

September 2013

# Exploring the Iranian-Canadian Family Experience of Dementia Caregiving: A Phenomenological Study

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A thesis submitted in partial fulfillment of the requirements for the degree in Master of Science

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EXPLORING THE IRANIAN-CANADIAN FAMILY EXPERIENCE OF DEMENTIA

CAREGIVING: A PHENOMENOLOGICAL STUDY

(Thesis Format: Monograph)

by

Sevil Deljavan

Graduate Program in Health and Rehabilitation Sciences

A thesis submitted in partial fulfillment  
of the requirements of the degree of  
Master of Science

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## **Abstract**

Presently in Canada, there are approximately 500,000 individuals living with dementia, which is expected to increase to over one million by 2038. With Canada's minority elderly population growing, the number of Iranian-Canadian older adults living with dementia is expected to rise as well. Family caregivers are a significant source of help among Iranian-Canadians and the provision of informal care by adult children for parents with dementia in the Iranian culture is an expression of love and dedication.

This study explored the meaning of the experience of Iranian adult children in Canada caring for a parent with Alzheimer's disease, the values and attitudes they held in regards to their utilization and expectation from formal and informal care services, and the role of culture in shaping these experiences. A phenomenological study was used to investigate this phenomenon. In-depth, semi-structured interviews were held with four adult child caregivers and rich data were obtained. The research findings focused on the dual reality of dementia caregiving, the importance of fulfilling filial obligations, and the expression of preferences in formal dementia care.

**Key words:** dementia, minority, Iranian-Canadian, family caregiver, informal care, culture, phenomenology

## **Acknowledgements**

First and foremost, I'd like to thank my amazing family who has been there for me every step of the way. Mom and dad, thank you for spending hundreds of hours and thousands of dollars on gas going back and forth with me to London just to keep me company. Most importantly though, thank you for always believing in me and being my number one fans. Your love and support is the main reason I am where I am today. I truly do have the best parents anyone could ever wish for. And Maral, my little (but not so little) sister, I especially thank you for your witty sense of humour and sarcasm, which has made the stressful times a little more easy to get through. Love you to death, "bebee"! Aaand thank you to all my friends and relatives as well, for cheering for me on the sidelines!

I'd also like to thank Western University for providing me with such a fulfilling and rich postgraduate experience. I'd like to thank the most wonderful supervisor, Ms. Sandra Hobson. I have been so so incredibly lucky to have you as my supervisor, and your guidance and words of encouragement have made a world of a difference! I'd also like to thank my amazing committee members, Dr. Fielding and Dr. Magalhaes for providing me with invaluable help and support. And lastly, I'd like to thank my fellow students for making my postgraduate experience at Western so memorable.

Cheers!

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## Chapter 1: Introduction

### Background

Dementia refers to a large class of progressive degenerative brain syndromes (Costa et al., 2013) characterized by cognitive decline (Perry & O'Connor, 2002) affecting various aspects of one's daily life. Its symptoms include impairments in cognitive capacity, performance of instrumental and personal activities of daily living, alterations in personality (Mebane-Sims, 2009), as well as changes in mood, behaviour, and communication abilities (Alzheimer Society of Canada, 2010). Dementia is a major cause of disability among older adults worldwide (Chow & MacLean, 2001), ultimately affecting independence.

In 2010, there were 35.6 million people worldwide living with dementia. With 7.7 million new cases of dementia each year, it is estimated that by 2050, there will be over 100 million people worldwide living with dementia (World Health Organization & Alzheimer's Disease International, 2012). Specifically in Canada, approximately 500,000 Canadians have dementia today, which is expected to increase to over one million by 2038 (Alzheimer Society of Canada, 2010). In Ontario, dementia is predicted to rise 40% to more than a quarter of a million Ontarians by 2020 (Alzheimer Society of Ontario, 2011). With a large majority of the 60,000 new cases of dementia in Canada per year living in the community, many receive care informally from a family member (Corcoran, 2011).

In 2008, Canadians spent approximately 231 million hours on informal care, which refers to unpaid caregivers, usually family or friends. This number is expected to more than triple by 2038, reaching 756 million hours. The value of the time contributed

by dementia caregivers is estimated at approximately \$5 million dollars annually (in foregone wages), which is expected to increase to more than \$55 million dollars annually by 2030. Over the next 30 years, dementia is expected to cost society over \$872 billion dollars in direct health costs, unpaid caregiver opportunity costs, and indirect costs associated with the provision of unpaid care, a dramatic rise from \$15 million dollars in 2008 (Alzheimer Society of Canada, 2010).

It has been recognized that caregiving for a family member with dementia is typically an expression of love and dedication, but it can also be extremely challenging and have adverse effects, such as a sense of burden and feelings of depression and anxiety (Bookwala & Schulz, 2000). Caring for a family member with dementia and coping with the loss of exchange in the relationship require many changes in a family's life. Many researchers have linked the caring experience with long-term exposure to numerous stressful events (Connell, Janevic, & Gallant, 2001).

Despite the negative outcomes that may accompany dementia caregiving, caregivers also may experience reward throughout the journey. Research findings show that some caregivers gain a sense of self-worth and mastery (Martire, Stephens, & Atienza, 1997). Caregivers value positive aspects of relationships with their family member who has dementia. In addition, they appreciate their own feeling of confidence that caregiving provides them (Farren, Miller, Kaufman, Donner, & Fogg, 1999).

### **Iranian-Canadian Dementia Caregivers**

The minority elderly population of Canada is growing, and Iranian-Canadian older adults are one of the fastest growing groups. Statistics Canada (2007) revealed that the proportion of Canada's population who were born outside the country reached its

highest level in 75 years. The census recorded 6,186,950 foreign-born residents in Canada in 2006. They represented virtually one in five (19.8%) of the total population, the highest proportion since 1931. Among the more than 1.1 million recent immigrants who arrived between 2001 and 2006, 58.3% were born in Asian countries, including the Middle East (Statistics Canada, 2007). Iranians accounted for 2.5% of immigrants who arrived between 2001 and 2006, ranking 8th among the top ten countries of birth of immigrants to Canada between 1981 and 2006 (Statistics Canada, 2007). It is unknown what percentage of these immigrants were older adults, however the 2011 Iran Census revealed that 7.22% and 8.2% of the population in Iran in 2006 and 2011, respectively, were over the age of 60 (Noroozian, 2012).

Compared to other immigrant groups, the Iranians are relative newcomers to Canada. There were some 89,000 Iranian-Canadians living in Canada in the year 2001, and the main destination of these Iranian immigrants was, and still is, Ontario, more specifically the Greater Toronto Area (Garousi, 2005). Because age is a primary risk factor for dementia, the growth of the dementia problem in Canada will accelerate as the population ages. Therefore, as the number of Iranian-Canadian older adults increases, the population of dementia patients and caregivers also increases. In Iran, dementia disorders are not screened yet, but it is estimated that in 2009, there were more than 200,000 people suffering from dementia in Iran (Sabayan & Bonneux, 2011).

Family caregivers are a significant source of resource among Iranian-Canadians. These caregivers can be expected to be different from Western dementia caregivers due to difference in norms, practices, and expectations concerning their role. In the traditional Iranian family, households are often multi-generational. As a result, nursing home

placement for a loved one is perceived as unacceptable and a failure of filial piety. Older Iranians in need of care, therefore, are more likely to be cared for by a loved one in their homes. Furthermore, due to the migration of Iranians from Iran to North America, extended family may still be living in Iran, thereby limiting support with caregiving, increasing caregiver strain. Iranian caregivers have also identified other barriers, such as language, which impede access to caregiver support services. Additionally, an overriding sense of duty and responsibility in caregiving is a barrier because it causes reluctance to seek assistance. Thus, Iranian caregivers are less likely to utilize services that might otherwise ease the burden of caregiving (Azar & Dadvar, 2007).

### **Importance of Culturally Competent Care**

Minorities have difficulty getting appropriate, timely, high-quality care because of language barriers and their differing perspectives on health, medical care, and expectations about diagnosis and treatment. Achieving cultural competence in health care would help remove these barriers, with a system more responsive to the needs of an increasingly diverse population (Saha, Beach, & Cooper, 2008).

One of the primary concerns is the issue of language discordance between provider and patient (Saha et al., 2008) and in health education material, compounded by lack of interpreter services. Studies have shown that this can lead to patient dissatisfaction, poor comprehension and adherence, and lower quality care (Betancourt, Green, & Carrillo, 2002). Other communication barriers, apart from language barriers, lead to disparities in care. When health care providers fail to understand socio-cultural differences between themselves and their patients, the communication and trust between them may suffer. This in turn may lead to patient dissatisfaction, poor adherence to

medications and health promotion strategies, and poorer health outcomes (Betancourt et al., 2002). Moreover, when providers fail to take socio-cultural factors into account, they may resort to stereotyping, which can affect their behavior and clinical decision-making (van Ryn & Burke, 2000). Studies have also shown that insufficient culturally competent care can lead to poor communication with persons with dementia (PwDs), which can in turn cause significant harm such as loss of cognitive ability. It is further suggested that improving communication may have positive effects on PwD, on family caregivers, and even on people working in formal care environments (Young, Manthorp, Howells, & Tullo, 2011).

Caregiving is culturally influenced and strongly determined by socio-cultural beliefs about caregiving (Corcoran, 2011). This area is not well understood and contributes to a knowledge gap that may not allow the development of effective interventions tailored to families' unique needs and preferences for care (Zarit & Femia, 2008). Minimal research has been done to investigate the experience of dementia caregiving in the Iranian population, and none in regards to this group in Canada. Comprehensive studies on this topic can reduce barriers to appropriate programmes and organizational planning, providing optimal care and support for many patients and their families (Brach & Fraserirector, 2000). This information can also aid clinical practitioners in providing more appropriate care.

### **Purpose and Significance of the Study**

This study uses a phenomenological approach to explore the lived experiences of Iranian-Canadian adult children caring for a parent with dementia, and it provides a subjective account of the material reality of the caregiving experience. Phenomenology

addresses the nuances of everyday experience and shows a more complete picture of the life-world of caregivers (Dowling, 2007). Adult child caregivers were chosen as interviewees, as opposed to other family caregivers, because it would provide a unique look into their negotiation of dual cultural influences, both traditional Iranian views and their acculturated Western values, and its affect on their caregiving experiences. In addition, the dual role of these caregivers as both their parents' children and as their pseudo-parents (caregivers) might further influence their experiences.

The first aim of this research is to explore and understand the lived experiences of Iranian-Canadian adult children caring for a parent diagnosed with dementia. The second goal is to uncover the values and attitudes of these individuals in regards to their utilization of and expectation from formal and informal care services. The final objective is to investigate the role of culture in shaping these caregiving experiences.

This study is aimed at ultimately helping geriatric social and health care systems find ways to provide caregivers and recipients with adequate and sufficient resources in a culturally competent manner, through an approach consistent with their values. Through the design and implementation of effective interventions conforming to the specific needs of this particular population, dementia care can be improved. These family caregivers can benefit from resources that are consistent with their values and cultural beliefs and can potentially have the advantage of learning more appropriate ways to cope with and plan their caregiving responsibilities.

## **Chapter 2: Literature Review**

### **Introduction**

This chapter will begin by providing the reader with an overview of dementia and Alzheimer's disease. Then, particular attention will be paid to informal dementia caregiving and tasks and roles that differ and are similar amongst caregivers. Following this, consequences of dementia caregiving will be outlined, which include both negative and positive psychological and physical health effects. The risk factors that are attributed to these health consequences are also discussed. Additionally, culture-specific aspects of caregiving are introduced, and existing literature on dementia caregiving amongst Iranians in several countries is reviewed. Research on Iranians' view of the Western healthcare system and the barriers they face in accessing and using formal healthcare in the United States is included. Finally, the importance of and need for cultural competency in dementia care is discussed, as well as gaps in dementia caregiving literature that is concerned with cultural diversity.

### **Dementia**

Dementia has been defined as an acquired syndrome of intellectual impairment produced by brain dysfunction (Cummings, 1992), affecting memory, executive function, and other forms of cognitive impairment, leading to persistent, progressive, and often irreversible deterioration. In general, dementia involves three main types of symptoms: losses in cognitive capacities, difficulties in performing instrumental and personal activities of daily living (Cotter, 2007), and declines in interpersonal functioning (Le Navenec & Vonhof, 1996).

Dementia can be further divided into reversible and irreversible types (Kaplan, 1996). Reversible dementia may be caused by factors such as reactions to medications, brain tumours, environmental toxins, and nutritional deficiencies. Irreversible dementia is caused by degenerative brain diseases, such as Alzheimer's disease (AD), cerebrovascular diseases, and neurological diseases such as Parkinson's (Vitaliano, Zhang, & Scanlan, 2003). Alzheimer's disease is the leading cause of dementia in the elderly, accounting for 50% to 70% of all dementias (Agronin, 2004). It involves impairments in memory, attention, and cognition and a gradual progressive intellectual and functional deterioration (Vitaliano et al., 2003).

Age is a critical risk factor in dementia prevalence, where the prevalence rate at 65 years is 3%, and it increases up to 47% after 85 years (Hebert et al., 1995). Other major risk factors include family history (Huang, Qiu, von Strauss, Winblad, & Fratiglioni, 2004) and education level (Katzman, 1993). Dementia progresses slowly, where the average length of the disease ranges from two years to eighteen years (Turner, 2003).

**Diagnosis.** The standard approach for the diagnosis of dementia is taking a structured history focused on cognitive and functional changes with confirmation from a reliable informant, such as a caregiver or family member. A detailed medical, psychiatric, and substance use history is used to assess for other causes of memory loss. A physical examination, as well as a neurological examination, is performed (Neugroschl & Wang, 2011). The Mini-Mental State Examination (MMSE) (Folstein, Folstein, & McHugh, 1975) remains the most widely used instrument to test for dementia, with high sensitivity and specificity for separating moderate dementia from normal cognition (Feldman et al.,



2008). However, it is not particularly sensitive in those with mild dementia. A newer cognitive screen, the Montreal Cognitive Assessment (MoCA) (Nasreddine et al., 2005) is designed to be more sensitive for early AD as compared with the MMSE. Both tests use a scale of 30 points, with a score of  $\leq 26$  usually indicating cognitive impairment (Neugroschl & Wang, 2011).

There are no laboratory tests that definitively diagnose AD; the purpose is to exclude other etiologies for memory loss, particularly reversible or treatable causes (Neugroschl & Wang, 2011). Standard laboratory tests include complete blood count, electrolytes, and fasting glucose (Feldman et al., 2008), and thyroid stimulating hormone (Neugroschl & Wang, 2011). Testing of serum B12, folic acid, rapid plasma reagin (syphilis), and HIV antibodies is also recommended (Feldman et al., 2008).

Neuroimaging permits a detailed assessment of the structural patterns of brain atrophy, with particular attention to the medial temporal lobe, where the early atrophy in Alzheimer's disease can be seen (Feldman et al., 2008). It also allows for the exclusion of neurosurgical lesions, including conditions such as stroke, severe white-matter disease, and tumor (Neugroschl & Wang, 2011).

A biological marker of a disease can be defined as a measurable change in the physical constitution of a host that indicates the presence of that disease (Feldman et al., 2008). There is no ideal biomarker currently available for the diagnosis of AD. However, decreased levels of  $\beta$ -amyloid1-42 and increased levels of phospho-tau (p-tau) proteins in the cerebrospinal fluid levels are currently the most accurate and reproducible chemical biomarkers for early-onset Alzheimer's disease (Blennow & Hampel, 2003; Hampel et al., 2004). Presently, these cerebrospinal fluid (CSF) biomarkers may have utility for

specialists who seek to distinguish between frontal variants of Alzheimer's disease and frontotemporal dementia (Feldman et al., 2008).

### **Informal Dementia Caregiving**

Informal caregivers are caregivers who are not financially compensated for their services. They are usually relatives or friends who provide assistance to persons who are having difficulties with daily activities due to physical, cognitive, or emotional impairments (Vitaliano et al., 2003). With the rapidly changing demographic structure of society, more and more adults are providing informal care for persons with dementia (PwD) (Cranwick, 1997). Often, one family member serves as the primary source of informal care, although others in the network of family and friends may serve as secondary caregivers (Montgomery, Rowe, & Kosloski, 2007).

The average duration of dementia is approximately 5.8 years (The Canadian Study of Health and Aging Working Group, 2000). Research on caregivers suggests that 6 in 10 caregivers provide care to an elderly family member or friend for more than two years, with one-fifth providing care for 5 years or more (Stone, Cafferata, & Sangl, 1987). Despite increased physical and mental health demands placed on caregivers and the continual increase of informal expenditures with dementia progression, which exceeds formalized care costs (Cotter, 2007; Langa et al., 2001; Messinger-Rapport, McCallum, & Hujer, 2006; Nichols et al., 2008; Schulz & Martire, 2004), families prefer to care for relatives in the home (Nichols et al., 2008).

#### **Caregiving tasks and roles.**

*Differences by sex.* Females are the main informal caregivers of adults in need of help and support (Pinquart & Sörensen, 2005), comprising 77% of all family caregivers

in Canada (Health Canada, 2002). They tend to spend more time with their care recipients (Chiou, Chen, & Wang, 2005) and are involved in more caregiving tasks than men (Pinquart & Sörensen, 2006), while receiving less assistance with caregiving tasks (Lutzky & Knight, 1994). Women are able to juggle both caregiving responsibilities and their other duties without compromising the amount of time spent providing care for an elderly person, whereas men are more likely to reduce caregiving time when dealing with familial responsibilities. Women are also more likely than men to be involved in personal and domestic care, attending to the personal hygiene needs of the care recipient and engaging in household chores. In contrast, male caregivers typically provide transportation and help the older person with financial management (Stone et al., 1987).

Some research, however, indicates a greater involvement of men in caregiving (Houde, 2001), with some taking on primary care responsibilities (Harris, 2002) and performing personal aspects of care (Kaye & Applegate, 1993). Research has also found that, although men struggle with the demands of caregiving, they are more capable and willing to perform hands-on personal care than has been reported previously (Russell, 2007).

*Differences by relationship to the care recipient.* Spouses are the primary caregivers of PwD, but when they are no longer alive or unavailable, adult children, usually daughters, are the main source of help (Laditka & Laditka, 2000). Spouses and adult daughters provide assistance in a broader range of tasks and are much more likely to provide assistance with hands-on personal aspects of care compared to other caregiver groups (Pruchno & Potashmik, 1989). Spouses are more devoted to caregiving than adult children (Hope, Kenne, Gedling, Fairburn, & Jacoby, 1998), continuing in the caregiving

role for longer periods of time (Pruchno & Potashnik, 1989). However, adult children outnumber spouses as dementia caregivers because of the high rates of widowhood among the older population and sharing of caregiving responsibilities by multiple siblings (Spillman & Pezzin, 2000).

*Spouses as caregivers.* Among spouses, wives tend to provide more hours of care and accept less help from formal providers (Barusch & Spaid, 1996), and they tend to be more concerned with the emotional well-being of their husband. Husbands, on the other hand, are inclined to use a more managerial style of caregiving, focusing on the physical needs of their wives (Pinquart & Sörensen, 2006). These male spousal caregivers are task-oriented and focused on problem solving with the effective use of available resources, while maintaining meaning and satisfaction in their role (Pretorius, Walker, & Heyns, 2009). Bookwala and Schulz (2000) found that husbands and wives provide the same level of assistance. However, husbands are more involved in household tasks and are able to maintain their social activities outside the caregiving role, whereas wives are more involved in chores and focus primarily on caregiving, giving up their social obligations (Bookwala & Schulz, 2000).

