt that because he presented somewhat atypically and was younger, the support groups were of limited value. Jane felt that the events most significant in her life, back and neck pain and a large young family, were not weighted by the group as significant or relevant to her ability to manage and cope with Tom's disease and aggressive behaviour. Research specific to support groups and aggression was not located.

Jane and Tom openly discussed Tom's aggressive behaviour with their physician. They found the physician understanding and knowledgeable about the treatments for AD, but did not expect him to be of help in their management of the behaviours, as he "was not a psychologist." Jane was advised by the physician to challenge or confront Tom when he behaved aggressively. Jane did not act on this recommendation as she felt uncomfortable with this approach, certain it would have only caused Tom to escalate. Fear of escalating the care receiver results in the caregiver's reluctance to impose limitations on unacceptable behaviours which is strongly encouraged for the management of aggressive behaviour (Martin, 1995; National Crisis Prevention Institute, 1995). Ryden (1988) reported that of 183 family caregivers of aggressive relatives with dementia, only 38% reported that the health care professionals suggestions on how to deal with the difficult behaviours. Bill did not talk to his physician about Mary's aggressive behaviours for the same reason that he did not attend support groups. Bill did not believe that an "outsider" would be in a position to counsel him on how to manage his wife's behaviour as they would lack the personal knowledge of who Mary is and what her preferences are. These findings underscore the need for nurses to understand where the caregiver is "coming from." Caregivers have large stores

of experiences which nurses should build upon. Unless an individual has personal experience living with a loved one who displays aggressive behaviour due to AD, they cannot fully understand what the caregiver's life is like. Nursing experience in caring for these individuals provides only limited exposure (eight or twelve hours at a time, with days off), without emotional commitment or personal involvement. When the caregiver is in crisis, there is a need to provide counselling to the caregiver in management techniques, but before we can do this, we must as a profession ensure that we ourselves are properly educated.

#### Coping Methods

The coping techniques used by each caregiver are unique to their individual experiences. One common theme that appears for both Jane and Bill is the unconditional love and commitment they have for their respective spouses. The context of long term marriages and life long commitment is identified as the reason that fewer spousal caregivers institutionalize their cognitively impaired family member than non-spousal family caregivers (Hamel et al., 1990.) Neither of the caregivers in this study were willing to consider the placement of their partner in a Long Term Care Home. Both of the couples had an ability to laugh at some of their

experiences, and identified good times amidst the more difficult times. They relied on who they were and what they believed in to get them through one day at a time. These caregivers were also exceptionally patient and tolerant.

Both Jane and Bill accepted Alzheimer's disease and the aggressive behaviours in their partners without much questioning. For Bill, his acceptance arrived in understanding that as we age our systems will fail. Paramount for Jane and Tom was their unwavering faith in God and his guidance over their lives. They unquestionably accepted not only AD, but the associated aggressive behaviours as part of the life chosen for them, and only requested guidance to get through each day, one day at a time. The demands of the children, even though at times exacting also gave purpose to Jane's life.

Perhaps it was her strong faith, but Jane had a unique ability to separate the disease from the person. Jane did not take Tom's aggressive episodes personally. She identified that it was AD, a disease over which Tom had no control that caused him to behave aggressively. Putting Tom's aggression into "perspective" was a way that Jane coped with these behaviours. This was more difficult for Bill. Bill was not as accepting of Mary's behaviour changes and was often looking for a rational explanation for irrational behaviours. Bill

kept trying to make the insensible, sensible - the irrational, rational. This difficulty in separating behaviour from the individual has been well documented in the literature (Health & Welfare Canada, 1984; Teri et al., 1988; Ware et al., 1990) and was identified as a source of caregiver anger and frustration in this study.

Important to Bill was the need for resolution after Mary had an aggressive incident. After most incidents, Bill approached Mary. They hugged and expressed their fondness/love for each other. Time out or time away from the care recipient as was identified in the institutional literature (Crisis Prevention Institute, 1995) was not an option that was easily exercised by either caregiver. And, even if it was, it was not an option that either Jane or Bill would choose as they accepted that caring for their partners was their role. Even though Tom and Jane were very open and honest with the psychiatrist about the aggressive behaviours and have had discussions with their children, Jane does not confide in anyone else. Bill preferred to keep Mary's behaviours confidential and did not share his concerns or even the incidents of aggressive behaviour with family or with Mary's physician.

The difficulties experienced in recruiting participants for this study (see Reflexion & Reflexivity, p. 261) may be

indicative of people's reluctance to discuss aggressive behaviour in his/her loved one. Even though the participants in this research volunteered, they were both hesitant to discuss the aggressive behaviours in their spouse. Both Jane and Bill expressed beliefs that one should not talk about such behaviours. This reluctance to disclose may be attributed to the social stigma attached to aggressive behaviours (Hamel et al., 1990; Kiyak et al., 1994; O'Leary et al., 1993).

It is safe to conclude that caregiver reports of aggressive abusive behaviours in a family member are grossly under-reported. Research has therefore been completed on a very small number of caregivers who because of their willingness to discuss his/her experiences with aggressive behaviour, may be unique and not representative of this population at large. Caregivers of the aggressive family member must be encouraged to share his/her experiences, fears and concerns. Keeping these behaviours private can only make caregiving more challenging and prevent the caregiver from receiving advice which could be helpful early in the experience of dealing with aggressive behaviours. The potential for the caregiver to become increasingly isolated from friends and family in attempt to "downplay" the aggression is detrimental to both caregiver and care recipient.



### Summary

The findings of the study supported, challenged, and extended the knowledge base of existing research into the experiences of the spousal caregiver of individuals with AD who behave aggressively. For ease of review, these findings presented in a table format (see Tables 6-11, p. 255-260).

This study identified the need to understand the caregiver's "circle of life" (Figure 2, p. 220) as it relates to their definition of aggression and their understanding, management strategies and coping methods. Informal caregivers have a great deal of invaluable, irreplaceable "on the job training." The nursing profession must capitalize on what the caregiver knows and as a "team" (nurse, caregiver **and** care recipient), so that a plan of care can be designed that is individualized to both the caregiver and care receiver. Improved quality of care for these individuals that is specific to their situation and unique to their experiences may result. First, however, nursing must ensure that they receive education directly related to the understanding and management of individuals with AD who behave aggressively.

Of most significance was the discovery that individuals who are mildly to moderately cognitively impaired can tell us about their experiences surrounding their aggressive tendencies. For this to happen, we must make the effort to

ask and listen. The nursing community is encouraged to seize this opportunity for ground breaking research.

**Table 6 - Summary: Types & Incidents of Aggressive Behaviour**

Note: Further information regarding the studies referred to is available in Appendices B, C, D, & E.

<b>Findings</b>	<b>Research Supporting Findings from Study</b>	<b>Research Varying from Study Findings</b>	<b>Extending Current Knowledge</b>	<b>Comments</b>
. VAB the most common	Ryden 1988; Hamel et al., 1990			
. Hostile or accusatory language most common type of VAB	Hamel et al., 1990			
. VAB averaged 1.5 incidents per day	VAB occur at least daily in 16% of the population Ryden, 1988			
. Very few incidents of PAB		34% - 36% of all behaviours are PAB Hamel et al., 1990; Ryden 1988		
. Evening is the most common time of day	Malone et al., 1993			
. Duration of incidents < 5 minutes	Bridges-Parlet et al., 1994			
. VAB can quickly escalate to PAB	Beck & Heacock, 1988; CPI, 1995; Mace & Rabins, 1981			

**KEY:** VAB (Verbally aggressive behaviours)  
PAB (Physically aggressive behaviours)  
CPI (Crisis Prevention Institute)

Table 7 - Summary: Antecedents to Aggressive Behaviour

Findings	Research Supporting Findings from Study	Research Varying from Study Findings	Extending Current Knowledge	Comments*
. Premorbid personality not a predictor		Deutsch et al., 1991; Hamel et al., 1990; Marrant & Abalog, 1983; Ryden, 1988; Ware et al., 1990		
. Difficult relationships not an antecedent		* Hamel et al., 1990		Caregivers denied history of difficult relationships
. Hands-on care the most common antecedent		* Deutsch et al., 1991; Ryden et al., 1991; Hamel et al., 1990; Ware et al., 1990		Care recipients did not require hands-on care
. Being re-directed or prevented from doing something	Deutsch et al., 1991; Eastley & Mian, 1993; Hamel et al., 1990; Ryden et al., 1991			
. Challenging or scolding behaviour in the caregiver	Beck & Heacock, 1988; Mace & Rabins, 1981; Ware et al., 1990			
. Care recipient unable to recognize feelings surrounding episodes		Beck & Heacock, 1988; Mace & Rabins, 1981	Care recipients have insight into aggression and identify frustration as the specific antecedent	

**Table 8 - Summary: Care Recipient's Insight into Aggressive Behaviour**

Findings	Research Supporting Findings from Study	Research Varying from Study Findings	Extending Current Knowledge	Comments*
. Individuals with AD are able to identify antecedents and feelings surrounding aggressive behaviour			There is no existing research into the insights of the cognitively impaired individuals surrounding his/her aggressive experiences	
. Feelings of distress	* Beck & Heacock, 1988; Mace & Rabins, 1981			Semantics: Caregivers use terms such as frustration and suffering
. Strong need to be alone to deescalate after incident	Crisis Prevention Institute, 1995			

**Table 9 - Summary: Impact of Alzheimer's Disease and Aggressive Behaviour**

Findings	Research Supporting Findings from Study	Research Varying from Study Findings	Extending Current Knowledge	Comments*
. Loneliness			Loneliness not specifically identified	
. VAB the toughest to cope with	Health & Welfare Canada, 1984; Teri et al., 1988; Ware et al., 1990			
. Feelings of frustration	Health & Welfare Canada, 1984; Russell, 1996; Teri et al., 1988; Ware et al., 1990			
. Belief that you should not talk about aggression	Hamel et al., 1990; O'Leary et al., 1993;			
. Caregiver aggression in response to aggression in care receiver	Hamel et al., 1990; Ryden 1988			
. Focus of care is on the care recipient; caregiver needs not met by health care professionals	Ryan & Winslow, 1991; Bowers, 1987; Ryden, 1988			

Table 10 - Summary: Management of Aggressive Behaviour

Findings	Research Supporting Findings from Study	Research Varying from Study Findings	Extending Current Knowledge	Comments*
. Caregivers are able to adapt and individualize their approach	Evans 1996; Hap et al., 1996; Russell, 1996		The slow progression of the disease is a "tender mercy" in managing aggressive behaviour allowing adjustment to be made	
. Modifying the interaction the technique of most value	Crisis Prevention Institute, 1995; Ware et al., 1990;		The degree to which this "delicate dance" around the care recipient occurs is not emphasized	
. Retreat, ignore, accept behaviour	Hamel, 1990			
. Support groups not found to be of value				Research specific to the role of support groups in dealing with aggression not located
. Caregiver's reluctance to impose limitations	Martin, 1995; Crisis Prevention Institute, 1995			

Table 11 - Summary: Coping Methods

Findings	Research Supporting Findings from Study	Research Varying from Study Findings	Extending Current Knowledge	Comments*
. Importance of separating the individual from the disease and the difficulty in doing this	* Health & Welfare Canada, 1984; Teri et al., 1988; Ware et al., 1990			Effective coping method
. Time away not a employed as an option		* Crisis Prevention Institute, 1995  (Strongly encouraged)		Although the caregivers recognized this as an option, they were not willing to exercise it
. Not talking about it (Social stigma)	* Hamel et al., 1990; O'Leary et al., 1993			Possibly an ineffective coping method (May lead to isolation)
. Open communication and unconditional love for each other			Not identified in the literature	
. Depends on how aggression "fits" with your belief system			Not identified in the literature	



### **Reflection and Reflexivity**

Many researchers engage in reflection and reflexivity to capitalize on the insights gained by being both researcher and participant, and sharing this wisdom so that others considering similar research may gain from it (Streubert & Carpenter, 1995). Reflection is the review of our experiences. Reflection allows for our documented "feelings" during fieldwork to assist us in our understanding of how our observations and findings may have been affected by the "personal factor" (Rubinstein, 1991). Reflexivity requires "the active analysis and application of our experience to improve our data collection and interpretation" (Rubinstein, 1991, p. 27). As researchers before me, I too have chose to engage in reflection and reflexivity for both personal and professional growth.

After careful deliberation and evaluation of this research process I have concluded that the methodology and research design were appropriate for the purposes of this study. The difficulties in participant recruitment were considerable and necessitated the modification to the original design. Initial recruitment was attempted through the Alzheimer's support groups. Recruiting participants through the Alzheimer's support groups during the summer months when there were limited meetings may account for some of the

difficulty. The research topic was also of an exceptionally personal nature. Increased success with recruitment may result if the researcher actually attends the support group meetings to discuss his/her research proposal. Perhaps a "face to go with a name" instead of an impersonal letter being read by a facilitator would be of benefit. Also, participant recruitment would not necessarily have to be through the Alzheimer's Society. Future considerations should be given to geriatricians offices or perhaps the department of social work. These challenges to recruitment of participants necessitated a change to the recruitment strategy.

