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Dementia across cultural borders
Reflections and thought patterns of elderly Iranians
with dementia in Sweden, their relatives and staff at
a culturally profiled nursing home

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In memory of my dearly and endlessly loved dad, mom
and granny

Every time I think of you my heart just fills with pride, but also with longing

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ABSTRACT

Introduction: Today's multicultural society has resulted in major changes, with healthcare undergoing significant modifications. Healthcare workers and patients are increasingly confronted with "cultural" backgrounds other than their own. The world's population is ageing, and the number of people with dementia is growing, resulting in a growing number of older people with a foreign background whose care needs have increased at different rates.

Migration does not only mean moving from one place to another; it also involves the transition of an individual's lifestyle, life views, social and economic adjustments that may lead to certain changes. These transitions from the "old" to the "new" way of life and from a life without dementia to a life with dementia involve making sense of life's changes.

Aim: The aim of study I was to explore the experiences and perceptions of dementia among Iranian staff working in a culturally profiled nursing home (CPNH). The aim of studies II and III was to explore relatives' decisions to end caregiving at home, and Iranian families' and relatives' attitudes towards CPNHs in Sweden. The aim of study (IV) was to explore how the residents with dementia at the CPNH expressed the feeling of "home".

Method: This thesis is based on more than one year's fieldwork. The empirical material is based on interviews and observations. Three groups of participants were interviewed and observed: 10 people with dementia (IV), 20 family caregivers and relatives (II and III, respectively) and 34 staff members (I). The interviews were conducted in Persian/Farsi, Azerbaijani, English and Swedish. The choice of language was always up to the participants. All the interviews were audio-recorded, transcribed verbatim in the respective languages and then translated later into Swedish. The analysis of the material was based on content analysis blended with ethnography.

Results: Study I shows that people from different culturally and linguistically diverse backgrounds could have different perceptions of what dementia entails. A lack of knowledge concerning dementia affects how staff approach these people.

Study II shows that the CPNH is crucial when deciding to cease caregiving at home. It is important to ensure that relatives with dementia are

cared for by someone who speaks the same mother tongue. The results indicate that positive feelings of relief or comfort are dominant responses among the participants, some of whom even feel pride in the high standard of care provided by the home. In Study III, most participants based their views on a comparison between the CPNH and Iranian nursing homes after the Islamic Revolution. Negative views of the nursing home were evaluated alongside what the respondents considered to be typically Iranian. In Study IV, the results show that people with dementia's personal experiences of home played a great role, and although none of the participants felt at home, all of them stated that the CPNH was a place to live in.

Conclusion: Perceptions of dementia can be based on cultural and traditional understanding, although this can shift through transition and knowledge accumulation. A lack of knowledge concerning dementia and residents' sociocultural background, generational differences and incoherence, aligned with staff members' different sociocultural backgrounds, created many challenges. The staff wanted to learn more about dementia, to be able to manage daily communication with the residents. On another point, the staff admitted that only being able to speak a person's native language was not enough to claim that they were actually communicating. Family caregivers' decisions to end caregiving at home involve mutuality, capability and management, but decision-making sometimes has nothing to do with violating a person's autonomy and is more about protecting the person. The family caregivers do care for frail elderly family members. What has changed due to a transition is the structure and construction of family caregiving. The consequences of communication difficulties between staff and the residents have led to a small degree of social involvement, which in turn affects residents' daily social state. Overall, many family members stated that the CPNH resembled Iran too much, which disturbed them.

The residents thought of home as a geographical location, but also connected it with both positive and negative feelings. Furthermore, the CPNH reminded some of the residents of the nicer side of life back home in Iran, while for others it brought back sad experiences and memories from the past. Nevertheless, the nursing home, due to memories and experiences of life in Iran, "home", was a place to be and to live.

Keywords: Dementia, Transition, Culture, Culturally profiled nursing home.

SVENSK SAMMANFATTNING

Introduktion: Dagens mångkulturella samhälle har resulterat i stora förändringar, där även hälso- och sjukvården genomgår betydande förändringar. Hälso- och sjukvårdspersonal och patienter möter i allt högre utsträckning "andra" kulturella bakgrunder än sina egna. Världens befolkning är åldrande och antalet personer med demens ökar vilket får till följd ett växande antal äldre personer med utländsk bakgrund vars behov av vård har ökat i varierande takt.

