

**In Sickness and In Health: A Study of the  
Experiences of Caring for a Spouse at home with Alzheimer's type Dementia**  
**by**  
**Debra Dolhun**

**A Thesis submitted to the Faculty of Graduate Studies of  
The University of Manitoba  
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**In Sickness and In Health: A Study of the Experiences of Caring for a Spouse at home with Alzheimer's type Dementia**

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**MASTER OF SOCIAL WORK**

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**In Sickness and In Health:  
A Study of the Experiences of Caring for a Spouse with Alzheimer's  
Abstract**

Unlike other diseases, Alzheimer's type dementia displays few physical signs on the individual; however, its effects impact on a family's life in every aspect. This qualitative research study used a narrative approach with the intent to understand the experiences of caring for a spouse with Alzheimer's type dementia from the caregiver's perspective. Nine caregivers from Winnipeg, Manitoba were interviewed and their reported experiences were compared to what has been reported in the literature. Analysis of the data revealed the challenges care giver face in not feeling understood, the extensive impact that their care giving role has on them, the resources that they have mobilized to assist them to continue, and where they see the gaps in support. The outcomes of this research will assist health care providers to understand the caregivers' experiences better and reveal the gaps that do exist in the health care system for spousal caregivers in this situation.

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To Michael and Sarah Dolhun

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## **Chapter One: Significance of Understanding the Spousal Caregiver's Situation**

### **Introduction**

Research examining the health and social aspects of Alzheimer's type dementia and care giving has become an area of increasing interest by researchers, practitioners, and policy makers. Unlike other diseases, it displays few physical signs on the individual; however, its effects reach far beyond the individual with this diagnosis impacting on the family's life in every aspect. The onset of dementia defines what the family becomes from then on (Almberg, 2000). "Cognitive changes cause the discontinuity between past, present, and future, and the individual is perceived as increasingly incapable of rational intentional behavior and thought" (Perry and O'Connor, 2002, p. 2). As the disease progresses, the individual with this dementia becomes more and more dependent on others for care, but becomes increasingly less able to contribute to the caring relationship in any respect. The caregiver is left to take over more and more tasks once done independently by the individual. Moreover, the dementia slowly claws away at the characteristics that made the care receiver who he or she was and "the illness subsumes the individual" (Perry and O'Connor, 2002, p. 1). The caregiver is now caring for someone who no longer resembles his or her family member, except in physical appearance.

Statistics Canada (2006) determined that in 2006, 13.7% of the Canadian population was 65 years of age or older, which is a new record and expected to continue to climb as the baby boomers age. Moreover, the average age of seniors is also increasing. Statistics Canada (2006) found that the percentage of seniors over 80 years of



age in 2006 was 26.9%, up from 24% in 2001. As our population ages, the number of Canadians with Alzheimer's type dementia also grows. The National Advisory Council on Aging (1996) estimated that in 2001, there were 364,000 Canadians with dementia, and 75% of those have Alzheimer's. Approximately 1 in 11 Canadians over the age of 65 have Alzheimer's type dementia (Alzheimer's Society of Manitoba, 2009). Half of all Canadians diagnosed with dementia are living outside of care facilities, with 94% of these being cared for at least partially by unpaid family caregivers (Lee, 1999). Furthermore, Alzheimer's clients receive on average 9.5 hours each day from unpaid family providers of care, usually from a single caregiver (Lee, 1999). The Canadian Study on Health and Aging (1996) found that 45% of the elderly 85 years of age and older living in the community have mild dementia, 44% have moderate dementia, and 10% have severe dementia. More women than men are diagnosed with Alzheimer's type dementia (Parsons, 1997). The role of caregiving occurs as often for spouses as it does for adult children (McKibbin, Walsh, Rinki, Koin, & Gallagher-Thompson, 1999), with spouses usually keeping the care receiver at home longer than other family caregivers (Liken, 2001). Moreover, the Canadian Study on Health and Aging (1996) found that there was a low rate of community service use by family caregivers, but the rate was even lower for spousal caregivers of dementia patients.

Montenko (1989) suggests that spouses caregiving for someone with Alzheimer's type dementia may be at the greatest risk for caregiver stress, as they are elderly themselves and are likely to have physical health problems themselves that reduce their capacity to meet the constant demands of caregiving. This study examined the experiences of spouses caring for their wives and husbands who have Alzheimer's type

dementia at home. A review of the literature illustrates a lack of Canadian qualitative research on the unique experiences of caring for one's own spouse at home with Alzheimer's type dementia. In a time of what this researcher has perceived as constant change in health care and a movement to community – based care in Manitoba, it is essential that the experiences of this unique group of caregivers are understood. A better understanding may assist health care professionals to assist more effectively.

### **Theoretical Discussion**

This study was conducted through the lens of the contextual family stress model offered by Pauline Boss. Boss (2002) discusses how stress is inevitable for individuals and their families. She suggests that not all families are the same and that how each family deals with a situation is different, depending on their internal and external contexts. Internal contexts are things that an individual or family has some control over or ability to change, such as the form and function of the family, roles, boundaries, perceptions, values, and beliefs held by the family (Boss, 2002). External contexts are things that the individual or family has no control over, such as genetics, culture, current economic situation, stage of life/development, and history (Boss, 2002). Since the family members have the ability to control or change the internal contexts, there is also the ability to manage change.

Boss, Doherty, LaRossa, Schumm, and Steinmetz (2009) and Boss (2002) discusses the need for families to have boundaries, and when there is a disruption causing uncertainty as to who is part of the family and who is not, boundary ambiguity can occur, thus leaving the family in limbo. The result is that roles may become unclear, tasks go

undone, and there is disagreement between family members over membership and roles. An example of this is when the person with Alzheimer's type dementia is still physically present in the family, but is no longer psychologically present and contributing to the family (Boss, 2002). If the family is able to make sense of this partial absence of the family member and grieve what has been lost, there will be an increased chance of success in coping and a decrease in the potential of their own health deteriorating as a result of stress (Boss, 2002). Moreover, Boss (2002) states that all aspects of an individual are interconnected, and that the individual is part of the family system, which interacts with other systems, suggesting that a holistic approach is the best approach.

Stress occurs over one's lifespan, but not all stress is seen as bad stress. As a result, stress can take different forms. Stress occurs when there is a disruption in the family system's normal operation and those in the family system feel the pressure (Boss, 2002). Boss (2002) cites various types of stress, from normal, developmental stress to ambiguous stress and chronic stress. An ambiguous stressor is more difficult to deal with, as one is unable to obtain the clear facts about it, it may not be visible, and one may not be able to predict what will occur next, as can be the case when dealing with a disease, such as Alzheimer's type dementia (Boss et al, 2009; Boss, 2002). With this example, there is also the issue of the stressor situation being prolonged and seen as chronic when the situation cannot be changed. Boss (2002) suggests that if the chronic stressing situation is also ambiguous, then it is especially stressful.

## **Significance and Rationale**

Family caregivers, especially spouses, are essential for an individual with dementia to continue living at home. As the dementia progresses and the individual demonstrates poor insight and judgment in activities of daily life, he or she requires ongoing supervision to ensure his or her safety and well-being. This duty falls into the hands of family members, often the spouse. The spouse becomes responsible for all household management tasks, ongoing supervision of the Alzheimer's patient's activities, and his or her health needs. In many cases, the spousal caregiver is left to make all decisions about the household and the care receiver's needs without any assistance or opportunity for consultation from other family members. The caregiver is left to deal with the multitude of behaviors and emotional reactions associated with different stages of Alzheimer's type dementia that his or her spouse can develop. Beyond all of this, it appears that the caregiver needs to address his or her own health needs, including how to come to terms with the fact that Alzheimer's disease has now changed their life together. It is this writer's opinion that the effects of caregiving take a toll on a spouse in various ways, including physically, psychologically, socially, and so forth.

This researcher has seen first-hand the challenges that family caregivers can face. In the role of a family care provider of a grand parent with cognitive impairment, this writer has assisted with direct care and assistance in navigating the system. Moreover, this researcher has worked in the health care system since 1998, in a variety of roles including as a nurse's aid, personal care home social worker, psychogeriatric mental health worker, and as a home care case coordinator, which has provided an opportunity to view this topic from various perspectives.

Many formal services exist for patients with Alzheimer's type dementia. Some of these services provide care within a facility; others provide assessment and consultation, social opportunities or ongoing direct care in the patient's home. However, through all of these forms of assistance, it is this writer's opinion, based on being in the role of a family caregiver and having worked in Home Care, that the individual with the diagnosis of dementia is most often seen as the primary client.

Home Care is a community-based provincial program that provides home support to individuals who require health services or assistance with activities of daily living, with the intent to assist individuals to stay in their own homes for as long as possible (Manitoba Health, 2008). It is the largest component of community-based care (Forbes, Jansen, Markle-Reid, Hawranik, Morgan, Henderson, Leipert, Peacock, and Kingston, 2008). In Winnipeg, the Home Care program provides the following services: personal care, nursing, counseling/problem-solving, household assistance, respite/family relief, occupational therapy and physiotherapy assessments, referrals to other agencies, coordination of services, assessment for long term care and adult day programs, companion care and supportive housing programs (Winnipeg Regional Health Authority, 2009). Eligibility for these services depends on being a Manitoba resident, being registered with Manitoba Health, and the outcome of an assessment of need for health care services or assistance with activities of daily living.

The Alzheimer's Society of Manitoba offers a number of services for family and professional caregivers, as well as for individuals with dementia. Support groups for both individuals with dementia and for family caregivers are offered several times per week in

Winnipeg at the Society's office and in different locations around the city. There is also education sessions that are offered frequently in various formats. As well, there is a library of resource material that can be loaned out.

It has been this writer's professional and personal experience that the caregiver is often seen as secondary, or not viewed as the decision-maker on behalf of his or her spouse. In the study by Forbes et al. (2008), the caregivers commented that a comprehensive assessment of their own needs was often not completed. Although these formal services are intended to assist the caregiver by providing care to the individual with the dementia, it has been this writer's practice experience that these services do not always best suit the needs of a particular individual and his or her spouse. Perhaps the spousal caregiver needs to be given the opportunity to identify what resources he or she already possesses and what he or she requires to continue care giving at home. Moreover, Forbes et al. (2008) and, Wuest, Ericson, Stern, and Irwin (2001) suggest that health care service providers, including doctors, must gain a better understanding of the effects of Alzheimer's type dementia on the caregiver, so that they can facilitate care for the family. Formal services may also assist the caregiver to seek out what he or she requires to provide care in a manner that is healthy for both people in this caring relationship. Schmidt, Rapp, Shumaker, Naughton, and Anderson (1998) suggest that caregivers who organize and use their resources well experience better physical and psychological health.

In this aging society, there is increasing concern over accessibility to health care services when they are needed. Forbes et al. (2008) noted that Home Care programs have experienced enormous growth over the last 30 years, but the amount of funding provided

has not kept up with the demand. And without spousal caregivers, the cost of providing care to a person with dementia would most certainly increase. As a result, one must understand what the caregiver believes is needed in his or her system for successful spousal caregiving for a client with Alzheimer's disease. Borden (1991) suggests that there needs to be more study of the caregiver's perceptions of the illness characteristics and what resources are required to manage them. This is a multifaceted issue, taking into consideration all aspects of the couple's life together in the present and past. Many spouses choose to continue to care for their care recipient well beyond the early stages of forgetfulness, and provide what appears to be excellent, loving care. Others find themselves no longer able to cope with the demands of continuous care and supervision, and pursue long term care placement for their spouse.

As a health care professional and a witness to the family care giving experience, it is this writer's opinion that the current health care system often falls short in meeting the needs of the dementia caregiver. It has been this writer's experience, that often the services offered do not meet the needs of the caregiver in frequency, flexibility, immediacy, or they are just not available. As a result, it is this writer's opinion that the first step in reviewing how services may be revised, the caregivers need to be given the opportunity to voice what their experiences have been, what has been helpful, and what would have been helpful to them in providing care to their spouses at home. The spousal caregiver must be seen as the expert.

This study explored the experience of the caregiver from the caregiver's perspective. Family caregivers and health care professionals can benefit from a clearer

understanding of what it is like to care for a spouse with Alzheimer's type dementia at home. As a result of the study's findings, family and professional caregivers will hopefully gain insight into this unique and challenging situation, and work towards change in a particular client situation and perhaps within the greater service delivery system. This, in turn, may assist a caregiver in obtaining what he or she perceives to be required to make a choice as to whether or not he or she continues to provide care at home. Further, public education is needed to assist family members and members of the general community, to increase their awareness of the effects of caring for an individual with Alzheimer's type dementia and what support assists the caregiver and his or her family member (Wuest et al., 2001). The findings from this study will hopefully provide some information that would be helpful for such education.

### **Purpose of the Research**

The purpose of the research was to understand the experience of caring for a spouse with Alzheimer's disease from the caregiver's perspective. The intent was to explore the spousal care giving experience and identify how this type of care giving impacts on an individual, what resources are used, what resources are helpful or not helpful, and what the caregiver perceives is missing that would make his or her role easier. The outcomes will hopefully assist health care providers to understand the caregivers' experiences better and reveal to professional and research consumers, some shortcomings or gaps that do exist in the health care system for spousal caregivers of a demented patient.



## **Chapter Two: Review of the Literature**

This chapter will discuss the recent available literature that has explored the effects on family caregivers caring for a family member with Alzheimer's type dementia at home. Factors identified in research that play a role in a caregiver's ability to cope effectively and continue the care in the community will be identified. Finally, issues around admitting a care receiver to a facility will be discussed briefly as they pertain to a family caregiver's ability to cope and continue care in the community.

### **The Effects of Caregiving**

Alzheimer's type dementia is type of cognitive impairment which seems to be a common diagnosis given to people over the age of 65 years who have signs of memory impairment for which no other cause can be found. The Diagnostic and Statistical Manual for Mental Disorders (4<sup>th</sup> ed), or DSM 4 (1994) describes this type dementia as occurring in approximately 2 to 4% of the population over the age of 65 years, with the prevalence increasing dramatically after the age of 75 years.

The DSM 4 (1994) diagnostic criteria for Alzheimer's type dementia are as follows:

- A. The development of multiple cognitive deficits manifested by both
  - (1) memory impairment (impaired ability to learn new information or to recall previously learned information)
  - (2) one (or more) of the following cognitive disturbances:
    - (a) aphasia (language disturbance)
    - (b) apraxia (impaired ability to carry out motor activities despite intact motor function)

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

(d) disturbance in executive functioning (ie. planning, organizing, sequencing, abstracting)

B. The cognitive deficits in Criteria A1 and A2 each cause significant impairment in social or occupational functioning and represent a significant decline from a previous level of functioning.

C. The course is characterized by gradual onset and continuing cognitive decline.

D. The cognitive deficits in Criteria A1 and A2 are not due to any of the following:

(1) other central nervous system conditions that cause progressive deficits in memory and cognition (e.g., cerebrovascular disease, Parkinson's disease, Huntingtons' disease, subdural hematoma, normal-pressure hydrocephalus, brain tumor)

(2) systemic conditions that are known to cause dementia (e.g., hypothyroidism, vitamin B12 or folic acid deficiency, niacin deficiency, hypercalcemia, neurosyphilis, HIV infection)

(3) substance-induced conditions

E. The deficits do not occur exclusively during the course of a delirium.

F. The disturbance is not better accounted for by another Axis I disorder (e.g., Major Depressive Disorder, Schizophrenia).