A random mail out to spousal caregivers who have been in contact with the Alzheimer's society was completed. The random mail out list was generated by the Alzheimer's Society. With the aid of the computer the names of all spousal caregivers was generated. Unfortunately, the selection could not be narrowed to only those caregivers who attended support groups, or in fact those who were still alive. I received one phone call from a daughter identifying that the mother (caregiver) was deceased, and another phone call from the caregiver whose spouse was also deceased. In both cases the phone calls were very friendly and the family members denied being upset with the oversight. This recruitment strategy yielded greater than 20 phone calls from caregivers whose

partners were aggressive while at home, but are now in long term care. Unfortunately, even this recruitment strategy resulted in only two participants who fit the selection criteria.

The difficulty experienced in having one of the case study participants (Bill) "share his experiences" stresses the importance of establishing a trusting relationship which in time may allow one to disclose their feelings. Caregiver's willingness or ability to clearly recall incidents and types of aggression need to be considered when conducting research of this nature (Polit & Hungler, 1991). Yet at the same time, perhaps because of who Bill is, he simply does not dwell on issues or concerns upon which I might be inclined to focus. According to Bill, his mathematics background has him firmly rooted in cause and effect or quantitative measures. Perhaps that explains his desire to help me understand his situation and the challenges I faced in achieving this. Bill was a proud man, a man of precision and order, who fastidiously managed Mary's diabetes. Did he expect the same from himself in managing her aggressive behaviour, thus the details surrounding the incidents and aggressive behaviours are viewed by him as indicators of failure? When trying to validate my "hunches" with Bill, he would refer to the fact that he knew his wife best and that he would have to "be a buffoon" not to

know how to manage "simple human behaviour." Perhaps for Bill, a study over a longer period of time would yield data with greater depth.

For Tom and Jane their willingness to disclose yielded very rich and meaningful information. The study would have been enhanced if I could have gone on the van rides with Tom and Jane as this was often the scene of aggressive incidents. Because of the number of children and the absence of room in the van this was not possible. Bill and Mary rarely left the house, but again it would have been advantageous to accompany them on any outings they may have embarked upon.

The need for repeated interviews cannot be stressed enough. It was not until after the 10th interaction with the caregivers that I had the most significant interviews. I believe that it took until the 10th interaction for my relationship with the Jane and Bill to develop to the point where they were willing to disclose their more private feelings and experiences. Although I would recommend following the participants over a longer period of time it is not always possible. Ethical issues regarding the impact on participants when under study did arise in this study. Tom and Jane not only appeared to be tiring of the visits/interviews, but also verbally communicated this to me. In fact, Jane's involvement in the study became a source of

frustration for Tom. Invasion of privacy and the time commitment required of Jane to participate in the study were the specific sources of Tom's frustration. Jane had documented three verbally aggressive incidents which are presented in Appendix R (February 8, 25, and March 8). I noticed that the incidents, although still mild in nature, were taking on a more serious tone, and this was confirmed by Jane. Once I became aware of this I concluded the interviews slightly sooner than planned.

The RAS2 daily log sheet, although encouraged, was not used by either participant. Jane opted to keep a written record of the aggressive behaviours she encountered which for the purposes of case study was a more valuable tool. The journal of aggressive behaviours described the circumstances surrounding the behaviours. Antecedents were easily identified, as was Jane's response to the aggressive episodes. The detailed documentation gave context and depth to the aggressive behaviours and surrounding events. Once I read the journal, I had a deeper and more "personal" understanding of the aggressive behaviours to which Jane is exposed. As for the Winter Family, Bill continually reported that he had no aggressive behaviours to record. Despite sharing a few aggressive episodes, there was never an entry made on the log.

### My Journey

It was with excitement and trepidation (given my inexperience) that I embarked on my first "independent" research project. The challenges in trying to recruit participants and the frustration in trying to build trusting relationships were exhausting and at times discouraging. I somewhat expected to learn all about the participants and their lives without ever having to share mine. I was caught off guard when the participants wanted to get to know me on a more personal level than just as a graduate student conducting research. Also, when the participants did begin to share, I found myself losing my "researcher face" and began interacting at a different more empathic level. This was when real personal growth began.

When I found myself being part of the data as when Jane journalled an aggressive episode which surrounded my visits, I felt vulnerable. Initially I was very conscious of my invasion of privacy. As time went on, and as my relationship with the participants was more relaxed, I was less troubled with my invasion of their privacy. I felt more comfortable with interviewing, feeling more like an acquaintance with whom the participants were willingly sharing their stories. I was surprised when after two months of visits (during which Jane began sharing more and more both on and off the record), that

she would remind me that I was invading her privacy. I was not prepared for the impact that I as a researcher could and would have on my participants. In fact, terminating the relationship has been especially hard with Bill and Mary as Bill continues to call, just to "chat." The calls have diminished over time, and I anticipate a natural "end" to our contact shortly.

It is obvious that qualitative research is only as good as the data you generate. Tom and Jane were very candid and surprisingly open and honest when sharing experiences. I was on numerous occasions profoundly moved and saddened by their lives, yet at the same time felt so fortunate to be a brief part of it. Their willingness to share has yielded rich and meaningful data from which we can all learn. However, I was not as successful in achieving this level of trust with Bill and Mary. Although there was value in their participation I was unable to achieve the same depth of understanding of their experiences. So many times I thought of the well known saying "You can lead a horse to water, but you cannot make him drink." My experience of nursing in this field caused me to suspect that there was so much more to this situation, but there was no way I was going to be "let in" any further than Bill would allow. Although I felt a trusting relationship had been established, perhaps this was not the case as the

"quality of that relationship makes or breaks a study" (Brink & Wood, 1990, p. 148). What was most disappointing was the difficulty I experienced in trying to reflect (in the data collection) the variety and intensity of the non-verbal communication of both caregivers and care recipients. There is so much truth to the adage that a picture is worth a thousand words. I tried to capture this in the field notes but much was lost in translation from what I perceived and felt to the written form.

The impact of factors external to the aggressive behaviour must be considered for each individual. Jane's residual pain from the multiple motor vehicle accidents was a significant element which influenced how she views Tom's aggressive behaviour. Even after my frequent visits I still find it overwhelming to think that every pain she has reminds her of Tom's potential for physical aggression. Although I know this level of understanding takes time, I wonder how many times I have been ineffective in my practice because I was myopic and did not see the whole picture. I originally felt very sorry for Jane and Tom. Now, they have my respect and admiration. In spite of feelings of stress and sadness in their lives, Tom and Jane find love and happiness in every day events. The loneliness in Bill was evident, yet he seemed



reconciled and accepting for the most part. I feel strongly that there is more to his story.

I have experienced significant growth scholastically and personally by conducting this study. Without question I have learned about the research process, how so much depends upon other individuals or institutions, and the personal demands that completing the process takes. With renewed appreciation I thank those who conduct research so that our profession can have continuous growth. I have also experienced intangible rewards. Most importantly, this study has once more reminded me why nursing is my chosen profession.

#### **Strengths and Limitations**

As previously identified major limitations of this study relate to (a) the tentative diagnosis of AD, (b) the assumption (based on findings) that the aggressive behaviour is as a result of AD, and, (c) the potential for the aggressive behaviours, their antecedents, the caregivers response, coping, and management strategies to be shared by those who are not cognitively impaired. These limitations were recognized and efforts to account for and/or dismiss other causes for the behaviours (premorbid personality, history, life before AD) were made.

The strengths of case study design allow for the constant return to the participants for verification of information over time and eventual saturation of the data. This method of repeated interviews and observations lends strength, credibility and trustworthiness to the study (Brink & Wood, 1990; Streubert & Carpenter, 1995). In Case Study research, generalizability in the statistical sense is not of primary concern. The inability to replicate the study, is however, a weakness in this design. The relationship between the caregivers and the investigator is a significant component of this design and another individual cannot reproduce the relationship. The difficulties experienced in obtaining "thick data" from Bill also affects the accuracy of the findings as they relate to that specific case. Ideally, following the participants over a longer period of time would give further strength to the study. One must also be cautious of a sample bias when recruiting caregivers from support groups.

### **Conceptual Framework**

The conceptual framework underlying this study (A Theoretical Model for Aggression, Ryden, 1988) offered direction to the research. The internal and environmental origins of aggression appropriately categorized the

antecedents to the expression of aggressive behaviour. Tables 12 and 13 identify the elements specific to the internal and environmental origins of aggression that supported the framework. The presence of the feed-back loop, identifying aggression as a response to aggression, is an important component of the framework as both caregivers and care receivers identified response-aggression. The definitions of verbal, physical, and sexual aggression were only used as guides as caregivers themselves were encouraged to define aggressive behaviour. The behaviours the caregivers identified did fit easily into Ryden's categories (Table 14, p. 275) with the majority of the aggressive behaviours being verbal in nature.

This study identified how "connected" verbally and physically aggressive behaviours are. Verbal aggression can quickly escalate into physical aggression, and one assumes that physically aggressive behaviours may de-escalate to verbal aggression before the incident is completely resolved. Also, aggression is not an independent entity. Both the origins and manifestations of aggression are all situated within the life experiences of the individual predating the cognitive impairment. Ryden's Theoretical Model for Aggression in the Cognitively Impaired (Appendix A) was a useful framework for the generating and categorizing of data.

The model is a sound framework and should be used in further studies; however, it could be strengthened by addressing the above findings. Figure 3 (p. 276) illustrates the "adapted" version of Ryden's Theoretical Model for Aggression in the Cognitively Impaired (Appendix A) based on the findings of this study. Changes/additions to the model include situating both the origins and manifestations of aggression within the "circle of life experience," because this contextual element the framework was was not clearly identified. The origins of aggression, specifically the interaction with the environment are from the individuals "life experiences." However, the larger picture, that being the variety of life's experiences impact on certain origins of aggression, the types of aggression expressed and their targets. The placement of verbal, physical, and sexual aggression in a circle better identifies how one aggressive behaviour can escalate or de-escalate to another type of behaviour, challenging the impression that aggressive behaviours are "singular" in their expression.

**Table 12 - Internal Origins of Aggression (Identified in Study)**

Internal Origin	Summer Family (Tom)	Winter Family (Mary)
Instinct	Instinct may be "incorrect" if cognitive impairment predisposes a person to misinterpret their environment.	Instinct may be "incorrect" if cognitive impairment predisposes a person to misinterpret their environment.
Physical/Chemical (restraints)	Cause of AD not clearly understood, ? chemical ?  Prescribed anti-psychotics for aggressive behaviour.  Became aggressive if prevented from doing something.	Cause of AD not clearly understood, ? chemical ?  Became aggressive if prevented from doing something.
Genetic Components	Tentative diagnosis of AD.  Family history of AD.	Tentative diagnosis of AD.  Advanced age is a predisposition (Mary) was in her 80's.
Learned Responses	Not clearly identified, although aggressive behaviour may remove stimuli that are problematic to Tom.	Identified as being impatient and argumentative in her younger years.  Aggressive behaviour may remove stimuli that are problematic to Mary.