Migration innebär inte endast att flytta från en plats till en annan, det handlar även om transition, förändringar, av en persons livsstil, livsutsikt, sociala och ekonomiska anpassning. Dessa transitioner från den "gamla" till den "nya" livsstilen och från livet utan demens till ett liv med demens innebär omvälvande livsförändring.

Syfte: Syfte med studie I var att utforska erfarenheterna och uppfattningarna av demens bland personalen som arbetar i kulturellt profilerade vårdhem (CPNH). Syftet med studie II och III var att utforska närståendes beslutsgrunder för att sluta vården hemma och flytta sin familjemedlem med demens till CPNH. Syftet var också att utforska de närståendes syn på CPNH. I studie (IV) var syftet att utforska på vilket sätt de boende personerna med demens på CPNH uttryckte innebörden av "hem".

Metod: Avhandlingen är baserad på mer än ett års fältarbete. Det empiriska materialet är baserat på intervjuer och observationer. Tre grupper av deltagare har intervjuats och observerats: 10 personer med demens (IV), 20 närstående (II, III) och 34 vårdpersonal (I). Intervjuerna genomfördes på persiska/farsi, azerbajdzjanska, engelska och svenska. Valet av språk bestämdes alltid av deltagarna. Samtliga intervjuer spelades in och transkriberades på respektive språk, därefter översattes de transkriberade texterna till svenska. Analysen av insamlat materialet genomfördes med innehållsanalys kombinerad med etnografi.

Resultat: Resultatet i studie I visar att personer från kulturellt olika bakgrunder har mycket varierande uppfattningar om vad demens är. Bristande av kunskap om demens som också påverkade personernas förhållningssätt. I både studie II och III visar resultatet en positiv känsla av lättnad. Studie II visar att CPNH har haft avgörande betydelse för beslutet att sluta vårda

hemma. Närstående anser att CPNH är en plats där familjemedlemmen med demens tas omhand av personal som talar samma språk. Några närstående kände även stolthet på grund av den goda vårdkvalitet som tillhandahålls av CPNH. De flesta närståendes syn på CPNH baserades på en jämförelse mellan CPNH och iranska vårdhem efter den islamiska revolutionen, och de ansåg att CPNH var typiskt iransk. Det förekom en del klagomål beträffande kommunikation mellan den vårdboende personen och personalen på grund av svårigheter att förstå den vårdboende personens bakgrund före revolutionen. Resultatet i studie IV visat att bo på CPNH med beaktande av hemkänslan där spelade enskilda personliga upplevelser av hem en stor roll och trots att ingen av deltagarna kände sig hemma uppgav alla att CPNH var en plats att leva.

Slutsats: Uppfattningar om demens kan vara baserad på både kultur och traditionell förståelse, men detta kan variera beroende på transition och kunskap. Bristande kunskap om demens och de boendes livsstil, generationsskillnader och brist på sammanhang, i linje med personalens olika sociokulturella bakgrund, förorsakade många utmaningar. Kommunikationsvärigheter mellan personal och boende har lett till en del sociala meningsskiljaktigheter, vilket i sin tur påverkade de boendes dagliga sociala tillstånd. Personalen vill lära sig mer om demens, och att kunna hantera daglig kommunikation. Personalen erkände att kunna tala endast personens modersmål var inte tillräckligt för att kunna hävda att man faktiskt kommunicerade.

Denna avhandling visar att närstående bryr sig om sina äldre och tänker på äldres välbefinnande, men den tidigare traditionen att vårda äldre hemma har förändrats. Det som förändrats på grund av transitionen är strukturen och konstruktionen av familjeomsorg. Konsekvenserna av kommunikationsproblem mellan personal och boende har lett till en relativt liten delaktighet, vilket i sin tur påverkar de boendens dagliga sociala tillstånd. Sammantaget uppgav många familjemedlemmar att CPNH påminner dem för mycket om Iran, vilket störde dem.

CPNH påminde några av de boende om den trevligare aspekten av livet hemma i Iran, medan det för andra återkallade tråkiga erfarenheter och minnen från det förflutna. Sammantaget kände personerna med demens som bodde på CPNH att det var ett anständigt ställe att leva.

Nyckelord: Demens, Övergång, kultur, kulturellt profilerade boendehem.

