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**DEMENTIA IN IRAN AND SWEDEN:
EXPERIENCES OF PERSONS WITH DEMENTIA AND
FAMILY MEMBERS**

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**Karolinska
Institutet**

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Translation of the cover poem:

*'Remembering the days of youth torments me
Glad that slowly aging arrived and loss of memory''*

Interpretation: Sheda Vasseghi

Cover: Mohamad Hosein Zolfaghari Far

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ABSTRACT

The overall aim of this thesis was to explore the experiences of dementia from the perspective of Iranian people with dementia and their family members in Iran and Sweden. The thesis consists of four exploratory studies with qualitative approaches.

Two qualitative approaches, interpretive phenomenology (studies I and II) and qualitative content analysis (studies III and IV), were employed to conduct the studies in urban areas of Sweden (studies I and III) and Iran (studies I and IV). A total of 50 people participated in the studies, 28 female and 22 male, ranging in age from 26 to 88 years old. Participants were people with dementia (studies III-IV) and family members of people with dementia (studies I and II). All data was collected through semi-structured interviews, transcribed verbatim, and analysed with Benner's interpretative phenomenology (studies I and II) and qualitative content analysis (studies III and IV), respectively.

The results revealed that Iranian immigrant family members of people with dementia in Sweden (study I) experienced caring as one of fulfillment. They had difficulties in accepting the diagnosis of dementia of their family member. The shock of not being recognised by their family members with dementia was the turning point for them to accept the situation. Family members who lived with their next of kin with dementia in Iran (study II) described their concerns of losing a sense of togetherness, a sense of future, and social dignity. They created meanings through submission to fate and striving to look on the bright side, in order to make sense of their changed lives. The subjective experiences of living with dementia for Iranian immigrants in Sweden (study III) meant living with forgetfulness, feeling incompetent but still loved, and feeling confident and secure in society but also isolated. Living with dementia in Iran (study IV) was experienced as struggling with an altered life, which included becoming an altered self in the eyes of others, forgetfulness as an irritating condition, being a burden on others, longing to be a valued person, and finding strategies to deal with dementia.

Difficulties in accepting the diagnosis of dementia was beyond participants' cultural background or poor awareness of dementia but it seemed to be mainly related to their life' histories. People should be approached individually for comprehending their personal reasons and motives for resisting diagnoses or medical care. Family members need to learn how to interact with their relatives with dementia with respect and dignity. Nurses can help reconstruct families' broken life stories and recommence an effective connection between families and people with dementia. By gaining insight into the concerns and experiences of people with dementia and their families, nurses can meet them where they are in their unique contextual situation. Therefore, nurses can help people with dementia and their families obtain a meaningful life.

Key words: dementia, experience, immigrant, interpretive phenomenology, Iran, qualitative study, qualitative content analysis, Sweden

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LIST OF PUBLICATIONS

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- II. Mazaheri M., Sunvisson, H., Nasrabadi Nikbakht, A., Maddah, S.S.B., Heikkilä, K., Ekman, S-L., Emami, A. Living together with a person with dementia in Iran - Fate and destiny as an outlook on life. *Submitted for publication*.
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*To my father
And his great dreams*

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ORIGINAL ARTICLES I-IV

LIST OF ABBREVIATIONS

DSM	Diagnostic and statistical manual of mental disorders
IAA	Iranian Alzheimer Association
ICD	International Statistical Classification of Diseases and Related Health Problems
MMSE	Mini-mental Status Examination
NCDs	neurocognitive disorders
SBU	The Swedish Council on Technology Assessment in Health Care (Statens beredning för medicinsk utvärdering)

1 INTRODUCTION

The overall aim of my research project was to explore experiences of dementia from the perspectives of persons with dementia and their family members. Initially, I targeted people from Iran because the experience of dementia has not been well explored qualitatively in that specific context. Later on, when I was writing my research proposal for my PhD thesis at Karolinska Institutet, I thought including experiences of Iranians who live in another sociocultural context with a different health-care system, like Sweden, could enrich the findings. I found it interesting to see how dementia develops and what it is like to live with dementia or live with a person with dementia. I was interested in what it was like for Iranian residents and for those Iranians who migrated to Sweden (in other words, Swedes who were born and grew up in Iran) and experienced dementia or had a family member living with dementia who was diagnosed later in Sweden. I thought the finding could give other dimensions to the experience of dementia and deepen our understanding of the experience of dementia.

My interest in dementia research began in Iran with my encounters with people with dementia who had been hospitalized in psychiatric wards because of their behavioral disturbances. I was fortunate to serve mentally ill patients as a psychiatric nurse in both acute and residential wards. I was very proud of my choice to take care of those I felt are the least served citizens—those who were blamed and criticized by society and those close to them for behaviours that were not in their control. I felt they had not enjoyed life in the way I thought they should have a chance to do. Later, when I was transferred to a psychogeriatric ward, I was very much surprised to see how some of my colleagues treated people with dementia who had been hospitalized because of their personality and behavioural changes or because they had a concurrent psychiatric diagnosis. Many, including relatives and staff, approached people with dementia as if they could not recognize respect and dignity anymore or as if they were no longer the same people. The way they approached them was far from the way they met any other seniors in society. I wondered how those people with dementia perceived such situations, considering their memory fluctuations. How much were they aware or disturbed by our behaviours? I also wondered about family members, how they experienced seeing their loved one develops dementia and end up in a residential psychiatric hospital. I was eager to give those people with dementia a voice to speak up about their lives, to let us health-care workers or their relatives get to know their world. Hence, I decided to study the experiences of people with dementia in a rigorous way, and it became my passion in life.

2 BACKGROUND

In this section, I provide background information needed to facilitate comprehension of the research project of my PhD thesis. This includes information about dementia, living with dementia, living together with a family member with dementia and dementia caregiving, dementia and culture, caregiving and culture, and, finally, migration.

2.1 DEMENTIA

Dementia is one of the greatest challenges of health care and social care systems in low-income and middle-income countries as well as in developed economies (World-Health-Organization-and-Alzheimer's-Disease-International, 2012). The number of people with dementia in the world was estimated to be 35.6 million in 2010: that number is expected to double every 20 years (Prince et al., 2013). Most of the people with dementia live in low- or middle-income countries (58% in 2010), a figure that is estimated to rise to 63% in 2030 and 71% in 2050 (Prince et al., 2013). Rates of increase are not uniform; the numbers of people with dementia in developed countries are forecast to increase by 100% between 2001 and 2040, but by more than 300% in India, China, and their south Asian and western Pacific neighbours (Ferri et al., 2006).

Dementia is derived from the Latin word *demens*, which means 'without mind'. Dementia is a syndrome that results in the decline of the function of the mental system in cognitive and emotional aspects (McKeel, 2007). Dementia is an umbrella term and includes several clinical profiles with a wide range of causes; some are seemingly irreversible and others curable. The International Statistical Classification of Diseases and Related Health Problems, 10th Revision (ICD-10), classifies dementia in the block of mental and behavioural disorders. The ICD-10 defines dementia (2010) as 'a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgment. Consciousness is not clouded' (ICD-10, 1993). The most common types of dementia are Alzheimer's disease and vascular dementia (Qiu, De Ronchi, & Fratiglioni, 2007). The concept of dementia and classification of dementia has been developed based on clinicopathological entities and etiological factors (The Swedish Council on Technology Assessment in Health Care- Statens beredning för medicinsk utvärdering [SBU], 2008).

The term *dementia* has been eliminated from the latest edition of *The Diagnostic and Statistical Manual of Mental Disorders* (DSM-5, 2013), which was released in May

2013. What had been referred to as ‘Dementia, Delirium, Amnestic, and Other Cognitive Disorders’ in the previous edition (DSM-IV) was replaced by the neurocognitive disorders (NCDs), which include major and mild neurocognitive disorders. The term *dementia* is retained in DSM-5 for the sake of continuity, and it may be used where physicians and patients are more comfortable with the term (DSM-5, p. 591). In this thesis, we maintain the term *dementia* because the new terminology has not been used extensively yet, and using the new term in this thesis might be confusing. Moreover, the ICD-10 still keeps its application and definition of dementia.

Because of increasing life expectancy, the number of people who live with dementia is increasing rapidly across the globe. Dementia involves not only the patients but the family, caregivers, and society, bringing severe tension and economic burdens. Dementia is a serious health challenge that decreases older people’s chances for living independently. According to the Global Burden of Disease estimates for the 2003 World Health Report (World Health Organization, 2003), dementia contributed to 11.2% of years lived with disability in people aged 60 years and older—more than stroke (9.5%), musculoskeletal disorders (8.9%), cardiovascular disease (5.0%), and all forms of cancer (2.4%). The disability weight for dementia, estimated by international and multidisciplinary expert consensus, was higher than for almost any other health condition, apart from spinal-cord injury and terminal cancer. Luengo-Fernandez, Leal, and Gray (2011) report dementia as a significant economic burden to Europe. They estimated that the cost of dementia in 15 European countries was around €189 billion in 2007, including 68% informal care, 26% social care, 5% health care, and 1% productivity losses. Such estimates of the burden are critically dependent on the accuracy of the estimates of people living with the disease, which in turn depend on evidence from epidemiological surveys that are representative and well organized. In many world regions, the evidence of dementia is either incomplete or has low coverage. Even when a wider evidence base is available for country- or region-specific figures, these estimates are sometimes generated from single studies that have little regard for their generalizability.

Over the past 20 years, the discourse on dementia has changed noticeably from the dominance of the medical model that diminishes the person with dementia to a disease and its neurobiological or neuropsychological signs and symptoms to a view of the person with dementia and her/his individual experience of the disease (Innes, 2002; Lawrence, Samsi, Banerjee, Morgan, & Murray, 2011).

2.2 LIVING WITH DEMENTIA

Dementia research has experienced an increased number of studies that highlight direct accounts and subjective experiences of people with dementia (Beard & Fox,

2008; O'Connor et al., 2007; Roger, 2006), research that had been less well regarded before.