The above cited description illustrates the vast array of deficits that this condition can cause, much of which can have a dramatic impact on the individual's ability to carry out tasks independently and interact with others.

Parsons (1997) described caring for a family member with Alzheimer's type dementia as "a complex experience entailing many negative aspects such as burden but also consisting of many positive and rewarding experiences" (p. 2). The focus of most research in this area has been on the taxing aspect of caregiving. Several studies have demonstrated a high prevalence of psychological suffering, such as depression (Adams, 2006; Beeson, Horton-Deutsch, Farran, & Neundorfer, 2000; Deimling, Smerglia, & Schaefer, 2000; Kramer, 2000; Lachs & Boyer, 2000; Lee, 1999; Whitlach & Feinberg, 1997) and anxiety disorders (Mitrani & Czaja, 2000). Lachs and Boyer (2000) suggested that beyond the increased chance of depression, caregivers probably have a higher rate of suicide. However, there is no mention of suicidality in any of the other studies found. Research has shown that caregiving spouses are more likely to suffer depression than other family caregivers (Beeson et al, 2000; Deimling et al, 2001; Kosloki & Young, 1999; Lachs & Boyer, 2000), with women being at the highest risk (Beeson et al, 2000; Kosloki & Young, 1999). However, African American caregivers were found to be at a lower risk for depression than Caucasians (Kosloki & Young, 1999; Wright, Hickey, Buckwalter, Hendrix & Kelechi, 1999). No hypotheses have been put forward as to why there seems to be this ethnic difference.

Other areas of psychological impact discussed in the literature are loneliness, grief, and caregivers' perceptions of their situations. Adams (2006) found that spouses in her study described loss in their relationships with the care receiver in the areas of intimacy, shared activities and future goals, which led to a general feeling of loneliness. Beeson et al. (2000) found loneliness had a high correlation with depression and occurred in both genders of spousal caregivers, but it was more prevalent in care giving wives.

However, Adams (2008) found that in general, care giving spouses, who are caring for their partner with dementia, have more frequent depressive symptoms and are more depressed in greater proportion than spouses that are not in the care giving role. Parsons (1997) found that caregiving males, who had lost relationships with other family members and friends due to the demands of caregiving felt lonely and alone. Dunn and Strain (2001) noted that as the demands of care increased, caregivers, especially those who lived with the care receiver, either reduced or discontinued their leisure activities. In an earlier study, Loos and Bowd (1997) had the same findings, adding that caregivers who had purposely dropped social and recreational opportunities to increase time for care giving later felt regret and frustration over these losses. The sense of being alone and lonely even though the care receiver was physically present was also illustrated. Boss (2002) described this ambiguity of whether or not an individual is still a part of the family as ambiguous loss. The family member with Alzheimer's type dementia is still present in the family home, but is no longer able to participate in the family system to the same extent as before the dementia. When there is a discrepancy between the physical presence and the lack of psychological presence of a family member, how the family perceives this is termed boundary ambiguity, and it can be a risk factor for stress (Boss, 2002). The Alzheimer's care receiver is no longer able to reciprocate thoughts, feelings, or actions in the relationship. The caregiver often finds himself or herself grieving long before the care receiver has died, as this individual no longer has the personality that the caregiver knew and loved. Almborg (2000) suggested that family caregiving and bereavement were all part of the same chronic situation, and there is a sense that the care receiver dies twice. Parsons (1997) echoed this experience of grief before the death of the care receiver, and added that caregivers felt even more pain brought on by the fact that

the care receiver no longer recognized who they were. The loss of recognition about who the caregiver is to the individual tears away the connection that they have built together in all the years past. However, Boss (2002) suggests that if the family is able to come to a consensus or understanding so that the family may grieve what has been lost, but cherish what remains of the family member with the dementia, then the boundaries are adjusted and the potential for stress is reduced.

A caregiver's view of his or her situation has a bearing on psychological wellbeing. Rapp and Chao (2000) found that the caregivers who viewed various events in their caregiving experience in a negative light were more likely to feel a greater frequency of negative emotions than those who were able to view their experiences with some positive thoughts. This study also illustrated that women were more likely to view events as being negative than men. Kramer (2000) supports this idea in her findings, which indicated that over the caregiving career, husbands reported that although the stressors of providing care remained the same or increased, they seemed to adapt to the situation and perceived things as less stressful as time went on. Beeson, Horton-Deutsch, Farran, and Neundorfer (2000) found that the husbands in their study reported a higher emotional investment in the caregiving role and they experienced the demands of this role quite differently from the caregiving wives. However, these husbands reported a higher quality of past and present relationship with their partners than the wives in the study. This was the only study that noted such a finding, specifically. However, men in Parsons' (1997) study expressed a sense of reciprocity of love and caring throughout their caregiving relationship and as the dementia progressed, suggesting a high emotional investment, as well.

Family caregivers describe a wide range of negative emotions. Commonly reported emotions in the research literature are: impatience, resentment, disappointment (Adams, 2006) regret, frustration, bitterness, anger, worry, guilt (Loos & Bowd, 1997), feeling empty, deprived, alone, and in pain (Parsons, 1997). Continually experiencing these and other negative emotions wears on one's psychological health. This, in turn, has an effect on one's perception of physical health as well. Vedhara, Shanks, Wilcock, and Lightman (2001) stated that one's psychological morbidity influences perceptions of physical morbidity. However, the extent to which physical health is affected is debated in the research. Boss (2002) stated that psychological stress can make an individual physically ill, but does not provide specific details. Whitlach and Feinberg (1997) agree and state that there is a high correlation between caregiver mental health functioning and physical well-being, evidenced by worsening of the caregivers' health and depression as their study continued. Family caregivers use more psychotropic medications, more health services for themselves, and have a weaker immune system (Mitrani & Czaja, 2000). Loos and Bowd (1997) noted that caregivers spoke of a lack of sleep and time for themselves. Lee (1999) agreed that when the demands of care are high, caregivers are not likely to get enough sleep, exercise, time to see their physicians, or recover from an illness, but suggested that this group is not at a higher risk for serious illness than the general population. It seems that the areas of physical and psychological health and how they influence one another are difficult to measure, as studies appear to have examined these in part. Perhaps a more holistic approach is needed. Also, further study is needed to understand the relationships among the taxing role of providing care for a family member with dementia, the caregiver's psychological wellbeing, and the effects to his or her physical health.

Research on the positive aspects of Alzheimer caregiving is scarce. Lee (1999) acknowledges that although the role is burdensome, there can be a great deal of satisfaction that is derived from caring for a family member. Satisfaction comes from successes in various areas of caring, such as being able to endure the caregiving experience physically and psychologically with vigilance (Parsons, 1997). Adams (2006) found that there was a sense of accomplishment or mastery when a caregiver succeeded in completing a new task. Although not formal research, Heinrichs (1996) wrote about his caregiving experiences with his wife, Nora. In describing their adventures of daily life together with the disease, Heinrichs illustrates endurance and vigilance as he reviews events with a uniquely positive, problem – solving approach, and the occasional humorous reflection. He wrote this account of his caregiving experiences with his wife for other caregivers who may benefit from his challenges and successes. Husbands in Parsons' study (1997) reported finding they viewed their caregiving experience as rewarding throughout their journey of caregiving discovery. They also took the opportunity to share their experiences and wisdom with others faced with beginning their own journeys.

Some male caregivers saw their role as a final act of gratitude for all the caring they were once provided by that family member in years past. They saw this positive aspect of their care giving role as reciprocity to balance the scales (Parsons, 1997). Women are often seen as the natural caregivers through the course of life, but men are now also finding themselves in the care giving role, caring for their wives and mothers in a challenging reversal of roles.

## **Mediating Factors**

The experience is different for each individual. We are beginning to understand the factors which contribute to making the job easier, and also those factors which make the job more taxing. The literature provides some snapshots of these factors, but it also suggests the need for further investigation.

## Relationships

The quality of the relationship between the caregiver and the care receiver before the onset of dementia seems related to the amount of closeness felt in the caregiving relationship. Davies and Gregory (2007) noted that the marital relationship that pre-existed the dementia is an important lens to consider and the state of this relationship has to be considered when looking at the care giving situation, and go on to suggest that this is a consideration for shaping practice and policy. Caregivers who felt distant in the caring partnership experienced more relational deprivation and loneliness (Beeson et al., 2000).

The relationships between the caregiver and other family members were also important to the caregiver's well being. Caregivers with families that were more adaptable to changing needs of the caregiving situation had less chance of becoming depressed (Deimling et al., 2001). Furthermore, Mitrani and Czaja (2000) found that maladaptive patterns of interaction between the caregiver and the family, occurring most often in Caucasian families, stop the flow of support to the caregiver. This leads to further isolation as family members stop calling and offering to assist. Adams (2006) noted that some caregivers had distanced themselves from friends or family, as they were



tired of receiving criticism or advice that was not helpful. Wuest et al. (2001) also noted that some family members pass judgment on the care being provided while others express feelings of neglect and resentment towards the caregiver, thus adding to deterioration of family bonds. Finally, Adams (2006) found that some spousal caregivers chose to keep the full details of the situation from their adult children because they did not wish to burden their children with their problems.

### Informal Supports

Informal supports are invaluable to caregivers. Borden (1991) found that spousal caregivers who had good levels of peer support experienced higher levels of well-being than those caring for a spouse at home with dementia with no peer support. Whether it is social or practical assistance, support has been found to reduce feelings of depression and burden for the caregiver (Mitrani & Czaja, 2000). Participants in Parsons' study (1997) referred to this assistance as expected and necessary. The amount of social support received may determine how long one can continue caring at home (Schmidt, Rapp, Shumaker, Naughton, & Anderson, 1998). Almberg (2000) discussed the topic in great detail, stating that those caregivers with good supports felt comfortable in their situations, and the awareness that someone cares for them motivated caregivers to overcome feelings of burden. Also, it was suggested that it was important to the caregiver to have support from the same individual throughout all of the stages of the caregiving role, and beyond the death of the care recipient (Almberg, 2000). In their Canadian study, Wuest et al. (2001) agree, adding that a specific, reliable support was helpful in gaining control of everyday situations. This one individual is seen as always being there for the caregiver, a dependable support. Support systems that are sustained mean that caregivers do not have

to ask for help, as there is ongoing communication between the primary caregiver and his or her support system, assisting the care to continue at home longer than would otherwise occur (Wuest et al, 2001). Other informal supports that were assessed by caregivers as being helpful were watchful neighbors, letter carriers, storekeepers, and other community members, who caregivers felt they could rely on in emergencies (Wuest et al, 2001).

Caregivers with fewer social supports were more negative about themselves than those with more supports (Almberg, 2000). The amount of social support received by an Alzheimer's caregiver could be related to the amount of disruptive behavior displayed by the family member with dementia. Lee (1999) stated that as the care receiver's socially inappropriate behaviors escalate, the number of social supports decreases. Wuest et al., (2001) noted that as family members became afraid of the care receiver and his or her behaviors, they avoided visiting the couple. Friends and family can become uncomfortable with the behaviors displayed by the demented individual and also begin avoiding the caregiver. Worse yet, those who do not understand can be cruel towards the care receiver or make assumptions about the cause of his or her odd behavior (Wuest et al., 2001), adding yet another possible source of stress.

### Resourcefulness

Some caregivers appear to coordinate a network of friends and family to assist in the tasks of daily caring while others do not. The research discussed here indicates that this is an essential ingredient, so why would everybody not have this web of resources? Schmidt et al. (1998) could not demonstrate causality in their study, but they determined that a caregiver's social resourcefulness was related to perceptions of better physical and

psychological health, better quality of life, and the identification of more positive aspects of caregiving. Social resourcefulness was directly related to the amount of informal support received and the size of the social circle. Furthermore, contrary to Lee's finding, Schmidt et al. (1998) found that even as the care receiver's cognitive impairment and disruptive behaviors increased, the positive effects of this social resourcefulness did not subside.

### Formal Supports

The use of formal supports to assist in caregiving is paramount for the caregiver. Forbes et al. (2008) described the expertise of health care professionals as an essential resource to caregivers. However, there is a range in the amount and type of formal services used. Wuest et al. (2001) found caregivers to have both positive and negative experiences with professional supports. Caregivers found it more helpful if a physician provided a definitive diagnosis, as it provided the opportunity for clarity and possible access to support services, instead of prolonged uncertainty (Wuest et al., 2001). Also, professional service providers offered support and reinforcement to the caregiver, which validated decisions that the caregiver had made, boosted self-esteem and energy to continue care giving, and perhaps, assisted in making transitions (Wuest et al., 2001). Winslow (1997) agrees, adding that formal caregivers often provide "support and permission" (p.19) to the family caregiver for decisions that he or she has made.

Although causality was not discussed, Kosloki and Young (1999) noted that the more services used by a family caregiver to assist in caring, the more likely he or she is suffering from clinical depression. In-home nursing service utilization specifically has

been found to be correlated with the presence of symptoms of depression in the caregiver (Hawranik, 2001). It is difficult to determine from the available literature if the presence of depression in a caregiver causes a caregiver to obtain more services. Perhaps the presence of depression is only an indicator of yet another element that precipitates the use of formal services. Hawranik (2002) found that in Manitoba, the higher the caregiver burden and the greater the number of health problems reported by the caregiver, the more likely he or she was to use two or more home care services for his or her family member. Penning (1995) added that although there were no differences between adult children and caregiving spouses, those who perceived themselves to be in poor health and had a care receiver needing assistance with personal care and household management, utilized more formal services. However, increased care recipient dependence in all aspects of life was correlated with increased use of in-home services. Hawranik and Strain (2001) agreed, adding that even though the care recipient's diagnosis may not be available, the care recipient's functional level of dependence and the caregiver's ability to cope are more likely to be taken into consideration when assessing for the eligibility for home care services in Manitoba. Caregivers of a family member with dementia were four times more likely to obtain assistance with personal hygiene tasks for that family member than caregivers of people who did not have dementia (Hawranik, 2001). Dunn and Strain (2001) suggested in their Manitoba study that the use of adult day care and other respite programs may provide for the caregiver some beneficial time away from care giving duties. Winslow (1997) also noted the benefits of adult day programs reported by caregivers in freeing up time for caregivers to visit friends and accomplish errands, suggesting that this may assist the caregiver to keep his or her spouse at home longer. Care recipients living alone and living in rural areas in Canada used more services more

often than those who had a caregiver living with them or those in urban centers (Penning, 1995). Finally, some caregivers received benefits from attending support groups, by being provided with an opportunity to vent, receiving support from other caregivers, as well as being provided with educational information (Winslow, 1997).