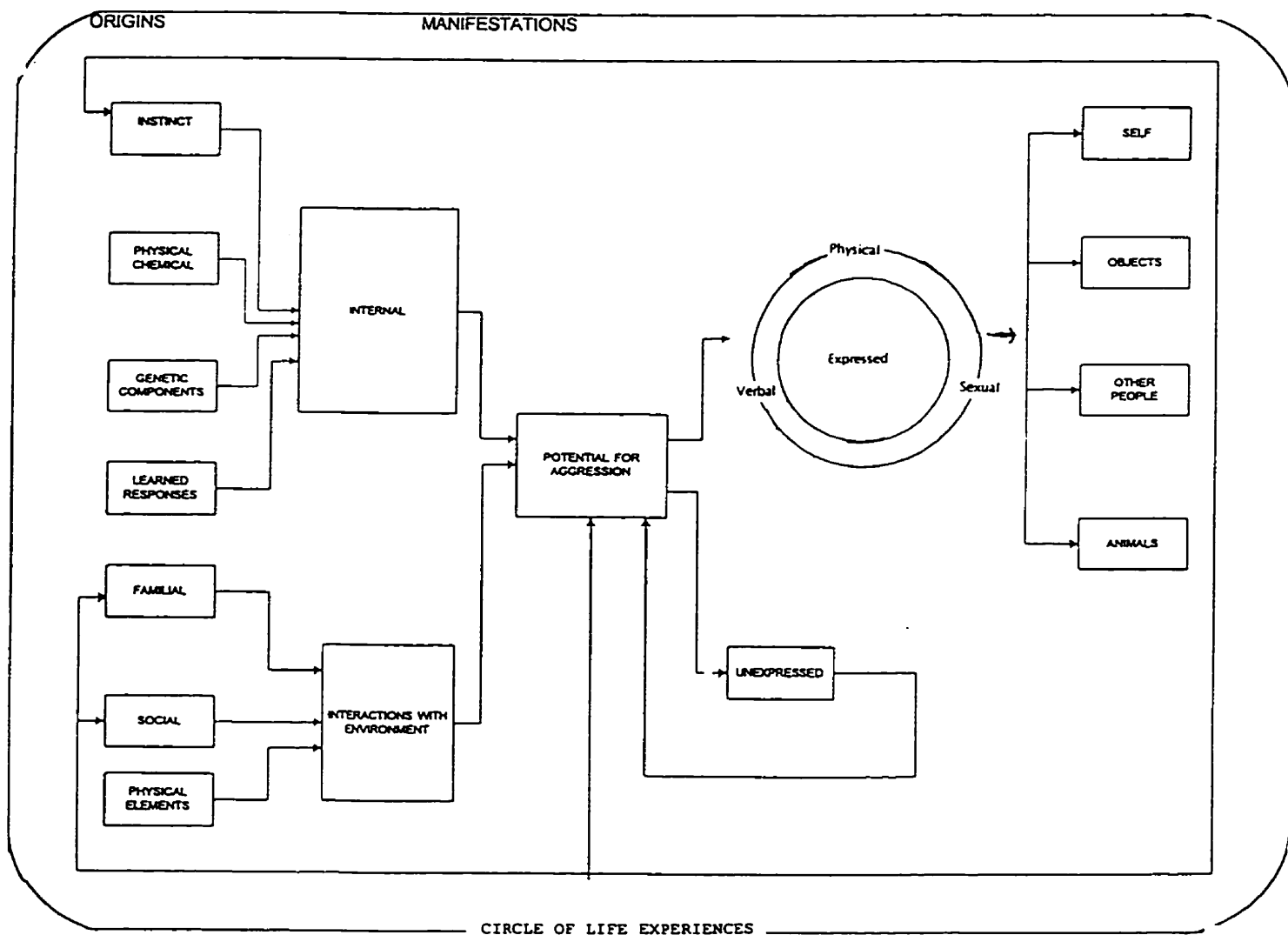
**Table 13 - Environmental Origins of Aggression  
(Identified in the Study)**

<b>Environmental Origins</b>	<b>Summer Family (Tom)</b>	<b>Winter Family (Mary)</b>
Familial	Mother had AD, and did on occasion for a short period display aggressive behaviour.	None identified.
Social	Social elements were the most significant antecedents to aggressive behaviour and are best summed up as environmental demands exceeding their capacity to manage (see Antecedents, p. 225).	Social elements were the most significant antecedents to aggressive behaviour and are best summed up as environmental demands exceeding their capacity to manage (see Antecedents, p. 225).
Physical Elements	Aggressive episodes are most likely to occur during the evening (increased stimulation) or while driving in the van (no where to escape).	None identified.

Table 14 - Categorizing Aggression Based on Definition

Categories of Aggression as Identified by Keast	Ryden's Examples (not exclusive)	Keast's Findings Based on Caregivers Definition
<b>PHYSICAL AGGRESSION</b>		
Mild:	Threatening gestures Throwing objects Damaging property	Throwing objects
Moderate:	Pushing/shoving Scratching	Pushing/shoving
Severe:	Punching Tackling Using a gun/knife	None identified
<b>VERBAL AGGRESSION</b>		
Mild:	Cursing (Directed at person) Name Calling Hostile/accusatory language Vulgar Language	Cursing (Directed at person and indiscriminately) Hostile/accusatory language
Moderate:	Verbal Threats	None identified
Severe:	None identified	None identified

Figure 3: Adapted Theoretical Model for Aggression in the Cognitively Impaired (Ryden 1988).





## **Implications and Recommendations**

### Nursing Practice

This study has practice implications for nurses working in the community and in the institutional setting who provide care to individuals with AD who exhibit aggression. The skill and experience of the spouse in identifying antecedents to aggressive behaviours and the management of aggressive behaviour in their partners needs to be acknowledged. The caregiver may initially be reluctant to share their experiences or be unable to identify the triggers or management techniques they have acquired. An environment of trust and support must be established. Active nonjudgemental listening to the caregiver and encouragement for their input into both the care and evaluation of care will serve to create this environment. Obtaining "knowledge about each individual requires good communication skills, with emphasis on attentive listening and careful observation of body language (Happ et al., 1996, p. 9)." Collaboration with the spouse, and his/her involvement in the care plan will initiate patient care that is truly personalized.

Capitalizing on the moments of relative lucid and coherent thought in the individual with AD is encouraged. The insight of the care recipients in this study not only helped me to understand what they were feeling but also provided

"insider" information regarding both the preventative and management techniques that are effective in the management of aggressive behaviour. This area of research remains undeveloped. Insights into the world of the cognitively impaired aggressive individual could assist us in the tailoring of care to this population, improving the quality of care provided.

An individualized approach challenges us to go beyond the narrow idea of dementia as a contraction of life to a new and more complex vision of a unique and creative world of those persons living with dementia.

Russell, 1996, p. 1401.

It is the responsibility of nurses to obtain this information so that the care, safety, and welfare of patient, family, and nurse are maximized.

Clearly caregiver experiences have significant impact on how they perceive, interpret, manage, and cope. The disease and the accompanying behaviours cannot be narrowly interpreted as the most significant events that are affecting the caregiver. In order for nurses to be effective in their support efforts, simply communicating an understanding of the difficulties with which the caregiver lives is not enough. Interventions that take in all elements of the experience will be much more effective in helping the caregiver manage and

cope. Specifically, when seeking information from the spousal caregivers, priority should be given to the following:

- . How does AD and aggression fit in with the overall belief system of the caregiver?
- . What behaviours does the caregiver identify as aggressive? Which behaviours are the most difficult to manage and why?
- . Can the caregiver identify the antecedents to aggression?
- . What experiences in the caregiver's life have helped prepare them in the management and coping of these aggressive behaviours? What experiences make this more difficult for them?
- . What management strategies have been implemented? What succeeded or failed? Why?
- . Who has the caregiver talked to about the aggressive behaviours? Were they of help?
- . Of "everything" they have been through, what has been the most difficult?

The caregivers in this study were exceptional individuals with established coping skills that were for the most part, effective. If and when coping skills become ineffective or are no longer adequate, it is the nurse's role to help restore and reinforce existing skills and/or teach different coping skills. This cannot be accomplished if we have not arrived at a good understanding of how caregivers have previously managed.

Preventative and management techniques specific to aggressive behaviours in those who are still living in the community have been identified (modifying interactions to control antecedents, allowing the individual to vent, providing a place for the care recipient to retreat to after an incident, and respecting that space). Fostering an environment where it is safe for the care recipient to verbally vent their frustration is important. The community nurse can assist the family in creating such a place. This environment can be created by providing the care recipient with their own room, or if not possible, a specific place in the house (away from the "main" area) where the care recipient has their own chair and some personal possessions. The care recipients strongly identified the need to "let off steam." Their need to withdraw after an incident must also be respected.

#### Nursing Education

This study revealed the importance of including both the caregiver and the cognitively impaired individual in their plan of care. Educators are in a role to ensure that students are made aware of the breadth of experiential knowledge that both caregiver and the cognitively impaired patient can provide. The caregiver may possess skills that are more

effective than the health care professional in managing aggressive behaviour.

The cognitively impaired individual is an untapped resource and students should be directed to interact with care recipients. The insight that can be gained from understanding aggression from the view point of the aggressor is important. Educational programs need to incorporate study of the aggressive individual. Specifically, educational sessions need to ensure an understanding of the antecedents to aggression, preventative techniques and management of aggression. Understanding of the counselling role of nurses and commitment to caregiver education was identified as a weakness in the literature. Nurses need to ensure that care is not only directed to the "obvious patient."

Implications for inservice education include the need to ensure that all members of the health care team are educated and trained in aggressive/abusive crisis management. A consistently applied approach to the care of individuals with AD who behave aggressively is in everyone's best interest. "Refresher" classes are also required so that skills and "energies" are rejuvenated.

### Nursing Administration

Although the focus of this study was on individuals residing in the community, administrators must commit to and foster controlled hospital/care home environments for the aggressive individual with AD. The role of increased stimulation as an antecedent to aggression is significant. So too is the need for quiet spaces that the patient can retreat to for de-escalation. Administrators must ensure that the employees of these areas are also educated in all aspects of aggressive behaviour, so employees can understand aggression, identify antecedents, prevent aggressive behaviour, and when not possible manage the aggressive incident. "Training" in the care of the aggressive individual would be of benefit (care, safety, welfare, and security) to both patient and care provider.

### Future Research

Absent in the literature is the experiences of the community spousal caregiver as they manage and cope with the aggressive behaviours in their spouse suffering from AD. Through case study, this research painted a portrait of the lives of two distinct caregivers. The study findings have implications for future nursing research, specifically:

- . Additional research is required with more caregivers to capture range and diversity in the caregiving experience. Are the experiences of the participants in the study unique or generic? Case study does provide for an in-depth examination of the experience of these individuals, but other methods such as survey research, with larger samples would provide additional understanding.
- . The care recipients' in this study exhibited mild to moderate cognitive impairment, yet were clearly able to communicate their feelings and experiences surrounding their aggressive behaviour. AD and aggressive behaviour must be studied from the care recipients perspective. The insights gained could significantly change how we perceive their world.

Accepting that there are diversities in the dementia experience and that the meaning of these experiences is uniquely individual, and perhaps creative, demands that we begin to embrace research methods that are sensitive to the personal and particular experiences of persons with dementia.

Russell, 1996, p. 1401.

Qualitative research methods including observation **and** interview of the individual with AD can provide valuable

information about their subjective experiences (Russell, 1996).

- . A longitudinal study identifying the changes and the impact of these changes over time would help to identify factors that are most significant in the progression of aggressive behaviours over time. The literature identifies aggressive behaviour as a cause for caregivers to seek long term placement for the care recipient. Neither of the caregivers in this study considered placing the care recipient in long term placement. In time, would this in fact be the case?
- . Hands on care is identified as the major antecedent to aggression in those individuals living in institutions. Is it advancing AD that causes the increase in aggressive behaviour or is it the actual hands on care? Does hands on care have the same significance for the individuals living in the community? Is the impact on the spousal caregiver the same?
- . Bill admitted to mild verbal aggression in response to Mary's aggressive episodes. Jane denied feeling that way. Is the difference based on gender? Are male



caregivers more likely to experience and/or admit to their own aggressive behaviours?

- . The random mail out in search of participants yielded 20 inquiries into the study by caregivers who did not fit the criteria because their partners were now in institutions. What is the caregiver's experience of institutionalized partners who display aggressive behaviour?

### **Conclusion**

The purpose of this study was to come to understand the experiences of spouses caring for aggressive family members diagnosed with Alzheimer's disease. The case study design has provided nursing with an improved understanding of a complex and challenging experience. Serendipitous to the purpose of this study was the insight that the cognitively impaired have about his/her expression of aggression. The cognitively impaired have an "experiential world" of which little, if anything is known. Insights about their experience could assist in the improvement of quality of care.

The implications for nursing practice, education and administration were identified. Specifically, the need for further research must be stressed. The future of health care places more and more previously institutionalized individuals

in the community with family caregivers directly responsible for care. Nursing is in the ideal position to positively impact those who are affected by this trend.

Ultimately, decisions for nursing intervention must be based on the unique behaviour of the individual...It is the task of nursing to recognize and value the wondrous variety of all mankind while offering ministrations that conserve the unique and special integrity (wholeness) of every man.