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- I. Antelius E & Kiwi M. 2015. Frankly, none of us know what dementia is. *Care Management Journals*, 16 (2), 79-94
- II. Kiwi M, Hydén L-C & Antelius E. 2018. Deciding upon Transition to Residential Care for Persons Living with Dementia: why do Iranian family caregivers living in Sweden cease caregiving at home? *Journal of Cross-Cultural Gerontology*, 33 (1), 21-42
- III. Kiwi M. 2017. Iranian relatives' attitudes towards culturally profiled nursing homes for individuals living with dementia. *Journal of Dementia*, 0(0)1-14 DOI: 10.1177/1471301217743835
- IV. Kiwi M. 2018. Away from home or a return home? What Iranian residents with dementia perceive living at a culturally profiled nursing home in Sweden [Submitted]

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INTRODUCTION

This thesis revolves around people with dementia who live in Sweden and who have an Iranian background. It includes people living with dementia, their relatives and the staff who take care of them (either in their home or at residential care facilities). According to Prince et al. (2016), 47 million people are living with a dementia disease. Every year, 10 million people fall ill. The prognosis for the number of people with dementia disease is 75 million in 2030 and 131 million in 2050 (Prince et al., 2016).

Because of a global society and increasing migration, Sweden now has a transformed population composition. People who speak different languages and come from different cultures meet every day in healthcare settings (Gaunt, 1998; Sundquist, 1998). Given that everyday life is increasingly diverse, there is a need to understand people with different cultural backgrounds, particularly their ways of living. It is necessary to consider the important elements of migration, culture and transition. Migration has changed in the last few decades, as many structures of society have altered and/or developed in some way into what we today call a globalized era. By conceiving of globalization in this way, it becomes possible to see how different culture encounter one another. When speaking of different cultures, we need to be reminded that there is as much, if not more, diversity within a culture as there is between cultures (Pedersen 1991).

What is obvious is that in the modern globalized world, people move and migrate between quite different ethnocultural systems. Migration from one geographical and cultural context to another, in most cases, involves a negotiation of practices and conceptions of, for instance, illness, sickness and dementia. According to Meleis et al., (1994) individuals will enter a phase of transition between two relatively stable periods, during which time they move from one life phase, situation or status to another.

The reason for choosing to write about Iranian immigrants living in Sweden who have developed dementia is both personal (I have an Iranian background) and academic (almost nothing academic has been written about elderly immigrants from the Middle East who have developed dementia while living in Sweden – or anywhere else, for that matter). Presently, there are no statistics on how many elderly Iranians in Sweden have been diagnosed with dementia, although many who need professional care have ended up in nursing homes.

BACKGROUND

Dementia and prevalence of dementia

‘Dementia is 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 judgement. Consciousness is not clouded. Impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behavior, or motivation.’ Source: *ICD-10 Classification of Mental and Behavioral Disorders: Clinical Descriptions and Diagnostic Guidelines*. Geneva: WHO; 1992, as quoted by Hughes (2011, p. 24).

The syndrome now known as *dementia* is a phenomenological diagnosis that is based on clinical observation. It has had various names over the past 2 500 years, including *paranoia*, *idiotism*, *fatuity*, *acquired imbecility*, *senility*, *senile psychosis* and *chronic organic brain syndrome*. Hippocrates (circa 400 B.C.) identified the brain as the locus of mental function and was the first to recognize disorders of mental function as diseases, which he divided into epilepsy, mania, melancholia and paranoia, the last term being equivalent to mental deterioration (Zilboorg, 1941, in Weiner et al. 2009, p. 3).

The word *dementia* comes from the Latin *dēmentia*, meaning *madness*, where *dēmēns* or *dēment-* mean *senseless*, i.e. *dē-*, *de-* (*without*) + *mēns* (*mind*) (Weiner et al., 2009). Another categorization was *senility*; in Latin, *senile* means *aged*, or *old man-like*. According to Ballenger (2006), the word *senile* itself was less a diagnosis than a term of abuse. It was then introduced into medical dictionaries as a diagnostic category.

In the latter half of the 1900s, several physicians claimed that senility was not part of normal ageing, but was in some cases conditioned by specific diseases (Ballenger, 2006). One of these was Alzheimer’s disease, which causes pathological changes in the brain and which was previously regarded as something that affected only younger people. During the 1970s that explanation was also abandoned. They began to consider cerebral infarction as the source of another form of dementia, multi-infarct dementia or vascular dementia. According to Hughes (2011), dementia is an umbrella term for different diseases or conditions that affect the brain: it covers various disorders of cognitive, behavioural, neurological or emotional functions.