It appears that caregiver strain is not the only factor related to the use of formal services, but perhaps some services are not utilized appropriately or often enough for the full effect of caregiver relief to be realized. Whitlach and Feinberg (1997) noted that those who used in-home respite services for a short time or infrequently were less likely to adapt to the changes in the dementia process than those who used respite services continuously or those who did not use respite service at all. A caregiver's acceptance of assistance from formal services is not seen as a sign of weakness, but rather addresses identified needs. Winslow (1997) noted that caregivers often find it difficult to accept help, as they feel that they need to be self-reliant. Male caregivers in Parsons' study (1997) found that there was an essential need for assistance from formal services for both emotional support and for direct care for their spouses. Caring for someone with Alzheimer's type dementia can be a 24-hour per day responsibility. For a caregiver to manage the demands of care, he or she usually needs to accept assistance from friends, family or the health care system.

The services provided by the health care system need to match the needs of the caregiver and his or her family member. These services must also be available on a consistent basis, so that they are also reliable. Caregivers reported that some support staff became like members of the family and were able to provide sensitive care, thus

alleviating the care demands on family caregivers. Limitations in the number of hours available and tasks that the staff members are allowed to perform became burdensome to caregivers (Wuest et al., 2001). Other limitations noted in Wuest et al.'s (2001) study were that although both adult day care programs and personal care home respite stays were helpful, these were either not available often enough or for long enough periods of time, or the care receiver became upset with the change in surroundings (Wuest et al., 2001). In the findings of the study by Forbes et al. (2008), it was also noted that the amount of helpful services was not sufficient to meet the caregivers' needs. It is this writer's opinion that issues related to service delivery systems and management of resources pose difficulties leading to some discrepancies between what the caregiver feels is needed and what is offered.

### Caregiver Characteristics

Certain attributes of the individual caregiver affect the amount of negative and positive effects caregiving has on the individual. The perceptions held by the caregiver regarding the caregiving situation have an effect on his or her well-being (Boss, 2002). A caregiver's perceptions of social expectations to provide care are related to the level of depression that he or she experiences (Kosloki & Young, 1999). If a caregiver believes that there is great social pressure to continue providing care regardless of situation and care needs, the caregiver is more likely to suffer from depression. Also, the caregiver's view of what is positive and what is negative has an effect on his her well-being. Borden (1991) reports that spouses caring for a dementia patient at home who maintained a positive focus and took a problem-solving approach to issues had higher levels of psychological well being than those who did not have the same focus. Decreasing what is

seen as a strain and increasing what is seen as a positive aspect to caring is helpful in decreasing the level of negative emotions experienced, thus reducing the potential for psychological morbidity (Rapp & Chao, 2000).

One's reactions to events are also factors of consideration. Vedhara et al. (2001) found that caregivers who used confrontation or escape-avoidance techniques to cope and displayed more neuroticism were at greater risk for psychological morbidity than those who did not. A sense of powerlessness and feeling unable to control the decisions being made also adds to the potential for caregiver depression. Deimling et al. (2001) found that caregivers who experienced less satisfaction with the care decisions being made had higher levels of depression than those who reported a high level of satisfaction with care decisions.

Finally, spiritual beliefs are seen as a positive aspect for the caregivers who follow a faith. It offers some structure and meaning for their emotional responses to grief and religion has been associated with a lower occurrence of depression in caregivers and a higher quality of relationship between caregiver and care receiver (Almberg, 2000). Moreover, it has been this writer's experience that spirituality often brings a sense of community and support from a community that belongs to the same faith.

### Self Care

How one cares for oneself has an impact not only on the individual's well being, but also on his or her ability to continue caring. Lee (1999) found that caregivers are more likely to receive immunizations for influenza and pneumonia and eat regular meals

than the general population. As compared to the general population, more caregivers drink alcohol, but they drink less alcohol than the general population (McKibbin, Walsh, Rinki, Koin, & Gallagher-Thompson, 1999). McKibbin et al.'s (1999) study also found that only 10% of women caregivers smoked, as compared to 12.5% of women in the general population. The other positive behavior illustrated by McKibbin et al. (1999) was that exercise is still a part of daily life, with 37% of the participants reporting that they are as active as or more active than other women their age. However, the women in this study who provided more personal care exercised less than those women who provided assistance with household management tasks. In contrast, Mitrani and Cazja (2000) found that caregivers of family members with dementia use more psychotropic medications and use health care services for themselves more often than the average population.

A decline in the caregiver's physical health is related to an increase in depression (Kosloki & Young, 1999). The caregiver's physical health and psychological health are linked, and if one aspect of the individual is affected by an illness, there are other effects on the caregiver. It is this writer's opinion that the illness could start the caregiver down a spiral of deterioration, which could accelerate when the caregiver is no longer able to meet the growing needs of the care receiver.

### Care Receiver Characteristics

Finally, the care receiver's level of cognitive impairment and related needs and behaviors also play a role. The effect of cognitive impairment on the caregiver is debated in the literature. Deimling et al. (2001) found that the care receiver's level of cognitive



impairment had no direct effect on the caregiver's psychological health. There were several indirect effects, such as ability to participate in decision-making, level of dependence on the caregiver, and behaviors. Also, physical impairments were found to have no direct or indirect effects in this study.

Kosloki and Young (1999) noted that the more problematic behaviors the care receiver had, the more depressed the caregiver was. Rapp and Chao (2000) add that there is a strong correlation between memory and behavioral problems, and a caregiver's perception of strain. In turn, this perception of strain correlates strongly with negative emotion (Rapp & Chao, 2000).

### **Issues of Placement**

Placing a family member in a long-term care facility is usually seen as a last resort after all other resources have been exhausted. However, there are differing opinions arising from the research as to what facilitates that decision. Tsuji, Whalen, and Finucane (1995) suggest that the only medical issue that increases the chance of admission is diabetes, and that the only physical limitations that are most likely to precipitate admission are visual impairment and incontinence. The primary catalyst for applying for placement is related to the caregiver. Whitlach et al. (1997) stated that the most influential factor in this decision is the caregiver's physical health. Lee (1999) disagreed, stating that the decision to place a loved one is related to high levels of emotional stress. Likien (2001) suggested that the decision is related to subjective feelings of burden, as well as severe memory impairment and behavioral problems that leave the individual at risk when living at home. Gold and Reis (1995) suggested that it is a combination of all

of these factors, with 81% of caregivers stating the decision was made due to deterioration in cognition and behavior and 52.1% noting their own physical and mental health as the deciding factor. It is likely that all of these issues play a part in the decision to admit a loved one into a long-term care facility, but each caregiving situation is different. Situational factors, such as the lack of time the caregiver has for providing care and living separately from the care receiver, increased the chances of admission to long-term care (Tsuiji et al., 1995).

Often there is a specific event that occurs that serves as the catalyst. Liken (2001) reported that all of the caregivers studied could identify an event that led to applying for placement, but only two of these did not see the event as a crisis situation. It appears that caregivers are so determined to keep their family member with dementia at home, that they often do not look ahead or explore alternative care plans should they not be able to continue. Perhaps other caregivers do not take notice of indicators that the caregiving situation is deteriorating until a crisis occurs. Caregivers may voice that they would like to have their freedom back, but they also state that they do not wish to give up the caregiving role by placing the individual in a facility (Loos & Bowd, 1997).

The experiences of caregivers following placement of a family member have also been varied. Caregivers have feelings of uncertainty about their decision, as well as guilt and a sense of failure (Liken 2001). "Guilt deepened and emotional well-being is at risk when full time care is transferred to an institution" (Loos & Bowd, 1997, p. 511). Some caregivers had second thoughts about the admission and contemplated discharging their family member and bringing them home again (Liken, 2001). It seems that many

caregivers have thoughts of discharging their care recipient and trying again to provide care at home, but no information on prevalence was provided. Kramer (2000) found that husbands who had placed their wives in facilities experienced an increase in physical and social resources following placement, but did not experience an improvement in their psychological health, as 50% of these suffered from clinical depression. Lee (1999) agreed that there is an improvement in physical health, but also that there is an improvement in psychological health after care is transferred to a facility. However, placing a care receiver in a facility does not necessarily mean that all the aspects of the caregiver's previous life can now be addressed. Many caregivers spend large amounts of time at the facility, assisting to care for their spouses (Loos & Bowd, 1997). Both Liken (2001) and Kramer (2000) noted in their United States-based studies that caregivers found the cost of facility care to be a source of burden and concern. No Manitoban or Canadian studies were located that offered findings related to cost of facility care.

## **Conclusion**

The literature identifies that the job of caregiving for a family member with dementia is very taxing. It affects emotion, as family caregivers experience more negative emotion, such as grief and loneliness, in comparison with other non-caregiving cohorts. Spouses in this caregiving situation are especially at risk for depression. The effects on physical health are not yet clear, but the physical burden, such as a lack of sleep and less recovery time from illness is known. However, each family caregiver's situation involves mediating factors that make the job easier or more difficult. The literature highlighted factors such as the availability of informal supports, previous relationship dynamics with the care receiver, the caregiver's personality and expectations,

and his or her spirituality. Beyond this, the degree of the care receiver's dementia is a factor in what behaviors are present. All of these highlight the complexity of caring at home for a spouse with Alzheimer's type dementia and the need for further holistic study.

## **Chapter Three: Research Design**

### **Research Interest**

What do spousal caregivers experience, what do they possess and what are they lacking in resources to continue caring for their partner with Alzheimer's type dementia at home? This study explored what caregivers perceive about how they manage to care for their demented spouses 24 hours a day, manage their households and keep themselves healthy as well. This research also examined how caregivers have utilized their own strengths to adapt to the demands of caregiving. As well, the research brought light to how caregivers utilize outside resources and what difficulties this presented for them.

### **Research Design and Methodology**

This qualitative research design is exploratory with the intent to gain a deeper understanding of this subject of caring for a spouse with Alzheimer's type dementia at home from the perspective of those involved, the caregivers. A qualitative research method was chosen over a quantitative method, as qualitative research allows for understanding the participants' experiences from their own perspectives without reducing these experiences to statistics (Taylor & Bogdan, 1998). Moreover, it provided the researcher with some insight into the thoughts and feelings of the participants and an opportunity to explore in depth the caregivers' experiences. Qualitative research can illustrate the participant's situation and experiences in such in-depth detail that it will "leave the reader with a sense of having walked in the shoes of" the subject (Rubin & Babbie, 2001, p. 203). Moreover, Reid and Smith (1989), Josselson (1993), and Taylor and Bogdan (1998) all agree that qualitative research is holistic. Denzin and Lincoln

(2003) were also in agreement and added, “it begins with a search for the understanding of the whole” (p. 57). Reid and Smith (1989) state that holistic knowledge about complex social situations is highly valued in the social work field. Also, Boss (2002) suggests that a holistic approach is the best approach as it is essential that a subject’s internal and external contexts be explored if his or her experiences are to be understood. Thus, a qualitative research method was the most suitable for this research.

### **Narrative Approach**

The methodology used in this study was the narrative approach. Boss (2002) suggested that the use of a narrative mode of inquiry is the most useful in recording and telling one’s story, stating, “Only after we see the event through a family’s eyes (and each member’s eyes) can we learn how to assess, support, and intervene without prejudice” (p. 26). It is this writer’s opinion that the narratives of the spousal caregivers were essential for understanding their experiences. It provided an opportunity for the caregiver to express in his or her own words what daily life was like for him or her.

The primary data collection method was the face-to-face interview, which was conducted with each participant individually. These interviews were what Flick (2002) has termed, episodic narrative interviews that allowed for the collection of concrete information with context-related narratives. Here, the interviewer asked questions about specific experiences. These questions were constructed in a way that allowed for the answer to take the form of a narrative and not just a “yes” or “no” answer. The core element of the episodic interview is the “periodical invitation to present narratives of situations” (Flick, 1998, p. 106). The interviewer’s questions allow for the opportunity

for the interviewee to tell a story about a specific experience, giving detail that will help the interviewer understand what that experience was like. Flick (2002) suggests that episodic interviews are useful in obtaining narratives about situations or experiences instead of an entire biography. To understand the experience of caring for a spouse at home with Alzheimer's Disease, a participant's entire biography would not be as meaningful to the study as would caregiving – related episodes. Moreover, Flick (1998) suggests that one's experiences and knowledge are stored in the forms of narrative-episodic and semantic information. By using an episodic interview approach, the interviewer accessed both types of information. This method was designed to collect and analyze the narratives of specific episodes, and gather the semantic, conceptual information elicited from concrete questions. This approach allowed participants to recount certain times in their caregiving, but also add depth to their accounts by the additional conceptual information collected by direct questions. Flick (1998) states that this method provides a link between the two types of data and creates a presentation of a participant's experience and the context in which the experience occurred. Further, Flick (1998) states, "By linking narratives and question-answer sequences this method realizes the triangulation of different approaches as the basis of data collection (p. 109).

The interviews were informal and were be modeled after normal conversation as much as possible, but the researcher still had an effect on the interviewees (Taylor & Bogdan, 1998). The interviewer's intention was to allow participants to tell their stories. There was an interview guide, which consisted of a set number of questions. This guide oriented the researcher to the topics that need to be discussed and allowed probing where there were opportunities for narrative accounts (Flick, 1998). Prior to asking the first

question, the researcher gave the participant an overview of what topics the participant would be asked about. The participants addressed each topic in the guide by responding to open-ended questions (see appendix 1 for interview guide). By using an interview guide, the same topics were covered for each participant's interview, but the researcher had the flexibility to probe into unexpected comments by the participants to gain further understanding and to assist in keeping the interview as close to normal conversation as possible (Rubin & Babbie, 2001).

Each interview was tape-recorded, as this was to ensure that the data collection is verbatim, and it allowed the interviewer to participate more fully in the conversation (Rubin & Babbie, 2001). The tape recordings from each interview were then transcribed and each line numbered. "Taping and transcribing are absolutely essential to narrative analysis." (Reissman, 1993, p. 56). By taping and transcribing, the researcher can be certain that the interviewee's responses are accurate word for word. The transcriptions were checked closely with the tapes for comprehensiveness and accuracy.

During the entire research process, including the interviews, the researcher took field notes. These notes detailed what the researcher observed and learned throughout the research process (Taylor and Bogdan, 1998). For each interview, the researcher took separate field notes. These were notations of observations made by the interviewer about the participant's nonverbal and paraverbal communication. Also, the researcher noted separately any personal reminders, thoughts or emotional reactions to the interviewee or the topics of discussion that the researcher, herself, experienced.



Each transcript was read and reread in its entirety, along with the corresponding field notes. A second copy of each transcript was made and coded line by line, as were the field notes. The field notes were used to add another dimension to the data. Coding is a means for organizing raw data into concepts or ideas that emerge from the text (Coffey & Atkinson, 1996). The codes were then collapsed into categories of commonality. This step of analysis was done by reviewing the codes and sorting them into categories of similar meanings (Winslow, 1997). Each category was named from interviewees' expressions, termed "in vivo codes", keeping the categories closer to the studied data (Flick, 2002, p. 178). From here, the data were read again and the categories were collapsed into themes. This final step in the process allows for the commonalities in stories to come together and "enables the caregiver's experience to be understood in new ways." (Winslow, 1997, p. 15). This form of research was selected as Flick (2002) suggested it is the most appropriate format for episodic narrative interviews. Although Labov's structural approach was considered as a framework for analysis, Riessman (1993) suggests that many narratives do not fit well with Labov's framework. It is this writer's opinion that this research did not lend itself to the idea that each narrative response had a common set of elements and that every clause had a function, as Labov suggests (see Riessman, 1993).