M. Levine, 1966, as reported  
in Happ et al., 1996, p. 7

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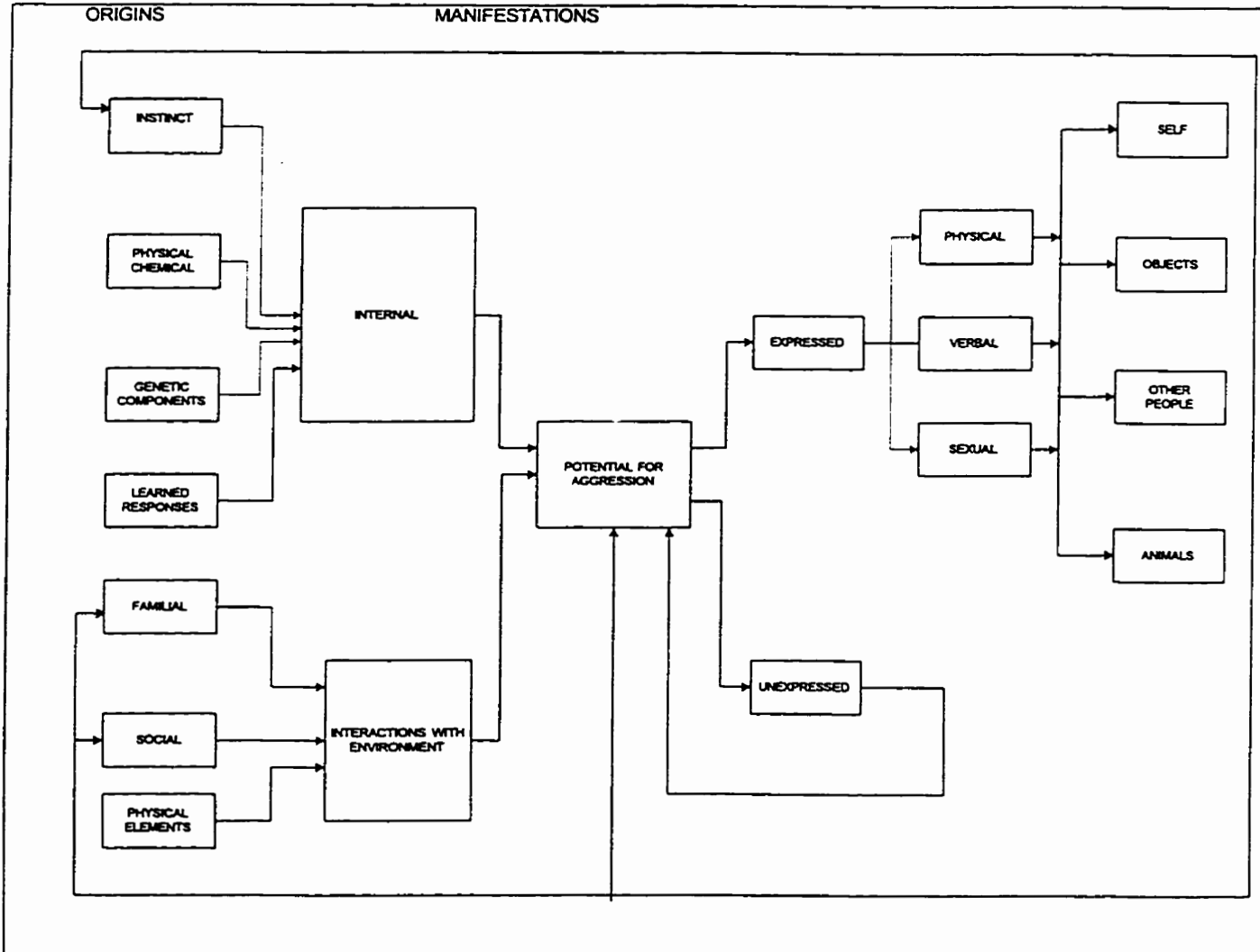
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## Appendix A A Theoretical Model for Aggression

Source: Ryden, M. (1988). Aggressive behaviour in persons with dementia who live in the community. Alzheimer Disease and Associated Disorders, 2(4), 342-355.



## Appendix B Definition of Aggression

For the purposes of this study aggressive behaviour was defined by the caregiver. For the initiation of data collection and early discussions, the following examples of aggressive behaviours were provided. Caregivers had the final say in identifying and defining aggressive behaviour and were free to disagree with any example offered.

### Physical aggression:

Pushing/shoving	Pulling hair
Hitting/punching	Elbowing
Pinching/squeezing	Threatening gestures
Slapping	Brandishing a weapon
Scratching	Using a weapon
Biting	Throwing an object
Spitting	Striking a person with an object
Tackling	Damaging property

### Verbal Aggression:

Cursing, directed at person  
Name calling  
Verbal threats  
Hostile, accusatory language

### Sexual Aggression

Note that these behaviours are aggressive only if they are against the expressed will and/or despite the resistance of the other person.

Hugging  
Kissing  
Touching body parts  
Intercourse  
Making obscene gestures

### **What is NOT aggressive behaviour**

Although these examples are used to guide the caregiver in identifying what may not be aggressive behaviour, the caregiver has the right to disagree and include any of these behaviour.

Noisiness, screaming, yelling, crying out. For example, "Help me!" Verbal aggression must be an expression of anger toward someone.

Spitting out food is not aggressive if it communicates, "I don't like this." or, "I don't want anymore." Spitting is aggressive only if it communicates that the person is angry with another individual.

If property is damaged because the person is awkward or clumsy, this is not aggressive behaviour. Property damage is only aggressive if it is related to an angry outburst.

Source: Muriel B. Ryden PhD, RN  
Director, Research Centre for Long Term Care  
of the Elderly  
University of Minnesota  
Minneapolis, MN

Appendix C

AGGRESSION IN INSTITUTIONAL SETTINGS				
AUTHOR/YEAR	CONCEPT	SAMPLE	METHOD	FINDINGS
1. Petrie, Lawson & Hollendar 1982	Aggressive Behaviour	Psychogeriatric inpatient unit N = 22	<ul style="list-style-type: none"> <li>All incidents of violence anecdotal or recorded included.</li> <li>Chi-square statistics used to compare groups.</li> </ul>	<ul style="list-style-type: none"> <li>62% of admissions involved aggressive behaviour.</li> <li>Aggressive acts (without a weapon) were more common in those with some form of cognitive impairment.</li> </ul>
2. Mesnikoff & Wilder 1983	Acting out Behaviour Antisocial Behaviour	Adults living in Adult homes (24 hr care) in NY state N = 1900 35% > 65 yrs	<ul style="list-style-type: none"> <li>Client assessment forms used to categorize behaviours which were identified as having face validity and strongly related statistically.</li> <li>No further information provided.</li> </ul>	<ul style="list-style-type: none"> <li>5-6% aged 65 and older displayed acting out behaviour.</li> <li>2% aged 65 and older displayed antisocial behaviour.</li> </ul>
3. Cohen-Mansfield & Kerin 1986 as cited in Ryden 1991	Agitated Behaviours	Nursing home residents N = 107		<ul style="list-style-type: none"> <li>87% exhibited one or more agitated behaviours weekly.</li> </ul>

### AGGRESSION IN INSTITUTIONAL SETTINGS

AUTHOR/YEAR	CONCEPT	SAMPLE	METHOD	FINDINGS
4. Cohen-Mansfield 1988	Agitated behaviours	6 randomly selected units with a 550 bed nursing home  N = 165	<ul style="list-style-type: none"> <li>• Brief Cognitive Rating Scale.</li> <li>• Cohen-Mansfield Agitation Inventory (validity and reliability not reported for either instrument).</li> <li>• Subjects rated by day charge nurse for two weeks.</li> </ul>	<ul style="list-style-type: none"> <li>• Cognitive impaired have higher frequency of agitated behaviours compared to cognitively intact (Multivariate analysis of variance).</li> <li>• Agitated cognitively impaired exhibit more agitated behaviours than agitated cognitively intact (T tests).</li> </ul>
5. Malone, Thompson & Goodwin 1993	Aggressive Behaviour	350 bed nursing home including a 60 bed AD unit  All incident reports of aggressive behaviour completed in 1 year N = 94	<ul style="list-style-type: none"> <li>• Retrospective review.</li> </ul>	<ul style="list-style-type: none"> <li>• 27% aggressive behaviours per resident per year.</li> <li>• 48% of incidents occurred in the AD unit of which 6 residents accounted for 44% of all incidents.</li> <li>• hitting most common 57.4% of incidents.</li> <li>• 50% of aggressive behaviours occurred during evening, 46.7% during day, 3.3% during night.</li> </ul>

### AGGRESSION IN INSTITUTIONAL SETTINGS

AUTHOR/YEAR	CONCEPT	SAMPLE	METHOD	FINDINGS
6. Bridges-Parlet, Knopman & Thompson 1994	PAB	Residents in 2 nursing homes  11 from AD unit 9 from general unit  N = 20  Patients identified as most aggressive	<ul style="list-style-type: none"> <li>• Direct Observation for 2 hrs per day for 4 days in 1 week.</li> <li>• RAS2.</li> <li>• Portable bar code readers (to measure incidents and duration).</li> <li>• MMSE.</li> </ul>	<ul style="list-style-type: none"> <li>• 65% of patients = PAB of which 82% of incidents were directed at staff during hands on care.</li> <li>• Duration of incidents:               <ul style="list-style-type: none"> <li>1-5 minutes 43%</li> <li>5-20 minutes 32%</li> <li>&lt; 1 minute 25%.</li> </ul> </li> </ul>

Appendix D

AUTHOR/YEAR	CONCEPT	SAMPLE	METHOD	FINDINGS
1. Rabins, Mace, & Lucas 1982	Troublesome Behaviours Impact of dementia on the family	Individuals diagnosed with dementia 52 living in community, 3 in institutions N = 55	52 question structured interview examining patient behaviours and problems the caregivers experience.	<ul style="list-style-type: none"> <li>• Catastrophic reactions reported by 87% of families of this 89% identified it as a problem.</li> <li>• Demanding critical behaviours reported by 71% of families, 73% reported as a problem.</li> <li>• Serious problem behaviours as identified by families were physical violence identified as occurring in 42% of families and hitting identified by 29% of families.</li> <li>• 42 of 52 caregivers identified feeling angry, sad, depressed or tired most of the time.</li> </ul>



## AGGRESSIVE BEHAVIOUR IN THE COMMUNITY

AUTHOR/YEAR	CONCEPT	SAMPLE	METHOD	FINDINGS
2. Ryden 1988	Aggressive Behaviours	Sample recruited from Alzheimer Association and dementia clinics  N = 183	<ul style="list-style-type: none"> <li>• RAS 1 (test-retest reliability .86).</li> <li>• Family members surveyed by mail.</li> <li>• Cognitive impairment rated by family members</li> </ul>	<ul style="list-style-type: none"> <li>• Aggressive behaviour present in 65 % of sample, occurring weekly in 31% &amp; daily in 16%.</li> <li>• VAB most prevalent accounting for 50% of occurrences, PAB 46%, SAB 18%.</li> <li>• SAB more common in men (t test).</li> <li>• Aggressive behaviour related to degree of cognitive impairment.</li> <li>• Prior aggression a predictor of aggression (analysis of variance).</li> <li>• Aggression by caregivers positively related to higher RAS scores in care recipients (analysis of variance).</li> <li>• Only 38.3% of caregivers reported advice from health care professionals helpful.</li> </ul>

### AGGRESSIVE BEHAVIOUR IN THE COMMUNITY

AUTHOR/YEAR	CONCEPT	SAMPLE	METHOD	FINDINGS
3. Rubin, Morris & Berg 1987	Passive, agitated, self centred, and suspicious behaviours	Subjects with mild dementia of AD type N = 44 Control subjects N = 55	<ul style="list-style-type: none"> <li>• Longitudinal study (50 months).</li> <li>• Evaluations every 15-18 months involving 2 hr structured interview with patient and then spouse.</li> <li>• Clinical Dementia Rating Scale.</li> <li>• Blessed Dementia Rating Scale.</li> <li>• Factor analysis used to identify the four behaviours examined.</li> </ul>	<ul style="list-style-type: none"> <li>• 24 of the 44 dementia subjects completed study:               <ul style="list-style-type: none"> <li>- 17 progressed from mild to severe dementia.</li> <li>- agitated behaviours increased from 25% upon entry to 67%.</li> </ul> </li> <li>• 46 of the 58 control group subjects completed the study               <ul style="list-style-type: none"> <li>- 45 remained asymptomatic, one developed questionable dementia</li> <li>- agitated behaviours increased from 4% upon entry to 9%.</li> </ul> </li> </ul>
4. Hamel, Pushkar, Gold et al. 1990	Aggressive Behaviour Caregiver Reaction	Community dementia patients N = 213	<ul style="list-style-type: none"> <li>• Hierarchic Dementia Scale (interrater reliability .89).</li> <li>• Standardized interviews in caregivers homes.</li> <li>• RAS 1</li> <li>• Multiple regression and discriminate function analysis.</li> </ul>	<ul style="list-style-type: none"> <li>• Aggressive behaviour present in 57.2% of subjects, VAB 51%, PAB 34.1%, SAB 7.2%.</li> <li>• VAB occurred daily in 10.6% of subjects.</li> <li>• 10.1% of caregivers report feeling angry but not responding angrily.</li> <li>• 10.6% caregivers admit to retro-aggression.</li> <li>• Aggression did not significantly predict caregiver burden.</li> <li>• Premorbid personality and history of difficult caregiver/care receiver relationships predictors of aggression.</li> </ul>