The term 'dementia' does not define the cause of the condition or even the exact nature of the symptoms. The word derives from the Latin and suggests that the person with dementia is out of their mind; this adds to the stigma of the conditions. The term 'demented' is an insult. 'Dementia' itself may be an unhelpful term to use since it is not a definition of disease in itself; rather it is an umbrella term for various diseases, which can vary from person to person.

According to Hughes (2011), the most common type of dementia is Alzheimer's disease. Alzheimer's typically affects the episodic memory first; generally, the person first forgets recent things, and gradually the things they can remember become increasingly distant. However, there are certain inherited conditions in which dementia appears later in life. Dementia is not congenital, even if its inherited causes are present from birth. Progressive dementia leads to losing some skills that the person once had and were able to perform (Hughes, 2011). There are many other types of dementia: Lewy bodies, vascular dementia, mixed Alzheimer's with vascular dementia, and other dementias, e.g. frontotemporal dementia, which generally presents between the ages of 50 and 60 years and is more common in cases of younger-onset dementias. (It is the second most common dementia in those presenting under 65 years of age after Alzheimer's.) There is a possibility that some cases are not diagnosed or are misdiagnosed as Alzheimer's (2011, p. 29).

Mild cognitive impairment (MCI) is increasingly used to describe 'a state in which a person is experiencing problems with memory, but it is not felt that this amounts to dementia' (Hughes, 2011 p. 33). If MCI is a pre-dementia state and can be diagnosed sufficiently early, then it could enable future planning for the person with the condition and the beginning of treatments to slow or stop the disease, if such treatments were to become available. Neuroimaging, genetic studies and the use of other biomarkers such as proteins in the cerebrospinal fluid have all been used to try to precisely identify MCI. With tighter MCI criteria, it is easier to determine the probability of subsequent development of dementia.

The world's population is ageing, and the number of people with dementia is growing. Dementia is not a part of normal ageing, but it is a manifestation of ageing (Hughes, 2011), although it does not only affect elderly people. Hughes warns against talking about "the elderly" as a potentially stigmatizing term, since it groups all older people together.

The World Health Organization (WHO) (2012) has stated that there is a lack of awareness and understanding of dementia, at some level, in most countries, resulting in stigmatization, barriers to diagnosis and care, and impacting on caregivers, families and societies physically, psychologically and economically. Dementia can no longer be neglected but should be considered a part of the public health agenda in all countries. The number of

people with dementia will continue to grow, particularly among the oldest, and countries in demographic transition will experience the greatest growth. According to WHO (2012), the total number of people with dementia worldwide is estimated to be 65.7 million in 2030 and 115.4 million in 2050. The total number of new cases of dementia each year worldwide is nearly 7.7 million, implying one new case every four seconds.

In Sweden, according to the Swedish National Board of Health and Welfare (SNBHW) (2017), 20 000 – 25 000 people fall ill every year. The estimate for the year 2030 is 180 – 190 000. The estimate for 2050 is 250 000. There are no statistics on how many of those with immigrant backgrounds are included in the numbers. According to Johansson (2004), the number of elderly people with immigrant backgrounds is rising in Sweden and dementia rates may increase among them.

Family-based caregiving

Family caregiving is the most primary and oldest way of taking care of each other within a family. It is based on informal care (Pearlin et al., 1990; Wright et al., 2005).

According to Gaugler and Kane (2015), family caregiving is a societal construct that permeates our lives, our communities and our cultures.

There is no a simple definition of family caregiving and family caregiving with dementia. Schumacher et al. (2000) highlight that caregiving is complex and involves much more than simply willingness or motivation. Family caregiving as an informal caregiving arrangement is not a new or contemporary phenomenon. The term “family caregiver” refers to any relative, partner, friend or neighbour who has a significant personal relationship with, and provides a broad range of assistance to, an older person or an adult with a chronic or disabling condition (Gibson et al., 2012). The meaning attached to a family caregiver has varied significance aligned with strong personal and cultural interpretations. Zarit and Edwards (2008) state that caregiving is a complex, multifaceted process, characterized by a great deal of individual variation at every point in the process. Although there is no standard definition of family caregiving, there is a consensus that it involves the provision of extraordinary care, exceeding the bounds of what is normal or usual in family relationships (Schulz et al., 1997). Family caregiving is a demanding responsibility and comes with different kinds of social and economic problems that can disrupt familial relationships. A person taking on this role is considered as an unpaid worker (Hileman & Hassanein, 1992). Schulz et al. (1997) argue that several studies undervalue the caregiver’s stress, due to how one defines the role. Sometimes, they are described as people who share a household with a care recipient, without clarifying whether or not the caregiver provides care (cf. Pinquart, 2003).