*Adult children as caregivers.* When adult children are the caregivers, initially it is difficult for them to adjust to their new role, because they feel more like the parent than the child (Betts-Adams & Sanders, 2004). They may experience feelings of jealousy toward friends and family not caring for aging parents, and they are, in fact, more likely to place their parents in nursing homes than spousal caregivers (Meuser & Martwit, 2001).

There are differences between sons and daughters assisting parents who have significant functional or cognitive impairment. Although daughters often seek assistance from their own immediate family members, including their husband and children, they tend to receive less assistance from siblings or distant relatives than do sons (Brody, Litvin, Hoffman, & Kleban, 1995). Daughters provide more hours of care than sons, perform a broader range of care tasks, and tend to provide help that must be performed on a regular basis (Cicirelli, Dwyer, & Coward, 1992). They are three times more likely than sons to provide assistance with activities of daily living (ADLs) and over twice as likely as sons to provide assistance with instrumental activities of daily living (IADLs) (Dwyer & Coward, 1991). Daughters are more likely to be affected emotionally by the caregiving role (Jansson, Grafström, & Winblad, 1997) and are also a greater source of emotional support than sons (McCarty, 1996). They are more capable and willing to care for parents with greater needs for assistance than sons, and the care recipient is more likely to be residing with a daughter than with a son (Brody et al., 1995).

*The sandwich generation.* Parents who care for both young children and aging parents, referred to as the “sandwich generation”, may face a double burden (Gwyther, 1998). These caregivers are confronted with competing demands that contribute to stress and a growing reliance on formal care (Spillman & Pezzin, 2000). They are also predisposed to health and psychological problems (Tebes & Irish, 2000).

*Other family members as caregivers.* Much less information is available about siblings and caregivers who are more distantly related to the care recipient because these groups tend to account for a smaller proportion of caregivers and have not been widely studied. Generally, however, more distant relatives and friends tend to take on a

secondary caregiver role, providing financial aid, assisting with shopping, providing respite services (Penrod, Kane, Kane, & Finch, 1995; Tennstedt, McKinlay, & Sullivan, 1989) and supporting primary caregivers with transportation and housework (Nocon & Pearson, 2000). These caregivers tend to provide assistance to persons with fewer needs and do so for much shorter periods than spouses and adult children. There is some evidence, however, that a small segment of siblings and distant relatives do establish close emotional ties with their elderly relative and assume caregiving roles that more closely resemble those of adult children (Montgomery et al., 2007).

### **Consequences of Dementia Caregiving**

The disease trajectory for AD and other forms of dementia varies by the individual and may range from 5 to 20 years (Alzheimer's Association, 2010). For this reason, it has been proposed that stress from prolonged and extended periods of caregiving may be detrimental to the mental and physical well-being of family caregivers of PwD (Prigerson, 2003). In addition to experiencing long-term stress and burnout, some researchers have found that family caregivers of individuals with dementia also experience personal growth (Ott, Sanders, & Kelber, 2007).

**Psychological health consequences.** Most caregivers of PwD face 3-15 years of exposure to physical and psychosocial demands (Teri et al., 1992). As dementia progresses, caregivers must continually monitor their care recipients and witness their cognitive decline (Stephens, Kinney, & Ogrocki, 1991), meanwhile managing their changing demands and unexpected problem behaviours (Tremont, 2011). They absorb household chores and are exposed to symptoms of depression, anger, agitation, and

paranoia in their care recipients (Teri et al., 1992). This exposure to chronic stressors can lead to psychosocial distress and risky health behaviours (Vitaliano et al., 2003).

One response to caregiving is “caregiver burden”, which results from the negative appraisal and perceived stress resulting from caring for a PwD (Kim, Chang, Rose, & Kim, 2011). These caregivers report more physical and psychological symptoms and express feelings of entrapment, resentment (Zarit, Reever, & Bach-Peterson, 1980), and loss of control (Morris, Morris, & Britton, 1988). They frequently exhibit maladaptive coping strategies and express concern about their poor quality of life (Molyneux, McCarthy, McEniff, Cryan, & Conroy, 2008; Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi, 2007; Serrano-Aguilar, Lopez-Bastida, & Yanes-Lopez, 2006).

There are strong correlations between caregiver burden and depression (Tremont, 2011), with persisting high levels of burden associated with a subsequent increase in depressive symptoms (Epstein-Lubow, Davis, Miller, & Tremont, 2008). Caregiver burden is also strongly associated with anxiety and elevated rates of mood disorders (Schulz & Martire, 2004). Many caregivers also experience other psychological changes during caregiving, including emotional and physical strain (Ory, Hoffman, Yee, Tenstedt, & Schulz, 1999) and social isolation (Schulz, O’Brien, Bookwala, & Fleissner, 1995). Correlates of depression and other aspects of distress in caregivers include care recipient behaviour problems, severity of cognitive and functional impairment, more hours providing care, greater number of caregiving tasks, and longer duration of caregiving (Davis & Tremont, 2007; Pinqart & Sörensen, 2003).

Researchers have acknowledged that a majority of family caregivers of PwD also experience grief (Meuser & Marwit, 2001). Caregivers with greater depression and

burden leading up to and during the end-of-life period are at increased risk of prolonged grief (Tremont, 2011). Some of the losses experienced by family caregivers that lead to grief include the loss of the established relationship to the care recipient, loss of prior social roles and supports, and loss of intimacy (Loos & Bowd, 1997; Sanders & Adams, 2005). Caregivers' self-rated health, perceived stress, and life satisfaction are also linked with their psychological health (Schulz et al., 1995).

**Physical health consequences.** Caring for an individual with dementia can lead to increased risk for physical health problems, both in terms of perceived health and objective health measures (Pinquart & Sörensen, 2003; Vitaliano et al., 2003). Researchers have suggested that the combination of loss, prolonged distress, the physical demands of caregiving, and the biological vulnerabilities of older caregivers may compromise caregivers' physiological functioning and increase their risk for physical health problems (Schulz & Martire, 2004). The chronic stress associated with dementia caregiving may impair immunological and hormonal functioning, thereby increasing susceptibility to illness. In addition, cardiovascular changes, such as increases in blood pressure (Vitaliano et al., 2005) and an increased risk for coronary heart disease (Vitaliano, Scanlan, Krenz, Schwartz, & Marcovina, 1996), may result.

There is evidence that caregiving can interfere with caregivers' preventive health behaviours (Connell, 1994) and cause them to neglect their own health (Vitaliano et al., 2003). For example, caregiving stress can interfere with proper nutrition, and lead to increased smoking and drinking (Connell, 1994), and lack of exercise or sleep (Fuller-Jonap & Haley, 1995). This lack of time to devote to self-care and preventive health behaviours may contribute to long-term negative health consequences for caregivers, in



addition to direct effects of objective burden and depression (Vitaliano, Young, & Zhang, 2004).

Caregivers may experience prolonged anticipatory bereavement over lost aspects of their relationships with their care recipients, and bereavement is positively associated with physical illnesses (Kaprio, Koskenvuo, & Rita, 1987) and mortality (Goldman, Korenman, & Weinstein, 1995). Schulz and Beach (1999) showed that caregiving was an independent risk factor for mortality, with caregivers experiencing a 63% increased risk of death over 4 years compared to non-caregivers. Spousal caregivers of individuals with dementia had a higher mortality rate after hospitalization of their spouse than spousal caregivers of individuals hospitalized for reasons not related to dementia (Christakis & Allison, 2006). Finally, recent data shows a six-fold increased risk of dementia in spousal dementia caregivers compared to non-caregivers (Norton et al., 2010).

**Positive outcomes of caregiving.** Not all caregivers experience distress and burden (Hirst, 2005). Positive outcomes of caregiving include development of strength and resilience, humility, selflessness, a sense of self-worth and mastery, positive affect, and an improvement in the quality of the dyadic relationship between the caregiver and the care recipient (Beach, Schulz, Yee, & Jackson, 2000). Some of these qualities are associated with greater family cohesion and marital satisfaction (Martire et al., 1997). Some caregivers report feeling needed and useful, feeling good about themselves, learning new skills, developing a positive attitude and appreciation for life, and strengthening relationships with others (Tarlow et al., 2004). Personal and spiritual growth are positive caregiving outcomes also mentioned in the literature. The personal growth experienced by the caregivers stem from several factors, including assuming

responsibility once not considered, performing new tasks, and handling extremely stressful events in positive ways (Sanders, 2005).

Factors that have been shown to facilitate the experience of gains include having a good relationship with the PwD previously, being a caregiver by one's own initiative, coping with less venting emotions, and being able to maintain leisure time despite the demands of caregiving (Lopez, Lopez-Arrieta, & Crespoa, 2005). Caregiver personality characteristics, such as extroversion and agreeableness, along with social support (Silverberg, Baete, & Shirai, 2009) and frequent or close contact with the PwD (Liew et al., 2010), are also associated with more positive outcomes of caregiving (Silverberg et al., 2009).

Other research has noted that within the pain associated with caring for a person with a debilitating condition lie great moments of gain, such as reflecting on memories, sharing activities, and enjoying togetherness (Butcher, Holkup, & Buckwalter, 2001). Butcher et al. (2001) found that caregiving allowed “an opportunity to cherish the relationship between caregivers and care recipient” as well as to “focus on and enjoy those aspects of their relationship with their loved ones that were still intact” (p. 49). Similarly, Murray, Schneider, Banerjee, and Mann (1999) indicated that caregivers felt gains, such as satisfaction that stemmed from feeling fulfilled in their caregiving role, a reciprocal bond with the care recipient, a sense of companionship, and a fulfillment of the obligation to provide care.

Positive aspects of caregiving are inversely related to burden and depression and have the potential to protect against the negative consequences (Hilgerman, Allen, DeCoster, & Burgio, 2007). Noonan, Tennstedt, and Rebelsky (1996) suggested that the

positive aspects of caregiving may serve as buffer between the caregiving role and the actual negative consequences of caregiving. Studies have shown that individuals who do not experience gains are predominantly providing caregiving in isolation, without much assistance from others (Sanders, 2005).

**Risk factors.**

**Age.** The literature on the relationship between caregiver's age and psychological well-being is inconsistent. Hayslip, Han, and Anderson (2008) noted that the age of the caregiver can make a difference in the level of burden, with younger caregivers perceiving more burden than older caregivers. In Russo, Vitaliano, Brewer, Katon, and Becker's study (1995), younger caregivers showed significantly higher depression. Harwood, Ownby, Burnett, Barker, and Duara (2000b) showed that caregivers' age is a significant predictor of appraisal of satisfaction in the caregiving situation, such that older caregivers present higher satisfaction. Pinquart and Sörensen's meta-analysis (2007), on the other hand, showed that higher age is related to caregivers' lower physical health. Tornatore and Grant (2002) found that older caregivers feel more burdens from dementia caregiving and found age to be the only statistically significant demographic factor associated with caregivers' burden.

**Sex.** Most studies indicate that female caregivers report poorer health compared to male caregivers (Mannion, 2008), including depression, anxiety, general psychiatric symptoms, and lower life satisfaction (Yee & Schulz, 2000). They have higher levels of burden and depression and lower levels of subjective well-being and physical health (Pinquart & Sörensen, 2006). Female caregivers also report greater burden and strain from role conflicts (Schulz, 2000) and higher levels of loneliness (Bookwala & Schulz,

2000), suffering from social deprivation more than men in a caregiving role (Papastavrou et al., 2007).

Men view caregiving with less negative and more self-efficacious attitudes than women (Adams, Aranda, Kemp, & Takagi, 2002) and experience less stress and depression. However, they are more at risk for burnout because of societal role expectations, their assumption of a role not traditionally associated with masculinity, and its perception as a burden (Hubbell & Hubbell, 2002; Thompson et al., 2004). Some studies have reported that men are equally as likely to experience depression or anxiety as women are, although they are less likely to report it (Hubbell & Hubbell, 2002).

It has been suggested that the gender differences in caregivers' outcomes exist because, compared with male caregivers, female caregivers face higher levels of caregiving stressors, have fewer social resources, and report lower levels of psychological and physical health (Pinquart & Sörensen, 2006). It has also been suggested that observed gender differences in caregiver health merely reflect gender differences in general well-being, rather than caregiving-specific factors (Vitaliano et al., 2003). Hepburn et al. (2002) also suggest that how caregivers perceive their caregiving roles or the meanings that their caregiving experiences hold for them may offer more insights into the differences that exist among caregivers and their caregiving than would gender.

***Race and ethnicity.*** Caregivers of different racial and ethnic groups may experience the caregiving role quite differently. Studies have found that Black caregivers experience higher levels of caregiving satisfaction and mastery and lower levels of burden, depression, and role strain compared than Caucasian caregivers (Janevic &

Connell, 2001). This trend may be due to the benefit of extended family and high levels of social support, which allows for better coping (Adams et al., 2002). African American caregivers also have been found to be more resourceful in their caregiving than Anglo-American caregivers (Gonzalez, 1997) and are more likely to report rewards or benefits than Euro-American caregivers (Picot, Debanne, Namazi, & Wykle, 1997). Despite this, Black-American caregivers experience equal levels of depression and anxiety in caregiving to Caucasian caregivers (Gonzalez, 1997).

Similar to African Americans, Hispanics exhibit more perceived uplifts of caregiving than Whites. Despite better mental health outcomes, however, ethnic minority caregivers often report more physical health problems than white caregivers, indicating that low reports of distress do not always imply the absence of risk for caregivers (Pinquart & Sörensen, 2005). Also, factors that contribute to caregiver depression differ significantly between white Hispanics and white non-Hispanics. The cognitive impairment of the care recipient is a predictor of caregiver depression among white Hispanic spouses, whereas patient psychosis is a predictor of caregiver depression among white non-Hispanic spouses. Similar factors appear to predict burden in Cuban-American caregivers as in Caucasian caregivers. Additionally, the patient's behavioural pathology, female caregiver gender, and lower levels of perceived emotional support are the best predictors of burden in Cuban-American caregivers (Harwood et al., 2000a).

Studies have also revealed high levels of caregiver burden and mental distress in caregivers across the European community and more reported depressive and physical symptoms among caregivers from both China and the United States. Asian Americans and Latinos do not differ from whites in reported burden, but they do report more

depressive symptoms (Pinquart & Sörensen, 2005). Behavioural and biological functional disturbances of the care recipient are related to caregiver burden in Japan (Arai, Zarit, Sugiura, & Washio, 2002) and Argentina (Mangone, 1996), and are the primary determinants of stress and caregiver depressive symptoms in Italy and India. The number of persons living in the household is also a significant determinant of stress in Italian caregivers, with higher numbers inducing less stress (Zanetti et al., 1996). In Hong Kong, dementia caregivers are most stressed by their dysfunctional social life, emotional responses, financial strain, and by the frustration caused by the inability of the person with dementia to cope with daily life (Chu, 1991).

***Employment.*** The literature on employment and its consequences on caregivers are not definitive. Some studies have shown that working has adverse consequences on caregivers' physical, social, or emotional stress (Bullock, Crawford, & Tennstedt, 2003; Scharlach & Boyd 1989). Working caregivers seem to experience more negative effects than unemployed caregivers in terms of declining health and physical illness (Lechner, 1993; Wakabayashi & Donato, 2006). Caregivers who are in the workforce have an increase in depressive symptoms as compared to those who are not working or non-caregivers who are only working (Lee, Walker, & Shoup, 2001), and they feel less caregiving satisfaction (Lopez et al., 2005). Compared with other working caregivers, family caregivers who feel conflicted at work and still remain on the job experience more personal strain or depression (Brody, Kleban, Johnsen, Hoffman, & Schoonover, 1987).

On the other hand, some studies have shown that women who are employed outside of the home and provide care have fewer health declines than women who are only caregiving and do not work outside of the home (Pavalko & Woodbury, 2000).

Women who are not even necessarily employed outside of the home but are quite social and active within their social network fare better than those caregivers who are not social, with a lower rate of depressive symptoms (Cannuscio et al., 2004). Employed caregivers have also shown lower levels of stress than their non-employed counterparts (Giele, Mutschler, & Orodener, 1987). Despite complaints of balancing work and caregiving, some women appreciate the chance to change directions and go to work to focus on things they need to do there, reporting they would otherwise feel very isolated (Rosenthal, Hayward, Martin-Matthew, & Denton, 2004). This also holds true for male caregivers (Rands, 1997).

***Education.*** The relationship between education and caregiver's psychological well-being is inconsistent. Some research has found that lower education in caregivers is associated with greater psychological illness (Meshefedjian, McCusker, Bellavance, & Baumgarten, 1998) and higher depression (Covinsky et al., 2003). Other studies show the opposite effect, such as Ory et al. (1999), who found that higher education of dementia caregivers is a predictor of higher emotional strain. However, several studies have found little relationship between levels of education and outcomes associated with the caregiving process (Hooker et al., 2002; Rapp & Chao, 2000).

***Income.*** Some research indicates that lower income and financial inadequacy is related to caregiver's mental health. Pinquart and Sörensen's meta-analysis (2007) showed that lower socioeconomic status is related to caregiver's lower physical health. Convinsky et al. (2003) found that caregivers who have lower household income report more depression. Schulz et al. (1995) also proved the negative relationship between income and psychiatric morbidity. Income is also positively correlated with caregiver's

life satisfaction. Lee, Brennan, and Daly (2001) found that caregivers with higher income appraise the caregiving situation as more satisfactory and beneficial. They also report less depression. Some studies, however, have not found any relationship between income and caregivers' mental health (Russo et al., 1995).

***Relationship to the care recipient.*** The relationship between caregiver and care recipient has been found to be a significant predictor of burden in some studies. Andr n and Elmst hl (2008) noted that the highest levels of burden, depression, and lower subjective well-being occurred in spousal caregivers. Spousal caregivers also exhibit higher levels of stress and lower levels of life satisfaction and participation in social activities than other family caregivers (George & Gwyther, 1986; Schulz et al., 1995).

However, there are inconsistencies in the research, with other investigators reporting that adult child caregivers experience more of the negative aspects of caregiving than spousal caregivers. In Lawton, Moss, Kleban, Glicksman, and Rovine's study (1991), the psychological well-being of adult children caregivers, unlike spousal caregivers, was very sensitive to the amount of care they provided and the extent to which they appraised caregiving burden. Hayslip et al. (2008) noted that adult children perceive more burden than spouses, especially adult daughters who are likely to be juggling multiple roles, such as parenting and employment outside the home (Pearlin, Mullan, Semple, & Skaff, 1990). There is also evidence that adult-child caregivers frequently experience conflict with their siblings over caregiving issues, resulting in caregiver burden and poor mental health outcomes (Strawbridge & Wallhagen, 1991).

Daughters are deeply affected by their caregiving responsibilities, experiencing significantly more caregiver stress than sons (Ingersoll-Dayton, Starrels, & Dowler,



1996). Daughter caregivers report significantly higher levels of strain, poorer self-rated health, less respite support, higher levels of caregiving role involvement, and more interference in personal and social life compared to sons (Mui, 1995).

***Living situation.*** Caregivers who live with the care recipient often experience greater burden and lower psychological well-being, compared to those who do not live with the care recipient (Brodaty & Luscombe, 1998). Zanetti et al. (1997) showed that caregivers who co-reside with their care recipients have higher depression and burden. However, some studies suggest that co-residency is not significantly related to caregivers' mental health (Russo et al., 1995).