Reporting of the data was incorporated into the thesis, describing the caregiver participants' narratives and was accompanied by an integrated literature review. This design and methodology allows for extensive exploration into the experiences of caregivers caring for their spouses with Alzheimer's type dementia at home in an urban Manitoba setting. The narrative design permitted in-depth analysis into the meanings

held by these caregivers about their experiences. Furthermore, these cases were bounded by time and location, and similarities in their situations will be outlined.

Rigor in this qualitative study was addressed in a number of ways. By combining the caregivers' narratives with the integrated literature review, triangulation was achieved. In qualitative research, triangulation enhances rigor by using two or more sources of information to create a more comprehensive view of the specific subject (Padgett, 1998). Also, the process of taking field notes, having interview transcripts, and making notations during the coding process, assisted in ensuring rigor. Lincoln and Guba in 1985 (Padgett, 1998) refer to this process as leaving an audit trail. Finally, ensuring rigor was assisted by the process of peer examination. This consisted of the thesis committee chairperson reviewing the taped interviews, transcript, and subsequent coding to examine whether or not the same conclusions are made as the researcher (Krefting, 1991). The results of this were that the conclusions were the same, and the researcher provided a rationale as to why some codes were kept rather than left out.

### **Target Sample**

The target group is a bounded system (Creswell, 1998, p. 61) of spouses of individuals diagnosed with Alzheimer's type dementia, who cared for their partners at home at the time of the study and received services from the Alzheimer's Society of Manitoba. These participants could have also been receiving services from any another community-based program. This sample consisted of spousal caregivers, who reside in Winnipeg at the time of the study and participate in the programs offered by the Alzheimer's Society of Manitoba.

The researcher contacted the Winnipeg office of the Alzheimer's Society of Manitoba, explained the study and requested to attend a caregivers' support group meeting to give participants information on the proposed research project. The researcher presented the proposed study and discussed the purpose of the study, the need to hear from caregivers what their experiences have been and what the study's benefits were to caregivers. The researcher explained that the caregivers were considered the experts in this study and their input was essential for better understanding of what is and is not helpful to them. The researcher left her contact information and a description of the study for each participant with the group's facilitator. By leaving the information with the facilitator, those interested voluntarily chose to contact the researcher to participate without the researcher's presence as an influence. Those interested in being participants in this study then contacted the researcher. This protected the identity of those who are connected with the Alzheimer Society and were not willing to take part in a study.

### **Participant Selection**

Those that chose to contact the researcher to take part in the study and met the criteria in the purposeful sampling, were provided with a consent form. The consent form outlined the background and purpose for the study, the procedures, risks and benefits, measures that were taken to ensure confidentiality and notation that this research was approved by the University of Manitoba's Joint Faculties Research Ethics Board. Also, the intent, design, expectations of the participants, measures to ensure confidentiality, and available resources should a participant find taking part in the research to become emotionally difficult were explained in the consent form. The consent form and its

contents were discussed with each participant. The researcher answered any questions that the participants had at that time and if the participant agreed, he or she signed it.

The participants were selected by purposeful sampling. Purposeful sampling allows the researcher to select participants that she believes will provide the most comprehensive, representative information on the subject (Rubin & Babbie, 2001).

Willing participants who responded to the researcher's request were selected if they met the following criteria: residence in Winnipeg, the caregiver reports that his or her spouse has the diagnosis of Alzheimer's type dementia, the spousal caregiver and care receiver reside together, and the caregiver is willing to participate in one tape-recorded face-to-face interview. The purposeful sampling was used in anticipation of selecting cases from the willing participants of both genders, and from varied cultures, backgrounds and situations, and, if possible, the care receivers were to be in different stages of the disease process. The number of participants interviewed was determined by data saturation. Once the participant responses become repetitive, then no further participants were interviewed.

### **Conducting the Interviews**

The appointments for the interviews between the researcher and the interviewees were set up over the telephone, at which time, the interviewer gave the participants the choice of meeting at their home, the researcher's home, at the office of the Alzheimer's Society of Manitoba, or at an interview space at the researcher's office. Two of the participants selected to come to the writer's home, two selected to meet in the office setting, and the remaining five participants invited the writer to attend their home. Most

of the interviews occurred during the day, with the exception of two interviews that occurred in the evening, at the request of the participant. Most interviews were completed in approximately two hours. However, two interviews exceeded three hours. Some of the interviewees chose to meet when their spouse was at an adult day program, others chose to meet with the writer when their spouse was present, and the two participants that attended the writer's home, chose times when they had someone staying at home with his or her spouse.

Most interviews were completed within two hours, however, there were a few that concluded after three hours. The first two interviews felt the most awkward to the writer, with the questions not flowing naturally. The writer found that any additional probing questions during these first two interviews did not come naturally and seemed to feel more mechanical. Perhaps part of the reason for this was that both of these first two interviews occurred in an office setting, which may set the mood to be more formal and mechanical. One of the first two interviewees commented that he was timing the writer, as he had other appointments to keep as well. Throughout the course of this particular interview, the writer was watchful of the time, and never relaxed for that hour. Nonetheless, as the interviews progressed and the writer became more familiar with the sequence of the questions, it became much more natural and the probing questions felt more like how a natural conversation might go, with the exchange of conversation occurring.

### **Methodological Limitations**

In working to select to best methodological approach for this study, this writer came to the opinion that there is no one perfect choice, as there are limitations to any approach. In saying that, the researcher had to be mindful of the limitations associated with this research project. To begin, the selection of the narrative approach means that the interviewer is asking the interviewees to tell their stories. However, as Creswell (2008) discusses, there is a potential for reactivity from the interviewer in the data that is collected. By the interviewer asking further probing questions or asking for clarification during the interview, the interviewer is having an effect on the story that is being told.

Also, the selection of the participants for this study may have led to a limitation in the potential for the stories that could have been told. The request for research participants was through the Alzheimer's Society of Manitoba only. Therefore, there was no opportunity for spousal caregivers who were not receiving services from this organization to either know about the research or to be offered the opportunity to participate. It could be argued that caregivers, who do not use this organization's services may have different experiences and different information to share. Furthermore, all of the participants in this study took part in the study because they volunteered and took the initiative to contact the researcher. However, it could be argued that these individuals' experiences may be somehow different than those who did not take the initiative to be a part of this study. Furthermore, one could speculate that their care giving experiences were even more stressful and physically draining, and this is perhaps why they were not a part of the study. Also, the sample of participants did not have any representation from different marital situations, such as second marriages. Perhaps if there would have been representation from these groups, the stories may have had some differences.

## **Chapter Four: Data Collection**

### **Interview Results**

This chapter discusses the content of the data collected from the researcher's one on one interviews with participants. There were nine participants in total interviewed. All of the participants resided with their spouses in their own homes within the city limits of Winnipeg at the time of the interviews. All of the care receivers, who's spouses were interviewed, had received the diagnosis of Alzheimer's type dementia. Some of these care receivers were in the early stages of the disease, while others were at later stages and required constant care and supervision. The reported range of years with the diagnosis was four to ten years with the median of five years.

The participant caregivers in the study consisted of two men and seven women. Their cultural backgrounds were varied, with two of the caregivers having immigrated to Canada. The participants' cultural backgrounds included: European, French Canadian, Jewish, Norwegian, and Filipino. All of the caregivers were married to their care receivers and the range was from 35 to 61 years of marriage with a median of 51 years. All of the caregivers had children with their spouses, with the range of three to six children with a median of three children.

### **Summary of Data Collected**

The data taken from the interviews consisted of the researcher's notes in a journal and 304 pages of transcription. The coding of the interview transcripts and the writer's journal notes was reduced to sixty categories. Out of this, came eight themes and some

extraneous data. Appendix 4 contains a listing of the sixty categories within the eight themes. The eight themes illustrated are as follows:

1. Need to walk in the caregiver's shoes to understand
2. Constant Vigilance and Care
3. Emotional and personal toll of care giving
4. Caregivers' Internal Coping Strategies
5. Practical techniques for survival
6. Importance of informal supports
7. Positive attributes of formal supports
8. Suggestions offered for improvement of formal supports

In discussing these eight themes, this writer makes reference back to specific interviews and the responses by the participants. The numbers noted in brackets refer to the interview in which the comments were made. This allows for a mechanism for reference back to a specific participant's views on a topic.

#### Need to Walk in the Caregiver's Shoes to Understand

During the participants' interviews, the researcher repeatedly heard the sentiment that caregivers did not feel that their situation was understood by family and friends that offered advice, and by services, such as Home Care. "Friends, they just don't realize, they just don't know the whole story. They just see what they see, you know, across the table or whatever and they really kind of think. And they just have no idea." One participant stated, "No one can tell really until you wear that person's shoes, so to speak." (#8), in reference to her struggle to appeal the decisions made by various parts of the health care system. This participant described her struggles to obtain services modified to



meet the needs of her husband's behavioral symptoms of dementia and her physical limitations. She also added, "Other people do not relate to your problems whatsoever" (#8). Another participant also noted that others do not relate and, "A person say well he's got Alzheimer, oh it's not that bad, but it always is" (#5). This participant recalled various episodes of challenge with the care receiver and stated, "the goings on like from hour to hour, day to day, you can't imagine what it's really like" (#5). Although a number of caregivers commented that at times they did not feel that they were being heard by their health care providers, one caregiver recounted conversations that she had had with Home Care staff and others whereby she was pleading with them for additional service (#8). The impact of this event on the caregiver was evident, as she described these conversations in tears. In reviewing the statements made by the participants on this topic, it was interesting to the writer that none of the participants made direct comment that they felt that their situation was being minimized by others. The sense that this researcher received from the participants was that those who do not live in the home do not have a true sense of the caregiver's situation.

The researcher also heard that everyone's situation is different, but yet there are similarities. One caregiver commented on his reactions to the stories he had heard from other caregivers in their support group and how different the issues of care could be from one caregiver to the next. In relation to how some one else's spouse was up frequently at night, wandering, he said, "Man and I thought I had it bad, but at least my wife sleeps through the night! (#2) Although the specific examples of challenges that were shared with the interviewer varied from one caregiver to the next, the common element was that the role is not easy at all. Some caregivers expressed frustration that their situation was

assumed to be the same as other caregivers', even though the stage of the disease may be different, or any other number of factors may be different. Furthermore, a common sentiment that was heard was that it is difficult to really give solid advice to someone until you know personally what it's like to be in their position. "You don't really know until you are there living it" (#1).

### Constant Vigilance and Care

Repeatedly caregivers spoke of having to be constantly aware and diligent. Comments such as, "you would like to be able to lay down, but you can't" (#6), being a "babysitter and caregiver" (#1), and never letting one's guard down, were common. Two of the participants noted that their care receive cannot cope if his or her spouse is out of sight. Both of them reported that their spouse becomes very anxious if he or she cannot find the caregiver. One of these caregivers noted that she cannot even go to the bathroom without taking her spouse with her, as he will begin to panic and will frantically begin calling out to her and banging on the bathroom door to see if she is in there. The other caregiver noted that this need to keep within sight of the spouse has come to a point that the services by Home Care had to be discontinued, as the staff could not deal with the care receiver's anxiety when the caregiver left. This was also mediated with the notion that if caregivers do not take breaks, they will soon come to a point that they will not be able to continue.

Issues related to care receivers repeatedly losing or misplacing belongings meant that the caregivers were always trying to keep track of important personal items, such as partial plates, hearing aids, glasses, and identification. One caregiver noted that after

having a couple of episodes of a lost diamond ring, he put away all of his wife's valuables, and left the costume jewelry. He added that he struggled with this, as his wife had always enjoyed dressing fashionably and wearing her jewelry, and now he was changing a part of who she is. Several caregivers in this study reported that they had taken away all of the important items from the care receiver's wallet or purse, such as identification, bank cards, and credit cards.

All of the participants interviewed confirmed that to at least some extent, they have to intervene on a daily basis with their spouses' personal care tasks. This ranged from one participant noting that she is directly providing care with bathing, dressing, feeding, and elimination, to other care providers reporting that their main role is laying out clothes in the order that their spouses need to put them on, and then providing supervision and coaching. Some caregivers noted that this is a great source of tension between themselves and their spouses, with one noting that his wife will often question, "Who made you boss?" (#1) during personal care routines. Another caregiver referred to any task related to bathing and dressing as "a battle" (#5). Some caregivers reported that their care receiver had difficulties with incontinence, thus leading to an increased need for supervision, hands-on assistance, laundry, and cleaning. Many caregivers expressed feeling uncomfortable about intervening in "bathroom duties" (#1), as some would not use direct language about the topic during the interview, and others did state that they found this to be the most intrusive task that they were involved in. One participant described her level of discomfort by saying that even after all their years of marriage together; she has a funny feeling about invading his privacy in the bathroom.

Medications and eating properly were also an area requiring supervision by the caregivers in this study. Ensuring that their spouses took their prescriptions as directed was reported to be a daily chore for these caregivers. Some noted that all they needed to do was to give their spouse the dosette and they could follow the schedule with minimal input from the caregiver. Others noted that they had to give the pills to the care receiver and then watch to ensure that they were swallowed. Although encouraging one's spouse to eat was only mentioned as an issue by one caregiver, two other caregivers noted that their spouses had diabetes and had the habit of eating items that were high in sugar. Both of these caregivers recounted stories of catching their spouses eating sweets, having arguments with their spouses about their desire to eat sweets, and then later removing all high sugar items from the home permanently. Generally, most of the caregivers in the study noted that they do need to cue their spouse around how to eat specific food items properly, whether it be taking something out of the fridge and eating it uncooked or drinking the salad dressing out of the bowl in a public dining setting.

Another area of increased physical toll was all of the additional duties that the caregiver has had to assume as the care receiver has lost the ability or the desire to complete. The researcher heard repeated stories related to the female caregivers needing to learn about household repair, car maintenance, and yard maintenance, such as one caregiver noted, "'cause now you are having to do all of the repair work and everything else" (#3). As well, the male caregivers commented that they needed to learn or reorient themselves to meal preparation, housecleaning and laundry, as one male caregiver described it, "I'm a bachelor, really" (#2). From one interview to the next though, it was interesting to note that there were several female caregivers who had always managed the

household bills and daily banking needs, so this task was not one of the new assumed roles. However, regardless of what tasks had always been the responsibility of one spouse or the other, the new reality described by the participants in this study is that it now all rests on them. One participant noted, "But it's always, it's always me" (#4). Another participant took this sentiment a little further, "I am the manager. This is no option here. I feel like I am his activity director too" (#7). From this, the researcher's understanding is that now every decision and task rests on the caregiver.