Living with dementia has been reported to involve severe challenges in everyday life. People with dementia commonly suffer from major cognitive decline, including severe memory loss as well as a decreased ability to judge and value situations, emotional impairments, and changes in personality (Volicer, Hurley, & Blasi, 2003). Experiences of cognitive loss and emotional problems have been described as terrifying (Tappen, Williams, Fishman, & Touhy, 1999).

Life with dementia has been described as being anywhere from 'not a big deal' to 'a nuisance' to 'hell' by people with dementia and their significant others (Hulko, 2004). These descriptions were found to be related to the people with dementia's social location and the reactions of people in their social worlds, including their significant others. Reviewing the existing literature on the experience of living with dementia shows variations such as living a heteronymous existence in which people with dementia are lost and strangers in their own world (Svanström & Dahlberg, 2004) or having an intact manifestation of selfhood (Sabat & Collins, 1999) and intact emotional and interpersonal responses (Evans-Roberts & Turnbull, 2010). Further, living with dementia is reported to be experienced as living on the threshold (De Witt, Ploeg, & Black, 2009), striving to incorporate a 'manageable disability' into existing identities of people with dementia whose views of life have not been erased by dementia (Westius, Andersson, & Kallenberg, 2009), with a common theme of a sense of loss (Acton, Mayhew, Hopkins, & Yauk, 1999; Harris & Keady, 2004; Menne, Kinney, & Morhardt, 2002; Ostwald, Duggleby, & Hepburn, 2002; Phinney, 2011; Snyder, 2001). A systematic review (Caddell & Clare, 2010) showed that almost all studies suggest there is at least some evidence for persistence of self in all stages (mild, moderate, and severe) of dementia.

Variations in experiencing dementia have been understood in different ways. Reviewing the current literature on the experience of dementia shows overwhelmingly negative images of being a person with dementia (Harman & Clare, 2006), which may be related to a lack of diversity (Hulko, 2009) in the participants of studies on subjective experiences of dementia. The studies conducted so far have focused mainly on people in early dementia stages (Renée L. Beard & Patrick J. Fox, 2008; MacQuarrie, 2005; O'Connor et al., 2007; Robinson, 2000; Steeman, Godderis, Grypdonck, De Bal, & Dierckx de Casterle, 2007). De Boer and colleagues (2007) conducted an international review on the experiences of dementia and reported that despite their comprehensive search, articles from only Western countries were found in the searched databases, which suggests that (i) not many studies were conducted in non-Western countries or (ii) these studies were not published internationally.

2.3 LIVING WITH A PERSON WITH DEMENTIA

People worldwide who live with dementia often live with their family members (Lane, Podgorski, Noronha, & King, 2012), which highlights the importance of taking into account families' perspectives on research and care. A common statement in the literature on caregiving and dementia is that caring for a person with dementia is one of the most devastating and demanding experiences people can carry out (Butcher, Holkup, & Buckwalter, 2001). People who live with a family member with dementia are essential to the possibility of allowing people with dementia to remain in their own homes rather than being moved to institutions (Benedetti, Cohen, & Taylor, 2013).

Family members who take care of their relative with dementia are the cornerstone of support for people with dementia. They experience substantial psychological, practical, and economic strains, according to literature—that is, a sense of burden and depression (McConaghy & Caltabiano, 2005), financial and employment problems and relationships issues (van Vliet, de Vugt, Bakker, Koopmans, & Verhey, 2010), and significant decreases in well-being and the quality of life (Milne & Chryssanthopoulou, 2005). Living with a person with dementia and taking care of her/him is particularly time- and energy-intensive. To understand the strains that families with dementia undergo, it needs to be mentioned that the burden of caring for people with dementia has been considered greater than that of caring for people with other chronic conditions (Ericson, Hellström, Lundh, & Nolan, 2001).

Family members approach in different ways the care needs of their dependent family members with dementia. Although some care for their loved ones at home and regard institutionalization as stigmatizing, others place their family member with dementia in a nursing home. A wide range of reasons has been reported for why people respond as they do to relatives' care needs, ranging from cultural issues such as children's obligations to take care of their parents (Park & Chesla, 2007), identifying it as an expected family role (Wallhagen & Yamamoto-Mitani, 2006), to practical concerns like using the available resources in society in order to be able to perform other roles and identifying caregiving as an unexpected career (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995)

It needs to be noted that providing care to a family member with dementia can be a positive (Carbonneau, Caron, & Desrosiers, 2010; McIntyre, 2003; Tarlow B, 2004) or a negative experience (Etters, Goodall, & Harrison, 2008; Takai et al., 2009). Some examples of positive experiences can be families that found living and taking care of a relative with dementia meaningful and a blessing (Shim, Barroso, & Davis, 2012) or families that experienced increased self-esteem because they were supporting their relatives with dementia (Constable, 2011). Factors such as education, having better mental well-being, using care strategies as active management, and being part of a

support group have been found to be associated in finding the positive in living and taking care of a family member with dementia (Liew et al., 2010).

Increasingly, researchers point to a growing need to qualitatively explore why those caring for relatives regard the quality of the caregiving experience as poor while others derive positive benefits (Hinton, 2002; Milne & Chryssanthopoulou, 2005).

2.4 DEMENTIA AND CULTURE

There is a body of knowledge about the impact of culture on human experiences throughout life (Feasby et al., 1984; Gilbert et al., 2007; Leininger & McFarland, 2002; Thomas, 2001). Because culture shapes perceptions and behaviors, it is also assumed to shape responses to cognitive impairment and dementia. Culture impacts actions that people take with regard to the symptoms and the treatment they seek. For example, the conflict between cultural values of individualism against collectivity and family values can clash when decisions on end-of-life issues concern care activities, caregiving roles, treatment plans, and service locations (Fielo & Degazon, 1997; Pierce, 1999; Thomas, 2001).

Dementia is pathology from a medical perspective, but it has been understood in many different ways as a normal stage of the ageing process. Lawrence et al. (2011) reported that the threats that commonly accompany dementia depend on the person's own understanding of her/his condition, her/his attitudes towards support needs, and the perceived interference with her/his life values. It even is considered special because it looks as if the person is communicating with the supernatural world, which has been the case among an American Indian tribe (Henderson & Henderson, 2002).

An Asian study showed that Japanese were found to be more afraid of 'old age' decline in general terms than specifically of Alzheimer's disease (Traphagan, 1998). Further, Ikels (2002) proposed that dementia among the Chinese does not evoke 'the kind of dread that is common among Americans' (pg. 297), a situation related to Chinese beliefs about dementia, cultural values, and situational features of contemporary life such as lack of alternatives to family care and different lifestyles. No published studies regarding personal experiences of dementia in Middle Eastern countries have been found.

Most of the research studies on living with dementia have been conducted on a mainstream population of white, middle-class, Western societies with a Christian background (Kitwood 1997, Phinney 1998, Clare 2002, Werezak & Stewart 2002). According to previous studies, the experiences are mostly negative, including a variety of losses for people with dementia and burdens, strains, stress, and poor physical and

mental health their families (Hooker et al., 2002; Savundranayagam & Montgomery, 2010; Torti, Gwyther, Reed, Friedman, & Schulman, 2004; Vitaliano, Zhang, & Scanlan, 2003). As for the rest of the world, we do know a bit about the experience of dementia among groups of people in east Asia (Mok, Lai, Wong, & Wan, 2007). The literature shows different cultural constructions of dementia, from a normative understanding in India (Cohen, 1998) to a 'supernormal' construct of the disease among American Indians (Henderson & Henderson, 2002) to dreadful images as of dementia sufferers as zombies (Behuniak, 2011). There are also few studies from Pacific Islander Americans (Braun & Browne, 1998) and other immigrant groups in the United States. However, there is still a lack of knowledge about subjective experiences of dementia in societies—notably, the Middle East, Africa, and Latin America—that differ in income, health-care structure, welfare system, socio-cultural discourses, and daily contingencies. A literature review on dementia research in Arab countries (Karam & Itani, 2013) revealed severe shortage of published articles about dementia in English. Karam & Itani (2013) found no particular studies in 11 Arab countries and only very few studies in the rest of seven countries. They believed low awareness of dementia, not allocating funds to dementia research and not having national registry in this regard were contributing reasons to lack of dementia research in Arab region. Therefore, the research body in the field of the individual's subjective experience of dementia suffers from lack of diversity (Hulko 2009) among the participants.

Most striking is the stark absence of research with people with dementia from minority ethnic groups. A review of the international literature and metasynthesis of qualitative studies identified 50 articles (de Boer et al., 2007) and 28 qualitative studies (Steeman et al., 2006), respectively, that examined the perspective of the person with dementia; none reported experiences within minority ethnic populations. Kitwood (1997) conceptualized dementia as a socially embedded phenomenon in which the person's neurological impairment interacts with the surrounding social environment. Accordingly, it is important to consider the experience of dementia within its cultural context (Downs, 2000).

There are many studies on family members from different cultural backgrounds but not much about people with dementia themselves. Schwartz and colleagues (2004) reported that 'there is substantial evidence that neurobehavioral test scores, cognitive decline over time, and dementia risk, vary substantially by ethnicity' (pg 314). These variations could be the case for subjective experience of dementia, which we have not explored in a broad range of contexts.

2.5 CAREGIVING AND CULTURE

Although many studies indicate that the experience of caregiving is deeply cultural (Chee & Levkoff, 2001; Hinton, 2002; Yen et al., 2010), and dementia caregiving has

been extensively presented in literature, we know little about the culturally related issues surrounding immigrant population.

Research has revealed that norms and beliefs have impact on meanings devoted to dementia (Dilworth-Anderson, Williams, & Gibson, 2002). A literature review on family members of people with dementia from Chinese and Vietnamese background found stigma as a common finding in reviewed studies (Liu, Hinton, Tran, Hinton, & Barker, 2008). Benedetti et al. (2013) showed that Italians who live in Australia were directed by values of familism in their community in terms of female family members being in charge of the care of the relative with dementia. African American family members showed lower burden and more rewards compare to their White American counterparts (Dilworth-Anderson et al., 2002). There are also studies on caregiving that address 'Asian' family caregivers' experiences but seemingly overlook significant heterogeneity and diversities among them. We should consider too, that 'Asian' has diverse meanings in different contexts. Furthermore, these studies mostly address east Asian countries (Park & Chesla, 2007) like China and Korea, and very few include any data from countries in the Middle East like Iran.