***Functional level of the care recipient.*** Findings on the link between care recipients' level of functioning and caregiver outcome have been inconsistent. A weak or no relationship between objective caregiving demands and caregiver outcomes has been reported in some caregiving research (Haley, Levine, Brown, & Bartolucci, 1987), however more studies have suggested caregiver burden and psychological morbidity are related to the behavioural, cognitive, and functional problems displayed by PwD (Papastavrou et al., 2007). Chappell and Penning (1996), for example, found that specific behaviours, particularly aimlessness, aggressive behaviours, forgetfulness, and restlessness, in care recipients were strong correlates of caregiver distress. Care recipients' feelings of apathy or lack of interest in daily activities also was strongly correlated with feelings of burden and depression in caregivers (Chappell & Penning, 1996). Caregivers who care for persons displaying more challenging behaviours and functional limitations also tend to receive less help from family and friends (Clyburn, Stones, Hadjistavropoulos, & Tuokko, 2000).

Some studies have reported that care recipient problem behaviours, but not level of cognitive and functional impairment, are predictive of negative mental and physical health outcomes among caregivers (Schulz et al., 1995). Barusch and Spaid (1996) concluded that some family members experience less burden when caring for a loved one with dementia than family members caring for a physically disabled person. This has been contradicted by other studies, which suggest greater stress among individuals caring for a relative with dementia as opposed to those caring for an elder with physical impairments (Lévesque, Ducharme, & Lachance, 1999).

***Quality of relationship between caregiver and care recipient.*** The relationship between the primary caregiver and the PwD prior to dementia may influence caregiver burden (McCarty, 1996). Several studies have found that caregivers who had had a close and affectionate relationship with their care recipient reported less burden and distress (Gilleard, Belford, Gilleard, Whittick, & Gledhill, 1984; Gold et al., 1995) and are less depressed (Williamson & Shaffer, 2001). The closer the prior relationship between the caregiver and care recipient, the less the strain is perceived (George & Gwyther, 1986; Harvath, 1994). Thus, caregivers who report a stronger and closer relationship with their afflicted relative would be better able to embrace the caregiver role and its responsibilities (Kua & Tan, 1997). Conversely, a close relationship with the care recipient may also prevent the caregiver from coping, because of an inability to remain removed from the situation (Duijnste, 1994). Specifically, the closer the caregiver and care recipient are, the higher level of perceived burden the caregiver reports (Andrén & Elmståhl, 2008). Unsatisfying prior relationships and poor family functioning are associated with stronger emotional reactions to care recipients' memory and behaviour

problems and increased burden compared to individuals with satisfying pre-dementia relationships (Steadman, Tremont, & Davis, 2007; Tremont, Davis, & Bishop, 2006).

***Social Supports.*** Caregivers who belong to a supportive social network may perceive their situations as less stressful or burdensome because of the emotional, tangible, and informational support that such a network provides. In a review of caregiver outcomes, Schulz et al. (1995) found a consistent relationship between lower levels of social support and poorer physical health among caregivers. Several recent studies have documented that lower levels of informal social support are related to increased burden and depression among caregivers (Coen, O'Boyle, Swanwick, & Coakley, 1999), whereas greater levels of social support are related to positive caregiver outcomes (Goode, Haley, Roth, & Ford, 1998). Social resources constitute the most significant factor related to caregivers' well-being, with caregivers with a broad social network reporting feeling less depressed and experiencing better quality of life (Rapp, Shumaker, Schmidt, Naughton, & Anderson, 1998).

Perceived emotional social support has been found to be positively related to a dementia caregiver's general well-being (Chapell & Reid, 2002). Perceived emotional social support and caregivers' satisfaction with their social networks are perhaps more important than the actual amount of informal help received (Schulz & Williamson, 1991). In Stuckey and Smyth's study (1997), it was found that a caregiver's subjective awareness of social ties is a stronger predictor of positive health outcome than their objective number of social ties.

***Coping.*** Coping, defined as the cognitive and behavioral attempts to manage specific demands that are appraised as stressful, is an integral part of the stress process

(Lazarus & Folkman, 1984). Coping strategies have been commonly classified as problem or emotion focused. Problem-focused coping refers to managing the problem within the stressful environment, whereas emotion-focused coping refers to adjusting the emotional response to the crisis (Lazarus & Folkman, 1984). Emotion-focused coping is associated with lower levels of resilience (Garity, 1997) and greater levels of distress, whereas more active, problem-focused coping is associated with greater caregiver well-being (Goode et al., 1998; Haley et al., 1987; Kramer, 1997; Pruchno & Resch, 1989) and resiliency (Garity, 1997).

***Importance of caregiver appraisal.*** Caregivers who positively appraise the caregiving experience and identify more beneficial components of caregiving experience fewer negative feelings, less burden, improved health and relationships, and greater social supports (Cohen, Gold, Shulman, & Zuccherro, 1994). This suggests that the subjective appraisal of stress, rather than the objective stressors, is important in determining a dementia caregiver's well-being (Harwood et al., 2000a), with positive appraisals acting as a buffer against caregiving stress (Rapp & Chao, 2000). Studies have also shown that caregivers who have a more positive mindset are more likely to want to attend caregiver training and support programmes (Liew et al., 2010). In addition, caregivers who have a better sense of well-being are more likely to see the positive and therefore express higher gains (Liew et al., 2010). Hooker et al.'s study (2002) showed that care recipients' increased problem behaviors and prolonged caregiving were strongly associated with a caregiver's worsening mental and physical health. However, the relationship between the PwD's behavioral and psychological symptom and the caregiver's mental and physical health is mediated through the caregiver's stress appraisal (Hooker et al., 2002).

In summary, research has shown that younger caregivers and female caregivers experience increased burden and older caregivers experience increased satisfaction with the caregiver role. Cultures with stronger extended family networks have lower rates of depression, whereas Europeans have higher levels of mental distress and burden. Unsatisfactory prior relationships and poor family functioning are associated with increased burden. On the other hand, perceived social support is important such that increased social support is related to lower burden and less physical health problems. Similarly, positive appraisal of the caregiving experience buffers against caregiving stress. Emotion-focused coping, as opposed to problem-oriented coping, is related to greater levels of distress. The effects of caregiver employment, income, and education on caregiver health are not definitive. Inconsistencies in research also exist in terms of caregiver burden and type and quality of the caregiver-care recipient relationship as well as living situation and care recipient functional level. What also appears to be missing from the literature is the compounding influence of these factors in the Middle Eastern population in Canada, particularly Iranians. This group has not been investigated in the Canadian context, and this contributes to a knowledge gap that exists in caregiving literature.

### **Cultural Diversity and Caregiving**

Canada is one of the most ethnically, racially, and culturally diverse countries in the world. In 2001, 13% of the Canadian population belonged to a visible minority group (Statistics Canada, 2005), defined as non-Caucasian in race or non-white in colour (Ontario Ministry of Finance, 2003). Between 2001 and 2006, the visible minority population grew approximately 27.2% (Statistics Canada, 2010), and it is estimated that

in 2017, between 6.3 million and 8.5 million people in Canada will be visible minority persons, accounting for 19% to 23% of the total population (Statistics Canada, 2005).

Canada's increasingly diverse population is accompanied by an equally diverse aging population and a growing population of visible minority caregivers. Culture plays an important role throughout the entire period of dementia caregiving, from designating a main caregiver to healing during the bereavement process (Etters, Goodall, & Harrison, 2008). Differences also exist in beliefs about illnesses, help seeking behaviours, utilization of formal and informal services, and desires for culturally competent interventions. These reflect the ethno-cultural diversity of caregivers and the need for rejection of a "one size fits all" model in health care.

**Filial piety.** Filial piety is a cultural belief that adjusts adult children's attitudes and behaviors toward their parents to ensure the continuance of parental well-being in old age (Mao & Chi, 2011). It is a family-centered cultural construction (Dai & Dimond, 1998), which is manifested through providing parents with the necessary materials for the satisfaction of their physical needs and comforts, including attending to them when they are ill, paying attention to their wishes and preferences, and behaving in a way to make them happy and bring them honor and respect in the community (Chow, 2001).

Research has shown that, in general, non-Caucasian minority caregivers have a stronger sense of filial responsibility and stronger kinship ties than Caucasian families (Markides & Black, 1996; Yeo & Gallagher-Thompson, 2006). For example, greater feelings of filial obligation have been found among African American, Mexican, other Hispanic, and Asian caregivers, when compared with Caucasian caregivers (Aranda &

Knight, 1997; Connell & Gibson, 1997; Cox & Monk, 1990; Wong, Kitayama, & Soldo, 1999; Wood & Parham, 1990; Yeo & Gallagher-Thompson, 2006).

There are also differences in perceptions of caregiving burden and stress among Caucasian and non-Caucasian caregivers (Aranda & Knight, 1997; Haley et al., 1996; Lawton, Rajagopal, Brody, & Kleban, 1992; Mehta, 2005). The prevailing attitude in Western cultures is that caring for aging family members is a burden that tends to interfere with other important responsibilities. However, in most non-Caucasian cultures, the idea that caregiving is a burden is foreign. When faced with the possibility of placing an aging family member in a nursing home, family caregivers from cultures with a high filial piety orientation believe they have an obligation to provide the care themselves (Triandis, McCusker, & Hui, 1990).

**Use of formal and informal services.** Studies support minority caregivers' preference for reliance on extended family networks rather than formal services in the caregiving process (Dilworth-Anderson, Williams, & Gibson, 2002). Non-Caucasian caregivers use fewer formal services than Caucasian caregivers (Braun & Browne, 1998; Cox & Monk, 1990; Ho, Weitzman, Xingia, & Levkoff, 2000). There are significantly fewer nursing home placements among the non-Caucasian elderly than among the Caucasian elderly (Aranda & Knight, 1997). Wood and Parham (1990) found that Caucasian caregivers attend support groups more frequently and are more likely to use nursing home services than African Americans (Miller, McFall, & Campbell, 1994). Research also suggests low levels of formal service utilization among Latino caregivers relative to Caucasian caregivers (Henderson, Gutierrez-Mayka, Garcia, & Boyd, 1993; Hinton & Levkoff, 1999).

Generally, formal services for frail elders and their caregivers are designed on the basis of Western values and marketed to middle-class Caucasian Americans, making them unappealing to minority groups who have a longstanding distrust of mainstream establishments (Wong et al., 1999). Minority caregivers may be especially likely to experience structural barriers to service utilization, including inadequate transportation, insufficient knowledge about services, cost of services, language barriers, negative prior experiences and dissatisfaction with services, and lack of culturally-sensitive services (Scharlach et al., 2006). However, the most common reason for underutilization of formal services is the view of caregiving as a personal responsibility. Some caregivers even say that, as the care recipients' condition deteriorate, familial responsibility to care increases and the desire for use of formal services decreases (Ayalong, 2004).

Minority caregivers often have wider and stronger informal support networks than White caregivers. These individuals tend to rely on assistance from informal supports, such as extended family members, friends, and others in the community (Aranda & Knight, 1997). Reasons for this are similar to those discussed previously, in addition to the fact that minorities tend to have larger families, resulting in a greater number of people who are available to provide care (Lawton et al., 1992).

**Cultural perceptions.** Cultural values and beliefs about illness and disease can shape the way older members of ethnic minorities assign meaning to dementia and influence the level and type of help they seek (Dilworth-Anderson & Gibson, 2002). Henderson and Gutierrez-Mayka (1992) suggest that culturally based illness meanings assigned to different diseases are part of a larger belief system of values and norms that help define caregivers and their responses to an ill relative. Hinton, Franz, Yeo, and



Levkoff (2005) reported that African, Asian, and Hispanic family dementia caregiver participants are significantly more likely to conceptualize dementia in ways that differ from the widely accepted biomedical model. For example, Hispanics view elders with dementia as being "crazy" or having "bad blood". Such cultural meanings among caregivers create barriers to seeking assistance outside the family circle (Henderson & Gutierrez-Mayka, 1992).

One common example of a personal belief among minority groups is that memory loss is a part of normal aging. For example, African Americans are significantly more likely to view dementia symptoms as a normal part of getting older (Roberts et al., 2003), as well as changes in personality and behaviour (Hughes, Tyler, Danner, & Carter, 2009). Similar findings have been found in studies involving samples of Hispanic American (Gelman, 2003), Asian Indian (Otilingam & Gatz, 2008), Vietnamese (Braun, Takamura, & Mougeot, 1996), Chinese, Japanese, and Korean American family caregivers (Jones, Chow, & Gatz, 2006).

Another common view among ethnic minorities is the personal belief that dementia symptoms are related to mental disorders or insanity rather than neurodegenerative brain diseases. Gaines (1989) reported that many African Americans believe that cognitive deficits can be attributed to excessive worrying or thinking rather than a brain-based disease, a belief also held by some Chinese American caregivers (Zhan, 2004). Watari and Gatz (2004) and Lee, Lee, and Diwan (2010) found that many Korean American caregivers view AD as a form of insanity or a failure to stay mentally active. Attributing dementia to "craziness" has also been reported in studies involving African, Asian, and Hispanic American older adults (Ayalon & Areán, 2004).

Sue (1994) reported that many Asian caregivers perceive shame in their culture for having a family member with dementia. For example, in Japan, the moral status of individuals who are categorized as “senile” is tarnished, because they fail to sustain social relationships in a mutual, culturally expected fashion (Traphagan, 1998). This finding is similar to that of Hinton, Guo, Hillygus, and Levkoff (2000) who found that “senility” may be stigmatized in Chinese families because it represents the “unbalanced” and “undisciplined” person. In addition, stigmatization of a family member with AD was highlighted in studies involving Hispanic American caregivers (Neary & Mahoney, 2005).

### **Dementia in the Iranian-Canadian Culture**

**Dementia in Iran.** Located in south Asia, Iran’s population has been growing for the past 50 years. It had a population of 16.5 million in 1950, and since then, the country’s population has reached over 65 million. An aging population, with 6.17% being 60 years old and over (Sheykhi, 2006), has led to an increasing number of dementia cases. There are 250,000 known cases of Alzheimer’s disease in Iran (Yektatalab, Kaveh, Sharif, Khoshknab, & Petramfar, 2012).

**Iranians in Canada.** Iranians are one of the largest immigrant groups from the Middle East (Bozorgmehr, 2001). As late as the end of World War II, there were about a dozen Iranians living in Canada, with ten to one hundred immigrating to Canada annually throughout the 50s and 60s (Garousi, 2005). The first big wave of Iranian immigrants to Canada arrived in the 1970s, when the number increased from 100/year to 600/year by 1978. Following the Iranian Islamic revolution in 1978, the rate of immigration accelerated to several thousand per year. This level was sustained throughout the Iran-

Iraq war and throughout the 1990s (Garousi, 2005). According to the 2006 census, approximately 24,285 Iranians immigrated to Canada before 1991, increasing to 27,600 Iranian immigrants between 2001 and 2006. The total Iranian immigrant population, according to the 2006 census, was approximately 92,090 (Statistics Canada, 2006). The main destination of Iranian immigrants is Ontario and, more specifically, the Greater Toronto Area (GTA) (Garousi, 2005).

**Recent research on Iranian immigrants.** Despite the large number of Iranian immigrants in Canada, little research has been conducted concerning the health status and healthcare needs of this population. Salari (2002) described older Middle Eastern immigrants as “invisible” in the aging literature. Moghari (2000) reported that “aged Iranian immigrants have more health problems than the other groups in the host country” (p. 7), but they are far less likely to seek or receive mental health services (Emami, Benner, & Ekman, 2001). Older Iranian immigrants are more vulnerable than younger immigrants (Emami, Torres, Lipson, & Ekman, 2000; Lipson, 1992) and have also been found more likely than their young counterpart to suffer from mental health problems (Ghaffarian, 1998). In general, older Iranian immigrants have been found to be resistant to acculturation (Ghaffarian, 1998), a contributing factor to poor self-rated health among Iranian immigrants (Wiking, Johansson, & Sundquist, 2004).

**Definition of health.** Martin’s (2009a) study of older Iranian immigrants in the United States found that Iranians view health as consisting of both physical and spiritual well-being. This is consistent with other findings, such as one by Emami et al. (2000), who studied older Iranian immigrants in Sweden. Iranians’ views on health are opposed to the biomedical model of Western medicine that divides health into two separate

categories of physical and mental health. In general, Iranians define being healthy as having balanced health and as an overall absence of worry, good nutrition, “happy hearts”, and a feeling of being connected to the family and community. Furthermore, Iranians believe that one of the greatest losses that a person suffers when faced with illness is the loss of his or her sense of self and identity, as well as “losing one’s appetite for life” (Martin, 2009a).

***Views on healthcare.*** Iranian immigrants desire a more holistic approach to healthcare that fits within their definitions of health and illness, with particular attention to their spirit. Care providers’ kindness, pleasant interactions with patients, curiosity about their lives and families, and focusing on the patient beyond the illness, are important to Iranians when it comes to healthcare (Martin, 2009a). An investigation of older Iranian immigrants’ experiences with the American health care system by Martin (2012) found that some participants talked about the fact that their doctors did not know anything about them except for their illness. They believed that their doctors see them as a “problem” that needs to be fixed rather than as a person or an individual who needs to be healed.

***Family caregiver experiences.*** Abdollahpour, Noroozian, Nedjat, and Majdzadeh (2012) investigated caregiver burden and the factors influencing it among caregivers of patients with dementia in Iran. Among family members, spouses of the PwD were reported to be suffering from the highest degree of burden. One might conclude that, due to the higher age of spousal caregivers, their physical and mental capacity might have been deteriorated as compared to other family members. The other explanation for this phenomenon is the quality of family interaction and its related factors. As a very common

practice, the spouse lives with the PwD and has to spend a longer time caring.

Consequently, spouses are at a higher risk for an increase in physical and mental health issues (Abdollahpour et al., 2012).

The stage of dementia did not play an important role in the level of caregiver burden in the above study (Abdollahpour et al., 2012). This finding could be supported by previous studies that point out that some caregivers adopt better coping styles as the time passes and as the patient steps into more advanced stages of dementia (Johnson & Catalano, 1983; Rabins, Fitting, Eastham, & Zabora, 1990). Gender also did not play a statistically significant role in caregiver burden (Abdollahpour et al., 2012). On the other hand, the level of dependence of the patient on the caregiver can be considered as one of the factors influencing the level of burden perceived by the caregiver. The level of the capability of the PwD to perform daily tasks declines and the burden of the caregiver increases due to the higher pressure caused by his/her increased involvement in supporting the patient with daily tasks (Abdollahpour et al., 2012).

A recent study by Navab, Negarandeh, Peyrovi, and Navab (2012) investigated the experiences of Iranian family member caregivers of persons with Alzheimer's disease in Iran and found that the family caregivers frequently recalled past circumstances and abilities of the PwD and compared them with present conditions. This dwelling on the past created feelings of worry and sorrow. Caregivers in this study often scrutinized the past to find the cause of their loved one's dementia. Also, in stressful times, caregivers saw dementia as punishment for their own or the PwD's past sins. Caregivers who participated in this study often blamed themselves if there was a delay in the diagnosis of AD, resulting in feelings of guilt, regret, and self-blame (Navab et al., 2012).

In the same study, taking care of a family member with Alzheimer's disease was also associated with the fear of future decline and inevitable worsening of the family member's condition. The authors believed that this fear was due to the fact that, despite spending so much time, energy, and care on the care recipient, they were failing to observe any improvement in the PwD's condition because of the progressive and unpredictable nature of dementia. Additionally, reports of other persons in more advanced stages of AD caused them to be fearful, not only of their family member's future but also of their own (Navab et al., 2012).

***Barriers to utilization of healthcare services.***

*Lack of knowledge and language barrier.* Within the Iranian culture, Alzheimer's disease and other dementias are viewed as a part of normal aging and not as disease processes. This lack of knowledge hinders the development of skills necessary for effective and appropriate caregiving. Furthermore, the lack of fluency in English in many Iranian households deters help seeking behaviours and access to support services (Azar & Dadvar, 2008). Language barriers were also found in a study by Dastijerdi (2012), which investigated the opinions of Iranian healthcare professionals and social workers on the barriers Iranian immigrant clients face in accessing health care services.