Caregivers commented on how all these extra duties, need to be available for supervising their spouse, and for many, a lack of sleep, were leaving them tired and not able to ever feel rested. One caregiver stated, "it's like taking care of a baby, it's exhausting, but the difference for me is that my husband does not have a nap during the day that could mean I could lay down to rest too" (#5). Two caregivers commented on how they now must shovel the snow, as their husbands were no longer able to do this, but that this task was difficult, given their own physical health conditions. When asked if the care giving role had had a negative effect on their health, five of the eight participants interviewed stated that they have indeed experienced an increase in health concerns. Since their spouses started experiencing memory problems, two of the caregivers are now receiving treatment for high blood pressure, one experienced a heart attack, two are now receiving treatment for diabetes, and another is experiencing increased episodes of rheumatoid arthritis flare ups and migraines.

### Personal / Emotional Toll

“I feel lonely” (#4) and “I don’t feel like they are there” (#9) were common themes throughout the interviews completed in this study. Participants repeatedly alluded to the fact that although their spouse still remains in the home with them, there is a huge void in presence. All of the participants spoke specifically about the lack of conversation with their spouse, with some commenting that there was no use telling their spouse about things that were going on now. Many expressed a literal hunger for conversation with some depth. A number of participants noted that this was the most difficult aspect of the illness, with one stating, “the biggest missing link is meaningful conversation” and commented again that he was essentially a bachelor (#1). Another participant stated, “I call myself a living widow” (#7).

Along with the change in conversation, many in the study noted that their role in the marital relationship had changed on another level as well. Several drew similarities to their new marital reality to that of parenting a small child or that of a custodian. One caregiver commented, “All of a sudden I have to do all those things like you would for a baby” (#3). To reinforce this perception of what daily life has become for the caregivers, the researcher heard that several of the care receivers are no longer recognizing their spouses and have come to see them as their parents, calling them, “Mom” or “Dad”. One caregiver recounted a point in her husband’s history when he did not recognize his daughter and believed her to be his mistress. This shift in the marital relationship that the participants have experienced was repeatedly described as difficult, with some struggling with acceptance of this new reality. One participant stated, “He’s not the man I married, but what can I do? Nothing.” (#8)

The level of conflict in several of the participants' relationships has increased as well. The researcher noted that there were frequent comments regarding arguments occurring more often than ever before in the marriage. As well, topics that were never a source of disagreement had become a constant sore spot. One caregiver noted that even though she and her husband had always shared the household financial decision-responsibility and had always had open discussions, this was no longer the case. In describing recent decisions that needed to be made by a certain deadline, she commented on how she had tried to include him on a level where he could still participate, but her best efforts did not succeed, and the feedback she received from her husband was that she was taking over and not allowing him a fair opportunity to participate. Again, another caregiver in a similar situation was faced with antagonistic comments from his wife that were outside of her character prior to the onset of Alzheimer's. Two caregivers described this repeated tension and potential for conflict as, "depressing" (#2, #3).

Caregivers shared the common theme of feeling overwhelmed, with some more than others. Two described their current lives as not going well and they knew that their situation was only going to get worse. There were comments about emotions showing at times, uncontrolled sobbing, feeling tired, anger, depressed, guilt, feeling like there is no one to turn to, and that he or she is "at the end of their rope". One participant said, "I can't help but shed tears, my depression just gets deeper and deeper" (#8). During one interview, there was a disclosure of having had thoughts to attempt suicide in the past, but that the participant knew that this was no answer, as if the caregiver was to die by suicide, then the care receiver would be left alone. During another interview, a caregiver disclosed that at times, the anger becomes so overpowering that the caregiver lashes out

at the care receiver with a verbal assault and then later regrets all the hurtful statements that were made.

The researcher received the message from the participants in this study that there is a distinct sense of isolation and feeling trapped. Unlike many people who have the option to just walk away and take a break before a stressful situation leads to regrettable actions, these caregivers do not have that option immediately at hand. There is a definite loss of freedom. Caregivers in this study noted that they cannot just pick up their keys and leave the home when they need a break, as the care receiver would be left in the home without any support and supervision. For those that had services or help from family or friends to provide respite to the caregiver in whatever form, they needed to make those arrangements ahead of time. The feedback that the writer received was that this option is still helpful to a point, but that the isolation and sense of being stuck still exists outside of those scheduled times. There was also a general theme that for the most part, participants had experienced a withdrawal of friends and sometimes family members, noting that they do not receive as many telephone calls or are no longer invited out. Although most expressed disappointment with this change, one participant commented about no longer seeing a couple that they had been close with, that the loss was very tough. Some commented that they believed those that had reduced their contact had their own reasons, such as deteriorating health within their own families. Others wondered if perhaps some were uncertain of how to approach them now. There was also some question of whether or not some were even aware, "They would hate to hear me say, that yes it has (friends distancing themselves), but it has somewhat" (#4).



The participants expressed a strong sense of worry about themselves. During the interviews, it was noted that participants were concerned about what would happen to them and to their spouses if they became ill. A few caregivers stated that if they were to suffer an injury or an illness, that there would be nobody to care for them, let alone their care receiver. Several noted that they try to be mindful of this, such as this statement from one, "I've gotta worry about my own health, 'cause nobody else is going to look after me if I get sick" (#9). Some of the participants have made some preliminary plans, such as one caregiver, who has started the process to have his wife placed on a waiting list for personal care home placement. Most of the participants stated that if they were to be admitted to the hospital, their spouse could not remain in the home for even a day without supervision. Along with their own health concerns and worry of how that may impact on the future, participants shared their worries about how the dementia will progress in their spouses. Participants said that they worry about what behavioral symptoms will develop next and what area of independence their spouse will lose next. From all of that, some caregivers also said they worry about how long they can continue living in their current home, be moving to a smaller residence, or some place with some services, or perhaps closer to family. A few also expressed worry about their financial situation, the cost of medication and maintaining their current living situation. One participant noted that the stress had come to the point that she started taking a prescription for the treatment of depression.

### Cognitive and other Internal Coping Strategies

Throughout the interviews, the researcher heard of the caregivers experiencing personal growth. One participant commented, "I had to draw on resources that perhaps I

didn't know I had" (#4). The growth continues, as the interviewees found that they learned day by day how to deal with things and how to adapt to the changes in their spouse's behaviors. Overall, this growth was seen as a positive and brought some out of their shells, so to speak. "It's been good for me; I've had to be the stronger one" (#7). The reasoning that came out in the interviews was that things have changed in the caregiver's lives, so they too must change and adapt, adding that they have had to take a realistic look at their own situation. One caregiver stated, "I have become more deeply aware and to look for the good side of things, but you don't expect that it's all going to be good" (#9). A few commented that they have recited the Serenity Prayer at times and have found this a helpful tool for grounding themselves. During one interview, the statement was made that people have a tendency to take their health for granted, but that one needs to relish his or her health and try to maintain what you have for as long as you can. It was also noted by a caregiver that she will often get so caught up in the chores related to caring for her spouse that she forgets all of the positives and can only see the negatives.

Certain skills were identified as essential by all of those interviewed. These included: patience, acceptance, understanding, and humor. Most of them agreed that their care giving role had caused them to enhance most, if not all of these areas. There were numerous examples given during the interviews of where these attributes are essential in a caregiver. One caregiver spoke of his wife repeatedly placing an electric kettle on the stove element, and thus he had replaced the kettle four times, and how he had to learn that in the grand scheme of things, repeated purchases were not important. Others spoke of all the times items went missing repeatedly because their spouse could not recall where the

item had been placed. Several interviewees said that these events were not worth stressing out about. Acceptance was another related aspect, as the examples of the memory loss noted above pushed the caregivers to look at how life has changed and adapt accordingly. This was still a struggle for many, as one caregiver stated, "I think I have accepted it, but I still get angry at times" (#4). Another participant shared that some mornings she wakes up, hoping that her current situation is just a dream (#3). For some, they are faced with not only their own acceptance, but also supporting their spouses, who are still struggling with the realization that they have dementia. One of those individuals described how his wife would often get angry about her memory loss and he said, "If you don't accept it, the denial will catch up on you" (#1), referring to both for his and her sake.

"I need to be more understanding" (#8) was a common recorded phrase during the interviews. Several commented on how they have let go of the things that do not really matter and understand that their spouses do the things they do because of the dementia. One caregiver was describing her husband's paint job and stated, "It was probably not his best work, but who cares, really" (#4). Others spoke of their spouses' new lack of attention to detail when it came to tasks such as shoveling snow, drying dishes, and so forth, but added that they no longer get angry at the lack of perfection and that they are learning to let go. One caregiver, discussed the new reality of the care receiver expressing frustration, and that it took a great deal of work on understanding that this is related to the disease process and to not take it personally. The comment was made, "I just ignore it and go on to the next topic" (#2). Some people said that they realize that their time with their spouse is limited, but that they do not know when that limit will

come, so they try to appreciate what they still have together while they have it. Another comment in support from another caregiver was, "Well, it's not going to be forever, so we'll go day by day and make the best of it" (#1). Further to that, two caregivers said that their philosophy around risk has changed a little, as they did not feel that they could take everything away from their spouses, so they have tried to continue with activities, such as going out to a cabin or going boating. Humor was seen as being an essential aspect in the continued effort to remain patient, accepting and understanding. Several examples were given during various interviews as to how the caregiver had initiated the use of humor to try to alleviate his or her spouse's frustration, his or her own frustration, and to lower the general level of stress in the home.

The final factor that caregivers identified as being a helpful aspect in care giving that they had complete control over was the importance of getting as much information as possible about the disease and what assistance is out there. Many caregivers said that from their experience it is nothing but harmful to sit silent about symptoms that are appearing. It was made clear that it is important to start asking questions and telling one's doctor about what is occurring, to receive intervention as soon as possible, whether it is one of the medications to slow the effects of Alzheimer's type dementia or the start of the process for long term planning. The researcher heard several accounts of how caregivers located the information that they needed for their own understanding and acceptance, as well as knowing where to obtain the practical assistance. Some participants also commented about the need to be open with family and friends as soon as possible about what is happening, so that they can understand what they have observed.

### Practical / Daily Techniques to Cope

Participants in this study shared what they have done themselves to help make daily care giving life a little easier. Almost all of them commented that they have found that to continue doing an activity, modifications needed to be made to maintain its success. One caregiver shared that because her husband always enjoyed carpentry, she now is involved with his projects to ensure his safety and decrease his self-directed frustration when he cannot recall how to use a hand tool. Another caregiver made the same reference to the theme of working together for success by noting that his wife always enjoyed baking, so now he buys the ready-made dough, so that she does not have the frustration of trying to follow a recipe and all of the measurements. Throughout the interviews, the writer heard accounts of how the caregiver now takes the role of standing by and providing cues and suggestions to the spouse, so that he or she can remain as independent as possible in whatever the activity may be. A number of the caregivers also shared how they have made efforts to ensure that their spouse still holds an important role in the family, such as one care receiver replying to his sons' emails with the help of his wife. Another caregiver stated, "We work together as a family to make things work" (#7) when commenting on how their adult children have stepped in to continue running her husband's business now as a family. She described how her son still takes him to the shop regularly and also out for lunch with other business contacts.

Some caregivers have found ways to continue doing some traveling with their spouses. One caregiver noted that although they no longer go to the southern United States for the winter months, they now go to British Columbia and stay with the care receiver's sister for a winter visit. When another caregiver and his wife go out to their

cottage, he makes arrangements with the Home Care services in that regional health authority to provide services to his wife while they are staying at their cottage. Yet another caregiver described how she and her husband still go up to their remote cabin, but that they no longer go to open it up in the spring without their adult children meeting them at the cabin. All in all, these individuals have made some adjustments to be able to carry on doing what they like to do.

Short trips or outings also required some adjustment. Two of the interviewees noted that the family bathrooms located in some malls and large department stores have been perfect for their purposes of ensuring a successful trip to the washroom. Caregivers also reported that they have found more success in going to familiar locations or “old favorites” whether it is to go out for dinner or just to get some fresh air. Routine and a regular schedule were reported to increase the success of a trip as well. Several caregivers shared that they keep a schedule or calendar of events and that certain events always occur on the same day of the week or at the same time each day. Some commented that they refer to their schedule sometimes several times per day with their spouse, to assist in reducing their uncertainty. Many of the care receivers have a variety of items on their weekly schedule, such as exercise classes, day programs, group meetings at the Alzheimer’s Society office, visits from home care, and often a weekly dinner engagement at their son’s or daughter’s home. Almost all of the caregivers felt that it was very important to keep their care receivers involved as much as possible in activities and opportunities for socialization.

Caregivers in this study noted that in recent times, they have seen the need to downsize and make preparations in the event that they were no longer able to manage their household and their spouse's care. Two reported that they had recently sold their cottages and two more were contemplating how much longer they could keep theirs. Three participants have recently sold their large family homes and downsized to either a small house or moved to an apartment building that offers some support services. Others commented that they were uncertain how long they could remain in their homes and manage the demands of keeping up the house and providing their spouse with care. One caregiver has been working hard to organize the home and reduce clutter, so that if something should happen to the caregiver, the adult children could easily pick up and manage all of the family affairs. A number of caregivers have services from Home Care, some of which noted that they had started receiving service, so that their spouse could get used to someone coming in and helping him or her, so that it would not be shock to them if something were to happen to the caregiver. One caregiver added that he was in the process of paneling his wife for a personal care home waitlist, should she ever need it, if he had to be hospitalized.

Legal arrangements were a topic of discussion for caregivers. Many of those interviewed disclosed that they had made arrangements to have an Enduring Power of Attorney in place for their spouse. Others had pursued their family physician for signing the application for the disability tax credit from Revenue Canada. One caregiver had not only completed all the steps previously mention, but she had completed all of the funeral planning and prepayment and she had updated her will.

### Informal Supports are Helpful and Necessary

“Accept and realize that you need help and do not be afraid to ask for it” (#7).

This was a comment made by one caregiver, who had described herself as always being stubborn and independent, had initially struggled with reaching out for assistance.

Caregivers need to ask for help, they cannot do this alone. Over and over again, the writer heard that participants have found that people in general are helpful and that a person just needs to ask for help. It was suggested by one caregiver that people may not be able to guess on their own, so they need to be told that their support is needed.

“Accepting graciously even though you didn’t have to do it before, but you take it now, when someone makes the offer (#6). Invitations for outings, support group meetings, and attending informational seminars are also things that should not be turned down. Several participants said that they had to learn how to ask for help and how to tell people what they needed.

Adult children were referenced time and time again during the interviews as being helpful in every aspect. Some took their parent out on regular outings to give the caregiving parent a break. Other adult children provided practical help, taking on some of the tasks that used to be the domain of the parent who now has dementia. Some were instrumental in helping the parents move to a smaller home, and most also were providing emotional support as well. One caregiver commented, “That’s one thing I can say, I really appreciate my kids” (#7). Most of the caregivers had at least one adult child living out of province, but noted that they were still supportive in whatever way they could be. It appeared that all of the participants in this study had a line of open communication with



all of their children that were involved and believed that it was essential to keep their children aware of what was going on. Some added, though, that they often felt worry that they were placing a burden on their children.