Lawrence, Samsi, Banerjee, Morgan, & Murray (2011) believed that many of the research on caregiving carried out during 1990s acknowledged ethnic and cultural variations in experience of care. Disparities in dementia care research and contribution of people from ethnic minority groups should be responded by extending dementia research to diverse populations (Nápoles-Springer et al., 2000; Zambrana & Carter-Pokras, 2001).

2.6 IMMIGRATION

There is no universally accepted definition for migrants. The United Nations defines a migrant as 'an individual who has resided in a foreign country for more than one year irrespective of the causes, voluntary or involuntary, and the means, regular or irregular, used to migrate' (Perruchoud and Redpath-Cross 2011). Immigrants could include people with residence permits, asylum seekers (with pending claims), refugees (accepted claims), refused asylum seekers, and undocumented migrants.

The number of people are living out of the country in which they were born has increased to 214 million in 2011 (IOM 2011), which is equal with 3.1% of the world's population. In Europe, 64.1 million people, (9% of the population) are immigrants and ethnic minorities (Wright & Henry, 2012).

Differences have been found among immigrants and the non-immigrants societies in terms of life patterns and practices which might be due to cultural differences or practical issues or else. In Canada, immigrants were found to live in multigenerational

families much more than Canadian born people (Milan & Hamm, 2003; Tsenkova, Lam, & Este, 2007). Immigrant seniors in Canada compare to Canadian born seniors had much lower income (Palameta, 2004). Compare to white American women, Mexican and black American women were reported to have higher prevalence of type II diabetes (Sundquist, Winkleby, & Pudarcic, 2001). Reviewing literature in Swedish context shows immigrants found to report poorer general health compare to the Swedes (Blomstedt, 2007), no difference between immigrants and Swedish people with heart failure in terms of symptoms, seeking healthcare, received medical care and health outcomes (Hedemalm, 2007), and higher prevalence of obesity and overweight among women born outside Sweden to women born in Sweden (Lindström & Sundquist, 2005).

Dementia care is the most frequently studied type of care presented in the literature, but few studies have focused on immigrant populations and exploring their experiences of living and taking care of people with dementia. It's even worse in field of research of people with dementia from immigrant groups specially immigrants from Middle Eastern countries.

2.7 STUDY CONTEXT

2.7.1 Sweden

Studies I and III were conducted in the three large cities in Sweden: Stockholm, Uppsala, and Lund. Sweden has become a multicultural country because of immigration (Björk Brämberg, 2010), and almost 13% of the population aged more than 65 years is of foreign origin (StatisticsSweden, 2005). Sweden is a high income country with a population of more than 9.5 million, located in northern Europe. More than 19% of Swedes are age 65 years or older (StatisticsSweden, 2013).



Figure 1: Study area

2.7.2 Iran (Persia)

Studies II and IV were conducted in Tehran, the capital of Iran. Iran is classified as an upper-middle-income country (The World bank, 2013) located in the Middle East. With a population of more than 76 million in 2012, Eight per cent of population ages 65 and above in 2012 (The World bank, 2013). Iran is the 18th largest country in the world. Iran is a diverse country, comprising people of many religious and ethnic backgrounds, who are cemented by the Persian language and culture. Iran also hosts one of the largest refugee populations in the world, with more than one million refugees.

The official state religion is Islam (Shia). Education at all levels is free of charge, as mandated by the constitution. The Iranian society in general and Tehran city in particular are transforming to modern mega-cities character. Similarly, as the families are transforming from traditional to modern, living spaces are becoming smaller and tight (Sheykhi, 2010), which makes it hard to continue taking care of parents and relatives according to the traditional family roles.

2.7.3 People with Iranian background in Sweden

Iranians make up one of the largest groups of immigrants in Sweden. There are more than 80,000 Iranian people in Sweden's population (StatisticsSweden, 2010). The great majority of Iranian immigrants moved to Sweden during the years after the Islamic revolution in Iran in 1978. This trend was reinforced during the long Iraq-Iran war. In 1975, there were 998 persons with Iran as their birthplace living in Sweden; by 1980 the number had increased to 3,348. At the end of 2000, the number was 52,038, and in 2007, Iranian immigrants accounted for 0.62% of Sweden's population (Statistics Sweden, 2007). In 2010, there were 81,190 Iranians and their descendants, and they made up the second largest non-European community in Sweden (Statistics Sweden, 2010). Many are now a part of the ageing population.

The majority of Iranian immigrants in Sweden were from the middle and upper classes in their home country (Darvishpour, 1999), and many had attained a high level of education. Second-generation Iranians in tertiary education are one of the biggest groups of immigrants in Sweden (Hosseini-Khaladjahi, 2012). Iranian immigrants in Sweden have a secular life (Ahmadi, 2003). The statistics of the Swedish National board (2006) show Iranian immigrants in Sweden are well represented in higher education in Sweden. Ethnicity has been described as an asset among Iranians in Sweden, considering their beliefs in the importance of education (Ahmadi & Ahmadi, n.d.). However, many researchers (Ahmadi, 1997; Bäckman, 1989; Darvishpour, 1999) have identified loss of a sense of inner integrity as a common issue among Iranian immigrants in Sweden. There is a growing trend among Iranian immigrants in Sweden to move from Sweden to a third country or return to Iran (Kelly, 2012).

Older Iranian immigrants in Sweden were reported to have lower scores in health-related quality of life compared to Swedes, but the same as Iranians in Iran (Koochek, Montazeri, Johansson, & Sundquist, 2007). Female Iranian immigrants in Sweden were reported to have higher body mass index (BMI) than their counterparts Swedes (Koochek, Johansson, Kocturk, Sundquist, & Sundquist, 2008).

2.7.4 Healthcare system in Sweden and Iran

Sweden benefits from a tax-financed health system with the responsibility of municipalities to provide general access to health care to those who live in Sweden (Wright & Henry, 2012). According to the Iranian constitution, the government should provide every citizen of the country with access to social security that covers retirement, unemployment, old age, disability, accidents, calamities, health and medical treatment, and care services. Iranians benefit from four major health insurance organizations that cover 90% of the population. Most health-care expenses are still paid out of pocket, however; many services thus are not available for those with low resources (Mehrdad, 2009).

Iran and Sweden have two different care systems with regards to dementia. Iran, with its family-based care system, has a high prevalence of intergenerational care and relatively strong filial obligations for taking care of relatives with health problems, including dementia. In Sweden, on the other hand, state-funded care services are available all across the country and the health-care system is highly regarded (Haberker & Szydlak, 2010). Although there is no cultural obligation and demand on adult children or other relatives to support and take care of a next of kin with dementia, families in Sweden feel responsible for their sick relatives' well-being (Brandt, Haberker, & Szydlak, 2009). Brandt et al. (2009) thus called the Swedish system one of specialization, where there is a division of labour between family and state in service-based care regimes.

2.7.4.1 Dementia in Sweden

It is estimated that there 142,000 people living with dementia in Sweden (Lennartsson & Heimerson, 2012). Many of them are cared for at home for as long as possible. There is special housing for older people who need around-the-clock attention, available when they are no longer able to fend for themselves. The Swedish National Board of Health and Welfare has developed guidelines on the treatment of dementia based on the research findings and knowledge developments in the area.

A good deal of formerly publicly financed and remunerated care is now being provided by the family in the form of 'unpaid care' and through privately purchased services. This change reveals a clear gender and social class bias: poorly educated older people often have family members as caregivers, and daughters in working-class families have assumed increased responsibility for family members. Purchasing

private care services is more common among well-educated elderly people (Larsson & Szebehely, 2006).

2.7.4.2 Dementia in Iran

There are no current statistics available regarding the number of people living with dementia in Iran. Lack of public awareness of dementia as a pathological feature of ageing has resulted in a very late referral of affected people to medical and social support service centers in Iran. Because of a general underestimation of symptoms such as memory loss among the older Iranian adult population, few consultations with physicians take place. Dementia has been neglected for a long time in traditional societies such as Iran. The symptom and signs of this disease are usually attributed to the 'normal' ageing process (Ohadinia, Noroozian, Shahsavand, & Saghafi, 2004). Because of stronger family bonds and lack of appropriate social services in elder care centers, this issue has a higher impact in societies like Iran. Family and relatives are the main, and sometimes the only, caregivers for the people with dementia (Abdollahpour, Nedjat, Noroozian, Golestan, & Majdzadeh, 2010).

Families in Iran traditionally have had the primary responsibility for taking care of their sick elder relatives. However, many structural and functional societal changes have contributed to lowering families' tendencies to continue taking care of their next of kin with dementia. Such factors include growing numbers of women in paid work, fast urbanization, smaller housing, shrinking family size, and longer life expectancy. On the other hand, families feel stigmatized if they take their older relatives to nursing homes. Moreover, there are no special nursing homes available for elders with dementia. Those who want to keep their elders with dementia do not receive domiciliary care services. Because of long-standing beliefs that family members and relatives would like to take care of their next of kin with dementia, there have been few official responses, which is true as well in countries in east Asia (Ineichen, 1998).

The Iran Alzheimer's Association (IAA) is the only specialized centre for people with dementia. IAA is located in Tehran and is a non-governmental organization that aims to support people with dementia (not restricted to Alzheimer's disease) in Iran. However, there are memory clinics, situated in psychiatric hospitals, at which people with dementia can get specialist visits. There are no national guidelines available regarding how to meet the health-care needs of people with dementia.

3 RATIONALE

Most people with dementia live in low or middle income countries and their numbers continue to grow much faster than the rest of the world. However, the current literature on subjective experiences of dementia and living together with a person with dementia mainly belongs to mainstream population of western societies and does not provide a high grade of diversity of the participants. This is especially apparent within Middle East contexts which we do not know much about how people with dementia live and experience their lives with dementia.

There is a gap of qualitatively explored knowledge regarding experiences of dementia and living with a family member with dementia in contexts where hardly any formal dementia care is available. Moreover, quantitative and qualitative enquiries on different aspects of experiences have been largely focused on family members than the person with dementia.