*Sense of duty and responsibility.* In the traditional Iranian family, households are often multi-generational. As a result, nursing home placement for a loved one is often perceived as unacceptable and a failure of filial piety. This sense of responsibility and obligation in caregiving often leads to reluctance in seeking assistance and utilizing formal services that might otherwise ease the burden of caregiving. Older Iranians in

need of care, therefore, are more likely to be cared for by a loved one in their homes (Azar & Dadvar, 2008).

*Distrust and need for privacy.* Lack of trust in modern medicine keeps many older Iranian immigrants from seeking care when they need it (Martin, 2009b). This lack of trust may stem from fear of disclosure, because confidentiality is very important to Iranians. As a result, they are hesitant to reveal sensitive issues to health care professionals, unaware of what is private and public information. They feel the need to save face and hold onto their honour and pride (Dastjerdi, 2012). Most of the Iranian health care professionals and social workers in Dastjerdi's study (2012) believed that their clients are skeptical and unable to trust the services and never feel completely comfortable using them. A few Iranians prefer to visit non-Iranian physicians or social workers in order to keep their personal life private and secure. Some participants pointed out that their clients have unrealistic expectations that lead to dissatisfaction and mistrust of health care providers and services (Dastjerdi, 2012).

### **Cultural Competence**

With the rapid growth of the racially, ethnically, and culturally diverse elderly population in Canada, current and future generations of diverse elders diagnosed with dementia and their caregivers are expected to experience complex and unique sets of service needs. If dementia caregivers are to be effective in their role over the long term, there must be greater recognition of their unique culturally-specific needs. Therefore, there is need for cultural competency in service provision for both the elderly and their families.

Cultural competence is “an ongoing process in which the health care provider continuously strives to achieve the ability to work effectively within the cultural context of the client (individual, family, community)” (Campinha-Bacote, 2002, p. 181). Cultural competence must be implemented in both dementia care and caregiver intervention programmes. The general goal is for practitioners to develop knowledge, skills, and attitudes so as to be able to provide effective service delivery to care recipients and caregivers within diverse socio-cultural contexts.

Culturally competent care can reduce barriers to appropriate programmes and organizational planning, providing optimal care and support for many patients and their families (Brach & Fraserirector, 2000). The ability to provide relevant and meaningful interventions to address the needs of elderly people with AD and other forms of dementia and their family caregivers is based on a complex understanding of the disease process in the cultural context of the elder and the caregiver. The incidence, course, and manifestations of dementia in the elderly, the meaning these manifestations hold for the elder and their families, and the underlying caregiving structure commonly used are all interrelated factors that affect provision of care for the PwD and the implementation of interventions for their caregivers (Patterson et al., 1998). Therefore, if health care professionals and organizations are to meet the needs of Canada’s diverse population, they must be culturally sensitive and well-informed, acknowledge the different health beliefs and practices, and be flexible in the way they approach health care and services (Brach & Fraserirector, 2000).

Psychosocial support interventions to promote the health of visible minority dementia caregivers must address cultural attitudes, such as distrust, perceived



discrimination, reticence toward having strangers in the home, and preferences for taking care of elders without support from those outside the family. However, these factors are seldom addressed in intervention studies. Providing information and addressing barriers to supportive home care services is a promising strategy (Kaye, Chapman, Newcomer, & Harrington, 2006).

There is evidence that cultural competence training impacts the knowledge, attitudes, and skills of health professionals, which in turn can impact patient satisfaction (Beach et al., 2005). Health care providers who are more knowledgeable about their patients' backgrounds, who have more positive attitudes towards their patients, and who have the skills to communicate and apply a patient-centered approach are likely to provide better care to their patients (Stewart, 1995). Studies have suggested that people from racially and ethnically diverse populations are more satisfied with care providers of their own cultural background (Barker, 1992; Lipson, 1992).

Pang, Jordan-March, Sliverstein, and Cody (2003) recommended that cultural competency training be included within procedures for licensure of physicians and healthcare personnel. They explain that this training is needed in order to improve communication between healthcare providers and immigrant patients and their families. Another study by Majumdar, Browne, Roberts, and Carpio (2004) found that a cultural sensitivity training program not only improves knowledge and attitudes among healthcare providers, but it also yields positive health outcomes for their patients and their caregivers.

Many Iranian immigrants may not receive culturally appropriate care once they reach the healthcare system, or they may not even approach the healthcare system when

necessary. It is important for healthcare providers to be aware of the cultural factors that influence care-seeking and caregiving behaviours among Iranian-Canadians.

Furthermore, in order to be effective, it is important to find a way of caring for older immigrants that fits within their cultural values and perception of health and illness. By being aware of possible ethnic and cultural variations in the caregiving experience, health care professionals and policy makers can better meet the needs of the diverse groups of patients and caregivers whom they serve. In addition to these practical benefits, contrasting the caregiving experience of different groups can also enhance the theoretical understanding of this experience by distinguishing its universal elements from those that are mediated by the norms, expectations, or experiences of a given cultural group (Patterson et al., 1998).

### **Gaps in Culturally Diverse Dementia Caregiving Literature**

Much of our understanding of caregivers of persons with dementia comes from research conducted in the United States. Although the body of knowledge on caregiving in the Canadian context continues to grow, our understanding of Canadian caregivers of PwD is still in development. With rising immigration rates to Canada, the number of ethnically, racially, and culturally diverse elderly diagnosed with dementia is increasing. Consequently, more people of diverse backgrounds are finding themselves taking on the role of caregiver to an elderly family member with dementia (Light, Niederehe, & Lebowitz, 1994).

Our understanding of the cultural distinctions among caregivers of persons with dementia is extremely limited. Very little research has been conducted on visible minority caregivers. Future research needs to be directed towards understanding

differences among different ethno-cultural groups in how the caregiving role is defined and enacted. Also, there is a need for research that examines the effectiveness of different interventions for caregivers from different ethnic groups and cultures to determine whether the efficacy of intervention strategies varies as a function of caregiver ethnicity or cultural background (Czaja, Eisdorfer, & Schulz, 2000).

The pattern of service use by visible minority caregivers should also be investigated further. Specifically, the issue of minority caregivers' expectation of and barriers to using services is an area that needs to be explored (Kuhlman, Wilson, Hutchinson, Wallhagen, 1991). Despite some similarities amongst caregivers, the insight gained from any differences would be of help to program planners, policy makers, and formal caregivers in developing and implementing culturally sensitive programs and policies to support diverse caregivers.

Furthermore, the role that ethnicity and culture play in the perception of unmet needs for minorities is still unanswered. Therefore, another goal should be to discover unmet patient and caregiver needs in order to foster better physician-patient-caregiver relations and to develop interventions targeted to specific populations with the purpose of maintaining PwD at home as long as possible. Knowledge of patient/caregiver and physician preferences, problems with policies, and knowledge about cultural effects on utilization of services, and the effects of cultural or ethnic differences between patients/caregivers and physicians, can enhance this (Lampley-Dallas, 2002).

Additionally, no research has been done on the dementia caregiving experience of Iranian-Canadian adult children caring for a parent with dementia. In-depth study of

family dynamics and the effects of acculturation could improve understanding of how the stress process unfolds for Iranian-Canadian dementia caregivers. This could contribute to culturally appropriate assessment and intervention protocols to strengthen caregivers' physical, psychological, and social well-being.

### **Chapter 3: Methodology**

This study is a descriptive phenomenological one, influenced by hermeneutics. In this chapter, the framework for a phenomenological study and its appropriateness for this project are discussed, as well as the elements of hermeneutics that are used. Following this, the procedures for the study, including sampling and study recruitment and data collection and analysis methods are also discussed.

#### **Phenomenology**

Phenomenology is a human science that strives to interpret and understand, rather than simply explain and observe (Morse, 1991). It is concerned with exploring the human experience as it is lived (Dowling, 2007) and how people describe and make meaning of a phenomenon experienced by them directly (Patton, 2002). Therefore, because this study is exploratory, phenomenology is an appropriate research methodology; it allows for an in-depth and rich view into the caregiving phenomenon among Iranian-Canadian adult children caring for a parent with dementia. It also allows for a deep exploration and understanding of how the meaning of this experience is influenced by the Iranian culture.

**Hermeneutic phenomenology.** Heidegger's hermeneutic phenomenology focuses on the everyday aspects of humans, going beyond mere description, focusing on the life world, or subjective human experience as it is lived, and its interpretation (Morse, 1991). It brings out a hidden meaning, illuminating the unknown, and achieving a sense of understanding (Palmer, 1969; Wilson & Hutchinson, 1991). Hermeneutical phenomenology has two important assumptions: 1) humans experience the world through language; and 2) language provides both understanding and knowledge (Byrne, 2001). In other words, a person's lived experience is expressed through the use of speech, writing,

or art for the purpose of uncovering and reconstructing the held meaning (Van Hesteren, 1986).

Hermeneutical phenomenology focuses on the concept of “Being”, which is how people interpret their presence in the world (Wilding & Whiteford, 2005) and everything embedded in their world (Vouzavali et al., 2011). It does not just refer to our subjective existence, but to the ways in which we are. Heidegger used the word *Dasein* or “being-in-the-world” to refer to the way human beings exist or are involved in the world (Dowling, 2007). Humans are inherently relational, thus they extend beyond their objective bodies and experience phenomena in relation to a specific context (Wojnar & Swanson, 2007). *Dasein* applies to the researcher as well as participants: “Hermeneutic phenomenology is grounded in the belief that the researcher and the participants come to the investigation with fore-structures of understanding shaped by their respective backgrounds, and in the process of interaction and interpretation, they cogenerate an understanding of the phenomenon being studied” (Wojnar & Swanson, 2007, p, 175).

**Hermeneutic circle.** Key to the hermeneutical methodology is the concept of the hermeneutical circle, which is the process by which people come to develop an understanding of something (Wilding & Whiteford, 2005). The hermeneutical circle is a reflexive and ongoing process, involving a dialectic movement between parts and the whole that specifies particular dimensions of the phenomenon and the phenomenon as a whole (Wilding & Whiteford, 2005). The whole can be understood by the study of the individual parts, and we understand the individual parts by understanding the whole (Walsh, 1996). In respect to this research, understanding and interpreting the caregivers’

stories is a dialectical interaction between the whole and the parts, between my research participants and me, as each gives the other meaning, and thus, understanding is circular.

**Fusion of horizons.** According to Heidegger, interpretations are made on the basis of the existing understanding and the view of the researcher (Palmer, 1969). Hermeneutic phenomenological study intertwines the interpretations of both the participants and the researcher about a lived experience to uncover layers of details and to identify the core essence of that lived experience (van Manen, 1990). During the process of engagement in a hermeneutic circle of understanding, data are co-constructed and hidden meanings are elicited by both the participant and researcher (a fusion of horizons), though an interactive dialectical interchange of dialogue and interpretation between these two. This brings life to the experience being explored (Koch, 1996).

By using phenomenology with hermeneutic underpinnings, it was my role as the researcher to collect and interpret descriptions of adult child caregivers' experiences to determine the structures or essences that comprised those experiences. The use of phenomenology created a space for the researcher (me) to explain meanings and assumptions of participants' experiences based on individual theoretical and personal knowledge (Ajjawi & Higgs, 2007b). The aim was to illuminate lived experiences, because the meanings of lived experiences are usually not readily apparent (van Manen, 1990).

***Location of the researcher and reflexivity.*** Qualitative researchers seek to provide a presence of the participants in their studies, while acknowledging their own impact as researchers (Goodley, Lawthom, Clough, & Moore, 2004). Heidegger makes it clear that as people, researchers cannot detach themselves from their views or

experiences (Palmer, 1969), so he did not believe in the ability to bracket a researcher's fore-conceptions or pre-understandings (Standing, 2009). For this reason, as a researcher, I am implicated in this study, because I too cannot detach myself from my experiences or preconceived views of the phenomenon being studied. This has a direct impact on this study because my own experiences affect my interpretations of the experiences of those that I am researching. Heidegger suggests that throughout a hermeneutic phenomenological study, researchers should engage in the reflective process of making understandings, biases, theories, assumptions, presuppositions, and beliefs related to the study explicit (Laverty, 2003). As a result, it is important for me as the researcher to recognize all assumptions and biases as they may relate to the research questions being studied (Creswell, 2008; Richards & Morse, 2007).

Reflexivity is particularly relevant in this study where I, the researcher, assumed the dual-role of an insider and an outsider: an Iranian-Canadian adult child of immigrant parents and a researcher and graduate student, respectively. Morse (2006) argues that to heighten reflexivity, the social location of the researcher must be acknowledged in the research process, because it affects not only the meanings assigned to an event, but also the value and the significance of any claims made (Alcoff, 1991). My location within the research process was an important factor, and I need to acknowledge the influence of my personal experience in the understanding and interpretation of the Iranian-Canadian dementia caregiving experience. The impetus for the study came from my years of volunteering at North York General Hospital, witnessing a diverse population of patients being admitted and released. I continually took notice of the evident patterns of behaviour among the ethnically diverse elderly patients and their families. I came to



wonder why such cultural patterns exist, despite the inevitable influences of living in a Westernized society, especially in the caregiving context. I am an Iranian-Canadian myself, and so my interest in the cultural aspect of caregiving was piqued, especially in the experiences of Iranian-Canadian adult children caring for a parent with dementia.

My insider knowledge of the influence of culture on caregiving of parents with dementia amongst Iranian-Canadian children was gained from the shared characteristic of culture. Also, I have personal experience in caregiving in that my dad's cousin has been caring for her extremely frail mother for the past five years. She and her family have dedicated a lot of resources towards caregiving in order to meet her growing needs, both in terms of finances and time. She does not have dementia, however her very frail body and old age hinders her from basic physical function capabilities. The family has a live-in "nanny", who not only cares for her, but also relieves them of housekeeping duties. The family has gone to lengths to make sure she continues living in the home with them and being part of the family, because Iranians believe it is simply their duty and responsibility to care for their elderly. Filial piety is very pivotal in the Iranian community, and any rejection of it or evidence of lack of care for the elderly is viewed as a disgrace and intolerable.

On the other hand, as an outsider/researcher, I recognize that my cultural background may discourage or influence Iranian-Canadian adult children's participation in this study. This is because Iranians attach a stigma to dementia and view it as a form of mental illness, believing other Iranians will look down on them in shame. For this reason, despite formal medical diagnosis, they continue to think of dementia as forgetfulness and part of normal aging. Regardless, they are hesitant to discuss it with others outside their

immediate family, making a deliberate effort to keep it a secret, especially from other Iranians in their community.

Being aware of my influences on the study, both as an outsider/researcher and an cultural insider, provided me with clues for what van Manen (1997) called orienting oneself to the phenomenon and thus to all the other stages of the hermeneutic research. As recommended by Arber (2006) and Rosedale (2009), throughout the research process, I maintained a reflexive journal that documented the research activities undertaken, such as the analysis and synthesis of data and construction of themes, as well as my emotional responses to the interviews.

### **Study Design**

**Sample.** Purposive sampling was used to gain an in-depth understanding of the experience of caring for a parent diagnosed with dementia. Participants were selected based on their experience with the phenomenon. All participants met the following inclusion criteria:

- Iranian-Canadian adults
- fluent in English
- primary caregivers for a parent suffering from dementia
- ongoing, prolonged responsibility in taking care of the parent with dementia

In addition, the parent had to have been formally diagnosed with dementia. There was a minimum age requirement of eighteen, because I was studying adult children. No other selection criteria as to demographic characteristics were imposed, in order to achieve as rich and varied a data set as possible.

Phenomenological research does not lend itself to large, randomized sampling methods (Creswell, 1998). Thus, a purposive sample of four participants was chosen to ensure that the key characteristics of relevance to the subject under study were covered and to ensure that within each key criterion, diversity was included, so that the impact of the characteristic concerned could be explored. The aim was to select information- rich cases for detailed study (Ajjawi & Higgs, 2007a), which is consistent with the goal of phenomenological research, aimed at developing dense descriptions of the phenomenon being investigated in a particular context.

**Confidentiality and ethics.** Ethical approval for this research was obtained from the University of Western Ontario's Health Sciences Research Ethics Board (Appendix A). Informed consent was obtained from each participant prior to the start of the study (Appendix C), and it included aspects of disclosure (providing adequate information), comprehension (understanding of the information), competence (ability of participants to make a rational decision), and voluntariness (no coercion) (Sim, 1998).

In the invitation email asking for potential participants' involvement in the study, I attached the Letter of Information (Appendix B), which details the aims of the research and the research process, as well as the Consent Form (Appendix C). All participants were given the opportunity to ask questions about the research and were made aware of the fact that they could withdraw from the research at any time, with no penalty, and that involvement was voluntary throughout the entire process. Prior to the commencement of the first interviews with each participant, a verbal explanation was given and a hard copy version of the Letter of Information was provided, as well as a hard copy of the Consent Form, with written consent being obtained from each participant.

Maintaining participants' confidentiality is often a major ethical concern of interpretive research, because of the personal nature of the research and the type of questions the participants are asked. Assigning a pseudonym to each participant ensured confidentiality in this study. All data (audio-tapes, transcripts and structured demographic questionnaire) used pseudonyms. Only the consent forms contained both the participants' full names and pseudonyms, linking a pseudonym with a specific individual. However, the consent forms were stored in a locked cabinet, separate from all other data. Participants were assured of confidentiality by informing them that we have a data collection agreement that binds us on data disclosure. Throughout the entirety of the investigation and after its completion, identifying information was not destroyed but kept in a separate location from pseudonyms. Pseudonyms and their corresponding data were also kept for reference. Only individual findings were emailed to each participant.

**Recruitment.** Research recruitment took place in Toronto, Ontario due to its very large Iranian community. Recruitment advertisements were placed in three popular local Iranian newspapers: Javanan, Shahre Ma, and Iran Javan. Advertisements were also placed at the YMCA at the Bayview and Sheppard intersection and in two local pharmacies around the Yonge and Finch area, because these locations are frequented by Iranian Canadians. Advertisements and posters were written in English and included the research team's main phone number.

Upon receiving responses from these advertisements and posters via telephone, further information about the study was given. In this initial contact with the potential participants, their email addresses were collected, along with information in regards to

their eligibility for participation. The telephone script for this conversation is in Appendix D.

Once this information was received from all respondents, I sorted through the profiles of these potential participants and purposively selected four participants who met the inclusion criteria. Two of the selected potential participants for this study were respondents to the advertisements at the pharmacy, while the other two approached the study through word of mouth after friends saw the advertisements placed at the YMCA.

Once these four selected participants were contacted via email and invited to participate in the study (email script is in Appendix E), all four agreed and interview dates and times were arranged. At the first meeting, I provided them with the Letter of Information, explaining it to them in detail. Informed consent for participation in the study was assured via signed consent forms from each participant.

**Interviews and data collection.** One in-depth, semi-structured, face-to-face data collection interview was conducted with one participant, and two data-collection interviews were conducted with the remaining three participants. In addition, there was a final interview with each participant for member-checking. All interviews were conducted with each participant in coffee shops preferred by the participants. Confidentiality was maintained despite the public location of the interviews, because it was decided that if anyone recognized the participants, they would disguise the interview as a meeting with a friend over coffee. All interviews were conducted by the same single interviewer, me, and each was 50 to 120 minutes in duration. By spending extensive amounts of time with the participants and interviewing them at length through intense

interaction and dialogue, deeper insight (hermeneutical discovery) was facilitated (Ponterotto, 2005). Interviews were audio-recorded and transcribed verbatim.