### AGGRESSIVE BEHAVIOUR IN THE COMMUNITY

AUTHOR/YEAR	CONCEPT	SAMPLE	METHOD	FINDINGS
5. Ware, Fairburn & Hope 1990	Aggressive Behaviour	Subjects with dementia known to be aggressive living in the community  N = 37	<ul style="list-style-type: none"> <li>• MMSE.</li> <li>• Interviews with caregivers.</li> <li>• Present Behavioural Examination (reliability established as high).</li> </ul>	<ul style="list-style-type: none"> <li>• VAB present in 11% of subjects, PAB (mild) 46%, PAB (severe) 43%.</li> <li>• 25 of the subjects became VAB &amp; PAB in response to intimate care.</li> <li>• Aggressive behaviour in 11% of subjects was in response to aggression in others (mainly caregivers).</li> <li>• 39% of behaviour was viewed as quite different from premorbid behaviour, 58% seen as an exaggeration of premorbid personality.</li> </ul>
6. O'Leary, Haley & Paul 1993	Behavioural Problems - adaptive or ineffective	Subjects recruited from AD clinics > 65 years of age, living in the community	<ul style="list-style-type: none"> <li>• Memory and Behaviour Problem Checklist (reliability/validity not reported).</li> <li>• MMSE .</li> <li>• Behavioural-log completed by caregivers for 48 consecutive hours (content validity reported as optimised).</li> </ul>	<ul style="list-style-type: none"> <li>• Problem behaviours filled 44% of care recipients waking time.</li> <li>• Problem behaviours occurred most frequently between 1600 and 2000 hours.</li> <li>• 5% of waking time was spent in acts that were harmful to self or others.</li> </ul>

**AGGRESSIVE BEHAVIOUR IN THE COMMUNITY**

<b>AUTHOR/YEAR</b>	<b>CONCEPT</b>	<b>SAMPLE</b>	<b>METHOD</b>	<b>FINDINGS</b>
7. Deutsch, Bylsma, Rovner et al. 1991	Psychosis Physical Aggression	Community patients with probable AD who attended a research clinic every 6 months for a maximum of 4.5 years	<ul style="list-style-type: none"> <li>• Summary notes from clinic visits which included.</li> <li>• MMSE.</li> <li>• 30 minute open ended questioning of the patient.</li> <li>• 30 minute interviews with caregivers to complete the Psychogeriatric Dependency Scales and Scales of Psychosis in AD.</li> </ul>	<ul style="list-style-type: none"> <li>• PAB data available on 169 subjects of which 29.6 of subjects reported as having at least one act of PAB since onset of illness.</li> <li>• 68% of PAB occurred while patient living at home.</li> <li>• Delusions best predictor of PAB (chi-square analysis and stepwise binary multiple regression).</li> </ul>

Appendix E

RELATIONSHIP BETWEEN AGGRESSION AND COGNITIVE IMPAIRMENT

AUTHOR/YEAR	CONCEPT	SAMPLE	DEMENTIA SCALES	BEHAVIOURAL SCALES	RESULTS	METHOD
1. Cohen-Mansfield 1986	Agitation	Residents from 2 nursing units for the agitated and cognitively impaired N = 66	Brief Cognitive Rating Scale (reliability/validity not reported).	Seven point rating scale (reliability/validity not reported).	No relationship established.	T-test
2. Ryden 1988	Aggressive Behaviour	Community patients recruited from Alzheimer's Association and dementia clinics N = 184	Rated by families based on behaviours.	RAS 1 (reliability and validity established).	Reached significance only on PAB.	Analysis of Variance
3. Teri, Larson & Reifler 1988	Behavioural Disturbance	Community patients with primary diagnosis of dementia of the Alzheimer's type N = 127	MMSE Blessed Dementia Scale	Based on literature search, problem behaviours were listed and behaviours were listed as present or absent.	Increased cognitive impairment is associated with increased incidents of aggression.	Not reported

**RELATIONSHIP BETWEEN AGGRESSION AND COGNITIVE IMPAIRMENT**

<b>AUTHOR/YEAR</b>	<b>CONCEPT</b>	<b>SAMPLE</b>	<b>DEMENTIA SCALES</b>	<b>BEHAVIOURAL SCALES</b>	<b>RESULTS</b>	<b>METHOD</b>
4. Hamel, Pushkar, Gold et al. 1990	Aggressive Behaviour	Community individuals with dementia  N = 213	Hierarchical Dementia Scale  (interrater reliability .89)	RAS 1	No relationship established.	Multiple Regression Analysis
5. Ryden, Bossenmaur McLachlan 1991	Aggressive Behaviour	Cognitively impaired residents from 4 nursing homes  N = 124	Short Portable Mental Status Questionnaire  (reliability/validity not reported)	RAS 1  RAS2	No relationship established.	Pearson Product Moment Correlations
6. O'Leary, Haley & Paul 1993	Behavioural Problems	Community subjects from Alzheimer's clinic aged 65 and older  N = 32	MMSE	Memory and Behaviour Problem Checklist (validity/reliability not reported).  Behavioural Log (content validity reported as optimized).	Increased cognitive impairment is associated with increased incidents of aggression.	Anecdotal

**Appendix F  
 Ryden Aggression Scale  
 (RAS2/Form 2)**

Date \_\_\_\_\_  
 Code \_\_\_\_\_

**FORM 11  
 RYDEN AGGRESSION SCALE  
 DAILY LOG SHEET  
 (MODIFIED FOR THE COMMUNITY CAREGIVER)**

Please record every aggressive behavior of your partner which occurs by making a check mark  opposite the behavior in the appropriate column.  
 Example. The person scratched someone once from 7 to 3:00 p.m. and hit or punched twice during the same time and three times in the evening. No aggression was noted during the night.

	11-7	7-3	3-11	
		///	///	Hitting/Punching
		/		Scratching

IF NO AGGRESSION WAS NOTED PLEASE CHECK "NO AGGRESSION NOTED."

**PHYSICALLY AGGRESSIVE BEHAVIORS**

	11-7	7-3	3-11	
				BITING
				ELBOWING
				HITTING/PUNCHING
				KICKING
				PINCHING/SQUEEZING
				PUSHING/SHOVING
				PULLING HAIR
				SCRATCHING
				SLAPPING
				SPITTING
				TACKLING
				MAKING THREATENING GESTURES
				THROWING A WEAPON
				USING A WEAPON
				DAMAGING PROPERTY

11-7

**VERBALLY AGGRESSIVE BEHAVIORS**

	11-7	7-3	3-11	
				CURSING/OBSCENE/VULGAR LANGUAGE
				HOSTILE LANGUAGE
				MAKING VERBAL THREATS
				NAME CALLING

**SEXUALLY AGGRESSIVE BEHAVIOR**

**NOTE:** Behaviors are considered sexually aggressive only if they are against the expressed will and/or despite the resistance of the other person.

	11-7	7-3	3-11	
				HUGGING
				INTERCOURSE
				KISSING
				MAKING OBSCENE GESTURES
				TOUCHING BODY PARTS OF ANOTHER PERSON

7 3

3-11

NO AGGRESSION NOTED	NO AGGRESSION NOTED	NO AGGRESSION NOTED
---------------------	---------------------	---------------------

**Appendix G**  
**Mini Mental State Exam (MMSE)**

Source: Folstein, M., Anthony, J. C., Parhad, I., Duffy B. & Gruenberg, E. M. (1985). The meaning of cognitive impairment in the elderly. Journal of the American Geriatrics Society, 33, 228-235.

**THE FOLSTEIN MINI-MENTAL STATE EXAM**  
**(MMSE)**

1. ORIENTATION

\_\_\_\_ Day \_\_\_\_ Date \_\_\_\_ Month \_\_\_\_ Season \_\_\_\_ Year  
10  
\_\_\_\_ Floor \_\_\_\_ Place \_\_\_\_ Street \_\_\_\_ City \_\_\_\_ Province

2. MEMORY

\_\_\_\_ Register 3 objects (Tree, House, Car) \_\_\_\_ Tries  
11 3

\_\_\_\_ Serial 7's (93, 86, 79, 72, 65)  
5

or WORLD backwards

3. LANGUAGE

\_\_\_\_ Name 2 objects (Pencil, Watch)  
9 2

\_\_\_\_ 3 stage command  
3

Take the paper in your LEFT hand, then  
Fold it in half, and  
Put it on the floor

\_\_\_\_ Repeat this sentence  
1 "NO IFS ANDS OR BUTS"

\_\_\_\_ Read and do (Top of page, other side)  
1

\_\_\_\_ Write a sentence (On the line, other side)  
1

\_\_\_\_ Copy pentagons (Bottom of next page)  
1

MMSE SCORE

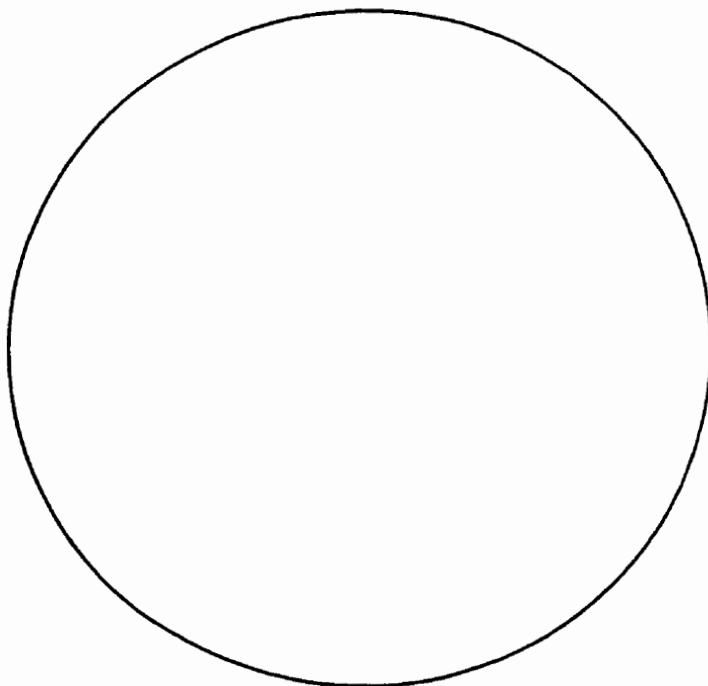
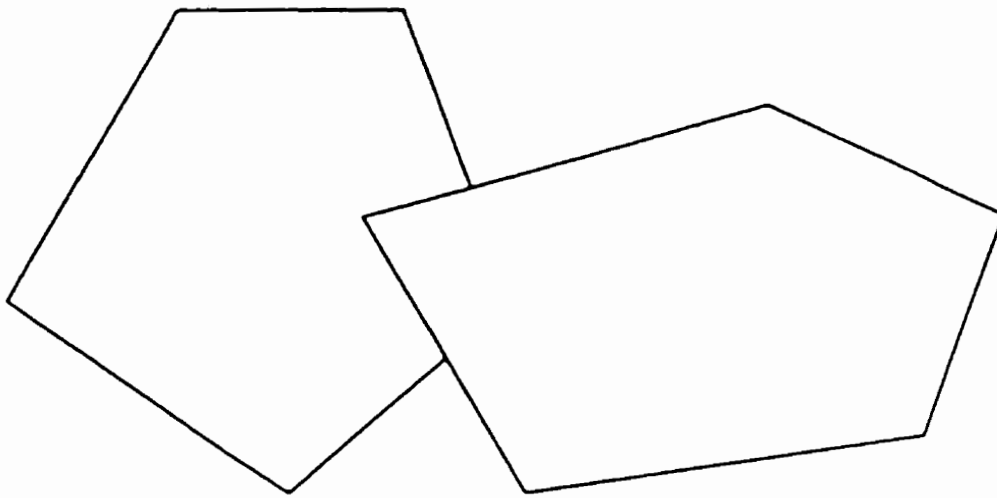
PATIENT SCORE \_\_\_\_\_

TOTAL POSSIBLE



Second page of MMSE

# CLOSE YOUR EYES



**Appendix H**  
**Mini Mental State Exam: Tom's Results**

**THE FOLSTEIN MINI-MENTAL STATE EXAM**  
**(MMSE)**

1. ORIENTATION

10  Day  Date  Month  Season  Year  
 10  
 Floor  Place  Street  City  Province

2. MEMORY

5  Register 3 objects (Tree, House, Car)  Trees  
 11 3  
 Serial 7's (93, 88, 79, 72, 65)  
 5  
 or WORLD backwards

3. LANGUAGE

9  Name 2 objects (Pencil, Watch)  
 9 2

3 stage command  
3  
 Take the paper in your LEFT hand, then  
 Fold it in half, and  
 Put it on the floor

Repeat this sentence  
1 "NO IFS ANDS OR BUTS"