The impact of caregiving has often been described as challenging in many ways. According to Haley et al. (2003), caregivers find satisfaction and benefits in their role and they believe that by modelling caregiving, their children will learn and do the same for their family. This satisfaction could be interpreted as a positive form of battling with stressful circumstances and situations, noting that caregivers who subjectively appraised caregiving tasks as less stressful found meaning and subjective benefits from caregiving.

Scholars have previously discussed outcomes of family caregiving in both positive and negative terms, reflecting that the central topic of concerns relates to physical and mental strength in assisting and neglecting patients in need of care. However, it is important to note and understand that family caregiving as a “profession” not only jeopardizes family caregivers’ physical or mental strength, but can also contribute to family members being in need of assistants’ self-development and well-being (Haley et al., 2003, Schulz et al., 1997, Brodaty et al., 2009).

Family-based caregiving in dementia

Being a family caregiver for a family member with dementia is a familiar situation for many people today. Schulz and Martire (2004) believe that family-based caregiving in dementia – in terms of providing unofficial care to a sick, disabled and family member or friend living with dementia – is not a particularly new phenomenon. This is because of life expectancy and ageing in the population, fluctuations in acute to chronic diseases and associated ailments, alterations in healthcare compensation and progress in the development of medical technology. Because of these changes, caregiving for family members with dementia has become commonplace. Usually the spouse assists a partner with dementia, but when the spouse is not available or not alive to provide help, adult children become involved in giving assistance. In most cases, adult daughters and daughters-in-law provide help with household chores and personal care over the long term rather than their male counterparts (Zhan Heying et al., 2003).

Several studies describe family caregiving in dementia in terms of both positive and negative outcomes. Hunt (2003) focuses on the burdens associated with the activities involved in caregiving. While these burdens can be extensive, great stress, longing, sadness, anxiety and depression can also come from the feelings of otherness and strangeness when a family member receives a dementia diagnosis. Schultz and Martire (2004) state that caregiving typically involves a significant expenditure of time, energy and money over potentially long periods of time; it involves tasks that may be unpleasant and uncomfortable, and are psychologically stressful and physically exhausting. There may also be worse relationships and even conflicts

between the family caregiver and other family members, due to the fact that family members often disagree about the division of responsibility for care-giving tasks and the best way to carry out these tasks.

Schulz and Martire (2004) go on to describe that family caregivers for those with dementia provide a valuable service to society, their relatives and their own well-being. There is a strong consensus that taking care of an older person with disabilities and dementia is a stressful and troublesome undertaking for many family members and can result in psychiatric morbidity in the form of a higher predominance and incidence of depressive and anxiety disorders. Female caregivers in particular describe higher levels of anxiety and depressive symptoms and lower levels of life satisfaction than male caregivers. Despite many difficulties, there is also a good deal of satisfaction to be gained from looking after a relative with dementia (Brodaty et al., 2009). As revealed by Mc Grew (1995) and Hirschfeld (1983), who identified the factors, family caregiving hereby decreases the need for care by family members due to the amount of input and outputs in reality and details, namely mutuality, personal capacity, tension and management.

Brodaty et al. (2009) also shed light on positive family caregiving in dementia, stating that family caregivers for those with dementia may be motivated to provide care for reasons such as a sense of love or reciprocity, spiritual fulfilment, a sense of duty, guilt, social pressures, etc. About 90% of family caregivers for those with dementia experienced positive experiences such as enjoying togetherness, sharing activities, and spiritual and personal growth.

Migration

Migrating to a new society involves many issues. Before going any further, it is necessary to consider the important elements of migration. Migration is not only a human story as Keeley (2009) states, it is human beings' history.

According to Keeley (2009), more and more people worldwide, in both developing and developed countries, are likely to consider migrating, either permanently or temporarily. Migration often takes place in order to seek out new opportunities. Transport links around the world have made it easier to travel, and the Internet is an ever-expanding storehouse of information about life in other countries.

Migration has no set time boundaries, key points or events. Some common key points are linked to the decision to immigrate, the journey itself, entry into the new place, and adaptation to the new place. Although these are common key elements in immigration, some of these may be events that

are noteworthy for some, while for others they are not. Migration is defined more by the change of lifestyle, cultures and living conditions than by the change of physical location (De Anne et al., 2010).