Initially, after informed consent was given by each participant, a structured demographic questionnaire (Appendix F) was used to collect both caregiver and care recipient information. Then, a semi-structured interview guide (Appendix G) was used to conduct the interviews. The initial few questions were meant to set the tone of the interview by uncovering feelings and descriptions about caregiving, the caregiver role, and the care recipient; caregiving burden, impact of caregiving, gains and costs of caregiving; and attitudes toward providing care. Later questions addressed the participants' views and interpretations of the role of culture in their experiences, the use and effectiveness of formal and informal care supports and services, service barriers, and future caring plans and preferences. The goal of the questions was to encourage openness and to have the interview process stay as close to the lived experience as possible by having the participants lead the discussion. Participants had the freedom to respond to questions and probes and to narrate their experiences without being limited to specific answers.

Field notes were taken before, during, and after interviews to jot down moments of silence, body language, and aspects of the interview and the environment that verbatim transcripts could not capture. These notes also included my own opinions and presuppositions about and previous experiences with the phenomenon being investigated, along with my thoughts, feelings, and mood before, during, and after the interviews.

After listening to the audio recordings of the interviews and transcribing them verbatim, the text was read and re-read in silence and then read while playing the audio

recordings. Meanwhile, I kept a reflective journal, which consisted of my thoughts and emotions that arose while reading the text and immersing myself in it. This interpretive process brought to light my own horizon of understanding, which allowed me to recognize the meanings and interpretations I was attaching to the readings of each participants' narrative. By taking into account my personal feelings and explicitly claiming them rather than bracketing them, I was able to use them in the interpretive process by incorporating into the data analysis, as described by Dowling (2007), causing a fusion of horizons, in accordance with hermeneutical phenomenology.

### **Data Analysis**

**Preliminary analysis.** In this study, the early analysis of participants' interview transcripts involved analyzing each interview separately, or going from the parts of the text to the whole (van Manen, 1990). This was done using the detailed reading or line-by-line approach and the selective or highlighting approach, as informed by van Manen (1990). I grouped together words used by the participants, which contained similar ideas, and then developed key words and concepts arising from these. Key words became concepts through reading and re-reading the data, being deeply engaged and immersed in it, going from the parts (aspects of each interview) to the whole data (the interview as a whole).

***The detailed reading or line-by-line approach.*** In the detailed reading or line-by-line approach, the researcher looks at every single sentence or cluster of sentences and asks, "What does this sentence, or sentence cluster, reveal about the phenomenon or experience being described?" (van Manen, 1990, p. 93). I used this approach as my first step, reading through each transcript and assigning key words and concepts to each

sentence or cluster of sentences containing a new idea. This approach allowed for a more in-depth and rich look at the actual words of the participants, along with unspoken words and meanings, emotions, sentence structures, hesitations, and body language.

***The selective or highlighting approach.*** The selective or highlighting approach involves reading and re-reading a text several times and inquiring which statements or phrases appear to be especially revealing about the phenomenon being explored. These statements are then underlined, circled, or highlighted. In the case of this study, they were highlighted, copied from the transcript, and tabulated.

**Formation of sub-themes and themes.** The progression of the analysis involved pooling all the early key words and concepts (going from the parts to the whole) by gathering up the four participants' transcripts after individual analysis and analyzing them together as a whole, looking once more for the implicit and explicit themes. Concepts from the preliminary analysis were grouped together in an additional column of the table, pooled with similar concepts after much thought on which ideas belonged together, to form the sub-themes, and finally the sub-themes were gathered together similarly for the development of themes. Table 1 provides a very brief example of how the two themes of Dual Reality and Sources of help developed from the pooling of sub-themes, which were a result of the grouping of similar concepts.



Table 1: Development of the Themes Dual Reality and Sources of Help

Words of participants	Key words	Concepts	Sub-theme	Theme
I sometimes think to myself, “Why did this happen to us?” I know so many older people, my aunts, uncles, others’ parents. Why do they still get to have their parents healthy and I don’t? ( <i>waves arms in the air</i> ) Why do we have to go through this? In the simplest terms, it’s so sad and I don’t wish it upon anyone. (Bill)	Why us?, don’t wish it upon anyone, sad	Feeling sadness	Facing the Stresses of Caregiving	Dual Reality
We don’t talk about it with her at all. We want to, you know, keep everything lighthearted and easy-going. I don’t want her to sense we’re being extra caring or extra whatever because of her Alzheimer’s. (Nancy)	Don’t talk about it, don’t want her to sense anything is wrong	Providing a sense of normalcy	Hiding Dementia	Dual Reality
I like to take him to his appointments and mostly take care of him in general because I almost feel compelled to do it for my father...because you know, it’s like they take care of you your whole life so you kind of ( <i>gentle smile</i> )...I want to do it for him because he has done so much for me. It’s my duty. (Jen)	Reciprocating the care, duty	Fulfilling a duty	Relying on Family	Sources of Help
My mom doesn’t speak English so if we were to get any kind of help in the future from a professional, how could we ever go about finding someone who speaks Farsi? ( <i>sarcastic look</i> ) (Mary)	Doesn’t speak English, finding professional who speaks Farsi	Implementing bilingual and bicultural care	Identifying Preferences in Dementia Care	Sources of Help

## **Standards for Evaluation**

Establishing trustworthiness is the foundation of sound qualitative research (Koch, 1994). Qualitative research is trustworthy when it accurately represents the experience of the study participants. Trustworthiness of data is achieved through rigour: rigorous qualitative research must show the process by which the researcher developed his/her interpretations so the reader can comprehend how the interpretations were created (Connell, 2003; Koch, 1994). The goal of rigour in qualitative research is to accurately represent the study participants' experiences (Streubert & Carpenter, 1999). Trustworthiness in this study was established through three strategies: credibility, dependability, and transferability.

**Credibility.** Credibility seeks to address the issue of "fit" between participants' accounts and the representation of them by the researcher (Koch, 2006). It is demonstrated when participants recognize the reported findings as their own experiences (Streubert & Carpenter, 1999). In this study, activities that were used to increase the probability that credible findings will be produced were peer debriefing, member checking, and maintaining field notes and a reflective journal (Lincoln & Guba, 1985).

Peer debriefing exposes a researcher to the searching questions of others who are experienced in the methods of enquiry, the phenomenon or both (Lincoln & Guba, 1985). In this study, I exposed the research work to committee members for constructive criticism and guidance.

Member checking involves the presentation of themes, interpretations and conclusions that emerge from the analyzed data to the participants in a follow-up interview. This is the most crucial technique for establishing credibility (Lincoln & Guba,

1985). In this study, follow-up interviews with participants involved feedback discussions where the purpose was to establish whether the results were realistic and accurate representations of their thoughts and words, to ensure interpretations reflected their intent. Participants were given a brief summary of their own interviews, along with the main points, themes, sub-themes, and my interpretations gathered from them. All participants verified the information and deemed it a truthful illustration of their words and thoughts and what they were trying to convey in their interviews.

**Dependability.** Guba and Lincoln (1985) recommend auditability as a way to address the dependability issue directly. To establish dependability, the processes within the study should be reported in detail, thereby enabling a future researcher to repeat the work, follow the decision trail in the study, and interpret the data in a similar manner. The interpretation does not have to be exact, but it should not be contradictory (Koch, 1994; Sandelowski, 1986). In this study, I built a path for other researchers and readers to follow through the discussion of methodological and analytic choices through the course of the study (Koch, 1994). This was done through auditing, which consisted of my elaborate and rich documentation of data, methods, and decision making throughout the study.

**Transferability.** According to DePoy and Gitlin (1993), the findings of qualitative research are specific to the context only, and it is not the desired outcome of this design to generalize from small samples to a larger group of people with similar characteristics. A study can meet the criterion of transferability, or fittingness, if the findings can fit into the context outside the study situation and when the participants view these findings as meaningful and applicable in terms of their own experience (Kock,

1994). In this study, transferability was achieved by describing all aspects of the participants, as well as the research context in precise detail (Krefting, 1991), within ethical constraints.

Thick description was key, because it produces for readers the feeling that they have experienced, or could experience, the events being described (Denzin, 1989). Thick description also enables other researchers to transfer information to other settings, provided they may be shared (Creswell, 2007). I documented and justified the methodological approach and described in detail the critical processes and procedures that have helped me to construct, shape, and connect meanings associated with the phenomena. Also, throughout the process of this study, I was sensitive to possible biases by being conscious of the possibilities for multiple interpretations of reality.

## Chapter 4: Findings

### Participants

A total of four participants (caregivers) were included in this study. Three were females and one was male. The average age of the participants was 52.5 years (ranging from 45-64 years). All participants were born in Iran and their primary language was Farsi, and they were all Muslim. All participants had at least a high school diploma and three had post secondary education. All were married, having emigrated from Iran to Canada 25-32 years ago. The income for all households was in the range of \$50,000-\$74,000 and all the participants lived in an urban setting (city of Toronto), either in a condominium or house. Three of the participants had one to two children living at home with them, whereas one had two children, both living outside the home. Three participants had siblings, none of whom lived in Canada. One participant was retired, two others worked full-time and part-time, and one was on leave from work due to disability. All participants reported providing informal care to a parent with dementia, spending an average of 23.25 hours per week providing care (ranging from 10-35 hours). None utilized any type of formal care services.

All four parents with dementia (care recipients) were born in Iran. Three were mothers and one was a father, and all were formally diagnosed with dementia within the past one to two years. Two parents had co-morbidities, including arthritis and severe depression. Two care recipients were widowed. One lived on her own, 5km away from her daughter's home, and one had lived with her son since her immigration to Canada decades earlier. Meanwhile, one parent was single, living with her daughter since her diagnosis, and the other lived with his wife in an apartment 1km away from his

daughter's home. A summary of the demographic information of these caregivers and some important care recipient information is provided in Table 2 below.

Table 2. Caregiver and Care Recipient Information.

Caregiver Information				
Caregiver Characteristics	Participant 1: Mary	Participant 2: Nancy	Participant 3: Bill	Participant 4: Jen
Age	52	45	64	49
Gender	Female	Female	Male	Female
Highest level of education	College degree	Bachelor's degree	Master's degree	High school diploma
No. of siblings , sex and age	2 sisters, 49 and 55	1 sister, 53	n/a	3 brothers, 33, 45, and 43
No. of years in Canada	30	25	32	26
Housing type	Condominium	House	House	Condominium
Children in the home, sex and age	2 daughters, 17 and 24	1 daughter, 18	n/a	1 daughter, 16
Type of work, part- or full-time, hours per week	Interior designer, part-time, 25	On disability	Retired	Business owner, full-time, 60
Care Recipient Information				
Relationship to caregiver	Mother	Mother	Mother	Father
Time of diagnosis	2 years ago	1 year ago	1 year ago	1 year ago
Co-morbidities	Arthritis	n/a	n/a	Severe depression
Amount of time receiving informal care from adult child caregiver	20 hours/week	28 hours/week	10 hours/week	35 hours/week
No. of years in Canada	27	19	24	25
Marital status	Divorced	Widowed	Widowed	Married
Place of residence	With caregiver	Senior retirement building	With caregiver	Apartment building
Distance from home to adult child caregiver's home	n/a	5 km	n/a	1 km

## Emergent Themes

This thesis deals with the lived experience of four people who are of Iranian descent who live in Canada and care for a parent who is diagnosed with dementia. The goal was to make meaning of the lived experience as described by them. The results of my interpretation are a “fusion of horizons” (Gadamer, 1975), where my ideas and understandings are merged with those of the participants to create a new perception of reality.

Two themes that were uncovered from my analysis of the study are: Dual Reality and Sources of Help. Each theme possesses a set of sub-themes that provide insight into the lived experiences of these Iranian-Canadian adult children caring for their parents who have dementia (Table 3).

Table 3. Emergent Themes and Sub-Themes

Theme 1: Dual Reality	Theme 2: Sources of Help
Sub-theme 1: Hiding Dementia <ul style="list-style-type: none"> <li>• Protecting and projecting an image</li> <li>• Providing a sense of normalcy</li> </ul>	Sub-theme 1: Relying on Family <ul style="list-style-type: none"> <li>• Working as a unit</li> <li>• Fulfilling a duty</li> </ul>
Sub-theme 2: Facing the Stresses of Caregiving <ul style="list-style-type: none"> <li>• Neglecting oneself</li> <li>• Feeling sadness and frustration</li> </ul>	Sub-theme 2: Identifying Preferences in Dementia Care <ul style="list-style-type: none"> <li>• Increasing awareness of services available</li> <li>• Implementing bilingual and bicultural care</li> </ul>

**Theme 1: Dual Reality.** The first theme, Dual Reality, is comprised of two sub-themes, Hiding Dementia and Facing the Stresses of Caregiving. These sub-themes are linked by the fact that they speak of the two realities of caregiving: one is the public display that there are no problems, keeping the dementia hidden from outsiders, and the other is the stressful reality of the situation experienced in private.

*Sub-theme: Hiding Dementia.* The sub-theme Hiding Dementia represents efforts to protect and preserve the image of the family and care recipient and to project an image different from reality while simultaneously attempting to provide a sense of normalcy for the care recipient and the family.

*Protecting and projecting an image.* Participants in this study acknowledged being aware of the misjudgments society places on individuals with dementia and their families. Therefore, they felt the need to shield their parents and family from stigmatization by concealing the dementia altogether from the outside world. This way, they could project a more positive, healthy, and almost invincible image. The caregivers agreed that consulting health care professionals was essential when necessary but believed that these professionals were the only outsiders who should be aware of the dementia. They felt this was the primary and sometimes only way to protect and preserve the positive image of their family and their parents living Alzheimer's disease. Although the participants acknowledged that this might be a superficial way of coping with the situation, they deemed it to be crucial.

Caregivers who had the strongest relationships with their parents prior to the diagnoses revealed the greatest desire to hide dementia from the outside world. These adult children justified their choice in hiding the dementia from outsiders by stating that they knew that would be what their parents would want. They focused on the influence that negativity from the outside world could potentially have on the parent. This was depicted in Mary's comment:



She wouldn't want other people to think she's weak. She's one of the most independent people I know. To take that away from her, or to make people think she's not that anymore, I think it would hurt her a lot. I know it would. (Mary)

Nancy and Jen, like Mary, felt the need to hide the dementia from outsiders to protect the image of their mother and father, respectively. Despite their close bond with their parents, they deliberately chose to live in separate homes to perhaps further support the image of their parent's independence and lack of need for daily support. Of all the caregivers in this study, Jen and Nancy provided the least number of hours of assistance to their parents per week and maintained that nothing much had changed, that their parents' diagnosis had not and should not change the living dynamic, because their parents remained self-sufficient.

I love my mom. She's been through a lot in her life and for her to stand strong and take care of herself, it's very...it's very admirable. And the fact that she still lives alone just goes to show how independent she still is (*fiddling with thumb*). Still doing her own chores, still pretty much doing everything she did before, just a few minor adjustments. (Nancy)

He doesn't need to live with us. Him and my mother have each other. They're so adorable. It's like any other marriage, definitely very functional. (Jen)

It seemed that Nancy and Jen were trying to convince themselves that their parents were still as independent and self-reliant as they were prior to their diagnosis and that maybe by sticking to these living arrangements, that conception of "no change" would actually remain true. Perhaps a little bit of denial was allowing them to protect

even themselves from negatively viewing their parents and unintentionally stigmatizing them.

Bill, who did not outwardly express or emphasize a close bond with his mother, focused more on the overall image of the family and the protection of his entire family from the negativity of others.

We have a handle on it. No need to spread the word or you know... (*pauses, then chuckles*) announce it to the world. What do you think that'd make us look like?

Like we need help, or sympathy or pity. (Bill)

It's important to note the use of "we" and "us" in comparison to the previous participants. Not having a particularly strong relationship with his mother could have possibly caused Bill to disassociate the stigmatization from the care recipient and to associate it more with the family as a whole and to the family's shortcomings and weaknesses. It is important to note that Bill was the only adult child caregiver in this study who was a male. This fact could have contributed to him placing greater importance on the strength and resilience of his family and not just of his mother.

Despite these differences, all the adult children emphasized the importance of others seeing the family as strong and healthy. Others' knowledge of Alzheimer's disease in the family would be a detriment to their image and, in their opinions, would adversely affect the health of the parent. Because of the negativity or stigmatization the parent would receive from others, the caregivers believed their parents' condition would worsen and, in turn, would make the family seem incompetent and unfit.

Lastly, all the caregivers seemed to address concern for the fact that, eventually, they would no longer be able to hide the dementia in its more progressed stages.

It won't be possible to hide her obvious behaviours that aren't normal. I know eventually we'd have to just give up and kind of come clean. It'll be a difficult process that's for sure. (Nancy)

*Providing a sense of normalcy.* The objective of providing a sense of normalcy for the parent with dementia was consistent among all of the adult child caregivers in this study. The goal was to make life for the parent with dementia as normal as possible, in hopes of protecting his or her self-image and preserving his or her self-esteem and independence as much as possible. It was one of the major challenges with which the caregivers were confronted.

We really take it day by day. And we've all made it a point to do our day-to-day activities as if my mom is the way she was before. Obviously we tend to her needs but we keep her from seeing us doing things differently and treating her differently because of her dementia. Leading a life as normal as possible is what we want for her (*nods*). (Nancy)

The experience of always trying to make life seem to the care recipient as normal and uninterrupted by dementia as possible was very prominent in the interviews. All the caregivers believed that by carrying out daily life in a normal fashion, they would be able to protect their parents and allow them to lead a normal life, not feeling different from those around them. This may also have been a coping mechanism for the caregivers; the more they acknowledged the dementia, the more real it became even for them and, thus, the more negative consequences and burden they themselves may have experienced as a result. Therefore, by trying to lead a normal life and treating the parent as they once had prior to dementia, it gave everyone involved, not just the care recipient, the feeling of

normalcy. However, providing a sense of normalcy for the entire family was not explicitly stated by any of the participants.

There was also mention of the importance of focusing on the parents' abilities rather than their shortcomings.

I never understood the reason for over emphasis on the situation. It doesn't serve a purpose (*shakes head*). It makes it uncomfortable for everyone. Why would I want to make my mother feel like there is something wrong with her, when we can work on the things she can do instead? (Bill)

I tell my mom to let him do his own things around the house. When they need groceries, I actually go pick him up and drop him off at the grocery store and come back in an hour to see how he's doing. It's simple things, but things that can encourage him. When he sees he can do something, I'm sure he feels good about it and wants to maintain that ability. It makes us all feel good. Takes away from the reality of it too. (Jen)

Focusing on the positive could have instilled confidence in the parent with dementia and allowed him/her to feel that he/she was still as able as ever. It also seemed that by focusing on the positive aspects of the person with dementia, the caregivers were finding comfort for themselves. It was consoling for adult children when they focused on their parents' abilities, reminding them of the "old" parent and how they used to be and the parts of them that were still the same.

All the caregivers expressed that staying consistent with the activities they used to do together as a parent and child prior to dementia was key, because it gave both them

and their parents the sense that nothing had changed and that their parent-child relationship was and would remain the same.

I think one of the most important things is to never make her feel like she's different. I really do try my best to make the times we have together very lighthearted and not serious. Just like a normal mother and daughter relationship. We still do a lot of things together. Hair appointments, nail salon, running errands, things like that. (Nancy)

In addition, all the adult daughter caregivers felt that bottling up their emotions and hiding their feelings when they were feeling overwhelmed with emotions was a way of protecting their parents.

When I do get overcome with emotions, and that happens a lot, I go into my room and give myself a moment, let it out, and leave it at that. It'd be inappropriate and wrong of me to show my mom how I'm feeling when I'm sad. If she sees me crying, or if my kids or husband see me crying, they'll automatically know why. I don't want to burden them with my feelings. It'll just make it all the more real, especially for my mom. She doesn't need that. All we want to give her is positivity, positivity, positivity. (Mary)

Hiding emotions seemed like a sacrifice on the daughters' end to ensure that everyone else around them, especially the parent with dementia, did not feel anything to be out of the ordinary. It seemed that they are carrying this emotional burden on their own.