Read and do (Top of page, other side)  
1

Write a sentence (On the line, other side)  
1

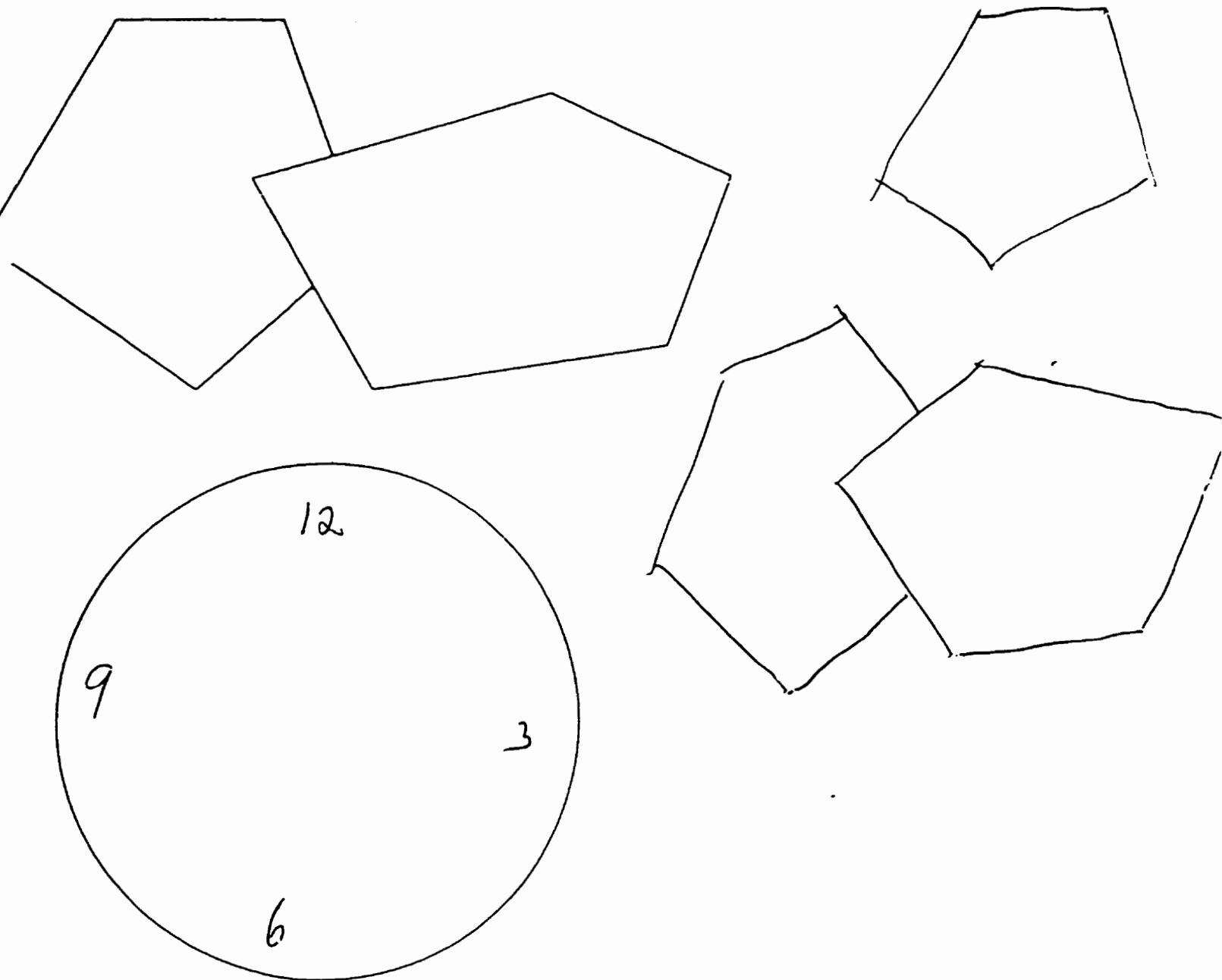
Copy pentagons (Bottom of next page)  
1

MMSE SCORE	PATIENT SCORE <u>24</u>	TOTAL POSSIBLE <u>30</u>
code: <u>010</u>		

# CLOSE YOUR EYES

*I love Jesus.*

---



Appendix I  
Mini Mental State Exam: Mary's Results

THE FOLSTEIN MINI-MENTAL STATE EXAM  
(MMSE)

1. ORIENTATION

$\frac{6}{10}$   Day  Date  Month  Season  Year

Floor  Place  Street  City  Province

2. MEMORY

$\frac{2}{11}$   $\frac{0}{3}$  Register 3 objects (Tree, House, Car) \_\_\_\_\_ Tries

$\frac{2}{5}$  Serial 7's (93, 88, 79, 72, 65)

or WORLD backwards

3. LANGUAGE

$\frac{6}{9}$   $\frac{0}{2}$  Name 2 objects (Pencil, Watch)

3 stage command

3  
Take the paper in your LEFT hand, then  
Fold it in half, and  
Put it on the floor

Repeat this sentence

1 'NO IFS ANDS OR BUTS'

Read and do (Top of page, other side)

1

Write a sentence (On the line, other side)

1

Copy pentagons (Bottom of next page)

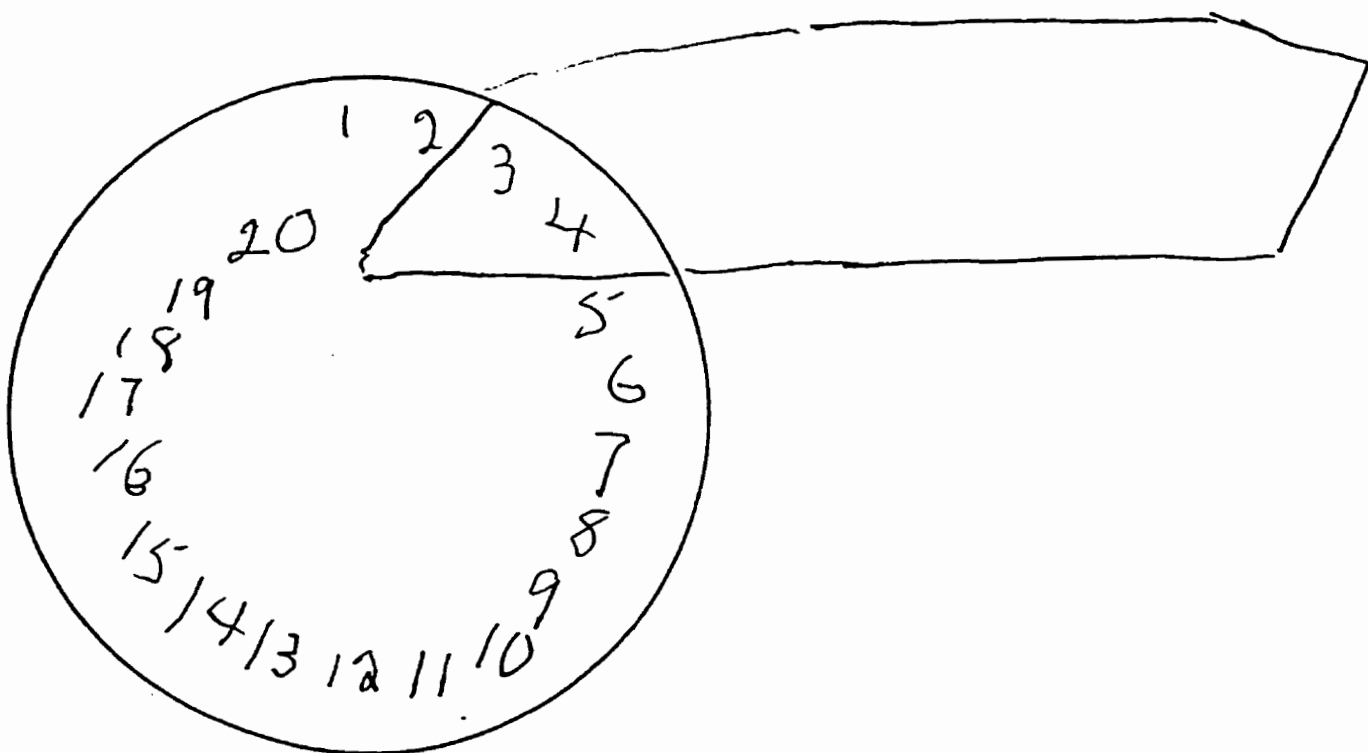
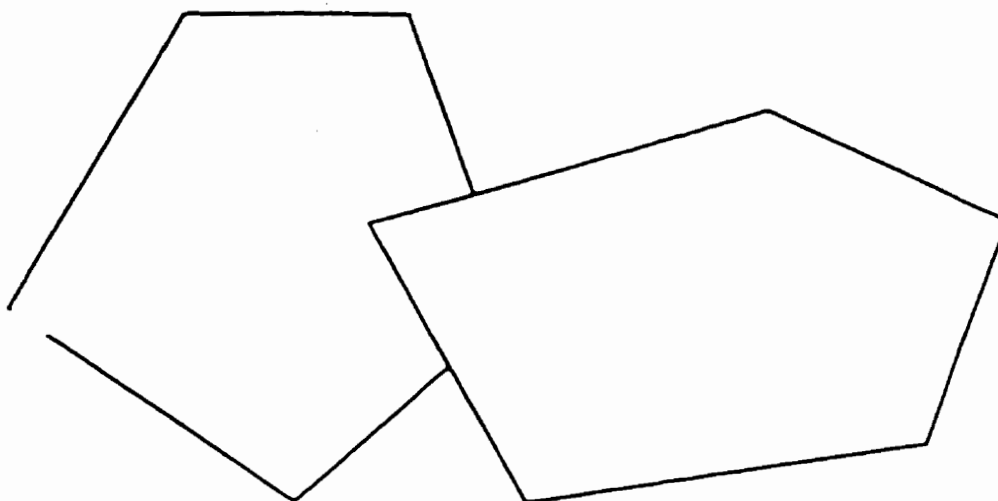
1

MMSE SCORE	PATIENT SCORE <u>14</u>	TOTAL POSSIBLE <u>30</u>
code: 0101		

# CLOSE YOUR EYES

I love you truly truly dear!

I love my husband



**Appendix J**  
**Letter to Provincial Program Director Manitoba Alzheimer**  
**Society to be shared with Support Group Facilitators**

Shelley C. Keast  
 19 Somewhere Drive  
 Winnipeg, Manitoba  
 R3K XXX  
 XXX-XXXX (home)  
 YYY-YYYY (Office)

May 20, 1997

Wendy Schettler  
 Community Development Manager  
 Alzheimer Society, Manitoba  
 120 Donald Street  
 Unit 10 Mezanine  
 Winnipeg, MB R3C 4G2

Dear Ms. Schettler:

Re: Accessing Support Groups for research participant recruitment

Thank you for your willingness to assist me in the recruiting of participants for my thesis research.

As you are aware, I am a Masters student in the Faculty of Nursing at the University of Manitoba and am working on my thesis. My thesis title is the "Experiences of Spouses Caring for Aggressive Family Members Diagnosed with Alzheimer's Disease." The aim of this research is to provide an understanding of the caregiver's experience and perceptions so that the nursing profession is better able to meet the needs of the growing population of community spousal caregivers. Chair of my thesis research is Dr. David Gregory 474-6655, Faculty of Nursing.

I have received ethical approval for my research from the Ethical Review Committee, Faculty of Nursing, University of Manitoba and am ready to proceed with recruitment of participants. As you are aware, I will need your assistance in recruiting 8 participants, spouses of partners who display aggressive behaviour due to Alzheimer's disease. As discussed, my best success in accessing this population will be through the Alzheimer Support Groups. I appreciate your willingness to assist me in the notification of the facilitators of these support groups so that they can inform members about the study and the need for participants.

I will keep you informed as to the progress of my participant recruitment and data collection. Should you have any questions, please do not hesitate to contact me at either number.

Once gain, thank you for your cooperation.

Yours truly,

Shelley C. Keast  
 RN, BN, Masters Candidate

**Appendix K**  
**Letter to Support Group Facilitators for Recruitment of**  
**Participants for Study**

Shelley Keast  
19 Somewhere Drive  
Winnipeg, Manitoba  
R3K XXX  
XXX-XXXX (Home)

Date October 8, 1997

Dear Support Group Members:

I am a Registered Nurse studying at the University of Manitoba in the Masters in Nursing Program. I am requesting your participation in a study I am conducting titled "Experiences of Spouses Caring for Aggressive Family Members Diagnosed with Alzheimer's Disease." The purpose of this study is to gain a better understanding of the aggressive behaviours spouses are exposed to, the impact of these behaviours on spousal caregivers, identify ways in which caregivers manage or cope with the behaviours, and to identify those factors that are perceived to be or not to be of help. This study has received ethical approval by the Ethical Review Committee, Faculty of Nursing, University of Manitoba. My thesis work is being supervised by a committee of three professors at the University of Manitoba: Dr. David Gregory, Faculty of Nursing (474-6655), Professor Nettie Peters, Faculty of Nursing, and Dr. Dale Berg, Faculty of Human Ecology.

Your participation is voluntary and would include two 1-hour visits in your home and a 1-hour interview away from your home. I would be conducting the visits/interviews during which you would be asked to share your experiences and feelings. During the 2 home visits I will also be observing interactions between you and your spouse. You would also be required to complete a record of your spouses behaviour over 3 consecutive days. As the responsible person for your family member I will also be seeking your permission to meet with your spouse so that I can assess their level of understanding.

At all times your privacy will be respected and all information will be kept confidential. If you are interested in participating in this study please contact me for more information. Thank you for your consideration.