Migration is also affected by what migrants take with them. Some migrants arrive with wealth that helps them thrive in their new country. Some arrive with high levels of education, technical knowledge, language skills and social skills. Unfortunately, this is not the norm. Some migrants arrive with little or no formal education, no knowledge of the host language, and few useable work skills. Regardless of what they have, many migrants are also subject to xenophobia, discrimination, racism and sexism (De Anne et al., 2010).

Despite many countries having benefited from having immigrants, many are rendering migration and the life of migrants more insecure and riskier from a health perspective (De Anne et al., 2010).

Migrating is not just the physical movement from one area to the other, but also how one moves and adjusts between different life conditions, statuses and phases that result in an evolving redefinition of oneself, which makes migration a life change (Meleis, 2010). Immigrants migrate in all corners of the earth, whether internally or externally, and with them comes a wide spectrum of social and socioeconomic status.

Health and caregiving among migrants is a concern for healthcare professionals and researchers. While some migration can be a healthy process, others fall victim to physical and psychosocial difficulties, anxiety and isolation. As Meleis explains, “Immigrants’ health practices and decisions and actions related to seeking healthcare occur within transnational social fields; therefore, provision of care must take into consideration individual, family, community, and environmental patterns, properties, and conditions of migration transitions” (Meleis, 2010, p. 230).

Cultural studies of dementia

Dementia must be understood not only in biological terms but also as something influenced by culture and by cultural practices and outlooks. Culture is highly important in understanding and dealing with dementia. Recognizing personhood is also important since studies show that people with dementia have often not felt treated as individuals; not treated as a person with selfhood and their own voice. The findings show the importance of integrating personhood into treatment, of recreating ritual and past experiences, and of understanding and treating core symptoms and the person with dementia (Leibing & Cohen, 2006).

Cultural studies have revealed that every culture is unique and it is important to have an understanding of the cultural influence that determines

a community's perception and understanding of dementia (Dilworth-Anderson et al., 2002; Henderson et al., 1992). Although diagnostic labels like Alzheimer's disease offer an explanation of why individuals living with dementia are the way they are, there is a difference between medical and cultural perception of ageing and it is important to resolve these differences so as to rethink the medicalization of the elderly.

Cohen (1998) studied old age by examining understanding of the body and how it behaves over time, why it decays and its ability to have a voice that can be heard. He presented divergent narratives on old age and what he called "senility", as well as views on culture, society, nature and ageing.

In India, Cohen found no diagnostic counterpart for what was labelled in North America "Alzheimer's disease". Instead, dementia-related issues with the elderly were described as the result of younger family members not taking good care of their elders, by eschewing traditional practices. Leibing and Cohen (2006) noted that dementia in India is indicated by an elder's angry voice and not the fact that he or she is forgetful. From this perspective, attention shifts from the social to the individual's body, from cognitive signs to emotional signs. Therefore, Alzheimer's disease, according to Cohen (1998), might relieve families of the stigma associated with caring for an elderly person individual suffering from this disease. Consequently, Cohen used the term "senility". He did not deny that Alzheimer's does indeed explain some behaviours exhibited by the elderly, but he also encouraged us to rethink their medicalization, especially when they are subjected to a reduction in political, social and philosophical complexities associated with ageing.

When writing about the fear of "senility", or *boke*, in Japan, Traphagan (2002, 2005) argues that it is a moral category described as antisocial behaviour when an elderly person is denied the normative values that would enable them to engage actively in society.

Being involved in group activities is believed to help the elderly maintain good health. Local government states that self-cultivation and engagement in the project means they are good *rojin* (elderly people), as they engage in positive behaviour for their own benefit (Traphagan, 2002, 2005, 2009).

Furthermore, *ikigai* is knowledge, power, selfhood and self-discipline, sustained through *omairi*, i.e. individual and collective well-being. This well-being is also developed through an ongoing and active expression of emotion for the living and the dead, which in turn prevents *boke*, the loss of self.

Traphagan (2002, 2005) looks particularly at the links between Japanese religious practice and health amongst the elderly. In Japanese culture,

concern is expressed through ritual, active engagement with the community and the promotion of individual and collective well-being, to avoid “senility” in later life.

Like Cohen (1995), Traphagan (2009) rejects the term “dementia” in favour of “senility” and *boke*, to de-medicalize the issue and to highlight the importance of engaging in activity to prevent “senility” or *boke*, the latter of which is very much moral as opposed to biomedical.