Iran is a middle income country in Middle East with a low fertility rate (1.6) in spite of its young population (The World Bank, 2011). Therefore, it is expected that Iran face a sudden increase of older people considering the baby bomb in early 1980s, current decreasing death rate, increasing life expectancy together with slow population growth. However, Iran is not prepared to meet the demands of an aging population. There is no statistics on people with dementia in Iran. In fact, dementia research is relatively novel in Iran (Fallahi, Mazaheri, & Nazari, 2010). Exploring perspectives of people with dementia is considered central to developing proactive and effective dementia care (Steeiman, De Casterlé, Godderis, & Grypdonck, 2006). Therefore, to be able to meet needs of growing number of people with dementia and their families in Iran and developing appropriate services which be responsive to their contextual situations, this thesis can serve as a ground for further investigation or care planning.

This thesis also explores experiences of Iranian immigrants with dementia or those how have a family member with dementia. The necessity of including immigrant population to this qualitative research, was the gap of voices of non-mainstream populations including immigrants in dementia literature in terms of subjective experiences. Because non-EU immigrant are a considerable group in Europe including Sweden and considering constant growing numbers of dementia cases, we need to investigate experiences of immigrants with dementia or with a relative with dementia. In order to theorize dementia widely and more accurately, there is a need to investigate diverse contexts and people with varied life histories. Immigrants might conceptualize their experiences of living with dementia or with a family member with dementia different than the native population due to many reasons. People who do not talk the official language of the countries they live in, are often neglected in

research especially in interview studies. Iranian immigrants in Sweden are a large group and counted as the second largest non-European community. Though, voice of Iranian immigrants with dementia is absent in well-established dementia research in Sweden. Azita Emami and Mazaheri (2007) found it difficult to recruit immigrants in Sweden including Iranians to a quantitative study on family members with dementia.

Studying Iranians with dementia or a family member with dementia in Iran and Sweden together, can further our understanding of living with dementia and the variations or similarities of experiences in these two different contexts. Both populations have not been included in research while outcomes can provide valuable insights for conceptualizing diversity or universality of living with dementia and its qualities. The finding can help to outline effective and situation-based responses to needs of people with dementia and their families within the societies.

The way people understand dementia has shaped throughout history (Ballenger, 2008) and helps people to transform the reality to something that they could recognize. That influence the way they approach dementia, seek helps and handle implications of living with dementia or with a family member with dementia. That is why O'Connor et al. (2007) suggest that we need to comprehend the subjective experiences of people with dementia as cornerstone for dementia research framework.

4 AIM

The overall aim of this thesis is to explore experiences of dementia from the perspective of Iranian people with dementia and their family members in Iran and Sweden.

Paper I

To explore Iranian immigrant experiences of living and taking care of a family member with dementia

Paper II

To explore family members' experiences of living with a next of kin with dementia in Iran

Paper III

To explore the subjective experiences of living with dementia among Iranian immigrants in Sweden

Paper IV

To describe people's experiences of living with dementia in Iran

5 METHODS

Two qualitative approaches, including interpretive phenomenology and qualitative content analysis, were used to conduct the studies in this thesis.

Studies I and II were designed and carried out following an interpretive phenomenological approach (Benner, 1994; Chan, Brykczynski, Malone, & Benner, 2010; Benner & Wrubel, 1989; Heidegger, 1962; Merleau-Ponty, 1962). The phenomenological approach attempts to describe human experiences within the complexity of their contexts (Morse, 1994). According to Valle and King (1978), phenomenologically oriented research answers questions like, what is the phenomenon that is experienced and lived? What is its structure? Which commonalities exist among the many diverse appearances of the phenomenon? According to Benner's (1994) interpretive phenomenological perspective, people experience their world through their embodied intelligence, their skillful habitual bodies, background meanings, and concerns and understandings of the situation. From this viewpoint, the investigators wanted to gain a deeper understanding of the participants' experiences through their descriptions and reflections on having a relative with dementia, which offered a window into their life worlds.

Studies III and IV benefitted from qualitative content analysis (Graneheim & Lundman, 2004) as the methodological approach. Qualitative content analysis is a widely used qualitative research technique (Hsieh & Shannon, 2005) that has been applied to a variety of data and to different depths of interpretation in research and education (Graneheim & Lundman, 2004). Qualitative content analysis is defined as a research method for the subjective interpretation of the content of text data through the systematic classification process of coding and identifying themes or patterns (Hsieh & Shannon, 2005). Content analysis offers researchers a flexible, pragmatic method for developing and extending knowledge of the human experience of health and illness. Therefore, we found it suitable for analysis of interviews with people with dementia.

5.1 PARTICIPANTS AND RECRUITMENT PROCEDURE

The data collection was conducted in urban areas in the countries of Iran and Sweden (Fig 1). In Iran, data were collected at the Iranian Alzheimer Association in Tehran or in participants' homes, according to their wishes. In Sweden, participants were interviewed in their homes or daycare centers based on their own decisions.

A total of 50 persons participated in the studies. Participants were people with dementia (Studies III-IV) and family members of people with dementia (I-II) in Iran (II &

IV) and Sweden (I & III). Tables 1 and 2 provide information about participants' characteristics, study areas, and research methods.

Table 1- Participants' characteristics

Participants		Family members of people with dementia	People with dementia	Total	
Age (range)		26-72	60-88	26-88	
Gender	Male	6	16	22	50
	Female	14	14	28	
Relationship to whom they were living with	Children	15	7	22	50
	Spouses	5	12	17	
	Others*	0	11	11	

* Living alone or in dementia group dwelling houses

5.1.1 Study I

Ten participants were recruited to the study through a purposeful sampling (Morse, 1994). I contacted specialized care centres for people with dementia in different cities in Sweden. The main inclusion criteria were that candidates should be Iranian immigrants in Sweden, primary caregivers for relatives with dementia, and be able and willing to talk about their experiences. Furthermore, the relatives with dementia should have been diagnosed at least one year prior to the interview session. Those who fulfilled the inclusion criteria were contacted by the staff at these centres and were asked whether they would like to participate in the study. All who were contacted agreed to participate. The author then contacted each participant herself to give her/him more information about the study and to schedule an appointment for the interview.

The participants included seven women and three men, ranging in age from 40 to 65, from Stockholm, Lund, and Uppsala. All of them had been living in Sweden for at least 20 years. Their family member with dementia had been diagnosed two to eight years prior to the interview. The participants included two spouses and eight children of people with dementia.

5.1.2 Study II

Family members of people with dementia in Iran were recruited purposefully for this study. I contacted the IAA to recruit the participants, who either had been visited by their specialist physician in their main centre in Tehran or who attended the dementia daycare center. The potential participants were informed first by IAA staff, who asked them if they would like to participate in the study. Upon accepting the invitation, the author met these individuals to give them more information about the study and to

schedule an appointment for conducting interviews. All those contacted agreed to participate in the study. The main inclusion criteria were that candidates with an Iranian background should be primary caregivers for a next of kin with dementia and can talk about their experiences. Their family member with dementia should have been diagnosed at least one year before the interview.

Ten Iranian family members participated in the study. The group included seven women and three men (aged 26 to 72 years) from Tehran province, the country's capital. The participants included three spouses of the people with dementia (two wives and one husband), and seven adult children (two sons and five daughters) of people with dementia. The Mini Mental Status Examination (MMSE) scores (Folstein, 1975) of their family members with dementia were found to vary; however, they all had moderate dementia, had been examined and assessed by physicians experienced in dementia, and had their diagnoses registered in their medical records. The participants' next of kin were diagnosed with dementia between one to seven years before the interview.

5.1.3 Study III

Fifteen Iranian immigrants with dementia were recruited to the study. I contacted specialized care centres for people with dementia to reach the potential participants. The main inclusion criteria were that candidates had been diagnosed as having a dementia with Alzheimer's disease or vascular dementia at least one year prior to the interview, had the ability to talk about their experiences, and were an Iranian immigrant to Sweden. Staff at these centres made the first contacts with potential participants and their families to ask if they would like to participate in the study. The author then contacted each participant directly by phone to give them more information about the study and to schedule an appointment for conducting the interview.

The participants included fifteen people with dementia including eight women and seven men, ranging in age from 68 to 88 years. They had immigrated to Sweden between 10 and 30 years before the interviews. Ten of them were living at their home either alone (6 persons) or with their family member (2 with their spouses and 2 with their daughters), and the rest were living in group-dwellings for people with dementia.

5.1.4 Study IV

Fifteen participants were recruited to this study. The main inclusion criteria were that candidates with an Iranian background had been diagnosed as having dementia (Alzheimer's disease or vascular dementia) at least one year before the interview and had the ability to communicate and talk about their experiences.

The participants were recruited by help of IAA in Tehran. The IAA staff asked the family members of people with dementia if they would let their next of kin to be

approached for interview. Upon accepting the invitation, the potential participants got oral and written information about the study, and if consent was obtained, an appointment was scheduled for the interview.

All 15 participants were from the urban population in Tehran including 6 women and 9 men, ranging in age from 60 to 87 years. One was illiterate, four had post-secondary education, and ten had 6-to-10 years of education. All were pensioners (ten had had paid jobs and five had been housewives). Three participants were living alone in separate flats close to their children; three were living with their spouses and children, two with their children and seven with their spouses only. Their MMSE scores varied between 12 and 17 points (they all had moderate dementia) according to their medical records. All participants had been diagnosed with dementia between one and six years before the interviews.

5.2 DATA COLLECTION

Semi-structured interviews were conducted to investigate the participants' experiences. The interviews were conducted in the Persian language, which was the mother tongue of all participants as well as that myself that conducted the interviews and some of the co-authors (ANNA, SSBM, AE) who reviewed and co-analyzed the data. The interviews took place either in the participants' homes or in care centres, depending on personal preferences. Every interview was audio-recorded.

The main questions for study I and II were, What comes to your mind when you think about dementia? What is it like to live with / take care of a next of kin with dementia? Describe some concrete situations in this regard. Additional questions of a probing nature were asked when appropriate.

The main question for study III and IV was an open question—Please tell me about your experience of dementia—that was expanded with more specific questions to get clarifications and more detailed or concrete examples of what they shared with the interviewer.