Other people that were identified as being a support to caregivers were: siblings, in-laws, cousins, friends, neighbors, and members of their faith organization. The ability to access a supportive person over the telephone was also seen as very valuable. A few of the caregivers commented that due to the age of their supportive relative and distance, they kept in touch by telephone. One caregiver said, "Sometimes I call just because I need to hear their voices" (#4). Friends were noted to have an important role, from taking the care receiver out to give his or her spouse a break, to offering an invitation out for themselves, to being available to listen and offer support. Friends were seen as outgoing, interested and understanding. One caregiver commented that without her friend's support, her situation would be very difficult (#3). Along with that, members from the care receiver's church or synagogue, and other organizations have also stepped up and taken a more active role in ensuring that the care receiver can still successfully participate in the organization's activities. There were also stories of neighbors being helpful with snow shoveling, yard work, bringing over food, and so forth.

#### Positive Impact by Formal Supports

All of the participants in this study receive services from one agency or another. As the sample was selected with the assistance of the Alzheimer's Association of Manitoba office, all receive some support from this agency as well. Every single participant spoke very highly of the supports and services offered by the Alzheimer's

Society of Manitoba office. Comments, such as “very helpful, good people, provide excellent information, were all repeated by a number of the participants. In comparing the services offered in other provinces, one caregiver stated, “we’re lucky to have them” (#4). They identified the support group for caregivers as essential for their ability to carry on in the care giving role. One person described her experiences in the group by saying that she feels that she is not alone in her experiences, that there are others there who are experiencing the same struggles, she gains insight in to her situation, and there is an opportunity to exchange ideas on how to approach problems. Several participants noted that the group for the care receivers is also very helpful and has become a standard appointment in their household calendar. Others focused on the benefits of attending the information sessions offered by the Alzheimer’s Society of Manitoba office, on topics such as how to select a personal care home, and the disability tax benefit from the Canadian Revenue Agency. Generally, the collective message is that everyone has learned a great deal from the Alzheimer’s Society of Manitoba office, on a number of different levels.

Physicians were also seen as an essential part of success in this situation. Over half of the people interviewed mentioned the importance of getting a person to the doctor as soon as the symptoms of dementia are noticed. The physician can complete a thorough assessment and determine if the person would benefit from one of the prescription medications shown to slow the progress of the dementia. One spousal caregiver discussed the benefits of her husband taking the prescription medication, Aricept, and said, “We figured we’ve had four more years that we might not have had if we hadn’t done anything” (#4). Others echoed her sentiment regarding the medication and stressing

the importance of starting the medication as soon as possible, even though it is not a cure. One caregiver added that he believes his physician is not only supportive, but that he has the added benefit, as his family doctor is also a pharmacist. Others relayed stories of their family physicians taking the time to explain options and offering to sign a disability claim form. All of the caregivers agreed that supportive physician involvement is crucial.

Most of the caregivers in this study have accessed Home Care. Some utilize Home Care services just for in-home respite for once or twice a week, or have their spouse enrolled in an adult day program, or are receiving assistance with providing personal care to their care receiver. For the most part, the feedback from the study's participants was positive regarding how the staff has been helpful, understanding and cooperative with their requests. One of the caregivers said, "When I ask for something, they do their best to help me out" (#5). Others see the in-home respite service as invaluable, with one caregiver referring to it as "a godsend" (#6) and another referring to it as "peace of mind" (#5). A few see the services of Home Care as the difference between being able to continue providing care to their spouse at home and having to place him or her in a personal care home. The self-managed care program offered through Home Care was only used by one individual in the study. This is a special service delivery option offered by Home Care for when the needs of a Home Care client are complex, cannot be met by the regular program, and there is an ability for the family or the client to hire his or her own staff to provide the care, which is in turn, funded by Home Care. This caregiver noted that the regular Home Care services were not meeting the care receiver's need to be with a familiar person, so the self-managed care program was meeting that need, as familiar people were then able to be hired to provide the care.

The adult day programs offered in a variety of locations around Winnipeg and accessed through Home Care were also a popular service among this group. Almost all of the participants in this study have their care receiver enrolled in a program. The feedback the writer received is that the adult day program offers the caregiver some respite time, but without having to leave the home if he or she does not wish to. One caregiver commented "I have all day off you see" (1).

There were a few other services that were accessed by only a couple of the participants in this study. Two of the caregivers had registered their spouse in the Wanderers' Registry, which is a means to register a person, who has the potential to wander in to the police data base. This way, if the individual becomes lost, the police have a description of the person, their photo, and their family's contact information to be used to assist in locating them. The individual registered in this system also wears a Medical Alert tag, indicating that he or she is in the Wanderer's Registry. One of the two care receivers did in fact wander away and the registry did prove itself, as Winnipeg Police Service did take note of the bracelet and then used the registry to locate the person's home address and return the person home to the caregiver. Another caregiver has completed the ERIK document, which lists medical information, medications, and personal information about those living in the residence, should he or she not be able to speak for him or her self during a medical emergency. She reported that she keeps this updated and has it available for emergency services if they should ever need to attend the home. And finally, one of the participants in this study recalled her husband's involvement with the Memory Clinic, which specialized in cognitive testing to assist in determining a diagnosis and any possible treatments. She described how positive the

experience was and how beneficial the assessment information was for their family physician. However, the Memory Clinic is no longer in operation in Winnipeg.

### Feedback from the Caregivers

Although the researcher received the overall impression that the caregivers were generally satisfied with the formal support people in their lives, they did offer suggestions for areas in the system that they believed could be enhanced. Several caregivers in this study commented that although the Home Care staff that was providing the care and in-home respite was kind and well-meaning, there were usually challenges with the care receiver accepting the presence of the staff. Caregivers would note that there was no consistency as to who was sent to provide the care and that meant that the care receiver could never get used to or expect the same person, nor could the Home Care staff person get to know the habits of their client. Some caregivers commented that based on their observations, they believed that the Home Care staff did not receive enough training on how to provide care to someone with dementia. A couple of the caregivers said that they have observed Home Care staff not knowing what to do in response to their spouse's behavior or repetitiveness. One caregiver recalled an event where the Home Care staff did not stay to provide the respite services "you know it's not working because they just leave in the middle of, they just left" (#8). The other big topic that came up during the interviews was that of the Home Care staff not being able to take the care receiver out for a walk while providing the in-home respite services. Caregivers repeatedly noted that their spouse loves to walk and that a regular schedule of exercise assists in keeping frustrations down and having a better sleep at night. However, several of these caregivers stated that the in-home respite staff is not allowed to take clients for a walk outside. A

final suggestion that was offered was that the block of time for in-home respite service needs to be longer than three hours, as one caregiver put it, “Well, try shopping and seeing your doctor in three hours: (#3). Although self-managed care through Home Care could address some of these issues, the suggestions for improvement for this program offered by one participant is that setting up and maintaining the requirements for staffing is a huge amount of work. Beyond that, self-managed care is “not meant to create a job for family” (#8), which was a great drawback for the one participant in this study, who was seeing this program as her only option for care for her husband. This participant has tried the services of the Home Care staff, but the care receiver literally could not cope when the caregiver would leave to go to work, so the Home Care services were discontinued and the caregiver quit her job to care for her husband. As the disease has progressed, her husband has become less and less accepting of having anyone other than his wife present. However, the self-managed care program does not allow the wife or any other family member to be paid through the program to provide care. Given the unique nature of this care receiver’s symptom development, his wife has requested that Home Care consider being flexible with the program’s policies. This caregiver stated to the researcher that she needs to work to pay the bills, so if she cannot have her request granted by Home Care, she will eventually come to a point whereby she will have to place her husband in a personal care home, just so she can work to bring in an income again.

The feedback for adult day programs was not focused as much on changing what is already in place, but rather increasing the amount that is available. Some caregivers commented that it would be even more helpful if their spouse was gone to the program

for a longer period of time, instead for three hours in the middle of the day. Others said that they would like to be able to have their spouse attend a program more often, but that this was not available. There were also a few comments received that there needs to be more of a variety of day programs offered, such as one for younger clients, who have experienced early onset dementia, as well as some that are more structured and some that are more for social gatherings. One caregiver expressed regret for the loss of her husband's ability to attend a day program, as there are no programs currently that can accept a client whose dementia has progressed as far as his has. She added that he used to enjoy attending a day program and she benefited from the break, but the day program discontinued accepting him, as he was no longer able to participate in their programming due to the progression of the disease. Now, this caregiver has no opportunity to have a break without leaving her home. The final suggestion offered was that there needs to be some access to adult day program space, so that a caregiver who needs to continue working, can have his or her spouse in a day program while he or she are at work.

## **Chapter Five: Analysis Discussion**

### **Introduction to the Analysis**

This chapter will analyze the major findings from this writer's research and past research findings highlighted in the literature review through the lens of Boss' contextual family stress model. Comparisons will be drawn and contrasts underlined as this analysis works towards answering the research question posed by the writer: what do spousal caregivers experience, what do they possess and what are they lacking in resources to continue caring for their partner with Alzheimer's type dementia at home? There will also be suggestions for the direction of future study in the drive to understand the experience of someone caring for his or her spouse with Alzheimer-type dementia at home.

### **Theoretical Base**

As noted on page 3, Pauline Boss (2002) stated that even though families are different, all families and individuals experience stress at points in life. Stress is inevitable. However, Boss (2002) suggests that every family and every individual faces and deals with stress differently, based on a range of influences, which she places in one of two categories, internal and external contexts. External contexts are factors that one has no control over, such as genetics, culture, the current economic state, one's stage of life or development, and history (Boss, 2002). Internal contexts are described as those factors that one has some amount of control over or ability to influence change upon, such as the form and functions of the family, individual roles, boundaries, one's perceptions, as well as values and beliefs that are held by the family (Boss, 2002).



Although the external contexts of the participants in this study are discussed to a certain level, the focus of this research is on their internal contexts. Boss (2002) states that the ability to manage change and stress depends on the ability to manage internal contexts. Throughout this discussion, the participants' structural, psychological, and philosophical internal constructs will be brought to light. Challenges with ambiguity, boundaries, and the chronic nature of the care giving role, are repeated in the stories told by the research participants.

### **Discussion of the Major Findings**

In reviewing the themes that emerged from this study, five major areas of findings emerged. These are:

- 1) Care giving spouses in this situation generally believe that to truly understand their situation, a person needs to experience it for him or herself.
- 2) There is a substantial personal and emotional toll that this care giving role takes on a person.
- 3) Care giving spouses have found that there are a number of internal coping strategies that they have employed to survive this job.
- 4) Assistance from others, whether it be from a formal service or friends and family, is essential
- 5) These participants have some suggestions for the health care system that they believe, based on their experience would make their jobs easier.

Each of these areas will be discussed in reference to the literature that exists.

To truly understand, one needs to have had the same experience

Throughout the interviews, participants told the writer that they often do not feel understood. Many had noted that they had received advice from various sources that would suggest that the person offering the advice did not fully understand what that caregiver's situation was really like. Some spouses noted that they had heard others comment that caring for someone with Alzheimer's disease was not that bad, but this comment left the caregiver feeling that the person making the comment really had no idea. When asked about this belief, one caregiver commented that a relative had suggested to her that given the fact that the care receiver was able-bodied that there was little physical toll on the caregiver. The caregiver added that when that comment had been made, she had just endured a number of sleepless nights, as her husband had been out of bed, wandering around the home repeatedly looking for her, and that during the day he was urinating in inappropriate places within the home. Other caregivers noted that the additional workload of taking on their partners' tasks within the household, as well as providing personal care to their spouse, was more than they had energy to accomplish. The writer learned from these spouses that even though there are likely some similarities, every caregiver's situation is different. Boss (2002), highlights the vast number of variables among individuals and among families. Many examples of these variables came out in the statements made by these caregivers, such as differences in the signs and symptoms of the dementia that the care receiver was experiencing, what amount of support from family and friends was available, personal character traits of both the caregiver and the care receiver, personal and family values and beliefs, what formal services were in place, and so forth. No two situations could possibly be the same.

These differences were seen as both positive and negative. Some caregivers commented that when meeting with other spousal caregivers, they shared their experiences and gained knowledge from others. They exchanged ideas on how to manage certain situations, learned more about how the disease can present itself, gleaned information on services, and supported each other. On the negative side, caregivers noted that just because a service worked for one caregiver, it did not work for them, due to different circumstances, the progression of the dementia, or perhaps the limited parameters of the service. So, the caregiver was left, still struggling. Generally, the feedback from these spouses was that they often feel unheard by those around them, such as other family members, neighbors, friends, and even some health care providers, which adds to their feelings of isolation. One caregiver gave examples of where she had been told by her insurance company that her situation was not that stressful, so therefore does not have any impact on her health and she should be able to return to work. This caregiver's perception of her own situation was quite the opposite, whereby she was uncertain how she was going to continue caring for her husband in the weeks to come. This same caregiver stated repeatedly during her interview that she does not feel understood by the professionals around her, including the health care service providers. Her reason for this belief is that if these healthcare providers really understood how physically and emotionally difficult it is to care for a spouse as cognitively impaired as hers, then they would not be making the suggestions that they were, and instead would be willing to offer her the services that she was requesting. In this study caregivers stated that they do not always receive solid advice and are often unable to obtain service that can be modified to meet the needs of their situation.

### Personal and Emotional Toll

The sense of loneliness was a common theme repeated by caregivers. Loneliness was described as feeling alone and with no one to turn to for companionship or support. Interviewees talked about the irony of feeling alone, even though their husband or wife was still living at home with them. Some made comments, such as being a bachelor or a widow. Boss et al. (2009) and Boss (2002) discuss this situation and the ambiguous loss. Almberg (2000) and Parsons (1997) comment on the phenomenon of the caregiver's grieving for the loss of the care receiver before he or she dies. When there is a lack of clarity as to who is an active part of the family and who is not, Boss (2002) refers to this as boundary ambiguity and it is a potential predictor of depressive symptoms in those that it affects. Many in the study shared stories of conflict between themselves and their spouse or family members, regarding what role the care receiver was taking at the present time.

This blurring of boundaries is further complicated by the fact that the traditional roles that these couples had developed over the years of their marriages are now greatly altered. Some expressed continual struggle with this new marital reality, commenting that their role resembled more of a parent than a marital partner. This was echoed by the stories from caregivers, including the symbolic removal of a wedding band by one caregiving spouse in Boss et al. (2009). However, one participant commented that after all the years that his wife had managed the home and cared for their children; he believed it was now his turn to be the caregiver, suggesting that he had taken this change in role and accepted it. This husband's account of his situation is reflective of Parson's (1997)

finding that men experienced a positive sense of reciprocity and opportunity to give back to their family member.