Sincerely,

Shelley C. Keast RN, BN, Masters Candidate

**Appendix I**  
**Information Provided to Potential Participants**  
**during Formal Recruitment**

Thank you for your interest in this study. My name is Shelley Keast and I am a Registered Nurse studying at the University of Manitoba in the Masters of Nursing Program.

The research I have chosen for completion of my Masters degree is concerned with the experiences of spouses caring for aggressive family members diagnosed with Alzheimer's disease. The purpose of this study is to gain a better understanding of what it is like living with someone whose illness causes them to become aggressive. How does this behaviour make you feel? How do you cope or deal with the aggression? Are there things you do that make the situation better or worse?

The study has received ethical approval by the Ethical Review Committee, Faculty of Nursing, University of Manitoba. The research is being supervised by Dr. David Gregory, Faculty of Nursing, University of Manitoba (474-6655). Dr. Dale Berg, Faculty of Human Ecology, University of Manitoba, and Professor Nettie Peters, Faculty of Nursing, University of Manitoba, are also involved in the study as advisors.

Your participation in the study is voluntary. Total time requested of you is 16 to 24 hours of visits/observations and 4-6 hours of interviews spread out over an 8 to 12 week period. The 16-24 hours of visits/observations break down into eight to twelve 2-hour visits/observations to take place in your home, and four to six 1-hour interviews to occur outside of the home, away from the care recipient. During the first interview I will answer any questions you may have, ask you questions about you and your spouse related to age, years married and illnesses. I will also be reviewing a chart on which you will be requested to keep track of any aggressive behaviours displayed by your spouse for a minimum of 4 weeks and if necessary and able, for the duration of the 8-12 week study. During the first home visit I will ask you more questions about your experience, and, if you approve, complete a 5-10 minute exam on your spouse called the Mini Mental State Exam so that I can assess his/her understanding. Throughout all the home visits/observations I will be watching how you and your spouse spend time together, asking you more questions about you and your spouse, and learning more about your life.



For the four to six 1-hour interviews it is best if they are completed away from the home as the stories you share, may be upsetting to you or your spouse. A place and time that is good for you and me will be selected and if it is easiest for you to attend after any support meetings you go to, this will be arranged. The purpose of these interviews is to review and discuss the aggressive behaviours that you have been faced with, how you felt at the time, and the actions you took to manage the behaviours.

It is easiest for me if the interviews are tape recorded, however if you do not agree with having the interviews tape recorded then I will not use the tape recorder. The purpose of the tape recorder is so that I do not make any mistakes in remembering what you have shared with me. I will also be making notes after I leave each interview of my thoughts and feelings. Each of the interviews will last approximately 1 hour in length.

If during the visits or interviews I become concerned about the aggressive behaviour you are exposed to, I will inform you of my concerns and together we will identify a plan and/or available resources to help ensure your safety. If the stress of caring for your spouse has caused you to act aggressively yourself, jeopardizing your spouse's safety, I am morally obligated to act on you and your partners behalf. If I feel your aggression towards your spouse is of a moderate or severe nature, I will discuss my concerns with you and you will be expected to take actions (with my assistance if necessary) to receive the help and support you need as a care giver. This may include contact with the Elder Abuse Resource Centre if the abuse is considered to be moderate and the City of Winnipeg Police Department if the abuse is sever. I will keep you informed of any contacts I make on your behalf to help you manage in your situation. If the safety of your spouse is in moderate or severe jeopardy, I will be morally obligated to act on behalf of you and your spouse to ensure the safety of your spouse. In these situations confidentiality cannot be guaranteed as your names may need to be released to any counsellors or police as needed. Partial confidentiality will be maintained as your names will only be given to these individuals as needed and will not be revealed to the Thesis Committee Members.

The information that you provide will in no way identify you or your spouse. To ensure that no one can identify you a code number will be given to you and only I and Dr. David Gregory (Thesis Advisor) will have access to the number. If the tape

recorder is used the tape will not have your name recorded. Your name or your spouses' name will not appear on any reports or in any magazine. Although I may write an article in a magazine about my research results, you and your spouses name will not appear.

You can quit the study at any time by simply telling me. The care you or your spouse receive will not be affected by your decision to quit the study. No one else will know that you are participating or have withdrawn from the study.

## **Appendix M**

### **Consent to Participate**

I \_\_\_\_\_ have volunteered to participate in the study entitled, "Experiences of spouses caring for aggressive family members diagnosed with Alzheimer's Disease."

The purpose of this study is to describe the experiences of spouses' living with individuals with Alzheimer's disease in which the disease has caused the person to act aggressively, to gain an understanding of impact of these behaviours, and to identify those factors that are perceived to be or not to be of help.

The study is being supervised by Dr. David Gregory, Faculty of Nursing, University of Manitoba, 474-6655. Dr. Dale Berg, Faculty of Human Ecology, University of Manitoba, and Professor Nettie Peters, Faculty of Nursing, University of Manitoba, are also involved in the study as advisors. The study has received ethical approval by the Ethical Review Committee, Faculty of Nursing, University of Manitoba.

My participation in the study involves a 8-12 week commitment. During this time I agree to 1 visit/observation per week with each visit/observation lasting approximately 2 hours. These visits will occur in my home. I also agree to 4-6 interviews (approximately 1 hour in length) away from my home. It is preferred that the interviews be tape recorded, however if I feel uncomfortable in any way, I may request that the tape-recorder not be used. The interviewer, Shelley Keast will also make field notes about the visits and interviews once she leaves. I agree to monitor the aggressive behaviours of my spouse using the Ryden Aggression Scale throughout the 8-12 week duration of the study. During the home visits/observations the interaction between my spouse and myself will also be observed.

**I also agree to have the Mini-Mental Status Exam completed on my partner by the researcher, Shelley Keast.** I have had this test explained to me and understand that this exam takes 5-15 minutes to complete. The completion of the exam will occur at a mutually agreeable point during the first interview. Should I feel that my partner is being upset by the testing, I can request that the test be stopped. I may choose to identify an alternative date/time for the test, or request that the test not be attempted again. My decision to discontinue the test will in no way affect the care my partner or I receive, and does not mean I want to discontinue the study. Should I wish to withdraw from the larger study, I will communicate this to Shelley Keast.

The information that I provide will in no way identify myself or my spouse. To ensure my confidentiality I will be given a code number, and only Shelley Keast will have access to the coding system. If the tape-recorder is used the tape will in no way be identified as my interview. My name or my spouses' name will not appear on any reports or publications. Findings from the research may be published, but my partners and my anonymity will be assured.

If during the visits/interviews the researcher becomes concerned about the degree of aggressive behaviour I am exposed to, she will inform me of her concerns and together we will identify a plan and/or available resources to help ensure my safety. If there are situations where the stress of caring for an aggressive partner is such that I in return act aggressively towards my partner, the researcher will be morally obligated to act on our behalf.

If the researcher has concerns that aggression directed towards my partner is of a moderate or severe nature, she will inform me of her concerns. I will be expected to take action independently or if unable to do so, the researcher will assist me, or act on my behalf until I receive the help and support as a caregiver. This may include contact with the Elder Abuse Resource Centre if the abuse is considered to be moderate and the City of Winnipeg Police Department if the abuse is severe. The researcher will keep me informed of any contacts she makes in the effort to assist me or my partner. A list of all available contacts will be provided to me.

In the above situations where the safety of my spouse is in moderate or severe jeopardy the researcher is morally obligated to act on our behalf to ensure the safety of my spouse. In these situations confidentiality cannot be guaranteed. Our names may need to be released to the counsellor at the Elder Abuse Resource Centre or the Winnipeg Police. Partial confidentiality will be maintained as our names will only be given to these individuals and will not be revealed to the Thesis Committee members.

I understand that I am under no obligation to participate, and as such my participation is voluntary. I have read an explanation of the study and have had all my questions and concerns about the study answered satisfactorily. I may withdraw from the study at any time by simply telling Shelley Keast with no negative consequences. My decision to participate or not to participate will in no way affect the care I or my spouse receive. I will be offered a copy of this consent form to keep.

My signature indicates that I have read the this consent and have agreed to participate in this study. I am free to withdraw at any time after signing this form should I choose to discontinue participation in this study.

Participant Signature \_\_\_\_\_ Code \_\_\_\_\_ Date \_\_\_\_\_

Investigator Signature \_\_\_\_\_

Date \_\_\_\_\_

If You have questions regarding the study please do not hesitate to call Shelley Keast at xxx-xxxx, or Dr. David Gregory at 474-6655.

Upon completion of this research if you would like to receive a summary of the findings, please indicate the following:

Address \_\_\_\_\_

City \_\_\_\_\_

Postal Code \_\_\_\_\_

**Appendix N  
Demographic Data Collection**

Code \_\_\_\_\_

**Caregiver Demographics**

Age \_\_\_\_\_ Gender \_\_\_\_\_

Educational level \_\_\_\_\_

# years providing care \_\_\_\_\_

# years living together \_\_\_\_\_

Support Groups \_\_\_\_\_

Additional caregiving assistance

---

(home care/family/friends)

**Care recipient Demographics**

Age \_\_\_\_\_ Gender \_\_\_\_\_

Educational level \_\_\_\_\_

Age of onset of symptoms \_\_\_\_\_

Age of diagnosis \_\_\_\_\_

Onset of aggressive behaviour \_\_\_\_\_

Medications \_\_\_\_\_

Other major medical illness \_\_\_\_\_

---

**Appendix O**  
**Instructions for completing Ryden Aggression Scale 2 with Time Dimension**

Please record **every** aggressive behaviour of your spouse which occurs by making a check mark opposite the behaviour on the appropriate sheet (verbal, physical, or sexual). Place the check mark in the correct time column (11 p.m. to 7 a.m., 7 a.m. to 3 p.m., 3 p.m. to 11 p.m.) and across from the corresponding behaviour.

For example: Between 7 a.m. and 3 p.m. Mary was cursed at for 5 minutes on two separate occasions, and was verbally threatened for greater than one hour between 3 p.m. and 11 p.m. From 11 p.m. to 7 a.m. there were no acts of aggression noted. The completed aggression scale would look like this:

**VERBALLY AGGRESSIVE BEHAVIOURS**

11 p.m. - 7 a.m.							7 a.m. - 3 p.m.							3 p.m. - 11 p.m.							BEHAVIOURS	
1-3	3-5	5-10	10-20	20-30	1 hr	> 1 hr	1-3	3-5	5-10	10-20	20-30	1 hr	> 1 hr	1-3	3-5	5-10	10-20	20-30	1 hr	> 1 hr		
								✓														Cursing/Obscene/Vulgar Language
																						Hostile Language
																					✓	Making Verbal Threats
																						Name Calling



# VERBALLY AGGRESSIVE BEHAVIOURS

		BREAKFAST			LUNCH			DINNER			EVENING			BEHAVIOURS	NOTES
		5	15	45	5	15	45	5	15	45	5	15	45		
														Cursing/Obscene/ Vulgar Language Hostile Language Making Verbal Threats Name Calling	

Code \_\_\_\_\_ Day \_\_\_\_\_



# SEXUALLY AGGRESSIVE BEHAVIOURS

		BREAKFAST		LUNCH		DINNER		EVENING		BEHAVIOURS	NOTES
		5	15	45	1 HR	OR >	5	15	45		
										Hugging	
										Intercourse	
										Kissing	
										Making Obscene Gestures	
										Touching Body Parts of Another Person	
										No Aggression Noted	

Code \_\_\_\_\_ Day \_\_\_\_\_

**Appendix Q**  
**Letter of Permission**  
**Ryden Aggression Scale (1 & 2)**

UNIVERSITY OF MINNESOTA

---

*Twin Cities Campus*

*School of Nursing*

*6-101 Unit F  
 308 Harvard Street S.E.  
 Minneapolis, MN 55455-0342  
 612-624-9600  
 Fax: 612-626-2359*

November 28, 1994

Shelley Keist  
 19 Hagen Drive  
 Winnepeg, Manitoba, R3K 1-Y5

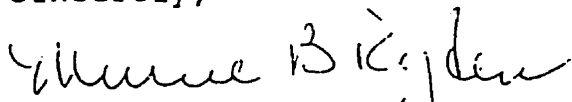
Dear Ms. Keist:

Thank you for your interest in our measure of aggressive behavior. I have enclosed copies of Forms 1 and 2 of the Ryden Aggression Scale, information about the psychometric properties of the measure, and a set of definitions of some of the behaviors on the scale. We are currently using the RAS, Form 2 in an experimental study funded by the National Institute for Nursing Research and the National Institute on Aging, "Cost-Effective Quality: Improving Resident Outcomes."

You have my permission to use the RAS. If you do so, please acknowledge the source. I would like to know how you utilize the instrument; if it is used for research/evaluation, I ask that you provide me with information about your findings, particularly any psychometric data and the range, means, and standard deviations with respect to particular populations.

Best wishes in your work! I look forward to hearing from you.