5.3 DATA ANALYSIS

5.3.1 Studies I and II

Analysis of Studies I and II was guided by Benner's interpretative phenomenology (1994). All the interviews were transcribed verbatim. Summaries were written for each interview in English, and two interviews for each study were translated in full so that they could be analyzed by the authors who did not speak Persian. All authors were fluent in English, enabling them to discuss their analyses with each other.

The transcriptions were compared with the recorded interviews for accuracy. All transcriptions were carefully read to gain an impression of each one and an overall understanding of the interview. The overall impressions of each caregiver's experiences were noted. Then the text of each interview was read, word for word, once more and interpretation of significant statements was formulated. Interpretation of the interviews moved back and forth between the whole and parts to allow understanding, comparison, and critical reflection on the text. Each participant's transcript was analyzed in order to identify themes. All analyses were compared and contrasted with the previous and following ones. Clusters of themes from the aggregated formulated interpretations were organized and referred back to each original description for validation. The results were integrated to yield an exhaustive description of the study phenomenon.

5.3.2 Studies III and IV

Analysis of the interviews was guided inductively by qualitative content analysis (Graneheim & Lundman, 2004). The transcribed interviews were first read through to acquire an overall understanding of the content related to the research aim. Then, the data were read word-for-word to derive meaning units. To achieve immersion and obtain a sense of the whole, all data were read repeatedly and discussed among the authors. The process continued to distill condensed meaning units and construct sub-themes and themes (Graneheim & Lundman, 2004).

Table 2 – A descriptions of four studies based on the participants, study area, and research methodology.

Studies	Participants	Residence	Numbers	Research approach
Paper I	Family members of people with dementia	Sweden (Provinces of Stockholm, Lund, and Uppsala)	10	Interpretive phenomenology
Paper III	People with dementia		15	Qualitative content analysis
Paper II	Family members of people with dementia	Iran (Province of Tehran)	10	Interpretive phenomenology
Paper IV	People with dementia		15	Qualitative content analysis

6 ETHICAL CONSIDERATIONS

The studies were granted ethical permissions both from National Ethical Committee in Iran (391/2005) and the Regional Ethical Review Board in Stockholm (111/05).

Considering the involvement of human beings in my research project, the codes of ethics by the World Medical Association Declaration of Helsinki (1964/2008) have been followed carefully.

The code of ethics from the Belmont Report as described by Polit and Beck (2014) includes the principle of beneficence (freedom from harm and exploitation, and benefits from research, including the principle of altruism), the principle of respect for human dignity (the right to self-determination, full disclosure and respect), and the principle of justice (right to fair treatment and privacy). These principles guided our ethical considerations.

Information about the study was provided orally and in writing, including the aim of the study, voluntary participation, and the opportunity to withdraw at any time. Informed consent was obtained from all participants. I tried to notice non-verbal signs indicating wishes to withdraw from the interviews during data collection. All participants were assured of confidentiality and the analysis was conducted with the intention of maintaining the integrity of all participants.

People with dementia have been considered a vulnerable population for research studies, although having dementia is not necessarily associated with incapacity in giving informed consent (The Alzheimer's Association, 2004). The Alzheimer's Association (2004) recommends including even people with dementia who cannot consent to their participation, by asking those who can authorize it legally for them. In my project, in addition to the person with dementia, at least one family member of the person with dementia who participated in the study was asked permission.

To address aspects of trustworthiness in qualitative research, concepts of credibility, dependability, and transferability were followed (Lincoln & Guba, 1985). Throughout the research process, the investigators strived to fulfill the ethical principles set forth in the Helsinki Declaration. I interviewed all the participants of four studies in Persian which they chose from three options of Swedish, Persian and English languages. However, Swedish and English information have been prepared to be used if necessary. The information consisted of the aim and the method of data collection; participants were also informed that participation was voluntary and that they could withdraw without an explanation.

7 FINDINGS

The findings of studies I-IV are presented separately here. Table 3 shows the themes and subthemes of all four studies based on country of residence and whether participants had dementia themselves or were family members.

Table 3 – Experiences of people with dementia and their family members according to themes and subthemes, studies I-IV

Participants Residence	People with dementia with Iranian background	Family members of people with dementia with Iranian background
Iran	Struggling with an altered life <ul style="list-style-type: none"> • In the eyes of others –an altered self • Forgetfulness as an irritating condition • Being a burden on others • Longing to be a valued person • Finding strategies to deal with the disease 	Being faced with different losses <ul style="list-style-type: none"> • Losing a sense of togetherness • Losing sense of the future • Losing social dignity Creating meaning in a changed life <ul style="list-style-type: none"> • Submission to one’s fate • Striving to look on the bright side
Sweden	Being a person with dementia means living with forgetfulness (personal sphere) <ul style="list-style-type: none"> • Understanding of the forgetfulness • Coping with the consequences of forgetfulness Living with forgetfulness in the private sphere means feeling incompetent but still loved <ul style="list-style-type: none"> • Feeling incompetent in family roles • Feeling loved and respected Living with forgetfulness in the public sphere means feeling confident and secure but also isolated <ul style="list-style-type: none"> • Feeling secure • Feeling confident in interacting with society • Feeling isolated 	Caring as an experience of fulfillment Admitting the diagnosis of dementia The shock of not being recognized by family members with dementia

7.1 FAMILY MEMBERS OF PEOPLE WITH DEMENTIA IN SWEDEN WITH IRANIAN BACKGROUND (STUDY I)

Interpretive phenomenological analysis of interviews with Iranian immigrants with dementia in Sweden revealed three themes including ‘caring as an experience of

fulfillment', 'admitting the diagnosis of dementia', and 'the shock of not being recognised by family members with dementia'.

Family members of people with dementia with an Iranian background in Sweden described their positive experience of being able to take care of their family members with dementia. They mostly had a fulfilling experience that made them highly satisfied. They perceived what they were doing for their family members with dementia as compensation for what they had done for them previously, such as during childhood or during particular hardships, like being forced to leave their homeland for a faraway country.

It was difficult for most of the participants to accept the diagnosis of dementia for their loved ones. They were skeptical of the diagnosis and of the healthcare system's provisions for older people. They wanted to give full support to their family members and show them their acts of love, togetherness, and care before they developed dementia and cannot acknowledge that.

It was their strong hope that their sincere and strenuous efforts would help to diminish the disease. Experiences of having and taking care of parents or spouses with dementia varied. Those with a father with dementia expressed their fear for their father's future as the disease progressed, while those with a mother with dementia talked mostly about their presence and how they could improve their mother's comfort and joy. Those with a spouse with dementia reported that they felt relatively restricted, with needs that went unmet while everyone was focused on the person with dementia. They felt themselves victimised by the situation.

Family members were shocked when the people with dementia were not able to recognise them. This was the ultimate reason for them to come to terms with dementia and finally accept that their efforts could not diminish or reduce the disease. They expressed how difficult it was to accept this, even compared to all the difficulties they had experienced while living with a person with dementia, including the cognitive and personality changes and inability to meet their basic needs.

7.2 FAMILY MEMBERS OF PEOPLE WITH DEMENTIA IN IRAN WITH IRANIAN BACKGROUND (STUDY II)

Living together with a family member with dementia for Iranians in Iran meant *being faced with different losses*, including *losing a sense of togetherness*, *losing a sense of the future*, and *losing social dignity*. They felt that they could not relate to their family members with dementia or enjoy their shared history as they had previously done. They experienced uncertainty regarding the future condition of their loved ones,

which had been changed by dementia. They were sorry not only for themselves for having to witness such a situation, but also for their family members with dementia who could no longer go on with their plans for the future. Since people with dementia were not able to meet social norms and expectations, the family members experienced the situation as a threat to the social dignity of the whole family.

The family members of people with dementia in Iran *created meanings* through *submission to one's fate* and *striving to look on the bright side*, in order to make sense of their changed lives. They accepted dementia and its consequences for their lives and that of their family members with dementia through talk about destiny and fate. At the same time, they tried to see the still intact functions and the current abilities of their family members with dementia and re-contextualise their condition.

7.3 PEOPLE WITH DEMENTIA IN SWEDEN, WITH IRANIAN BACKGROUND (STUDY III)

A content analysis of interviews with people with dementia with an Iranian background in Sweden revealed three themes and seven associated sub-themes that reflected participants' experiences of living with dementia in three areas: the personal sphere (*being a person with dementia means living with forgetfulness*), the private sphere (*living with forgetfulness means feeling incompetent but still loved*), and the public sphere (*living with forgetfulness means feeling confident and secure but also isolated*).

People with dementia in study III understood living with dementia as living with forgetfulness and strove to understand the forgetfulness. They reported a variety of circumstances that supposedly contributed to their forgetfulness including a hard life, a history of traumatic events, and age related issues. They developed a range of strategies to cope with the consequences of forgetfulness like normalising, rationalising, and downplaying the severity of their condition. They even tried to stop the development of their forgetfulness by, for instance, performing memory exercises.

People with dementia in study III felt *incompetent* to fulfil the expectations of their family roles in the private sphere where their family members knew their previous functional abilities and people with dementia had close and frequent interactions with them. They experienced conflicts with their family members due to the consequences of forgetfulness, such as misplacing other people's belongings. They experienced difficulties in performing some tasks, holding proper conversations, performing activities independently, and taking responsibility. However, they still felt *loved and respected*.

Participants in study III felt *secure* in moving around outside of their homes and felt *confident in interacting with society*. They mostly were not afraid to leave home and go out for recreational activities, using public buses, trains, and other kinds of transport.

However, some complained that they had difficulties in communicating with others in society because of language barriers and therefore felt isolated.

7.4 PEOPLE WITH DEMENTIA IN IRAN, WITH IRANIAN BACKGROUND (STUDY IV)

A content analysis of interviews with people with dementia in Iran revealed one theme as *struggling with an altered life* and five subthemes including: *in the eyes of others—an altered self*, *forgetfulness as an irritating condition*, *being a burden on others*, *longing to be a valued person*, and *finding strategies to deal with the disease*.

Most of the participants understood dementia as a medical disease. However, some attributed it to age related changes or a result of having had a hard life.