As previously mentioned, the potential for depressive symptoms exists for caregivers in this situation (Boss, 2002). Many caregivers commented on experiencing depressed mood and other symptoms of depression; some had been given prescriptions for antidepressants, and one caregiver disclosed that at times, she had contemplated suicide. There are numerous studies that indicate that depression and anxiety disorders have a high prevalence in caregivers. Several studies have noted that care giving spouses are at the greatest risk (Beeson et al, 2000; Deimling et al, 2001; Forbes et al, 2008; Kosloki & Young, 1999; Lachs & Boyer, 2000), with wives being at the highest risk (Beeson et al, 2000; Kosloki & Young, 1999). Although this researcher found no previous studies that spoke to specific findings regarding suicidal ideation in caregivers, Lachs and Boyer (2000) suggest that along with the increased chance of depression, caregivers probably have a higher rate of suicide. Other expressions of felt emotion included the feeling of being trapped, being isolated, angry, guilty, grief stricken, and overwhelmed, all of which have been echoed in the literature.

Another shared sentiment of this group was the general sense that there was great uncertainty about the future. Some expressed the worry about not knowing how the disease will progress and what symptoms will arise. There were also comments made by the interviewees about not knowing what to do if the interviewees could no longer continue caring due to a change in the care receiver's disease or if their own health should fail. Some spouses were struggling with decisions that needed to be made about the

household, finances and so forth. Many added the comment that this uncertainty about how much time they have left with their spouse or what the disease will display next is one of the great difficulties with Alzheimer's type dementia. This uncertainty compounds the fact that every situation is unique and potentially leaves the caregiver with a sense of being alone. Boss (2002) suggests that this combination of the ambiguity, the inability to predict the course of the disease, and the chronic nature of the situation, places the individual and or family at the greatest risk for crisis.

### Internal Coping Strategies

Caregivers shared how they had come to terms with their new marital reality and role. They identified certain skills essential for survival, such as acceptance, understanding, patience, and the use of humor. Heinrichs (1996) noted these same items as becoming a daily set of talents needed to be a care giving spouse in his situation. Many noted that they had seen a great deal of personal growth in themselves, as they had learned new skills, expanded their knowledge base, and worked on character development. Although acceptance was echoed time and time again in these interviews, another repeated psychological essential was that of letting go of things or events that do not matter and trying to remain positive about the situation. Borden (1991) noted that the spouses who maintained a positive outlook and took a problem-solving approach had a much higher level of psychological wellbeing. The importance of this approach was emphasized by a few participants who stated that they had come to accept that they cannot change the fact that their spouse has Alzheimer's, so they have chosen to not focus on worrying about the future, but rather to focus on the positives that remain and to take things as they come, one day at a time. This fits with Boss' (2002) emphasis on the

importance of perception of the situation and overall psychological management required to mobilize coping capacities.

Caregivers also noted that in their growth, many had experienced a shift in their own personal philosophies and to some extent in the family's philosophies. Again, Boss (2002) sees the area of philosophical beliefs as an area that one can modify to cope with stress. Some spouses had taken on roles within the household that had always been understood to be the domain of the other gender, whether it is by family tradition or by culture. This took the form of examples ranging from a husband providing hands on personal care to wives making major financial decisions that they had never been involved with earlier in their marital life. Other examples included now considering taking risks, so as not to take away all of the care receiver's activities that he or she still enjoys. A final example was a major shift in the belief of independence and keeping issues within in the family to now reaching out for help and talking openly about one's care giving reality. Several people stated that they believe that the sharing of information is not only essential as a caregiver, but powerful in facilitating change, whether it is with the doctor to have their spouse started on medication, or offering their own story to others with the hope of assisting them.

#### Assistance from others is essential

Over and over again, the researcher heard how receiving assistance from others is necessary for the caregiver to be able to continue caring for their husbands and wives at home. Many shared that this does not only mean accepting what is offered by family, friends, and neighbors; but also reaching out and asking for what one needs. The

literature supports this sentiment. Borden (1991), Mitrani and Czaja (2000), Schmidt et al (1998), Almberg (2000), and Wuest et al (2001) all concluded that the support of others had positive effects for the caregiver and allowed for the continuation of the care giving role. Parson's study (1997) commented that the assistance from others was not only necessary, but expected. The spousal caregivers in this study gave examples of assistance that had been helpful to them, which ranged from someone to talk to over the telephone, to the offer of a hot meal delivered to the home, to the offer to take the care receiver out for a few hours to give the caregiver some respite time. Again, caregivers noted that because others may not know how difficult the situation is or how to be helpful, it became important to speak up and ask for help.

Formal assistance was also seen as an important support. Participants spoke about the support and information that they had received from the Alzheimer's Society of Manitoba and how helpful it had been. Many spoke about how the family physician had played an important part and how this involvement had opened up other doors for the couple. Almost all of the participants in this study had at least some involvement with Home Care, whether it was for a connection to an adult day program for respite or in the case of one participant, the start of the paneling process for personal care home placement. Again, almost all of the participants spoke of how, initially, they were hesitant to reach out to formal services, but that after beginning the service, they had experienced benefits. In the literature, formal services were found to be of high importance for care providers. One study noted that it was helpful if a physician gave a definitive diagnosis (Wuest et al, 2001), which may lend itself to reducing some of the boundary ambiguity that Boss (2002) discusses. Overall, a number of studies found that



the role of the formal services went beyond just providing whatever service was offered. Formal service providers gave support, reassurance, and validation, which in turn had a positive effect on the caregiver's psychological well-being (Wuest et al, 2001; Winslow, 1997).

#### Suggestions to make their job easier

In this study, the spouses spoke very highly of the services that they had accessed. They expressed general appreciation for the amount of service that was available in Manitoba, with one caregiver making comparisons with what she knew to be missing in another western province. Overall, they were very complimentary of what was available via the Alzheimer's Society of Manitoba, suggesting that the drive for fundraising should not lose momentum for a moment. Others expressed their belief that more needs to be done to educate others, who were in a similar care giving role, so that they may benefit as much as these participants have. And, a few stated that they felt that there needed to be more opportunities to attend support groups, both for the caregiver and the care receiver.

Issues related to direct care and respite opportunities were a common topic among this group. Most spouses regularly accessed either in-home respite from Home Care or their care receiver attended an adult day care program, or there was a combination of both. The repeated feedback was that these two respite options were very helpful, but that the length of time on a given day was not long enough for the caregiver to get much accomplished, such as errands and medical appointments. Also, the frequency of the opportunity needed to be increased. Some commented that the in-home respite service was limited by what the staff person was allowed to do, the lack of consistency in

assigned worker, or how well he or she was trained in working with dementia-related behaviors. Wuest et al. (2001) heard the same feedback in their study. Some participants in the current study commented on how the adult day program opportunities were narrow, as they did not fit well for someone who experienced early onset dementia, and is much younger than others at the program, or their dementia had progressed past the point of being able to participate in the currently offered programming. Finally, this researcher heard that it would be helpful to caregivers if there were some mechanism for short notice respite, as sometimes caregivers need a break immediately, not next Wednesday, for example. All of these examples of inflexible care were also described by the caregivers that took part in the study by Forbes et al. (2008).

### **In Closing**

This study of the experiences of nine spouses, engaged in the role of caregivers to their marital partners with Alzheimer's type dementia at home has shown that there is much to be learned about what daily life is like in this round the clock job. The stories shared and views of their current state and the state of their support networks is certainly supported by the findings of previous studies. Each person in this study had a unique view and a unique story to share. However, there were also many threads of commonality among them. It was heard loud and clear that because each situation is unique and always changing, the views and requests of the caregivers need to be seen as that of the expert. Flexibility and adaptation are key for all involved, including the formal services that the caregivers access. The results of previous studies have indicated that when health care service providers have a better understanding of the caregiver's situation

(Wuest et al, 2001) and allow the caregiver to be the lead on organizing the required resources (Schmidt et al, 1998), there is a better outcome for care of both the care receiver and the caregiver.

The stories of the caregivers in this study echo the findings found in the literature. They discussed the level of personal toll that is part of their role, and how this toll encompasses every aspect of their well-being. In the literature, there is a demonstrated a high prevalence of psychological suffering, such as depression (Adams, 2006, Beeson, Horton-Deutsch, Farran, & Neundorfer, 2000; Deimling, Smerglia, & Schaefer, 2000; Kramer, 2000; Lachs & Boyer, 2000; Lee, 1999; Whitlach & Feinberg, 1997) and anxiety disorders (Mitrani & Czaja, 2000). There was also a sense from the participants in this study that there had been deterioration in their own physical health as a result of the care giving demands. Boss (2002) did state that psychological stress can make an individual physically ill, but does not provide specific details. Whitlach and Feinberg (1997) agree and state that there is a high correlation between caregiver mental health functioning and physical well-being, evidenced by worsening of the caregivers' health and depression as their study continued. Family caregivers use more psychotropic medications, more health services for themselves, and have a weaker immune system (Mitrani & Czaja, 2000). Loos and Bowd (1997) noted that caregivers spoke of a lack of sleep and time for themselves. However, it is this writer's sense that there needs to further research in to this area to determine a clearer picture of the relationship between the care giving role and the caregiver's health resiliency.

The caregivers in this study also shared a common opinion on the importance of using supports, whether that is from services and agencies or from friends and family. "Accept and realize that you need help and do not be afraid to ask for it." (#7) Every participant in this study had developed a network of supports for him or herself and identified this as an essential element to being able to continue in the care giving role. In the literature, findings repeatedly noted the importance for informal and formal supports. Just one example of this comes from Borden (1991) who noted that spousal caregivers who had good levels of peer support experienced higher levels of well-being than those caring for a spouse at home with dementia with no peer support. In this study, the participants provided more information on their experiences with and suggestions for formal supports than what this researcher had noted in the literature review. However, it is interesting to consider the findings of Hawranik (2001) that indicated that caregivers of family members with dementia were four times more likely to obtain assistance with personal hygiene tasks for that family member than caregivers of clients who did not have dementia. Spousal caregivers in this study certainly made it clear that the resources of Home Care supports are essential.

## **Chapter Six: What has been learned?**

As stated on page 8, the purpose of this research was to understand the experience of caring for a spouse with Alzheimer's disease from the caregiver's perspective. The intent was to explore the spousal care giving experience and identify how this type of care giving impacts on an individual, what resources are used, what resources are helpful or not helpful, and what the caregiver perceives is missing that would make his or her role easier. Although it is this writer's belief that there was a deeper level of understanding achieved in this study, more research needs to be done. This writer's initial goal was to come to the end of this research with the sense of what it was truly like to be a spousal caregiver in this situation. It is this writer's opinion that the intent, as described above, was followed. However, after hearing the participants' stories and listening to their depictions of events that provided examples of their unique struggles, this researcher can honestly state that there is a greater understanding of how complex their situations can be and therefore how little the researcher knows about what life is like for these caregivers. It is now this writer's opinion that to truly understand what daily life is like for a caregiver in this situation, one must be in the situation day in and day out as well. And even then, every individual's perception will be different to some degree.

### Contributions to the Literature and Future Research

This research provides another suggested starting point for further research. Its contribution to the literature is the experiences of the spousal caregivers told with the intent to educate. Further to that, it is a look at how spousal caregivers continue to provide care at home in the Manitoba health care environment, particularly in Winnipeg.

This study's unique contribution is its local focus. In the literature search, there was little for Canadian qualitative studies on this topic, and nothing that this writer found that was Winnipeg – based. This study gave an opportunity for caregivers in a small urban center to describe their experiences and give their feedback on what healthcare system enhancements would be helpful to them. This opportunity could be viewed as unique, in comparison to other parts of Canada where the health services may be delivered differently. This feedback could also be timely, as the current elected provincial political party has, in this writer's opinion, always appeared to have a strong interest in improving the province's healthcare services. The outcomes from this research could provide a starting point for further studies of this kind in either other Canadian urban settings or perhaps trigger studies on the care giving experiences in the rural areas as a comparison. This research has provided further information on the challenges that care giving spouses have faced as a result of the illness that their care receivers have, as well as their challenges that they have faced when they have attempted to address these by approaching both the formal and the informal systems around them. Perhaps what has been learned here will be of interest to the policy makers looking to make changes to the services that exist or to develop more opportunities for supporting caregivers.

### Recommendations for Change

Based on the feedback from participants in this study, there are some recommendations for enhancements that if implemented, would likely take some of the burden of the care giving role off of the spousal caregivers. First, all of the caregivers in this study were very clear in their message that the services provided by Alzheimer's Society of Manitoba were very helpful to them, but many commented on how its

programming is so dependent upon fundraising. Given the value of this organization, there should be guaranteed funding for this organization from government.

Also, the Home Care program was seen as very valuable, but just not enough access to really meet the needs of the caregivers. As a result, if Home Care services could be enhanced to allow more flexibility in the service that is provided, then the caregiver could be allowed to be more in a lead role to determine the care to be provided and on what schedule. Moreover, if the caregiver were to be the focus of the assessment of need, then perhaps there would be more potential for equity of service, based on the needs of the caregivers. This would be particularly needed in the area of in-home respite services, where several of the caregivers in this study stated that they need this service more frequently and for longer periods of time. Furthermore, if there were more resources available for in-home respite, then perhaps there could be capacity for some sort of standby service in which caregivers could call for in-home respite services without notice, so that they can take a break when something has occurred or if they have a medical emergency, themselves, that needs to be attended to. There was also some need noted for the Home Care staff that provide the direct service in the homes to have more specific training on how to work with individuals with cognitive impairment and to be able to take the client outside for exercise.

The self-managed or family-managed care program also could have some improvement as well. It was suggested by one interviewee that the criteria for who was eligible for this program and who would be hired as staff to provide the care was too narrow. At the time of the interview, this interviewee was in the process of advocating

for opening up the criteria to be more inclusive to unique care situations. It is this writer's opinion that perhaps there should be an open invitation for feedback from caregivers with experience in this program with the intent to make improvements where it is felt necessary based on the caregiver's experiences.

Finally, there is a need for more resources allocated to the adult day program system to provide more relief and respite time for caregivers. Based on the feedback from these participants, there needs to be an option for their spouses to attend day programs more frequently and for a longer period of time during the day. Another enhancement also needs to be having access to adult day programs that are geared to younger clients with cognitive impairment and clients who have more severe cognitive impairment. There needs to be some consideration to the needs of caregivers who are still employed in the workforce and need longer hours of day programming. Overall, it would be helpful for the assessment process for adult day program service to consider the caregiver as the lead in determining would best fit the needs of the situation.

#### Contributions to Social Work Practice

Social work practice may benefit from this study at a macro systems level and at an individual practitioner's level. As suggested above, policy and program development may be impacted by the findings in this study. When reviewing the current studies that exist on care giving experiences and the impact that services have on family caregivers, the findings in this study could certainly add to that review. Social work policy and community development may chose to take the documented feedback of the spousal caregivers in this study when considering changes to the current supports available.



During the course of this study there were some comments made by the participants on the availability of beneficial services within Winnipeg. Such services included those offered by the Alzheimer's Society of Manitoba and some direct care service components provided by Home Care may not be available elsewhere. This is but two examples of opportunity for comparison between services available within Winnipeg and the rural areas or perhaps other provinces. Other participants in this study made suggestions of ways in which currently offered services would be of more benefit if enhanced or increased in the frequency that they are available. The findings of this study are timely as it has been this writer's experience, health care services are in a constant state of evolution and there is an increased focus on evidence – based practice in health care.