Overall, all the caregivers viewed themselves as the ones who had to have it all together for the sake of the entire family, providing as normal of a life as possible to their

parents with dementia. They stressed the maintenance of normalcy, identifying it as being one of the most important contributors to the well-being of their parents, no matter what efforts they have to make to pretend. It also seemed that this maintenance of normalcy was a form of protection for the caregivers themselves, a way of holding onto their “old” parent. It is important to note that secrecy was not only towards the outside world, but also present within the home and toward the parent with dementia.

*Sub-theme: Facing the Stresses of Caregiving.* Contrary to the sub-theme Hiding Dementia, Facing the Stresses of Caregiving focuses on the real experience of dementia caregiving that is hidden from the outside world. In reality, the experience entails the daily stresses of caregiving that are experienced behind closed doors and in private. This includes self-neglect and feelings of sadness and frustration

*Neglecting oneself.* One of the main realities held in common by the adult daughter caregivers was the fact that they were neglecting their own needs. Some did not realize this until their friends and family brought it to their attention, while others did notice the lack of care for themselves. One participant rejected the idea altogether. Because each caregiver experienced this concept of self-neglect very differently, I will elaborate on each of them individually.

Nancy never admitted to self-neglect but said that others around her thought she was failing to take care of herself.

I have sacrificed a lot these past few years to take care of my mom. She doesn't live with me but I'm practically with her everyday. I don't mind it though. My husband tells me I'm overdoing it but he knows it's useless to say anything so he doesn't bother too much. (Nancy)

Nancy acknowledged that she had been devoting a lot of her time to her mother over the past year. She also stressed that, although her mother lived on her own and could manage a lot of things, she still felt the need to be there all the time, because she really had no other obligations. It seemed that Nancy's main focus in the moment was her mother, because her own needs could have waited, regardless of what others told her. This may be because of the short distance between her home and her mother's and the fact that her mother was widowed, living alone with no companion, which may have created anxiety for Nancy and furthered her need to be with her mother more than necessary.

Jen also had the desire to be with her father more often than not. Like Nancy's mother, Jen's father also lived on his own. As mentioned before, both Jen and Nancy had a very strong relationship with their parents prior to dementia. This may have instilled that desire in both caregivers to care for their parents and neglect their own needs. Jen explicitly stated that she did not go to the gym as often as she used to or take time to "take a breather". However, she was a self-proclaimed "daddy's girl". Perhaps also because Jen's father had severe depression, she felt a deeper obligation to keep him company and to prevent him from ever feeling isolated. Still, this may be over-worrying, because Jen's father lived with his wife. Furthermore, Jen attributed any self-neglect she was experiencing to her long work hours, rather than her caregiving duties.

Mary, on the other hand, seemed to be a little more resentful of the fact that she was juggling a lot and had no time for herself. Unlike the other women, Mary felt a deep sense of self-neglect and mainly attributed it to her mother's dementia. Interestingly, she said that those around her thought she over-dramatized how much she really had on her

plate and that her self-neglect was, for the most part, brought upon herself because her worries were excessive.

I'm so...overwhelmed...stressed out sometimes. There's too much on my plate. With the kids, husband, work, housework, you get the gist. To be honest with you, sometimes I forget to even shower because I do so much running around. I need some time for myself, for my own sanity. It's so hectic. My friends tell me I exaggerate. (Mary)

Although it did seem as though Mary had more on her plate than some of the other women, some of the feelings of self-neglect seemed to be exaggerated and overly emphasized. She seemed to have a more pessimistic outlook on the situation than the others. It could be that she was overwhelmed being employed and also taking care of two daughters who lived in the home. It could also be that, because Mary's mother lived with her, she felt more suffocated and confined, unlike some of the other caregivers whose parents lived in separate homes. Her mother's arthritis also required more care and attention, so Mary felt she had an even greater "workload".

Bill explained that his wife complained about him being too hard on himself and failing to see that his coping methods are destructive.

Sure I've gained a bit of weight and I smoke a little more. Yea, I'm stressed out for good reason. Even sad. But my wife just gets so upset when she talks about it. She says I need to take it easier (*shakes head, rolling eyes*). (Bill)

Bill seemed nonchalant about the effects dementia caregiving had had on him, and although he admitted he had not been taking good care of himself recently, he did not acknowledge it as self-neglect. He explained that his wife overstated his lack of interest



in his own well-being (the exact opposite is seen with Jen). What stood out when talking with Bill was that he viewed his excessive smoking, weight gain, and lack of sleep among other poor health behaviours, as normal when having a parent with dementia, the result of a “little bit of stress”. He explained that emotional unavailability to his wife was the only upsetting consequence of his caregiving. If anything, he thought he was neglecting his wife, not himself. Males tend to hide their weaknesses, and so perhaps Bill did not want to reveal that he was, in fact, neglecting his own well-being and could have been taking better care of himself, as his wife suggested. He might have just wanted it to seem that he was in full control and that his mother’s dementia was not affecting him negatively.

*Feeling sadness and frustration.* All the adult children in this study paid an emotional price as they cared for their mothers or father with dementia. They were aware that they were entitled to these emotions as they were mourning the gradual decline of their parents.

Sadness began to affect these caregivers at different times. Nancy and Mary began to experience sadness right after their mothers were diagnosed with Alzheimer’s disease. Jen and Bill, on the other hand, started to experience sadness when they began noticing role reversal and changes in their relationship with their parent. Also, the reasons behind their sadness were different amongst the caregivers.

You’re losing and being sad while you’re caring for them. My mom isn’t my mom anymore. It’s devastating to see your loved one slip away and know it’s only going to get worse. (Nancy)

Thinking about how things are going to just be getting worse is upsetting. I don't want to take my mind there but it wanders and gets me down. (Mary)

My daughters have already lost a grandpa. Now they're losing their grandma too. (Bill)

Nancy and Mary's sadness primarily stemmed from their thoughts about the future and their mothers' inevitable deterioration. Their realization that it was a gradual decline and that the dementia would worsen over time caused them sadness. Bill, on the other hand, mourned the loss of his mother's role as a grandmother to his older daughters. It seemed that his sadness mostly stemmed from his realization that his mother would not be able to fulfill her grandparenting role, so both his daughters and his mother miss out on that grandparent-grandchild relationship.

Jen's experience of sadness was attributed more to her thoughts that her father would be devastated at his own decline. She believed that her father was mourning his own loss of that strong, protective, and invincible man that Jen had known all her life.

It crushes me to think he knows what's going on with him. I can't imagine how helpless he feels. He's always been such a manly man and strong and dominant you know...and that's not him anymore. Must take a big toll on him. (Jen)

While experiencing sadness, all the caregivers expressed frustrations as being part of every day life. This is for two main reasons: a) having to pretend everything is okay when really it is not, and b) thinking life is not fair. By "hiding dementia" from the outside world, the caregivers felt irritated at the efforts it took to conceal the dementia and pretend everything was normal to outsiders. They found it difficult at times to keep friends at a distance so that they were not aware of what was really happening.

Having to pretend isn't always easy, given that you can't really tell them why you don't see them as often or why you don't get together and stuff like that. (Nancy). Also, their constant thoughts of why this happened to them or that their parents did not deserve this were a source of continuous frustration. Surprisingly, none of the caregivers attributed their parents' problem behaviours to their frustrations. Perhaps because problem behaviour is known to be uncontrollable and unchangeable for people with dementia, the caregivers had learned to cope with it rather than letting it be a source of irritation.

**Theme 2: Sources of Help.** The second theme, Sources of Help, relates to the caregivers' use of informal care and expectation from formal care services. This theme is made up of two sub-themes, Relying on Family (availability of informal care) and Identifying Preferences in Dementia Care (lack of suitable formal care). The overall theme focuses on the importance of and reliance on family when it comes to dealing with dementia in the family, the influence of Iranian culture in caregiving decisions, and the adult child caregivers' ideas of the types of professional help that should be available to them. The concept of culture and its primary role in the caregivers' use of formal and informal care services was constantly emphasized throughout the interviews.

***Sub-theme: Relying on Family.*** The importance of having a supportive family and working together as a unit to care for a family member with dementia was revealed through all the interviews. The caregivers said that it is an obligation to care for an aging parent, regardless of the circumstance.

*Working as a unit.* Having a solid family foundation is vital in caring for a parent with dementia. The parent is not the only one living with dementia, but rather the entire family is affected. Jen mentioned that her father's dementia was a "family illness":

When any sort of obstacle comes in the way, we deal with it as a family. This is just another one of those obstacles. We're a strong family so my dad knows he's never ever alone going through this. (Jen)

Jen also rejected the idea of any outside help, saying,

I know there are other kinds of support out there that are great, but the support of family is all we need. There is no need for anything else. If you don't have family, you have nothing. (Jen)

It is interesting to note that none of the other caregivers fully rejected the idea of receiving help outside the family. Perhaps because Jen's father was the only one in this study who had a spouse with whom he lived, Jen did not feel that he required any formal care or outside help. Also, because of his dominant and masculine persona prior dementia, perhaps she wished to maintain that image in her own mind by rejecting the idea of her father possibly requiring any sort of professional help.

Mary stressed that, as her mother's dementia began to progress within the last year, it was a family decision to have her move in with her and her family. This decision was not only the best thing for her mother, but a great decision for the entire family, because they could then work as a team and provide Mary support and aid in caring for her mother.

I think moving in with us was one of the best things that's happened to her. That's why family is so important. (Mary)

It also seemed that Mary not only focused on caring for her mother with the help of her family but also focused on the fact that all decisions regarding her mom were made as a family.

Bill stressed that caring for his mother was a way of setting an example for his daughters, showing them how important it was to stick together through rough times, being each other's backbone.

I want this to be a learning lesson for my kids. It's one thing to tell them family is number one but it's another to actually have to carry out what you say. (Bill)

Nancy went as far to say that, without her family, she would not know how to care for her mother.

Honestly, I wouldn't be able to do it without them. I'd be lost. They're always supportive. My mom is like their mom. When school's not in the way, my daughter will definitely help me too. They've all been great. And my husband is my rock. (Nancy)

It seemed that, maybe because Nancy herself was also a little dependent on her family as a result of her spinal cord injury acquired at work, she felt she would have been completely incapable of taking care of her mother if she did not have her family's support.

All the caregivers also said dementia in the family had brought the family closer together and had made them more tight-knit and appreciative of one another.

It's kind of a blessing in disguise believe it or not. We've all grown together.  
(Bill)

So it's apparent that having a strong family foundation and working together as a cohesive unit was valued by all the caregivers. This was their number one source of support for themselves as caregivers and of help to their parent with dementia.

*Fulfilling a Duty.* A sense of duty and responsibility were prominent in all the caregivers in this study. Caring for a parent with dementia was an unwritten rule for these caregivers, and they saw it as an obvious obligation. Nancy and Bill both explained that caring for their mothers was their form of giving back for all the time and effort their mothers had once devoted to raising them.

As a daughter, I feel like it's my responsibility to take care of her. She was always there for me when I needed her and now it's my turn to return the favour. It's not really a favour. It's more like...like I want to do it (*smiles*). (Nancy)

Mary and Jen, however, did not conceptualize it this way, but rather, stressed that it was a natural step in life where they had to care for their aging parents regardless of whether they have AD or not. They both also explained that they were very fortunate, and even honoured, to have the role of caregivers, because it had given them a chance to prove how much they truly loved their parents. They expressed more intrinsic reasons for caregiving, more of a desire to provide care rather than a need to carry out an obligation.

All the adult child caregivers in this study said that Iranians look after their own. They had all been in Canada for more than two decades and had been exposed to Western society's norms and values. Yet, surprisingly, all of them explicitly claimed their culture and upbringing were what had instilled in them these values of filial piety.

Like other Iranians, I think we all have the same idea, same values. That family always has to be there." (Nancy)

Family comes first. We take care of our own. I think all Iranians can agree with me. (Mary)

I'm Iranian. Sure I've been here for a long time but I still have those important values. That's how I was brought up. How we all are. (Jen)

Bill went further and compared Iranian caregivers with their Canadian counterparts and said,

Don't look at these Canadians and how they just leave their parents in the hands of others...sometimes people they don't even know. That's not how we Iranians operate. (Bill)

So it seems that all of the caregivers in this study viewed their role as caregivers a result of familial obligation and their sense of duty to care for their parents when they needed them the most. They all attributed their values to their Iranian culture and claimed that what they had seen and been taught throughout their childhood had influenced their caregiving decisions as adults.

***Sub-theme: Identifying Preferences in Dementia Care.*** The caregivers in this study had primary complaints about the lack of knowledge and information provided to them by health care professionals concerning the availability and accessibility of services for them as caregivers, their families, and their parent with dementia. They also expressed the strongest reservations about institutionalization and placing their parents in nursing homes or residential care. However, they did show interest in utilizing in-home respite care services in the future, when the need arises, if bilingualism and biculturalism were incorporated in service provision standards.

*Increasing awareness of service availability.* All the adult child caregivers in this study reported not receiving a lot of information from their parent's general practitioner (GP) about where to turn to next, after the dementia was diagnosed.

Just kind of left us hanging. Didn't really know anymore after than we did before.

(Mary)

To be completely honest, I found his doctor to be completely unhelpful. It's a shame, because I bet there are so many people just like us and none of us get a direction...a place to turn to. (Jen)

Some felt the doctor did not seem to be interested in the patient and did not focus on the patient as a person but more so as a case. This lack of interest in the patient and the family was what the caregivers believed influenced the lack of effort the GP put into providing them with the knowledge necessary to carry on and fulfill caregiving duties productively.

Complete lack of interest. I don't even think he cared to know her name. Just kind of seemed like he wanted to get the job done and move on to the next. (Bill)

Didn't ask us much about our family or her hobbies or anything like that (*shakes head in disapproval*). Maybe I'm old fashioned, but I think a doctor should at least seem a bit interested in who you are as a human being, no? That way, you could actually recognize what we need. (Nancy)

The caregivers also felt that they were given no information on the types of services that are available to them as caregivers, to guide them in the caregiving process and ease the strain that could potentially be caused by the caregiving role.



You know, as someone who's going to be looking after a person with such a serious condition, you'd think there was a protocol of some sort where the doctors have to go through with every patient's family, where they can go for help or call, kind of like a hotline. Things of that sort. (Nancy)

Most importantly, the caregivers in this study were knowledgeable about the types of services and supports available to them and their parent with dementia after independent and thorough investigation.

I'll take credit for it (*chuckle*). I know a little bit about what I can do or what there is for me if I need a little break or my mom needs a change in scenery kinda thing. There is information out there. It's just a matter of looking for it. (Bill)

After researching a little bit, I already knew what kind of services are available and which ones could suit our needs. I just wish we could have heard it from a professional rather than me finding out for myself. Makes me lose faith in doctors. (Mary)

In all, the emphasis on the disinterest of GPs in the patient and his or her individual needs and the lack of effort that was put into providing families with information that could aid in the dementia caregiving process were evident across the interviews. It was seen as a major potential barrier to service use, had they not themselves taken initiative and discovered the availability of some formal support services.

*Implementing bilingual and bicultural care.* All but one of the adult child caregivers (Jen) expressed interest in utilizing in-home respite services in the future, when they will no longer be able to manage everything on their own, with the increased demands of their parents' advanced dementia. Participants, while adamant about not

wanting to rely on formal services, said that they would welcome having someone for a couple of hours per day to help their parents with basic necessities, such as cleaning, cooking, or driving, so that they could have a break.

Not much wrong with getting a little help around the home once in a while when it starts to get a little harder. Like, you know, if I want to, or I need to go back to work full-time, I can get someone to come in every other day or something like that and do some chores around the house and help my mom with her routine.

Things like that. (Nancy)

At times throughout the interviews, it seemed that the caregivers were speaking almost nonchalantly about the use of these in-home care services.

Little bit of help here and there. (Mary)

Not too big of a deal. (Bill)

Perhaps this was their way of minimizing the potential stigma they may have perceived due to their desire for utilization of these types of services in the future. It could also be that they were protecting themselves from the realization that, eventually, they will not be able to handle everything on their own and will need outside support.

Regardless, these caregivers attached a condition to their use of formal home-based care by expressing preference for workers from the same language and cultural background.

Speaking the same language is huge. It's a must. (Mary)

Ideally, we'd love to have someone in the home who's from our culture, speaks our language, is almost one of us. So this way, it doesn't feel like a huge change.

(Nancy)

Nancy made it very clear that it was very important for her to have a support worker in the home who was Iranian, because it would not feel like a stranger was in the home. Perhaps it would allow for less of a need for adjustment for the family and for the parent with dementia, giving the sense that it is one of their “own people” in the home providing support and assistance. This way, the professional help may seem unobtrusive, providing comfort for the parent and his or her family.

Bill and Mary based the importance of having support workers in the home from the same cultural and linguistic background on the fact that it can give the family more comfort and provides a more person-centered form of care that is individualized for the family and their specific needs. They felt that existing service providers did not and could not understand their special needs, and so they wanted to see the services provided by people like themselves.

They'd understand who we are, what we need. If I'm not there, they'd know how to talk to her. What to cook for her. How to treat her. It's the little things that make the biggest difference. A White person wouldn't know any of that! (Bill)

The caregivers also believed that the in-home support worker could act more as a friend than an aid. Perhaps by conceptualizing the in-home care provider as more of a friend rather than a source of formal support, it was a way of keeping a sense of normalcy within the family, ignoring the fact that the only reason a support worker is needed in the home is due to the parent's dementia and consequent increasing care demands.

Additionally, Bill preferred to see dementia information available in the Farsi language. He felt it would be more appealing to have dementia information, in print and online, available in Farsi, not only for him but also for his mother. If this was to be

implemented, he believed his mother would also play an investigative role, wanting to find out more about her prognosis and the availability of dementia care services.

Having what's already out there be published in Farsi too would be really good.

It'd be almost exciting for her, I think, to realize, oh, I can go find this out and see what this is and what that is (*wry expression*). In a way, I think she'd almost be enthusiastic to be learning more instead of me just telling her, ok this is what needs to be done, this is what I learned. (Bill)

Although some of the parents with dementia in this study were able to speak English, albeit not fluently, interestingly none could read English. The children could translate dementia information in pamphlets, brochures, and online from English to Farsi for the parents' understanding. However, it seemed that perhaps by comprehending this information on their own, it would allow them to regain a bit of control. It is important to note that the adult children in this study did not acknowledge that, eventually, the availability of dementia information in Farsi would be irrelevant to their parents, because they will ultimately lose the ability to read and comprehend.

In summary, the results of this study revealed two themes, Dual Reality and Sources of Help. Dual Reality entailed the dual challenges of hiding dementia and dealing with the daily stresses of caregiving. Sources of Help included relying on family as the main source of help and having certain expectations when it comes to formal dementia care services. These themes and sub-themes were quite revealing and represented first-hand accounts of the experiences of these Iranian-Canadian adult caregivers of parents with dementia, allowing for deep insight into their lives as Iranian caregivers in a Western country, and recognition of their specific desires, needs, and

preferences in regards to their caregiving roles. Gender dynamics were apparent in the interviews and findings but the analysis of these dynamics was beyond the scope of this study.

## Chapter 5: Discussion

### Hiding Dementia

Stigma is “having some form of mark or sign that denotes disgrace or discredit (Alzheimer’s Society, 2008). It defines the person who possesses it and sets him or her apart from others (Byrne, 2001). It has been suggested that stigma is more typically attached to conditions of the mind, such as dementia (Link & Phelan, 2001). Possessing Alzheimer’s disease can therefore result in a perception that an individual differs from the general population and could subject a person to possible stigmatization and discrimination by others who do not have dementia (Joachim & Acorn, 2000). Stigma can affect the identity of an individual and even his/her caregivers and family members (Ablon, 2002).