Traphagan’s cultural studies are essential in understanding how the Japanese seek to prevent “senility”, by citing both medical and cultural definitions of dementia.

Henderson (2002) studied the native populations and subcultures in America, such as Hispanics and African Americans, and especially newly emerging dementia diseases in American cultures and others. The Native American population is living longer, and therefore dementia sufferers are increasing in number. Understandings of dementia differ depending on culture, magnitude and prior experience, and it is not considered a “devastating disease” in all cultures. Changes in a person may be noticed, but these are interpreted differently. Disease has many dimensions, and dementia is no different, in that it is based on experience and should not simply be understood medically.

In the Native American culture, people often view sufferers with “mystical awe”, believing that their hallucinations help them communicate with the supernatural and spirits of the dead.

Cultural themes among Hispanic caregivers are highlighted by Henderson et al. (1992), who emphasize that all stakeholders need to understand dementia within their sociocultural context, which is particularly important among older adults and ethnic minorities. Issues can include different attitudes to gender roles, stigma and traditional cultural values around accessing community help and submission to clinical authorities.

Henderson et al. (1992) suggest that caregivers understand senility from sociocultural contexts, and clinicians should be aware of this viewpoint.

Cohen (1995, 1998), on the other hand, examines the limitations of both North American and Indian gerontology in analysing old age in society. He warns especially about alarmist extrapolations of imminent population explosions, since age can look very different, not only between different countries, but also within individual countries, depending on the individual’s geographic and socio-economic position. Cohen places great emphasis on class in view of the ageing process and calls for an opportunity for Indians to age on their own terms, believing that gerontological scientists use marginal elderly people to legitimize a discipline that ultimately is

more interested in understanding middle- and upper-class, city-dwelling elderly males (Cohen, 1998).

Much of these authors' research on the cultural aspects of dementia is based on and clarifies the unitary and mono-cultural values, beliefs and traditions set within different societies and countries.

One problem with the cultural studies discussed so far is that they do not investigate how the economy, migration and transition can influence people's perceptions of ageing, sickness, illness and specifically dementia. When Henderson (2002) discusses subcultures existing in larger cultures (like Native Americans), he states, without discussing the impact of migration and transition in relation to Hispanics, that different generations will be less likely to accept the old ways of understanding old-age problems. Henderson argues that this may be described as an inter-personal conflict that can be understood as a movement of cultural values across generations, which in turn leads to an intergenerational shift. A central problem with this argumentation is that it lacks a focus on the principles underlying the issues of migration and transition and instead argues that different generations of Hispanics are reluctant to accept the old traditional order.

Cultural diversity and family-based caregiving

Family caregiving may be culturally diverse. When cultural diversity and family caregiving are of concern, researchers emphasize that the latter, in general, causes stress, but it has been shown that different cultures may experience it to different degrees. Zarit and Edwards' (2008) research shows that Afro-American caregivers have been found to show less distress while providing a more intense level of care than their white or Hispanic counterparts. However, in a study of culturally diverse family-based caregiving among Turkish families in the Netherlands, van den Brink (2003) found four caring constructs: "family care", "care as an obligation", "care as showing respect" and "self-care by learning and doing." According to van den Brink, culturally diverse care is not something people talk about – it is rather a taken-for-granted obligation: "one just does it".

Doing everything for sick elders is the main care activity in family care. These activities span the recipient's lifecycle, ranging from being present to caring until death. Culturally based family caregiving is not only an obligation, it is provided with one's heart. Sons have an obligation to ensure their parents' care in old age, and daughters-in-law are expected to help and take over most if not all of the household activities. Culturally family-based caring also includes emotional, financial and social support through regular visits and phone calls. Adult children accompany their elders to hospitals and on visits to their physicians, and they provide translations and explain to their elders what they need to know, do or avoid (van den Brink, 2003).

Regardless of cultural diversity in family-based caregiving, McGrew (1995) and Hirschfeld (1979) present another understanding of family-based caregiving. They identified some factors motivating caregiving and family caregiving. These include a commitment to social standards of behaviour and role fulfilment, “natural” responses to crises, being the “only one” and a commitment to family precedent, among others. Thus, providing care to a family member, they argue, can be meaningful and satisfying as well as challenging. In relation to family caregiving in cases of dementia, Gupta and Pillai (2002, 2009, 2012) state that caregivers to older adults with dementia may be considerably more distressed than caregivers to those who are only elderly.