The people with dementia in Iran were faced with their memory and cognitive deficiencies mainly through the comments and reflections of their families, relatives, and friends in addition to their own gradual insights to the changes. It was hard for them to cope with the reactions of their families and friends to their changes and shortcomings. They had always been the same person, while *in the eyes of others*, they were *an altered self*.

They found *forgetfulness as an irritating condition* that was the source of all their problems. They found themselves futile and *a burden on others* thanks to the many criticisms they received when they were not able to perform an activity correctly or forgot events, people, or stories. They experienced dependence on others in daily life activities and financially. The financial dependence was perceived to be very difficult to deal with and was a source of feeling futile and desperate. They were *longing to be a valued person* and regain their respect through being involved in making decisions, in being asked for help and advice as before, and in various family activities. They needed to be appreciated for their contributions and for the person they were. They endeavoured to *find strategies to deal with the disease* and its consequences for their lives. Some of the strategies included using humour to cover their shortcomings and the things they forgot, ignoring or normalising the changes, highlighting their previous life accomplishments, and working on their memories by reading or memorising poems.

8 DISCUSSION

The aim of this thesis was to explore the experience of dementia from the perspective of Iranian people with dementia and their family members in Iran and Sweden. In this section, I discuss findings in relation to other studies in an integrated way and then discuss methodological considerations. Finally, conclusions and implications for practice as well as directions for future research will be outlined.

8.1 DISCUSSION OF FINDINGS

The findings of these four studies show variations in the experiences of living with dementia or with a family member with dementia in the context of Iran and Sweden. Some experiences were shared between those living with dementia in Sweden and Iran, while some expressions and concerns were specific only to one of the studies. The similarities and variations of the participants' experiences are discussed below.

8.1.1 Experiences of living with a family member with dementia

The findings of study I and II provide salient insights concerning how family members deal with living with people with dementia in two contexts: Sweden and Iran. The participants shared their stories of living their lives as family members of a person with dementia and what it means to be shaped by their concerns. Experiences of living with a family member with dementia included experiences of caring, especially since, as Kottow (2001) mentions, care is a 'more fundamental form of human relatedness' (p. 60)—and of course family members care for their loved ones with dementia.

Family members of people with dementia in both a Swedish context (I) and an Iranian context (II) expressed their willingness to live and take care of their family members with dementia. However, those living in Sweden found it to be an experience of fulfillment and expressed strong motivations including as an act of reparation. This part of the results can be compared with a similar study of Swedish family members in rural and urban areas of Sweden (Ehrlich, 2005), which showed that the family members of people with dementia, especially marriage partners, would like to continue taking care of their loved ones with dementia. Some studies like Spitznagel, Tremont, Davis, and Foster (2006) reported that the children of people with dementia were reluctant to continue to be their caregivers when dementia progressed, and they preferred to institutionalise their parents. This was in strong contrast to our participants, who chose to provide care full-time for their parents even though qualified formal care was available for those living in Sweden. A study of healthy

elderly Iranian immigrants in Sweden (Azita Emami & Ekman, 1998) showed that they experienced disappointment in their children, who had adopted the individual-centred western morality of their new homeland. It may be that the participants in study I expressed satisfaction with caregiving because this allowed them to compensate for the suffering that their parents experienced because of them. If their parents suffered as a result of their children's special circumstances, being forced to emigrate and such, their parents' dementia offered them a last opportunity to satisfy them and fulfill the cultural responsibilities that their senior family members expected them to take on.

There was a considerable difference between participants in studies I and II in the ways they approached the fact that their loved ones had dementia. Those that were living in Sweden (I) struggled hard with admitting the diagnosis. In contrast, their counterparts in Iran accepted rather passively the diagnosis and their responsibility to take care of their family members with dementia. The differences in their response to the same phenomenon could be discussed in different ways. Family members of people with dementia in Iran (II) experienced major losses and were hurt by the things they were losing to dementia such as sense of togetherness, while their counterparts in Sweden (I) did not readily come to terms with dementia and hoped their sincere efforts in taking care of and supporting their loved ones with dementia could make a difference. The family members in Iran (II) tried to find meaning in the changes in their lives and the difficulties in order to accept their condition and face their considerable losses. They chose to be submissive to their fate, which was rooted in their religious beliefs. Meanwhile, most Iranian immigrants in Sweden reported not being religious and had a secular outlook on life before coming to Sweden (Ahmadi, 2003; Bäckman, 1989). When people have no control over a situation, capitulation to fate and destiny gives meaning to that hardship (Bhattacharji, 1982), which facilitates acceptance of the situation, all of which is a performance of an adaptive coping strategy. Transcending the problems in living with a family member with dementia through religious beliefs or spirituality has been found in other cultures as well. People from Vietnam who took care of people with dementia used spirituality and religion—sacrifice, compassion, karma, blessings, grace, and peace of mind—to come to terms with their own suffering and their motivations for providing care (Hinton, Tran, Tran, & Hinton, 2008). Family members of people with dementia from a Caucasian Judeo-Christian background used spirituality as a coping strategy that brought them comfort, peace, acceptance, and purpose in life (Acton & Miller, 2003). It needs to be noted that such submission might prevent people from looking for help and intervention (Benner, 2010). Benner believes 'even a positive acceptance of an illness may cause the person to adapt to a lower level of wellness than necessary' (1994, p. 248). Nurses should be alert that, even if family members of people with dementia don't actively look for help, that is not equivalent to not needing help.

Family members of people with dementia in Iran mourned for the loss of the way they had shared their life histories with their loved ones in terms of affection and connection (I). This is in line with the study by Gillies and Johnston (2004) of family members of people with dementia and cancer, which found that they lost a connection to the ill family member that had been previously maintained through sharing life histories and memories. In their perception, the people with dementia were no longer the same as they once were and some were beyond recognition. Family members of people with dementia, therefore, might need help mending such broken life stories in order to reconnect to their ill relatives (Örülöv, 2010). Iranian family members in Iran were afraid of losing social dignity, which impacted daily living and their contextualised interactions with others (II). Loss of social dignity in living with a relative with dementia has not been addressed often in the literature and thus needs to be studied in the future in order to understand contributing factors, ways to reduce it, and its diverse effects on family members and, consequently, on people with dementia. If families fear negative public reactions and perceptions toward their relatives with dementia, they might isolate the individual with dementia as an intervention to reduce harm, which may in turn unintentionally worsen the person's situation. By restricting people with dementia and lowering their level of autonomy, their self-respect and dignity could be compromised. Whereas some studies like Loos and Bowd (1997) have shown how family members of people with dementia regret their withdrawal from social and recreational activities with their friends and relatives because of the demanding tasks, family members who were living in Iran expressed their worries about communicating with their social networks. Primarily, they were concerned about the threat of losing face and disturbing the social dignity of their relatives with dementia as well as their own. They even preferred to restrict their contact with other relatives because of their fear of losing their dignity and the dignity of their relatives with dementia as a consequence of the latter's behaviour.

Both studies I and II showed that Iranian social values appear to guide the care activities of their family members with dementia even for those who immigrated to Sweden (I); this is similar to the way in which values of filial piety have been shown to play a role in East Asian countries (Park & Chesla, 2007; Sung, 1998). The core concept of filial piety as a social norm is to fulfill one's obligations to one's parents (Levande, Herrick, & Sung, 2000), which is understood as natural to human nature in these contexts (Sung, 1998).

Svanström and Dahlberg (2004) found that the relatives of people with dementia experienced a new life, but one with unknown meaning, which contributed to a feeling of uncertainty that left them in a quandary. That study showed how meaningful the new life could be for some family members. Being responsible demands hard work but gives our lives a hitherto unknown content and meaning (Lögstrup, 1992). As dementia progressed and the participants became more involved

in caring for their family members with dementia, they in turn developed new and different views on life. The satisfactory experience of caring seems to be conditioned by cultural living and beliefs. Being the primary caregiver for their close relatives had brought these family members a sense of satisfaction and importance.

8.1.2 Experiences of living with dementia

People with dementia in Sweden (III) and Iran (IV) were able to understand and capable of responding to study questions. They provided examples of their lives with dementia and recalled their interactions with family members and friends in relation to one study. Therefore, studies III and IV showed that people with dementia are able to participate in interview studies and provide information about their experiences with the disease. This finding is in the same vein as studies by Westius et al. (2009) and (Fazio & Mitchell, 2009). Our studies add to the literature by shedding light on the experience of people with moderate dementia, noting that Clare et al. (2008) reported that studies using direct accounts and interviews as a means of understanding the subjective experience of living with moderate-to-severe dementia were still rare.

Both Iranians with dementia in Iran (IV) and Sweden (III) attributed dementia to forgetfulness. However, most Iranians with dementia in Sweden recognised dementia as a medical disease, though some still perceived it in the same way as their counterparts in Iran—i.e., as a result of having a hard life or being age-related. Sayegh and Knight (2013) believed that cultural understanding impacts the way we understand dementia and allocate meaning to it and the causes of dementia. A review of the literature shows a variation in understanding dementia in different contexts. Each variation of understanding dementia has its implication for the way people seek healthcare service for diagnosis, treatment, and care; therefore, it is important for us to recognise people with dementia and their families' understanding of dementia. Hispanic and Chinese people in United States perceived dementia as a part of normal ageing (Gray, Jimenez, Cucciare, Tong, & Gallagher-Thompson, 2009). Believing that dementia is part of normal ageing or any distorted understandings may delay diagnosing and treating dementia, as well as contacting healthcare systems for help (Mukadama, Cooper, Basita, & Livingston, 2011). Dementia was perceived as a form of insanity by Korean Americans (Lee, Lee, & Diwan, 2010) and Chinese Americans (Zhan, 2004). Anglo Americans were reported to have more accurate knowledge of Alzheimer's disease than older Latino, Asian, and African American adults (Ayalon & Areán, 2004). A clear explanation of the course of dementia, its nature, progression, and how it develops is needed to be able to accept the diagnosis and learn how to deal with the range of complications surrounding dementia. Educating people with dementia as well as their families could help them acquire a better understanding of it. Public education is also necessary to make people more aware of dementia, as well as difficulties and consequences for the people with dementia and their families. Such awareness can increase understanding and respect for people with dementia since

many behavioural and communication problems can be attributed to dementia and not to individual personalities. Therefore, it might prevent families from restricting the interactions of their relatives with dementia with society.