In the present study, all the Iranian-Canadian adult child caregivers acknowledge that they believe their parent with dementia could be negatively stereotyped and stigmatized by others outside the family, if they were aware of it. As a result of this potential stigmatization, they make great efforts to protect their parents by hiding the dementia from outsiders. They controlled what others outside the family knew by concealing the dementia. This finding is supported by Blum (1991), who claims that where the PwD lacks the capacity to conceal stigma, it is the caregiver or family members who become the “team leader” in this matter. These team leaders attempt to conceal stigma in two ways: 1) collusive passing through the management of information to preserve the public face of the person with dementia and family, and 2) covering through active attempts to minimize the obtrusiveness, consequences, and embarrassment of dementia as it becomes more visible (Blum, 1991). This second phase involves the

disclosure of information to others on an incident-by-incident basis, initially to seek assistance and validation, then eventually in a remedial way. The caregivers thus become managers of both information and social control (Blum, 1991). This second phase is not yet demonstrated by the adult child caregivers in the present study. However, they do show their concern about the inevitability of having to ultimately reveal the truth to people at some point in the future when they will no longer be able to conceal the obvious signs of AD.

Aside from hiding dementia from the outside world, the caregivers in this study also indirectly hide dementia from their parent with dementia by providing them with a sense of normalcy. This is done through hiding their own emotions and focusing on the parent's capabilities and old activities and hobbies prior to dementia. They believe that leading as normal a life as possible is a way of protecting the care recipients from knowledge of their diagnosis and inevitable decline. A PwD continuously deteriorates and his or her self-image may become threatened, so protecting the care recipients from awareness of their decline is important. This finding is also seen in a study by Jansson, Nordberg, and Grafstrom (2001), which investigated the caregiving activities of spouses caring for a partner with dementia. They found that caregivers tried to live as normal a life as possible with their impaired spouses, protecting them from noticing their own deterioration. This type of care aimed at protecting or preserving the impaired person's sense of self is labeled protective or preventative care (Bowers, 1987, 1988; Nolan, Keady, & Grant, 1995). Many of the adult child caregivers in the present study deemed this as the most difficult and most important type of caregiving.

In addition to fearing stigmatization of the parent, the caregivers in this study also believed that stigma could be placed on their entire family and themselves, not just on the parent with dementia. This observation is supported by Goffman (1963), who claims that stigma is also felt by caregivers and family members. This is described in the literature as ‘courtesy stigma’ or ‘stigma by association’ (Werner & Heinik, 2008). Therefore, by hiding dementia from outsiders, the caregivers in this study felt they were protecting everyone in the family, and not just their parent, from stigmatization.

It is important to note that the caregivers in this study have made an assumption: if they do not conceal the dementia from the outsider world, their parents will, without doubt, be stigmatized. Studies have shown that when an individual is diagnosed with a neuropsychiatric disorder, such as Alzheimer’s disease, the person and those around him or her assume (often incorrectly) that their cultural ideas associated with PwD (such as useless and dangerous) are personally relevant, which fosters a negative self-image (Link, 1987; Link, Cullen, Struening, Shrout, & Dohrenwent, 1989). The desire to deflect this negative-self image the caregivers have brought upon themselves is perhaps another reason for their wish to maintain a sense of normalcy. Regardless, these personally relevant negative cultural meanings of dementia transform into expectations that others will reject them, and these expectations can trigger defensive behaviours aimed at preventing that rejection (Link, 1987; Link et al., 1989). In this case, the defense mechanism is the concealment of the dementia in fear of stigmatization.

Furthermore, the caregivers in this study suggested that, if outsiders were aware of their parents’ dementia, they would stigmatize and treat them differently, and thus, intentionally or unintentionally, adversely affect the health of the PwD. However, none of



the caregivers address the potential adverse effects concealing dementia could have for the care recipients. What they do not seem to realize is that protecting the image of the parent by hiding dementia entails keeping outsiders, such as friends and relatives, at a distance. As a result, people with dementia could be particularly vulnerable to social exclusion, which can negatively impact their health and well-being (Reidpath, Chan, Gifford, & Allotey, 2005). The isolation of the PwD devalues his or her potential contribution in society, which results in less interaction and an eroding of the relationship between the PwD and friends and more distant relatives who are unaware of the dementia. This deprives the PwD of the companionship of family and friends. The resulting isolation and lack of stimulation causes disability beyond that caused by the illness itself (Alzheimer's Disease International, 2012). Also, for the caregivers, managing information concerning a stigmatizing illness is a strong significant source of stress, anxiety and further stigma" (Dinos, Stevens, Serfaty, Weich, & King, 2004). Stress has been associated with the continuous threat of being stigmatized, which can increase a person's risk of acquiring other stress related illnesses (Link & Phelan, 2006).

### **Facing the Stresses of Caregiving**

The theme of sadness was evident throughout all the interviews with the adult child caregivers in this study. Sadness is a psychological experience in the grieving process (Alzheimer's Association, 2013). Grief is defined as the reaction to the perception of loss, with normative symptoms including yearning, sadness, anger, guilt, regret, anxiety, loneliness, fatigue, shock, numbness, positive feelings, and a variety of physical symptoms that are unique to the individual (Shuchter & Zisook, 1993). The concept of loss was a major contributing factor to sadness in all the caregivers in this

study. The grief they experience is attributed to the loss of the parent-child relationship prior to dementia, the loss of the parent's role in the family, and the continuous psychosocial loss and eventual physical loss of the parent. The current loss of the parent the adult children are experiencing is a reflection of the concept of "ambiguous loss" (Boss, 2011), where one has a loved one who is physically present, but psychologically absent. Ambiguous loss does not provide validation of feelings of grief and loss or support for caregivers, because the person with dementia is still alive (Boss, 2011). When a loss is complicated by ambiguity, the grief process is frozen (Boss, 1999). Grief is a prevailing theme in the literature, which indicates that coping with loss is an integral part of the caregiving experience. Holley and Mast (2009), Meuser and Marwit (2001), and Sanders, Ott, Kelber, and Noonan (2008) included grief or sadness in their studies. Holley and Mast (2009) indicate grief is more prevalent in family caregivers, and they believe it plays a key role in understanding caregiver burden.

In the present study, the finding of loss as a contributor to caregiver grief is supported by earlier research on grief and caregivers of individuals with Alzheimer's disease. Results of these studies indicate that grief originates from losses in the quality of the relationship, roles, control, well-being, health status, social interaction, communication, and opportunities to resolve issues from the past (Loos & Bowd, 1997; Sanders & Corley, 2003). These losses occur over the course of the disease and create a situation of so-called dual dying, where there is pre-death grief (experienced while caregiving) and then additional grief once the loved one is physically gone (Sanders et al., 2008). Thus, caregivers grieve as each loss occurs during the life of the parent with dementia, and then they experience an additional period of grief when the actual death of

the parent happens (Ott et al., 2007). Pre-death grief may affect post-death mourning and grief resolution (Mullan, 1992; Robinson-Whelen, Tada, MacCallum, McGuire, & Kiecolt-Glaser, 2001). It has even been suggested that grief associated with dementia caregiving may be the primary determinant of all other caregiver affects (Meuser, Marwit, & Sanders, 2004).

The adult child caregivers in this study were also experiencing anticipatory grief, and they expressed their sadness over upcoming losses in the parent, both psychological and physical. They were saddened by thoughts about the future decline and eventual death of their parent with dementia. In literature, anticipatory grief has been defined as the process of mourning, coping, interaction, planning, and psychological reorganization that occurs as a result of the impending loss of a loved one (Rando, 1986). Although death is the ultimate anticipated loss, many other losses such as psychosocial death (such as when PwD can no longer recognize familiar faces) occur and may foster mourning in the present (Meuser, Marwit, & Sanders, 2004).

Changes in the relationship between the caregivers and their parent with dementia and the loss of the relationship that existed prior to dementia was evident in the interviews. This is characterized as leading to a process of "becoming strangers" (Wuest, Ericson, & Stern, 1994, p. 437). Caregivers and care recipients are described as experiencing a progressive sense of loss of mutuality, personal disconnectedness, and detachment from each other (Jones & Martinson, 1992; Lynch-Sauer, 1990). Furthermore, these changes and losses in relationships experienced by the caregivers in this study reveal an identity challenge of caregivers. Chronic illness is an accepted cause of disruption and change in people's lives (Bury, 1982). In this study, for the adult child

caregivers, the chronic illness is not their own, but nevertheless, it caused disruption in their lives and forced changes in their ways of viewing themselves and their family members. Nancy said she felt as though she "didn't have a mother anymore". This represented changes not only in her perceptions of her mother's identity but also changes in how she regarded herself. Her own identity that was once embedded in the shared identity of mother and daughter was disrupted by changes in her mother (Hasselkus & Murray, 2007).

Attachment theory provides a basis for understanding the caregiver grief processes (Bowlby, 1969). Bowlby suggested that grief occurs when the safety and security that a person feels within a relationship becomes threatened. Children as well as adults long for bonded relationships with others. Despite the stress and strain that occur between a caregiver and a care recipient, a bond exists that creates an intense form of attachment. As the caregiver senses the attachment with the care recipient changing or becoming strained as a result of the disease progression, grief is the natural byproduct. Thus, as the disease and cognitive impairment worsen, the grief of caregivers increases (Meuser & Marwit, 2001; Ponder & Pomeroy, 1996; Sanders & Adams, 2005).

### **Relying on Family**

The Iranian-Canadian adult children in this study were all primary informal caregivers to their parents with dementia. They shared this responsibility with their immediate family members, including wives, husbands, and children. Caregiving typically is a shared responsibility of the entire family in many ethnic minority cultures (Gallagher-Thompson et al., 2006). Caregivers in this study had strong family values and

felt a deep obligation to care for their parent with dementia. They also tended to have strong beliefs about seeking support from their immediate family members.

Throughout the interviews, the caregivers focused primarily on their Iranian culture and the role it played in their caregiving decisions and practices. These adult children had a relatively high level of cultural values and provided care because of their cultural expectations. The enactment of Iranian cultural traditions and norms was represented by a central theme in the study: filial responsibility. Help-giving to a parent was described as a natural extension of one's responsibility to the family as a whole and to ancestral traditions handed down from generation to generation. From this perspective, caring for a parent with dementia was experienced not so much as a choice but as a duty or obligation. Moreover, the adult caregivers believed these norms of filial caregiving differentiated them from the majority culture. Levkoff, Levy, and Weitzman (1999) found that non-White caregivers believed that their way of taking care of elders "is much better than the American way" (p. 350).

A study by Ho, Friedland, Rappolt, and Noh (2003) of Chinese-Canadian female caregivers found that Chinese-Canadian caregivers accepted their caregiving role as a cultural obligation and expressed strong negative feelings towards institutionalizing their older relatives. These caregivers believed that placing an older relative in a nursing home did not conform to their traditional family values. For Chinese people, caring for older parents is one of the moral obligations that adult children are expected to fulfill (Holroyd, 2001). Cox and Monk (1993) and Clark and Huttlinger (1998) found that cultural values and norms also governed familial relationships and the care of elders among Hispanics, wherein the extended family was expected to provide care to older relatives.

Caregivers in this study tended to uphold their cultural values, despite the fact that they have been living in Canada for two decades or more. The caregiving situation of these Iranian-Canadian adult caregivers can be better understood by using a multidirectional transactional model of bicultural identity (Robbins, Chatterjee, & Canda, 1998). As first generation Canadians born in Canada or as foreign-born minorities, immigrants tend to develop the traditional adaptation pattern, where they have a high adherence to family cultural values and behaviours (Robbins et al., 1998). It seems that the caregivers in this study have held onto their own cultural traditions of filial obligation, even though they have been living in Canada for a long period of time. Many of these caregivers felt obligated to provide care for their older parents and did not want to place them in nursing homes, because this is an expectation of their traditional cultural values. A strong emphasis on family or filial obligation may often result in a family caregiver's unwillingness to use formal services (Chee & Levkoff 2001). Culturally-defined values, norms, and roles have been identified as major determinants of the caregiving experience and are likely to affect service utilization (Scharlach et al., 2006).

Eventually, the caregivers in this study may adhere to a bicultural orientation in adaptation (Robbins et al., 1998). As the dementia progresses, a simultaneous adaptation to necessity and preservation of cultural values can be seen (Neary & Mahoney, 2005). This is when caregivers will retain both their own cultural values and norms and the values and norms of the larger social system (Robbins et al., 1998), a co-existence of their traditional and acculturated perspectives. This is in response to their limited ability to practice the traditional adaptation pattern when feeling overwhelmed, not being able to handle the all the burdens of caregiving. Hence, despite holding traditional beliefs, most

caregivers in this study have said they would, in the future, consider utilizing in-home care and respite services, leading to a bicultural adaptation in caregiving. Similar findings were seen in a study by Neary and Mahoney (2005), who explored the experiences of Latino caregivers of PwD and found cultural beliefs to be influential on the beliefs about the nature of caregiving. All of the participants expressed a firm commitment to family-based home care. They were willing to ask for services and to utilize the formal care system, if doing so would allow them to take care of their relatives at home. Families viewed placement as a denial of their obligation to take care of their loved ones. They associated their commitment to home care with cultural beliefs about family obligation and intergenerational reciprocity (Neary & Mahoney, 2005).

### **Identifying Preferences in Dementia Care**

Most of the caregivers in this study admitted to initially not having a lot of knowledge about dementia support services available to them as caregivers and to their parents with dementia. Whatever it is that they know about formal dementia care services is from their own curiosity and search for answers. They attributed their lack of knowledge of dementia care services during their early experiences of caregiving to their parent's general practitioner (GP) and the fact that he or she did not provide them with sufficient information about their options in terms of care services and did not make any referrals or recommendations. A similar finding arose in a study by Bruce and Paterson (2000) that investigated caregivers' experiences and perceptions in the role of caring for someone with dementia. Their study included wives, husbands, daughters, and sons as caregivers, who reported considerable difficulty finding out about and gaining access to community care. Some were openly critical and felt that the GP had failed to refer them

to services and that some doctors did not even know what services and supports were available (Brunce & Paterson, 2000).

In the present study, the adult child caregivers felt that their parents' GP was not as interested in or focused on the patient as they would have liked them to be. They did not feel that an effort was being put into getting to really know the patient and exploring and discussing the options available to them. Similarly, Shanley et al. (2012) conducted a cross-cultural study of the perceptions and experiences of Arabic, Chinese, Italian, and Spanish-speaking family caregivers on the use of formative services for PwD. They found that although many caregivers described the help they received from their GP in positive terms, there were also many who perceived GPs as not adequately acknowledging the dementia, as unaware of support services in the community, or as not able to invest the time to explore the needs of patients and families to make appropriate referrals (Shanley et al., 2012).

In a study by Toseland et al. (1999), the ethnically, culturally, and racially diverse primary caregivers of community residing PwD in New York cited not knowing where to obtain services as one of the most important impediments to service use. A substantial proportion of the respondents did not know how and where to obtain out-of-home and in-home respite services or how to obtain information and referral services. When interviewers described the types of services that were available, caregivers frequently mentioned that they would use one or more of them (Toseland et al., 1999). Similarly, in the present study, once the caregivers educated themselves and became aware of the services available to them, they stressed that, although they would never consider residential care for their parents, some would consider in-home respite services in the



future. They said that, had they never done independent research about what is out there, chances are they would never utilize any form of services. Other studies (Lee & Yee, 1988; Spence & Atherton, 1991) suggest lack of knowledge about community services as central to ethnic elders' low utilization rates. Moreover, lack of awareness/knowledge about community services is one of the common reasons given for not using services among Whites, African Americans, and Hispanics (Casado, van Vulpen, & Davis, 2011; Cox, 1999; Daker-White, Beattie, Gilliard, & Means, 2002), as well as in Korean Americans (Moon, Lubben, & Villa, 1998).

The caregivers in this study also emphasized what they preferred to see in dementia care services. They preferred to have workers in the home capable of speaking Farsi as well as English and from the same cultural background, so that they could provide a personal and tailored service. This way, professionals could have an understanding of the culture of their clients and their families and be able to interact and communicate with them on a more personal level. The adult children also preferred to see dementia information be made readily available in their own language.

A study by Ortiz and Fitten (2000) revealed that language proficiency barriers were the second most commonly endorsed barriers to seeking a dementia evaluation and to healthcare access and utilization among cognitively impaired Hispanic older adults in Southern California. The shortage of well-trained bilingual-bicultural researchers also negatively influenced diagnosis, management, and service utilization patterns in this population. Similarly, Gelman (2003) found that language barriers were perceived as preventing access to a dementia evaluation and treatment among Hispanic Americans. Language barriers have also been raised as a concern among some Asian American

caregivers (Hinton, Fraz, & Friend., 2004). Chinese-American families in Hinton et al.'s study experienced considerable difficulties in accessing care and interacting with healthcare professionals due to linguistic barriers. Bilingual workers are frequently mentioned as important resources to reduce access barriers and enhance the quality of services (Guarnaccia & Rodriguez, 1996; Lecca, Gutierrez, & Tijerina, 1996).

Clinical barriers between the health care provider and the patient or family occur when sociocultural differences between patient and provider are not fully accepted, appreciated, explored, or understood. Patients may have very different socioculturally based health beliefs, medical practices, attitudes toward medical care, and levels of trust in doctors and the health care system (Berger, 1998). When cultural and linguistic barriers in the clinical encounter negatively affect communication and trust, this leads to patient dissatisfaction, poor adherence to both medications and health promotion/disease prevention interventions, and poorer health outcomes (Betancourt, Green, Carrillo, & Ananeh-Firempong, 2003). This may arise because, when providers fail to take social and cultural factors into account, they may resort to stereotyping, which affects their behavior and decision-making (van Ryn & Burke, 2000). In the worst cases, this may lead to biased or discriminatory treatment of patients based on their race/ethnicity, culture, language proficiency, or social status (Schulman et al., 1999; van Ryn & Burke, 2000). Therefore, in an effort to define the parameters of cultural competency, researchers have used the cultural and linguistic fit between staff and clients as one criterion among human service and mental health providers (Engstrom & Min, 2004).

## Conclusion

The present study focused on exploring the lived experience of Iranian-Canadian adult children caring for parents living with dementia. Certain values and attitudes were discovered amongst these caregivers in terms of the utilization of and expectation from formal and informal care services, along with the role their Iranian culture played in shaping their caregiving experiences.

One of the two themes uncovered was Dual Reality, which encompassed two sub-themes: Hiding Dementia and Facing the Stresses of Caregiving. The adult children in this study were aware of the stigma society, and more importantly other Iranians, place on Alzheimer's disease and other related dementias and so they chose to protect their parents' image by hiding the dementia from the outside world, projecting a more healthy image. Secrecy also existed within the family as they also inexplicitly made efforts to hide dementia from the rest of the family and from the parent him- or herself by attempting to maintain as normal of a life as possible, in order to preserve the parents' self-esteem. This was carried out through the concealment of any negative emotions the caregivers may have experienced and the adherence to the parents' interests and hobbies prior to dementia, focusing on their abilities rather than their disabilities.

At the same time as trying to hide dementia, these adult child caregivers were carrying out day-to-day life, dealing with the stresses of caregiving, which primarily resulted in them neglecting their own well-being and placing greater priority on their roles as caregivers. Although some of the children recognized this and accepted it, claiming their parents' well-being was more important than their own, others resented the care recipient or denied neglecting themselves. The emotional burden of sadness and

frustration were also overwhelming for the caregivers, as they were coping with the realization of the inevitable grim future and loss of their parents' role as the ones providing care and of the previous relationships the parents once held with the adult children as well as with other family members. Feelings of frustration resulting from pretending everything was well and from thoughts of unfairness were also evident amongst the caregivers in this study.