This study may also provide useful information for the individual practicing social worker, who is working with individuals in a similar situation. The descriptions of struggles and other experiences that participants have described in this study may ring a familiar tone to a social worker when reflecting on his or her caseload. It may provide some insight or suggestions as to what a care giving spouse is facing, thus offering a different lens in which to view eligibility for some services or an increase in other services. Creativity on the part of the social worker may also be sparked by comments made by the participants in this study, whether it be on where and what time appointments are set with clients or in what services with which to assist a client to connect. Or, perhaps the practicing social worker may become interested in learning more about a particular service or area of discussion in this study and pursue further research on his or her own. More specifically, social workers need to consider finding ways to allow the caregiver to be the lead on the service planning, including the amount

of service, the frequency and timing, and what the service will consist of. It will mean that social workers will need to step back and allow the caregiver to drive what occurs more, and perhaps mean that the social worker will need to take a more advocacy approach to make changes in the system to allow the caregiver to obtain the services that he or she needs. Based on what this writer learned from the caregivers in this study, it is this writer's opinion that service planning should be very individualistic to that caregiver's specific situation and be flexible to allow for changes in the situation.

### Contributions to Family Stress Theory

In reviewing the outcomes of this study and reflecting back on Boss' contextual family stress model, it does not appear to this writer that there has been much new knowledge contributed to family stress theory. Over the course of the interviews, the writer often found examples in the stories that the participants told that were direct examples of Boss' model. As a result, perhaps the most notable contribution is the confirmations in the content of the caregivers' descriptions of their situations. It is also certainly an example of the model within social work practice in Winnipeg.

### The Researcher's Own Learning

The researcher in this study has learned a large amount. It was surprising to this researcher how little there was available in local studies on this topic. Having been a practicing social worker for fifteen years and knowing from this writer's own practice how often this care giving situation has been referred to this writer's caseload, it was assumed that there had been a lot more research completed on this topic. Although there is some research available, as noted in this writer's literature review, this writer's

assumption that there would be extensive qualitative research available was incorrect. Also, this writer came to this research project with an assumption that there was already a substantial understanding of the topic, given this writer's personal family experiences with Alzheimer's type dementia and the formal health care system. Nevertheless, this writer was greatly mistaken. The participants in this study taught this researcher a great deal about the struggles and challenges that they have faced with great endurance and resilience. Although at times the writer felt that some participants were attempting to further explain their situation in terms with which they thought the writer would identify. Some would describe their level of responsibility and never – ending tasks as being like caring for an infant, as many of the participants in the study noted that the researcher had an infant at the time of the interview. But in reflection, the writer's role as a parent of a newborn pales in comparison to that of these caregivers both in physical and emotional demand.

As a social work student, this study resulted in a wealth of knowledge. Boss' contextual family stress model (2002) introduced and described on pages 3 and 4 came alive in this study. The relationships between the caregivers and their individual internal and external contexts were clear and this lens helped the researcher in asking further probing questions during the interviews. In application of this model to the research, the writer became comfortable with the model and this has had a creative impact on the writer's social work practice. Stepping back in to the exercise of overtly applying theory to practice has occurred more often now for this writer as a result of this research project. Furthermore, the writer will be forever impacted by the stories shared by these participants. It is this writer's belief that it has had a positive effect on the writer as a

student, viewing the research and evaluating the services that exist. Furthermore, as a social work practitioner, this exercise has been a valuable reminder to view each client and his or her situation individually and to spend more time and energy trying to gain a better understanding of the client's own perception of the situation, and what he or she believes is needed to address the situation at hand. Boss (2002) clearly stated that each individual and family will experience stress and there are many variables that play in to how this will impact the family or individual. This was certainly true when comparing one spousal caregiver's situation to another. So, to that end, it is this writer's opinion that one needs to defer to the care giving spouse as the primary expert in determining what gaps exist for a given situation and what needs to be put in place.

In reference to the original research question, this writer believes that the question was only partially answered. The question, what do spousal caregivers experience, what do they possess and what are they lacking in resources to continue caring for their partner with Alzheimer's type dementia at home, was perhaps too extensive for the researcher to accomplish. Although the outcomes discussed to provide extensive information on what the spousal caregivers in this study experienced, what their resources were and what they felt that they were missing, it is this writer's opinion that unless one was in the role of these caregivers, day in and day out, one can only capture a glimpse of what daily life is like for these caregivers. Perhaps this researcher would have felt a deeper understanding of the caregivers' experience if this researcher would have met with the caregivers repeatedly over several years or if the researcher would have had first-hand personal experience as a spousal caregiver for someone with Alzheimer's disease. Participants in this study did share from where they drew their strengths and where they wished they

could; all of which was of value to the researcher in the intent to better understand how to assist caregivers in this type of situation.

#### Future directions for research

This study focused on a narrow group of spouses who reside in one specific urban area. There is likely much more that can be learned if this area of research was expanded to consider the experiences of those in a similar role in rural or northern communities or perhaps comparing one province's urban setting to another. Also, it may be helpful to consider focusing on the experiences: of those still in the paid workforce, those who may be recent immigrants and the unique challenges that they may face, or perhaps more of a focus on the experience of care giving husbands, as this study only had two men participating. There could also be research focusing on the impact of pre-existing marital relationship or the length of time in the care giving role on the caregiver's experience. Further to that, all of the caregivers in this study had only been married once, to their care receivers, so the potential dynamics related to second marriages, blended families, and so forth were not addressed in this study.

Also, there is certainly great opportunity from this study's information to research the topic from a different research design. From a quantitative perspective, further research could consider the use of various scales to add another dimension to the information. Or perhaps, a longitudinal design over several years could be considered. As the population ages, and the focus continues to turn to services providing support to family caregivers, this research topic will continue to be of interest.

## Conclusion

Caring for a spouse or parent with Alzheimer's type dementia challenges one's physical, emotional, and mental well-being. The tasks and responsibilities in this work are far reaching, causing the caregiver to often place his or her life on hold, including career, retirement dreams, financial goals, and family and social involvement. In comparison to other debilitating diseases, Alzheimer's seems to present a contradiction in that it is often the caregiver who suffers more than the individual who has the disease (Parsons, 1997). The literature reveals that the effects on the caregiver are varied, but that there are many factors that play a role, making the experience different from one caregiver to another. Caregivers often do not wish to give up caring for their loved one at home, and will make great personal sacrifices to continue keeping their family member at home. Further study is needed to understand the full effects of factors that may assist in reducing stress on the caregiver. Healthcare professionals could benefit from understanding what is needed to reduce this stress and assist the caregiver to continue the care if so desired. Current services are of assistance, but what changes are needed in these services so that they may be more helpful to a caregiver in the community remains to be found.

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## **Appendix 1**

### **Biographical Questions:**

- 1) How many years have you been married?
- 2) Do you have any children? If so, how many?
- 3) Do your children assist you in any way to care for your spouse?
- 4) Have your living arrangements changed since your spouse's diagnosis? And if so, how?
- 5) How long has your spouse had Alzheimer's Disease?
- 6) What is your ethnic background?

### **Interview Questions:**

- 1) Has your life changed since your spouse started to have memory problems? If so, how?
- 2) Describe your marriage before your spouse began to have memory problems.
- 3) How has your relationship with your spouse changed since your spouse started to have memory problems?
- 4) Have your relationships with friends and family changed since your spouse started to have memory problems? If so, how?
- 5) What tasks do you do now to help your spouse?
- 6) What things do you now do yourself that your spouse used to do without your help?
- 7) What are the positive experiences for you in this care?
- 8) What are the experiences that you don't see as positive in this care?
- 9) Has caring for your spouse affected your own health? If so, how?
- 10) Describe what has been helpful to you in caring for your spouse at home.

11) Has anyone or any service been helpful to you caring for your spouse at home? If so, how?

12) What other arrangement or services would be helpful to you in caring for your spouse at home?

What advice would you give that would be useful for other caregivers whose spouses are beginning to experience symptoms of Alzheimer's Disease?

## **Appendix 2**

### **Informed Consent Form**

#### **In Sickness and In Health: A Qualitative Study of the Experiences of Caring for a Spouse with Alzheimer's type Dementia**

Debra Dolhun, a graduate student in the Faculty of Social Work at the University of Manitoba, is conducting this study.

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more details about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

### **Background Information**

The purpose of this study is to gain a better understanding of the experiences of caring for a spouse at home with Alzheimer's Disease.

### **Procedures**

If you agree to participate in this study, you will be asked to participate in one interview with me, which will be audio-taped with a cassette recorder. The interview will last two to three hours and can be divided into two meetings if you prefer. The interview will be held at a location of your choice. Within one month of the interview, the researcher may contact you by telephone to ask questions to clarify some of your responses.

### **Benefits and Risks**

The benefits of this study will be an opportunity to state their experiences and views on caregiving and what would be helpful to them. This study will give you, the caregiver, the opportunity to give your expert opinion on what it is like to care for someone with Alzheimer's Disease at home. You will be able to state what is helpful to you and what has not been helpful. A report on the experiences of caregivers caring for a spouse at home with Alzheimer's Disease, will be available to professional health care providers as a source of education and perhaps an illustration of where health care services could support caregivers to a greater extent. This study will give you a chance to express your views on what services you believe should be changed or added and what services should remain the same.

The risks are that discussing experiences of caregiving during the interview could be emotionally upsetting for a participant. Supportive counseling will be available through



the Alzheimer's Society of Manitoba to the participants should they experience such a reaction to the interview.

### **Confidentiality**

The records of this study will be kept private. Research records will be kept in a locked file; only the researcher and the thesis chair will have access to these records and to the identity of the participants. The tape recordings of the interviews will be erased as soon as they are transcribed and the data is collected from them. In any sort of data that is published, there will be no information included that will make it possible to identify a participant.

### **Feedback from the study**

The findings from this study will be made available to the Alzheimer's Society of Manitoba and to the participants in the study. A print copy of the summary of findings will be offered to the participants, should they so choose to have one. A copy of the published thesis will be available at the University of Manitoba as well.

### **Voluntary Nature of the Study**

Your decision to participate will not affect his or her current or future relations with the Alzheimer's Society of Manitoba or the University of Manitoba. If you decide to participate, you are free to withdraw at any time without affecting these relationships or any other services that you may be receiving.

### **Statement of Consent**

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researcher or involved institutions from their legal and professional responsibilities. You are free to withdraw from this study at any time, and / or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

Principal researcher: Debra Dolhun (phone #: 489-9698)  
Advisor: Professor Sharon Taylor-Henley (474-6669)

This research has been approved by the Joint Faculties Research Ethics Board. If you have any concerns or complaints about this project you contact and of the above-name persons or the Joint Faculties Research Ethics Board at 474-7122, or email

margaret\_bowman@umanitoba.ca. A copy of this consent form has been given to you for your records and reference.

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Signature of Researcher: \_\_\_\_\_ Date: \_\_\_\_\_

## **Appendix 3**

### **In Sickness and In Health: A Study of the Experiences of Caring for a Spouse with Alzheimer's type Dementia**

#### **Information Sheet**

#### **Purpose for Research**

The purpose of this study is to gain a better understanding of the experiences of caring for a spouse at home with Alzheimer's Disease. The hope is that with a greater understanding of what these caregivers experience, health care professionals will be better able to assist them.

#### **Procedures**

If you agree to participate in this study, you will be asked to participate in one interview with the researcher, which will be audio-taped with a cassette recorder. The interview will last no more than 2 to 3 hours and could be divided in to two meetings if you choose. Within one month of the interview, the researcher may contact you by telephone to ask questions to clarify some of your responses.

#### **Benefits and Risks**

The benefits of this study will be an opportunity for caregivers to let their views be heard. Also, a report on the experiences of caregivers caring for a spouse at home with Alzheimer's Disease will be made available to professional health care providers as a source of education and perhaps an illustration of where health care services could support caregivers to a greater extent.

The risks are that discussing experiences of caregiving during the interview could be emotionally upsetting for a participant. Supportive counseling will be available for the participants should they experience such a reaction to the interview either during or following the interview.

#### **Contact Information**

If you are interested in taking part in this study through the University of Manitoba, please contact:

**The researcher: Debra Dolhun**

## Appendix 4

### 60 Categories in 8 Themes

Themes	Categories
1) Need to walk in caregiver's shoes to understand	<ul style="list-style-type: none"> <li>• have to walk in caregiver's shoes to understand</li> </ul>
2) Constant Vigilance and Care	<ul style="list-style-type: none"> <li>• Caregivers take over all duties of the other person / "jack of all trades"</li> <li>• Caregiver does personal hygiene care for spouse</li> <li>• Care receiver cannot cope with caregiver is out of view</li> <li>• It's a 24/7 job, need to take breaks</li> </ul>
3) Emotional and personal toll of care giving	<ul style="list-style-type: none"> <li>• Loneliness / loss of companionship</li> <li>• Care giving has negatively effected health</li> <li>• Caregiver worries about own health</li> <li>• New negative marital issues</li> <li>• Increased sense of isolation</li> <li>• Friends distance themselves from caregiver</li> <li>• Loss of freedom</li> <li>• Caregiver feeling overwhelmed</li> <li>• New marital reality that spouse no longer recognizes the caregiver</li> </ul>

4) Caregiver's internal coping strategies	<ul style="list-style-type: none"> <li>• Use of humor to cope</li> <li>• Acceptance</li> <li>• Live day by day attitude</li> <li>• Need for patience</li> <li>• Let things go that do not matter</li> <li>• Need to be understanding</li> <li>• Learning is part of the care giving role</li> <li>• Need to look at things realistically</li> <li>• Positive thinking / cognitive restructuring</li> <li>• Need for caregiver to research / educate self</li> </ul>
5) Practical techniques for survival	<ul style="list-style-type: none"> <li>• Preparing and downsizing</li> <li>• Adjust how things are done to continue</li> <li>• Keep a schedule / calendar of appt / events</li> <li>• Preparation advice</li> <li>• Try to keep life as normal as possible</li> </ul>
6) Importance of informal supports	<ul style="list-style-type: none"> <li>• Friends remain a good support</li> <li>• Family are supportive and help out locally</li> <li>• Family are supportive from afar</li> <li>• Importance of accepting help that is offered</li> <li>• Others are helpful</li> <li>• Need to accept and seek support</li> </ul>

7) Positive attributes of formal supports	<ul style="list-style-type: none"> <li>• Alzheimer's Society is helpful</li> <li>• Home Care is helpful</li> <li>• Adult Day Programs are helpful</li> <li>• Self-Managed Care (via Home Care) good</li> <li>• Family physician is helpful and essential</li> <li>• Memory Clinic was helpful</li> <li>• ERIK is helpful</li> </ul>
8) Suggestions offered for improvement of formal supports	<ul style="list-style-type: none"> <li>• In-home respite needs to be increased in length of time and in frequency</li> <li>• Improvements to in-home respite service needed</li> <li>• Need for day respite that does not need to be pre-booked</li> <li>• Improvements to day programs needed</li> <li>• Limitations of accessibility to self-managed care need to be addressed</li> <li>• Need more caregiver support groups</li> </ul>