Although the participants had to face many problems because of their illness, their primary concern was to be viewed as a valued person who should be respected and understood. This finding is consistent with Steeman et al. (2007), who found that individuals with dementia are less concerned with cognitive decline than with remaining someone of value.

Some strategies that the people with dementia in Sweden and Iran used in dealing with their condition have also been found in other studies in diverse contexts: choosing a fatalistic attitude of 'what comes, comes' (Clare, 2003), normalising their forgetfulness and associated problems in various ways (Clare, 2002; Clare & Shakespeare, 2004; B. A. Gillies, 2000; MacQuarrie, 2005; Pearce, Clare, & Pistrang, 2002), working harder to perform at previous levels, trying to overcome task difficulties by using cognitive or practical strategies, repetitive reading to improve retention, relying on others for practical help (Beard, 2009; Clare, 2002; Pearce et al., 2002), using humour (Werezak & Stewart, 2009), concealing inability to remember or respond satisfactorily (Burgener, 1999), and using medication (Clare, 2002; Pearce et al., 2002; Young, 2002). These are mainly self-protective strategies rather than integrative strategies (Steeman et al., 2007) According to Harris and Sterin (1999), reaction patterns of people who struggle with dementia vary from a strong and positive fighting spirit to denial and giving up the fight and thus losing a sense of continuity. Our participants' expressions showed that they had not given up and longed to provide meaningful contributions to their own and to others' lives. This calls for further considerations in supporting people living with dementia in their struggles with their altered lives and to remain connected to everyday life.

Another difference between the people with dementia in Sweden and Iran in this research was that Iranians with dementia in Iran (IV) experienced being burdensome to their families, which was not raised in interviews with people with dementia in Sweden (III). People with dementia in Iran were unhappy about their financial dependence (IV), contrary to their counterparts in Sweden, some of whom even mentioned providing financial aid to their families in Iran (III). People with dementia in Iran were shown to be aware of the burden they placed on their family members. Similarly, Gillies (2000) and Robinson (2000) found that people with dementia feared becoming a burden on their family, which in turn created feelings of guilt and shame. Ward-Griffin (2007) reported that especially their female participants with mild to moderate dementia felt guilty about being a burden on their daughters who also were their caregivers (Cahill, Lewis, Barg, & Bogner, 2009). Wolverson (2010) also showed that people with dementia could recognise their caregivers' level of anxiety and

psychological health. They claimed that people with dementia had enhanced memories of emotionally related issues/events, which enabled them to remain aware of their caregivers' level of psychological health, irrespective of their general memory difficulties.

All people with dementia who participated in this research project regardless of their context and where they were living had conflict with their family members at home due to issues connected to their forgetfulness. However, Iranians in Iran (IV) expressed their severe inconvenience because of the extent of criticisms and corrections by their families and friends. Svanström and Dahlberg (2004) found feelings of futility among Swedish couples where one partner had dementia. They also reported that feelings of loneliness intensified and amplified a couple's sense of futility. This finding is aligned with the Iranian people with dementia who also expressed feelings of futility. However, for Iranian people living with dementia, financial problems and being financially dependent on others were expressed as the main reasons for feelings of futility vulnerability, and, for some, hopelessness. Prince (2004) reported many more financial difficulties for people with dementia in developing countries compare to the developed world.

Some aspects of the experience of living with dementia in Iran (IV) seem to be similar to those of participants living with dementia in other contexts. Steeman et al. (2006) showed that losses are present in the post-diagnostic phase of dementia, a finding confirmed in our study as well. Kitwood (1997) argued that certain aspects of the self (e.g., feelings, emotions, and reactions) could be sustained in relationships with others because they were not bound to the preservation of memory. Therefore, family members and health care workers need to consider the preferences, interests, values, and needs of their care recipients with dementia (Woods, 2001). Knowing the life story of people with dementia is important for providing person-centred care, that is, care that places the person with dementia at the centre and considers the needs of their family members too (Sunvisson, Habermann, Weiss, & Benner, 2009).

People with dementia in Sweden with an Iranian background reported themselves secure in moving around and confident in interacting with the society (III), results that were not found in the study on those with dementia in Iran (IV). This could be understood in light of their previously mentioned dependence on their family members in doing activities and in financial matters. It was also found that family members in Iran restrict the social activities of their relatives with dementia in fear of losing social dignity (II), which may be a contributing factor.

People with dementia in Sweden with an Iranian background (III) felt comfortable in public spheres, whereas they had problems interacting with their family members in the private sphere. One explanation could be that their families reacted to their

changes and behaviours as if they were not able to recognise the person they knew well. The families also expected them to behave according to cultural norms and routines while they were strangers to the people in the streets and outside their private sphere with less expectation. Most of the participants in study III did not know the Swedish language well and because of cultural differences, they might not be able to read the cultural codes; that is, others' possible dissatisfaction, surprise, and other such reactions weren't recognisable to people with dementia with an Iranian background in Sweden. The participants (III) used their understanding of their own cultures as a frame of reference to interpret the events and their interaction with Swedish society. Part of that could be related to the characteristics of their dementia, as well as to the lower degree of communication with society compared to that with their own family members. However, their understanding of the situation and their subjective experiences are assumed to be the reality (Brooker, 2004) and should be the point of departure for explaining their behaviour and planning care and support services. Learning to be sensitive to and aware of differences involving people's experiences can prevent stereotyping in the design of planning and intervention care services.

8.2 PERSON CENTRED CARE

Nowadays, it is widely accepted that a one-size-fits-all care approach could not meet the personal differences that each new person brings to the table since people's experiences vary based on many variables including life course events and history, cultural background and extent of contextual factors. As presented in this thesis, Iranian family members in Iran approached the dementia diagnosis for their loved one, much different than their counterparts in Sweden (Studies I and II). Furthermore, experiences of interaction with society were different between Iranians living dementia in Iran and Sweden (Studies III and IV). So, it's not only ethnicity that mainly defines responses to dementia, therefore the focus of care programming should be the person rather than pre-defined characteristics such as ethnicity. In fact, treating people as individuals is the first main principle of person-centered care (McCormack, & McCance, 2010) that is considered as 'the best quality care' for people with dementia (Edvardsson, Fetherstonhaugh, & Nay, 2010; Slater, 2006). One part of centralizing the persons is to take their life stories into account as this thesis contribute in presenting experiences of the people with dementia in Iran and Sweden.

The second principle of person-centered care is to respect rights of people with dementia as a person (McCormack & McCance, 2010). This thesis illustrated how family members of people with dementia in Iran (Study II) restricted the social interactions and space of their loved one with dementia because they were afraid of losing social dignity. While, people with dementia should be allowed to get involved in social communications which is not only their rights as person but also can be stimulating and important in their health and wellbeing.

The third and fourth principles of person-centered care (McCormack & McCance, 2010) include building mutual trust and understanding and developing therapeutic relationships which could not be met without awareness to each person with dementia's needs, understanding of their situation, wishes and preferences. In fact, one of the very promising trends in dementia research in the last decade has been a core of consensus that person-centered care involves valuing and using people's subjective experience of illness regardless of cognitive ability, and acknowledging that the person should be the focus of care delivery and not the disease or illness (Brooker, 2004; Edvardsson, Winblad, & Sandman, 2008; McCormack, 2004; Penrod et al., 2007).

8.3 METHODOLOGICAL CONSIDERATIONS

A limitation of the studies included in this thesis is the small sample sizes and a one-time interview with each participant. Due to nature of qualitative studies, we do not intend to generalise the results; nonetheless, the results can be transferred to similar contexts and to people with shared history and characteristics. The intention was to explore and describe the experiences of the people with dementia and family members of people with dementia within studies population; therefore, we didn't need to have representative samples. Our studies could provide the basis for further quantitative studies. Multiple interviews might have been helpful in collecting more information over the course of living with dementia. However, that could decrease the spontaneity of the answers that may reflect the direct responses to questions of experiencing something.

As with any interview study, there is a likelihood of producing different results with different investigators, for example, by having a non-Iranian interviewer or researcher. However, having an interviewer that knows the culture and was able to communicate in the mother tongue of the interviewees (Persian language) could have helped them to open up and facilitate sharing their experiences. Including other sources of data collection like observation could also have enriched the results.

Another methodological point was that although family members were asked to narrate their lives with relatives with dementia, they didn't talk about the daily activities and difficulties in meeting their relatives' needs, for example, basic needs such as moving, spending time with them, etc., which was in contrast to other studies (Perry, 2004; Teel & Carson, 2003; Wermuth, 2011). In fact, what mattered to them the most at the point of the interviews were the things they were losing (viz. Benner (1994) who posits that people's concerns show what matters to them).

Trustworthiness was assured through different actions. Participants in all four studies had variations in regard to their gender, age, and education. By asking about the same issues with all interviewees and having an open dialogue within the research team, we

addressed part of the dependability of the studies. All the interviews were recorded and transcribed verbatim and the process of developing themes in analysis was noted for the sake of credibility.

A group of five to six authors involved in the analysis and discussion of the results to minimise missing any valuable data and points. We had prolonged engagement with the data with the intention of better understanding of the meanings. We discussed all steps of analysis back and forth with all the authors who were experienced in field of dementia and qualitative research. We also tried to be responsive by working inductively, using only data and not any other previously held assumptions, focusing on our data and listening to them, peer debriefing, and abstracting, synthesising, or moving beyond the technicalities of data coding. The co-authors tried to reach an agreement when they had different understandings of data. During analysis, the concern was to choose the most suitable meaning units, and to find the best way to illustrate them, the subthemes, and themes. Representative quotations were presented to show the similarities and differences between sub-themes. The results of the studies were presented in the research seminars in order to get feedback from other researchers and to discover potential blind spots and less obvious points.

To address transferability of the study, some suggestions were provided on how our findings could be transferred to other contexts. Also, contexts of studies, process of the research in each context were presented.