Sincerely,



Muriel B. Ryden, PhD, RN, FAAN  
 Long Term Care Professor

Director, Research Center for Long Term Care of the Elderly

**Appendix R**  
**Interview Guide**

1. You and your spouse have been married for a number of years. Can you tell me a little bit about what your years together have been like?
2. If you were to recall the things you remember as most positive in your spouse and marriage before he/she was ill, what things or situations would come to mind? What about the not so positive events?
3. Tell me about the types of aggressive behaviours you have faced in the past with your spouses illness.
4. Can you identify any events in your life that make these behaviours either easier or more difficult to accept and manage?
5. Can you recall how you felt with each of these aggressive behaviours?
6. Has the aggressive behaviour in your spouse changed since the onset of the dementia? Is this a brand new set of behaviours for this individual, or an extension of a their personality before the onset of Alzheimer's disease?
7. What techniques do you use to deal with the verbal, physical, and sexual aggression?
8. Do you talk to others about the aggressive behaviours in your spouse? How does this make you feel?
9. Have you received any advice, helpful hints, techniques from any health care professional on how to manage the behaviour? Who? Was the advice helpful? What specifically was most helpful?
10. Do you feel the health care professional was listening and understanding of your situation?
11. Which behaviours do you find the most difficult to deal with? What is it about these behaviours that makes them harder to manage/cope with than others? (Reviewing the findings on the RAS2 and from observations)

12. How do you feel when facing these behaviours?
13. Have you ever wanted to act aggressively yourself in response to the behaviour in your spouse? Have you ever acted on your feelings? Can you give me examples?
14. What do you feel could be done to help others in your situation cope with the aggression?
15. What advice do you have for health care professionals when trying to assist you in your situation?

**Appendix S**  
**Available Community Referrals and Supports**

Living with a loved one who has become aggressive due to Alzheimer's disease is very hard on those who provide care. The following are a list of Community agencies that are understand and can provide you support. I encourage you to contact any of these resources and discuss your situation.

Manitoba Alzheimer's Society  
120 Donald Street  
Unit 10, Mezzanine  
Winnipeg, Manitoba R3C 4G2  
943-6622

Manitoba Alzheimer's Society  
Your Support Group Facilitator  
or any member of your Support Group

Manitoba Society for Seniors  
803-294 Portage Avenue  
942-3147

Klinic - 24 hour crisis line  
786-8686

Salvation Army Mobile Crisis Unit  
946-9402

Elder Abuse Resource Centre  
304-323 Portage Avenue  
Winnipeg, Manitoba  
942-6235

City of Winnipeg Police  
986-6222

Family, Friends, Neighbours

Your Doctor

Your Clergy

**Appendix T**  
**Incidents of Aggression**  
**Case Study One: The Summer Family**

The following entries are a few examples of the aggressive incidents Jane journaled from January 9, 1998 to March 10, 1998. The incidents are transcribed verbatim with explanations given (if necessary).

January 11, 1998

Tom throws a dish (plastic) into the sink (about 5 feet).

Tom - (daughter) wants to buy something.

I'm talking to him, not (daughter)

- The dish was thrown from the dining room through the kitchen doorway into the kitchen because he is upset that L has informed him that the daughter wants to purchase something.

January 13, 1998

TV commercial - new pastor

Damn \_\_\_\_\_

Trying to get to living room from dining room before commercial over.

- Tom became very angry with the commercial because he does not like the new pastor and needed to turn the TV immediately.

January 17, 1998

Tell her to get her ass out here.

(Take - out order. They overlooked our soft drink bottle)

1-2 min.

- Children came to the van with the pizza and not the complementary 2 litre of pop. He was yelling at the children to tell the pizza clerk to...

January 18, 1998

Help me with this d\_\_\_ toilet paper dispenser.

I can't do it. I dropped the spring.

- Tom was unable to reassemble the toilet paper holder (the plastic roll).

January 24, 1998

Tom: Where is (daughter's) mail?  
 Why don't you know where it is"  
 What did you do with it"  
 ...repeats everything and won't let it rest  
 5 minutes

Jane: I drop what I'm doing  
 I look for (daughters) mail until I find it.  
 Tom stops fretting

January 29, 1998, 2110 hrs

Leaving Learning Together Conference

Tom: Get in the back seat you little b\_\_\_\_\_

2130 hrs

- at home again

Tom: Get rid of her.

- Tom is referring to one of his children

February 1, 1998 1730 hrs

(child) wants toys (walker) out of storage room in basement.

Tom is yelling at (child)

(another child) comes to the rescue.

(I'm gone to pick up (another child) from a church outing)

2030 hrs

Return home from church.

(child) leaves school bag in van and zipper completely undone.

Her belongings fall out.

Tom: \_\_\_\_\_ stupid a\_\_ \_\_\_\_\_

- Hell, stupid asshole

February 3, 1998

I'm driving

Tom's explaining something to me

Tom: Hell, why can't you listen.

February 7, 1998 1215 hrs

We've dropped (children) off at the church for a field trip.

While waiting for their bus to leave (a remaining child)

"drops" the back of the bench seat so that it folds down.

Tom: What did you do that for?

you stupid a\_\_\_\_\_

What did you do that for?

I don't know how to fix it.

I don't know what to do.  
 2 minutes  
 I fix it and all is well for now.

1810

Tom and Jane (child) sit in van waiting while (children) take their piano lesson.

Then we drive to the car wash.

(child) keeps putting the front passenger seat in sleep position.

Tom is upset. You stupid butt head

child: You're wasting all your money in the swear jar.

Tom: She's driving me crazy

child: Dad has to put more money in the swear jar

(another child): Why are you so obnoxious. You get so upset over every little thing.

Tom: I'm taking the bus home I've had it. She's driving me insane

(Tom doesn't take the bus home. At the car wash everything is fine).

30 minutes

February 8, 1998

Tom: Hurry up and phone that dumb woman so I can make my plans.

Why are you sitting on your ass? (directed at L)

[to (child) using the toilet]

Tom: (sibling) just "pissed" in the bathroom (waiting for the toilet - sibling had cut her off)

- Jane needed to confirm plans with me and then Tom was going to make his plans. While this was going on the children were fighting over the washroom.

February 10, 1998

Tom almost mowed down a toddler while intent on pushing a shopping cart in Walmart.

I screamed just in time for him to stop.

- Fighting over who was going to push the shopping cart

February 11, 1998

I crawled into bed after finishing putting together my appeal to Adipic.

Tom: If there was a stake, you'd be burned.

Jane: You just gave me a compliment.



February 25, 1998 1115 hrs

Arriving home while still in the van.

Jane: She'll be upset with me that I didn't go to the Alzheimer support group.

Tom: Tell her to go to hell. I don't care what she thinks. We'll soon be rid of her.

- Referring to me.

1135 hrs.

While looking over the bank books

Tom: We're fucked

We're screwed

Jane; You're right.

February 28, 1998

In Wal-mart (at the rain boots)

Tom needs the bathroom.

Tom: Where the hell is the bathroom?

Jane: I tell him and away he goes

March 4, 1998

By 7:50 am - 3rd foul language

1000 hrs

Driving (children) to school the gas gauge is one notch above E.

Tom is upset - two "hells" by the time we get to (street names)

Tom: It's never been this low before. He doesn't want me to drive to school until getting gas. Tom doesn't allow the gas gauge under half or else he becomes anxious.

We drop the girls off at school and buy \$5.00 worth of gas from station near the school, so Tom will stop fretting.

- Children were going to be late for school. Tom verbally vented calling everyone names until situation remedied.

March 5, 1998

After our supper-

(child) is talking on the phone.

Tom is loading up the dishwasher.

(child) knocks over some clutter off the top of the dishwasher.

Tom: Why are you in here? You \_\_\_\_\_

- Stupid Ass

March 8, 1998

Loading into the van. Evening service is ended.

Tom: Where is the lid? (for wind-shield wash)

I left it on the floor.

Jane: I put it in the garbage

Tom: You stupid ass. My hands ae frozen.

(child) You can walk home and freeze your feet.

(another child) My (friend) finally heard my Dad swear. This is great.

(Friend went to church with us)

(first child): More money for the swear jar.

March 9, 1998

Tom is looking at the mail. We need to make an appointment.

5 min of verbal diarrhea

Tom: Why do you hang your laundry for everyone to see?

We have no privacy

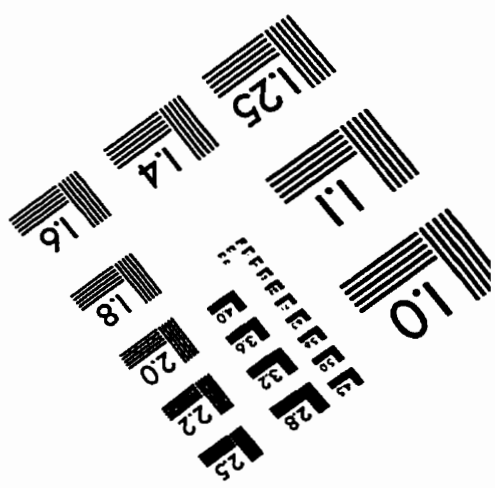
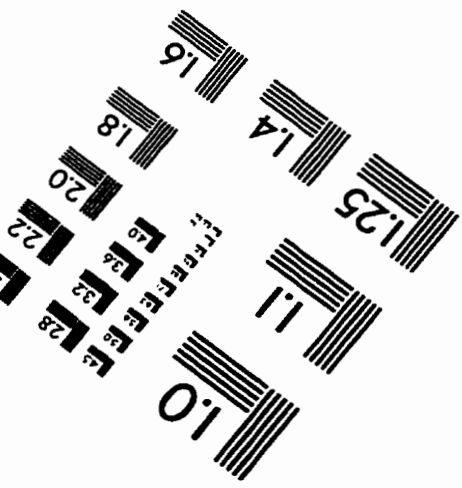
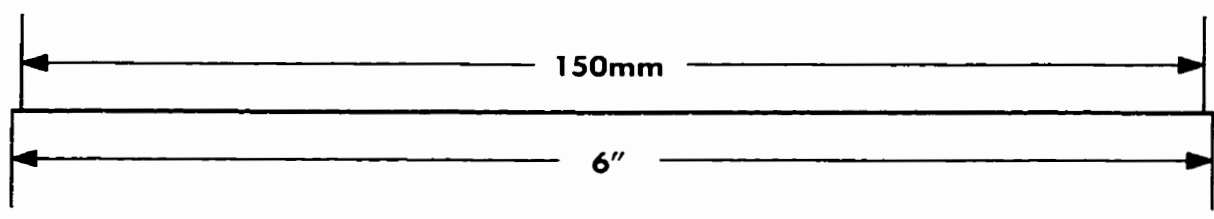
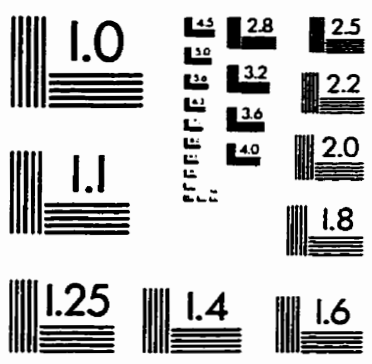
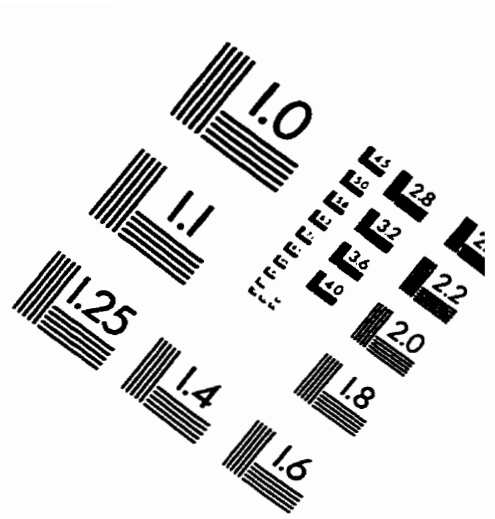
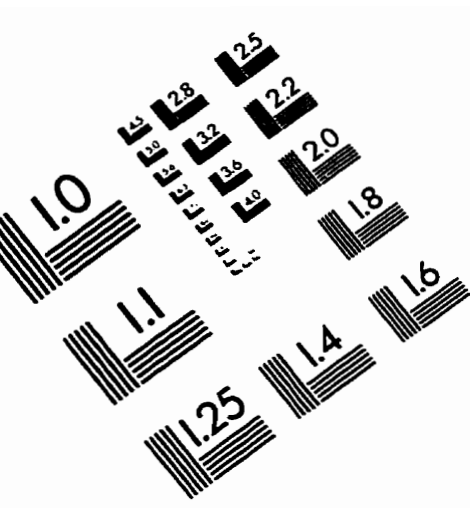
Do you realize what you're doing?

You stupid ass.

Why can't people leave us alone?

What is going on?

# IMAGE EVALUATION TEST TARGET (QA-3)



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