The second uncovered theme in this study was Sources of Help, consisting of the sub-themes Relying on Family and Identifying Preferences in Dementia Care. The participants placed great importance on the significance of providing informal care to aging parents. Some of the adult children expressed that caring for their parents was their way of giving back, and others saw it as another natural step in life. Regardless, they all attributed their focus on family and filial obligations to their Iranian culture and their upbringing, despite their continual exposure to Western society's norms and values. Decisions concerning the parent were made as a family and the caregiving experience had in fact, in their opinions, brought the family closer together.

While acknowledging the importance of family and the responsibility to care for their parents, most of the caregivers admitted they would take professional support programmes in the form of in-home care services into consideration in the future if the need ever arose. Most of what they knew about the availability of formal services was a result of their own investigations, and so they wished that health practitioners would be more proactive in increasing awareness of service availabilities, in addition to expressing greater interest in the patient with AD and his or her family beyond the dementia. Aside from their interests in greater availability of dementia information in print and online in

the Farsi language, the adult children also suggested the implementation of bilingual and bicultural care, which would be critical in the future when formal service use might be considered. In their views, this alignment of culture and language between formal care services and patients and their families would allow for a more person-centered care, increasing comfort because the care providers would not seem like strangers, who would otherwise be oblivious to the unique values, interests, and needs of their linguistically and culturally diverse patients and their families.

### **Study Limitations**

This study features the voices of four Iranian adult children in Canada caring for a parent living with dementia. One of the limitations of this study is that the participants were homogenous in terms of their place of birth, which could have accounted for some of the similarities the respondents experienced. I was unable to explore the influences of acculturation amongst first-generation Iranian-Canadian children and its impact on caregiving decisions and experiences. Also, further emphasis and focus on the relationship between the adult children and their parents prior to the onset of dementia could have potentially strengthened the results of this study.

In addition, all the participants in this study had parents with mild dementia, so I was unable to explore the experience of caregivers caring for a parent with advanced stages of Alzheimer's disease. Also, the study was done in Toronto and could have contributed to the similarity in experiences of the adult child caregivers. However, sampling and recruitment in Toronto is justifiable because Toronto has one of the largest Iranian populations in the nation.

Furthermore, the fact that I am an Iranian-Canadian may have led the participants to not be fully truthful in conveying their thoughts and emotions in fear of judgment and ridicule. Also, the sensitive nature of the study may have inhibited the participants from revealing some aspects of their lived experiences as dementia caregivers.

### **Implications for Policy and Practice and Future Directions for Research**

In this study, we shed light on how family values, attitudes, and culture influence the experiences of Iranian adult children in Canada who care for a parent living with dementia. When working with caregivers from culturally diverse backgrounds, it is important to provide assistance that is culturally appropriate and accessible, in order to reduce the risk of caregiver burden and potential health problems. By being more culturally aware, professionals can better understand the types of assistance and services families need and would consider utilizing.

Therefore, healthcare and social service workers should be trained in cultural awareness and sensitivity, placing emphasis on person-centered care. Professionals should be able to comfortably ask questions of caregivers in regards to their care strategies, preferences in care, and their culture's role in shaping their caregiving journey. Awareness of these issues is essential and can facilitate caregivers in becoming better informed about services, referrals, interventions, and support programmes that are designed for the unique needs of this specific population of caregivers and their parents. Culturally sensitive programs and services should be provided to offer support, provide information, recognize resources, and strengthen family relationships. Providers should also recognize the coexistence of acculturated and traditional belief systems and assist caregivers in negotiating the potential conflicts between the two.

In addition, the Iranian community can take on a proactive role in educating fellow Iranians on dementia, taking initiatives to de-stigmatize it, in order to ultimately improve the lives of Iranians living with dementia and their families. They can also take the initiative to advocate on behalf of fellow Iranian-Canadians for more culturally appropriate care to service providers and policymakers.

Furthermore, outreach efforts and educational materials to inform older adults and their families about dementia and services in their original language would be beneficial. Native-language videos and brochures can help increase the knowledge of symptoms and likeliness of professional help seeking for many Iranians. In addition, the availability of more bilingual and bicultural workers would play a vital role in educating, supporting, and caring for individuals and their families from diverse cultural backgrounds who are affected by dementia. This could build trust and cultural understandings, and encourage and facilitate the use of formal supports.

Studies about family dementia caregiving to date have been based primarily on information from individuals already receiving services and have shed minimal light on the perspectives of dementia caregivers from a wide range of racially, ethnically, and culturally diverse groups. Future research should aim to explore caregivers' experiences and attitudes about service use from their own cultural perspectives and in their own languages. Especially lacking is information from Middle Eastern caregivers in Western society. Emphasis on gender analysis, and its interplay with culture, in the caregiving context would be an area of great interest in future research. Further research should also address the extent to which caregiver interventions for diverse caregivers, especially Iranians in the Canadian context are effective and culturally appropriate. Optimal

methods for culturally tailoring psychosocial interventions is not yet well understood. Also, the contribution of bilingual and bicultural workers within the dementia field has not been adequately recognized. There would be benefit from further research that provides a greater understanding of bilingual/bicultural workers' role in the dementia field, and how these workers can be best supported to continue the fundamental responsibilities they have.

In summary, this phenomenological study explored the experience of Iranian-Canadian adult children caring for a parent living with dementia. After the completion of this study, I have come to realize how much time and devotion these children dedicate to their parents, in hopes of providing them with as normal as a life as possible, full of love and acceptance. I have learned that along with the daily stresses of caregiving, there are joys in caring for a loved one, which stems from a deep appreciation of and commitment to family. The fundamental experience of these Iranian-Canadian children caring for a loved one with dementia is to attempt to preserve an image and cope with the burdens of caregiving at the same time, in addition to adhering to traditional values while recognizing the ultimate need for professional support.



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## Appendices

APPENDIX A

Ethics Review Form



## Use of Human Participants - Ethics Approval Notice

Principal Investigator: Prof. Sandra Hobson  
 File Number:102862  
 Review Level:Delegated  
 Approved Local Adult Participants:6  
 Approved Local Minor Participants:0  
 Protocol Title:Exploring the Iranian-Canadian Family Experience of Dementia Caregiving: A Hermeneutic Phenomenological Study  
 Department & Institution:Health Sciences/Occupational Therapy,Western University  
 Sponsor:  
 Ethics Approval Date:September 26, 2012 Expiry Date:August 31, 2013  
 Documents Reviewed & Approved & Documents Received for Information:

Document Name	Comments	Version Date
Western University Protocol		
Letter of Information & Consent		2012/09/01
Advertisement		
Other		
Other		

This is to notify you that The University of Western Ontario Research Ethics Board for Health Sciences Research involving Human Subjects (HSREB) which is organized and operates according to the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans and the Health Canada/ICH Good Clinical Practice Practices: Consolidated Guidelines; and the applicable laws and regulations of Ontario has reviewed and granted approval to the above referenced revision(s) or amendment(s) on the approval date noted above. The membership of this REB also complies with the membership requirements for REB's as defined in Division 5 of the Food and Drug Regulations.

The ethics approval for this study shall remain valid until the expiry date noted above assuming timely and acceptable responses to the HSREB's periodic requests for surveillance and monitoring information. If you require an updated approval notice prior to that time you must request it using the University of Western Ontario Updated Approval Request Form.

Members of the HSREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussion related to, nor vote on, such studies when they are presented to the HSREB.

The Chair of the HSREB is Dr. Joseph Gilbert. The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 0000940.

Signature

## Ethics Officer in Contact for Further Information

<input type="checkbox"/> Janice Sutherland (jsuthera@uwo.ca)	<input checked="" type="checkbox"/> Grace Kelly (grace.kelly@uwo.ca)	<input type="checkbox"/> Sharral Watson (sharral@uwo.ca)
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This is an official document. Please retain the original in your files.

APPENDIX B

Letter of Information





## Letter of Information

**Project Title:** Exploring the Lived Experience of Iranian-Canadian Adults Caring for a Parent with Dementia

**Principal Investigator:** Sandra Hobson, B.Sc. (OT), M.A.Ed., LLD, FCAOT,  
Department of Health and Rehabilitation Sciences, Western University

**Co-investigator:** Sevil Deljavan, B.Sc. (honours), M.Sc. (candidate), Department of  
Health and Rehabilitation Sciences, Western University

### 1. Invitation to Participate

You are being invited to participate in this research study, which is aimed at exploring the lived experience of Iranian-Canadian adults caring for a parent with dementia. This is because you meet the criteria for inclusion and we believe you will provide rich insight into your lived experience as an adult child dementia caregiver of Iranian descent. We are interested in seeing how your caregiving experiences, activities, and decisions are specific to you and are influenced by your culture.

### 2. Purpose of the Letter

The purpose of this letter is to provide you with information required for you to make an informed decision regarding participation in this research.

### 3. Purpose of this Study

The purpose of this study is to uncover the values, attitudes, and experiences of Iranian-Canadian adult child dementia caregivers in regards to their caregiver roles, their utilization of and expectations from formal and informal care services, and the role of culture in shaping their caregiving experiences.

### 4. Inclusion Criteria

Individuals who a)are Iranian-Canadian adults, b)are fluent in the English language, c)have a parent diagnosed with dementia by a medical doctor or clinic, d)identify themselves as the primary caregiver for their ill parent, and e)have an ongoing and prolonged responsibility in caring for their ill parent are eligible to participate in this study.

### 5. Exclusion Criteria

Your parent's diagnosis is not based on your opinion but rather is a diagnosis made by a medical doctor or clinic.

### 6. Study Procedures

If you are eligible for inclusion in the study, it does not guarantee your participation in the study. However, if you are selected to participate and you agree to do so, you will

be asked to take part in one to two individual, in-depth, face-to-face interviews, each one to two hours in length. It is anticipated that both interviews will be conducted within a period of two weeks to one month. The interviews will be conducted in a location preferred by both the researcher and the participant, based on a mutual decision. There will be a total of six participants involved in this study.

#### **7. Possible Risks and Harms**

Emotional distress and sadness may occur due to the sensitive nature of the study. Therefore, a list of resources available to you will be given to you during the first meeting.

#### **8. Possible Benefits**

Participating in this study may help enlighten you about new caregiving and caregiver burden coping strategies and ways to make use of available resources, in order to foster some positive changes in your experiences as a caregiver. It may also allow you to see more positive aspects of caregiving and can provide you with the opportunity to vent to a sensitive audience. More generally, this study may help geriatric social and health care systems find ways to simultaneously minimize the costs of caregiving and maximize its positive aspects, in hopes of providing caregivers and recipients with adequate and sufficient resources through an approach consistent with their values, in a culturally competent manner.

#### **9. Compensation**

You will not be compensated for your participation in this research.

#### **10. Voluntary Participation**

Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions or withdraw from the study at any time with no effect on your future.

#### **11. Confidentiality**

All data collected will remain confidential and accessible only to the investigators of this study, including personal information (full name, sex, year of birth, and email address). If the results are published, your name will not be used because you will be assigned a pseudonym. However, inclusion of your year of birth and your sex may allow someone to link the data and identify you. If you choose to withdraw from this study, your data will be removed and destroyed from our records. Representatives of Western University Health Sciences Research Ethics Board may contact you or require access to your study-related records to monitor the conduct of the research.

#### **12. Contacts for Further Information**

If you require any further information regarding this research project or your participation in the study you may contact investigators Sevil Deljavan or Sandra Hobson.

If you have any questions about your rights as a research participant or the conduct of this study, you may contact The Office of Research Ethics (519) 661-3036, email: [ethics@uwo.ca](mailto:ethics@uwo.ca)

**13. Publication**

If the results of the study are published, your name will not be used. If you would like to receive a copy of any potential study results, please contact Sevil Deljavan.

*This letter is yours to keep for future reference.*

APPENDIX C

Consent Form



## Consent Form

**Project Title:** Exploring the Iranian-Canadian Family Experience of Dementia Caregiving: A Phenomenological Study

**Study Investigators' Names:** Sandra Hobson, B.Sc. (OT), M.A.Ed., LLD, FCAOT  
Sevil Deljavan, Honours B.Sc., M.Sc. candidate

I have read the Letter of Information, have had the nature of the study explained to me and I agree to participate. All questions have been answered to my satisfaction.

Participant's name: \_\_\_\_\_

Participant's signature: \_\_\_\_\_

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

Name of person obtaining consent: \_\_\_\_\_

Signature of person obtaining consent: \_\_\_\_\_

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

APPENDIX D

Telephone Script

### Telephone Script for Recruitment

(This script is in response to phone calls we will be receiving from potential participants who are responding to our advertisements.)

*\*Pick up phone call and say: "Hello."*

*\*Participant explains they are responding to an ad they saw about the study.*

"Thank you for calling about the study. Before we go any further, I'd like to ask you a few questions. Is that okay with you?"

*\*If no, thank them for their time and say good-bye.*

*\*If yes, begin asking the first question.*

"Are you of Iranian-Canadian decent?"

*\*If no, thank them for their time and say good-bye.*

*\*If yes, continue to ask more questions.*

"Are you fluent in English?"

*\*If no, thank them for their time and say good-bye.*

*\*If yes, continue to ask more questions.*

"Do you have a parent who has been diagnosed with dementia by a medical doctor or clinic?"

*\*If no, thank them for their time and say good-bye.*

*\*If yes, continue to ask more questions.*

"Do you identify yourself as a primary caregiver for your parent suffering from dementia?"

*\*If no, thank them for their time and say good-bye.*

*\*If yes, continue to ask more questions.*

"Do you have an ongoing and prolonged responsibility in caring for your ill parent?"

*\*If no, thank them for their time and say good-bye.*

*\*If yes, then: "Ok great. Based on the information you have given me, you qualify as a potential participant in this study. However, I'd just like to clarify that your inclusion in the study is not guaranteed. Right now, you are in the pool of potential participants. Now I will proceed to explain to you the details of the study". \*Read the content of the letter of information.*

"Do you have any questions or inquiries?"

*\*Based on participants' questions, respond accordingly.*

"Do you agree to participate in this study?"

*\*If no, thank them for their time and say good-bye.*

*\*If yes, then ask:* “Now, can I please have your full name and e-mail address? This way, we can inform you if you have been selected to participate in our study.”

*\*If no, thank them for their time and say good-bye.*

*\*If yes, take their information down.*

“Okay, \_\_(caller’s name)\_\_. Thank you for your time. We will inform you via email if you have been selected to participate in this study. Thank you and have a great day.”



APPENDIX E

Invitation Email

### **Invitation to Participate in Research**

Dear (full name of selected participant),

Following our phone conversation on the date of \_\_\_\_\_, I am glad to say you have qualified as a research participant and I would like to formally invite you to participate in the study that I, Sevil Deljavan, am conducting.

Briefly, the study involves one to two face-to-face interviews (along with a demographic questionnaire during the first interview), each approximately one to two hours in length. The location of the interviews will be mutually decided, where both parties, you and I, will feel most comfortable. Based on your availability and preference, the two interviews can span across two weeks to one month.

If you would still like more information or would not like to participate in this study, please contact me at the contact information given below. However, if you wish to participate and have no further inquiries, please contact me and specify a precise date, time, and location where you would like our first meeting to take place.

Also, please take note of the letter of information and consent form that is attached to this email. Please thoroughly read through these two documents. Upon our initial meeting, I will clarify all that is written in these documents and following this, you will authorize your understanding and comprehension of the study and what it entails with your signature.

Thank you.

APPENDIX F

Demographic Questionnaire

## Demographic Questionnaire

### Caregiver Information

1. What is your age?
2. What is your gender?
3. What is your primary language?
4. What is your religious affiliation?
5. What is the highest level of education you have completed?
6. What is your current marital status?
7. How many siblings do you have, if any, and what is their age and sex?
8. How long have you been living in Canada?
9. Where were you born?
10. In what housing type do you live?
11. In what area do you live? Urban or rural?
12. What is your current household income in Canadian dollars? (Pick range)
  - Under \$25,000
  - \$25,000 - \$39,999
  - \$40,000 - \$49,999
  - \$50,000 - \$74,999
  - \$75,000 - \$99,999
  - \$100,000 - \$124,999
  - \$125,000 - \$149,999
  - Over \$150,000
  - Choose not to answer
13. How many children live in your household and what are their gender and ages?
14. What is your primary area of employment? Part-time or full-time? Approximately how many hours a week?

### Care Recipient Information

1. Who in your family is diagnosed with dementia? Mother or father?
2. When was he/she diagnosed formally with dementia?
3. What is their official diagnosis and for how long have they been ill?
4. Do they have co-morbidities?
5. In terms of caregiving, how many hours per day and/or how many hours per week do you provide assistance on average?
6. In which country was your parent who is diagnosed with dementia born?
7. If not Canada, then how long has he/she been living in Canada?
8. What is the marital status of your parent who is diagnosed with dementia?
9. Where and with whom does he/she reside?
10. What is the approximate distance between your home of residence and her/his home of residence, in kilometers?

APPENDIX G

Semi-structured Interview Guide

### Semi-structured Interview Guide

1. Are you the sole caregiver or primary caregiver and why? Do you live with your parent and what is the reason for this decision?
2. What do you have to say about caring for your parent with dementia?
3. What do you think is most important when caring for a parent with dementia?
4. Tell me about your parent with dementia and your relationship with him/her.
5. How do you feel about your experience caring for a parent diagnosed with dementia?
6. As your role as a dementia caregiver, what sorts of things do you think you do well and why?
7. Can you describe a situation where you had the most difficulty in caring for your parent? Describe this one incident and why you found it to be most difficult.
8. What are the most uplifting things about caring for your parent with dementia?
9. What made you decide to be the main caregiver of your ill parent? What do you think most influenced your decision?
10. Have you considered institutionalizing your parent and placing him/her in a nursing home? When? Why or why not?
11. What good things do you see coming out of this?
12. How would you compare your role as an Iranian-Canadian caregiver with other caregivers of similar and different cultural backgrounds?
13. What would you want to be done for you, if you were the one with dementia?
14. How much of your experience do you share with others and what forms of help do you seek from other family members and friends, if any?
15. Talk about the types of informal and formal support you believe you have at your disposal. Do you use any formal supports? Which type? Are they good or bad? Why?
16. Do you think more resources could be available to you in helping you care for your parent? If so, elaborate.
17. What has this experience so far taught you about yourself and your relationship with your parent? Overall, would you consider it a negative or positive experience?

## Curriculum Vitae

**NAME: SEVIL DELJAVAN**

### EDUCATION

**Master of Science, MSc. (candidate): Health and Rehabilitation Sciences**

2011 - present

Western University, London, Ontario

**Honours Bachelor of Science, BSc.: Integrative Biology and Health Studies**

2006 - 2010

University of Toronto, Toronto, Ontario

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### RELEVANT EXPERIENCE

**Graduate Student**

Western University, London, Ontario

2011 - present

**Teaching Assistant**

Western University, London, Ontario

2011 - present

**Marine Biology Field Researcher**

University of Toronto, Toronto, Ontario

2009 - 2010

**Psychology Lab Assistant**

University of Toronto, Toronto, Ontario

2009 - 2010

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### ADDITIONAL EXPERIENCE

**Recreation Coordinator**

Jadaco Recreation Management, Toronto, Ontario

2009 - 2011

**Volunteer**

North York General Hospital, Toronto, Ontario

2007 - 2011

**Lifeguard and Swim Instructor**

City of Toronto Parks and Recreation, Toronto, Ontario

2004 - 2010