The researchers did not regard having signed consent forms as vital in studying Iranian immigrants in Sweden, since Iranian immigrants in Sweden have been reported to be possibly suspicious of any contact with authorities (Emami, 2000). However, verbal consent was obtained and recorded as the interviews.

During the interviews, family members of people with dementia in Sweden (I) particularly shared very detailed stories about their lives. They show an eagerness to express what they were doing for their family members with dementia in detail. A way to understand this could be that, as Hannah Arendt (1993) mentions, '[i]t exists to the extent that it is spoken out, even if it occurs in the domain of privacy' (p. 238). Arendt claims that memory is conjured principally in order to address another, to impress upon a listener, or to appeal to a community. Hence, testifying was not only as narrating a story, but also to commit the narrative to others—that is, to take responsibility (Felman, 1992). All of the participants' efforts and their sacrifices could turn out to be meaningful and worthy if someone else could have confirmed and recognised it. Besides the need to have witness for their acts, an alternative explanation for these participants' detailed descriptions, is linked to methodological aspects. Perhaps, the reason beyond being keen to narrate their lives was that I had the same cultural background, and they wanted to be witnessed through me that they

have fulfilled their family-role related tasks and reciprocating as they felt was expected according to Persian cultural values. However, according to Ahmadi (2003), personal desires are of central importance for Iranian immigrants in Sweden which might accompany with less connected to their cultural values and norms of their country of origin.

9 CONCLUSIONS AND IMPLICATIONS FOR PRACTICE

The findings of this thesis add to the current literature and contribute to knowledge and insight to the experiences of living with dementia and living with someone with dementia. Many aspects of the experience of living with dementia and living together with a relative with dementia seem to be universal. Seeing these results in relation to other studies, we can acknowledge the complexity and range of experiences people with dementia undergo as well as the uniqueness of each life story.

Difficulties in accepting the medical diagnosis of dementia was not solely related to the culture or lack of information about the disease. Iranian immigrants in Sweden struggled with labeling their loved ones as having dementia since they had to accept that their relatives with dementia could not acknowledge whether they had adequately 'reciprocated', as required by Iranian cultural norms. We did not find the same pattern among Iranians in Iran. Therefore, every person regardless of their ethnicity should be approached in such a way as to understand their personal reasons and motivations in resisting diagnoses or medical care. Life course events like migration could play a strong role in determining our response to events like the onset of dementia or having a relative diagnosed with dementia.

The results can inform healthcare workers and researchers of the main concerns of people with dementia and their families and their experiences. In order to establish effective communication with people with dementia and their families, nurses as well as other involved healthcare professionals need to be sensitive and receptive to the variations in understanding dementia and in the experience of living with dementia. This sensitivity and openness lets them get to know people's histories, health beliefs, and practices, which are crucial in designing interventions that are appropriate for their clients' needs and concerns.

Family members need to be helped in accepting the diagnosis of dementia for their loved ones. They also need help in dealing with the consequences of that at both the personal level (e.g., that they cannot decrease the symptoms and signs or stop the disease but they can comfort their loved ones to some extent) and in relation to society (how to inform others and how to handle people's curiosity and different approaches to the behaviours of their loved ones with dementia). Family members also need to be educated in how to communicate with people with dementia with respect and dignity, to adjust their expectations and accept the limitations, reorder their lives according to the changes occurring due to having a family member with dementia, and how to support themselves in keeping up with those changes. Activities

that promote self-dignity, social interaction, and feeling valued and needed as well as being loved and supported could improve their well-being and satisfaction with life. Nurses can help reconstruct families' broken life stories and recommence an effective connection between people with dementia and their families.

By gaining insight to the concerns and experiences of people with dementia and their families, nurses can meet them where they are in their unique contextual situation. Therefore, nurses can help people with dementia obtain a meaningful life with dementia.

People with dementia need to be helped to feel useful, and to make valued contributions to their own and others' activities. Families also need to be more aware of the world of people with dementia and their feelings and thoughts regarding the ways families deal with them. Families need to be helped to provide a supportive environment for their loved ones with dementia and ways to decrease conflicts, solve practical problems, and improve communication. Since looking at the world from the perspective of the people with dementia is a key element in providing appropriate services for them, this thesis study can provide a basis for healthcare workers to understand the experiences of living with dementia from this specific perspective.

Feelings of being a financial burden and the experience of being criticised for their shortfalls by family members represent a specific contextual aspect of living with dementia in Iran. It seems that the people with dementia in Iran suffer from losing their role as financial provider, which can cause problems for their family identity and damage their sense of dignity with respect to their senior position in an extended family structure. This calls for further efforts in supporting people living with dementia in their struggles with their altered lives and their struggles to retain their connections to everyday life. Nurses should provide assistive plans to support people with dementia in their struggles with an altered life. Nursing plans can be directed towards retaining and maintaining the connections of people with dementia to everyday life. However, such nursing plans should be developed considering the specific contextual situation of people with dementia.

These studies provide a basis for nurses and other healthcare workers to look at the world from the perspective of people with dementia, which is a key element to appropriate interventions. Responses to the experience of dementia or living with a family member with dementia might differ since individuals understand and behave differently in different contexts. Therefore, nurses should tailor their clinical practice to the subjective experiences of their clients. Nurses need to see the uniqueness of each person's experience of the situation and adjust their care to those specific experiences and needs.

The findings can contribute to the development of appropriate dementia care plans based on the specific contextual situation of people with dementia and their families. There seems to be a need for nursing interventions to help people with dementia and their relatives to accept problems associated with forgetfulness and loss. Nurses can help improve the lives of those living with dementia by fostering a social environment that allows people with dementia to engage in various activities and decisions, all of which promote the individual's self-dignity and self-worth. Furthermore, nurses can support family members by providing information about the course of dementia, its causes, and prognosis, as well as advice on how to help their family member with dementia.

10 FUTURE RESEARCH

The multidimensional impact of ethnicity, culture, and life history on the experience of dementia and living with people with dementia needs to be explored further.

Studying the experience of other people involved in the care and lives of people with dementia can be of interest since people other than family members are increasingly involved with providing dementia care.

Gender issues deserve to be examined more carefully. Our studies revealed some gender aspects of care practices within the family. However, we cannot draw definite conclusions due to the nature of the study, the number of participants, and the gender distribution of participants in these current studies. Comparative studies in terms of gender, age, relationship, severity of dementia, sexual orientation, literacy, and socioeconomic status could be of value.

Conducting research in rural areas could also contribute to broadening our understanding of dementia and living with dementia in different settings. The number of people who live alone with dementia is increasing. Therefore, we also need to study the experiences of people with dementia who live alone to be able to aid them and support them in their endeavors to manage life with dementia.

Factors that contribute to the experience of living with dementia or living with someone with dementia as being positive or negative with different weights could be investigated further. Healthcare workers, relatives, and significant others, as well as healthcare policy makers can use the results to improve the care and quality of life and well-being of people with dementia and their families.

11 SVENSKA SAMMANFATTNING [SUMMARY IN SWEDISH]

Det övergripande syftet med denna avhandling var att utforska upplevelser av demens ur perspektiv från iranska personer med demens och familjemedlemmar till personer med demens i Iran och Sverige. Avhandlingen består av fyra utforskande studier med kvalitativ ansats.

Två kvalitativa ansatser, tolkande fenomenologi (studierna I och II) och kvalitativ innehållsanalys (studierna III och IV), användes för att genomföra studierna i storstadsområden i Sverige (studierna I och III) och Iran (studierna I och IV). Sammanlagt deltog 50 personer inklusive 28 var kvinnor och 22 män i åldrarna mellan 26 och 88 år (studierna I-IV). Deltagare var personer med demens (studierna III-IV) och familjemedlemmar till personer med demens (studierna I och II). Data samlades in genom semistrukturerade intervjuer, transkriberades ordagrant och analyserades med Benners tolkande fenomenologi (studierna I och II) respektive kvalitativ innehållsanalys (studierna III och IV).

Resultaten visar att iranska invandrade familjemedlemmar till personer med demens i Sverige (Studie I) upplevde den egna omvårdnaden av sin anhörig med demens som ett personligt fullbordande. De hade svårt att erkänna att sina familjemedlemmar hade diagnosen demens men chocken av att inte bli igenkända av sina familjemedlemmar med demens blev vändpunkten för dem när det gäller att acceptera situationen. Familjemedlemmar som bodde tillsammans med sina anhöriga med demens i Iran (Studie II) beskrev oro för att förlora känslan av gemenskap, en gemensam framtid och social värdighet. De skapade mening i situationen med ett förändrat liv genom att underkasta sig sitt öde och en strävan efter att se saker från den ljusa sidan. Subjektiva upplevelser av att leva med demens hos iranska invandrare i Sverige (Studie III) innebar att leva med glömska, känslor av inkompetens samtidigt som att fortfarande uppleva sig älskad, att känna sig säker och trygg i samhället men också att vara isolerad. Att leva med demens i Iran (Studie IV) upplevdes som att kämpa med ett förändrat liv vilket innefattade ett ur andras ögon förändrat själv, glömska som ett förargligt tillstånd, att vara en börda för andra, längtan efter att vara en uppskattad människa och att hitta strategier för att hantera demens.

Svårigheterna att acceptera diagnosen demens var bortanför deltagarnas kulturella bakgrund eller kunskap om demens. Människor bör bemötas individuellt för att underlätta sin förståelse av orsaker och drivkrafter bakom svårigheter att stå emot mot att acceptera diagnosen eller medicinsk vård. Familjemedlemmar behöver hjälp att lära sig att interagera med respekt och värdighet med sina anhöriga med demens. Sjuksköterskor kan bidra med hjälp till att binda samman familjernas trasiga livshistorier och återupprätta en meningsfull kontakt inom familjer där en person har demens. Genom att få insikt i problem och upplevelser hos personer med demens och deras familjer, kan sjuksköterskor få instrument för att bättre möta dem där de är i sin unika situation och för att hjälpa dem i att skapa ett meningsfullt liv med demens.

Nyckelord: demens, invandrare, Iran, kvalitativ studie, kvalitativ innehållsanalys, tolkande fenomenologi, Sverige, upplevelse

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