Family caregiving can thus be perceived as cultural, traditional and socio-cultural. The activity as a profession, whether through ideologies, through institutions or within private homes, has the same concerns in practice as in theory: care for a sick person involves attending to their needs and ensuring that their health and well-being are monitored and encouraged. Moral and emotional support is of central concern in care. Family caregiving within some culturally diverse group is highlighted by scholars differently. Even though providing care for a family member in need of help is described as meaningful, it is also challenging. In relation to families with diverse cultures, family caregiving is discussed as being distinct through ethnocultural and traditional perspectives and agreements within socio-cultural groups and settings. The degree of motivation in caregiving is described ultimately as a coping buffer employed to protect caregivers in the face of stress and tension (Gupta & Pillai, 2002, 2009, 2012).

Ageing in Iran

There is no universally accepted definition of old age; instead, it has been argued that “aging is a multifactorial concept involving cultural, biological, and social aspects, which in turn create different definitions across different parts of the world” (Koochek, 2008, p. 7).

The idea of what constitutes being “elderly” in Iran varies depending on which community is being studied within the country. Iran is the only country in the world that has adopted the age of 45 for disabled and 50-60 for able-bodied adults as the official retirement age. Whereas other countries are trying to increase the age of retirement to reduce the dependency ratio and benefit more from the abilities and skills of older workers, the Iranian government takes a reverse approach as seen by a reduction in the retirement age (Amini et al., 2013). Regarding perception of old age, ageing and the elderly, Rudi (2014) believes that although there is a retirement age of 60 in Iran, there are also many different perceptions of what “old age”,

“ageing” and “the elderly” are. The ageing female in Iran is generally regarded as “not attractive”, whereas different standards hold for the ageing male. There are elderly females who are most highly respected in society because of their ageing in life rather than ageing with life or not because of the time passed by, but how the time passed for that person. Nevertheless, according to Sharia law, a woman is counted as half a person.

Riyahi (2009) notes that cultural, social and economic changes in Iran have impacted on growth in the older part of the population. The decrease in the birth rate in recent decades, as well as reduced mortality through improved health and healthcare, are among the factors that have brought about this development. Riyahi goes on to explain the rule of thumb in traditional Iranian society, in which older people have power and authority, are present in the local culture, and are seen to possess knowledge, experience and wisdom. The elderly is called “rish-sefid”, meaning “white beard”, and gather in the Office of the Elderly. Age also goes with wealth, as represented by the land, which goes on to be inherited by the eldest son or eldest man in the family. Riyahi (2009) further argues that the oldest person in the community traditionally had the highest authority in the general government and had at his disposal the necessary tools for taking care of the family as well as others in the community in need of support, as he possessed wealth, power, status and prestige. These promoted him to fill key roles, such as collective bargaining, secretary, manager, farm owner, pet owner, water manager and a judging role in tribal disputes, family disputes, etc. After modernization, most of these powers disappeared. Modernity gave increasing value to work in an office or a factory. Pensions now meant a loss of authority, of work, and of contact with others.

Iranian author Meysam Mousaei (2005) has studied the social psychology of the elderly and argues that the fast modernization rate, for example in technology, and other dramatic changes have reduced the value of older people’s knowledge and skills. Young people do not respect the experiences of the elderly, which had been customary in the older traditional society (Mousaei, 2005). One limitation is that Mousaei does not discuss how individuals evaluate the quality of their social relationships, the activities that they engage in, and the nature and meanings of notions such as isolation, exclusion and loneliness.

Other studies, such as Alipur et al. (2009), do suggest that there is a cultural reverence of elders in Iranian society today, though some of that reverence has fallen from its once normally accepted standard, as modern social norms continually change the culture of Iran. Depending on the area, it is arguably still possible to observe a high degree of respect for elders, whose white hair and wrinkles are considered a symbol of the wisdom they have received through years of learning and experiences. Out of respect for their age and wisdom, they are included in many roles in life: they pray in

the front rows of mosques ahead of everybody, they are used to settle debates and arguments, and their opinions are welcomed and expected on many issues, such as “khastegaari”, a premarital meeting, in which elders might be included, between the parents and the young people to be married.

Although some places in Iran have a healthy respect for the elderly, Maryam Ala Amjadi (2014, p. 98) poses the question of “[w]hether the youth-centered modern life and its constant emphasis on ‘individuality’ could really and eventually wipe off [Iran’s] old accustomed traditions and good manners”. While the young may not have surpassed their elders in terms of social class, they have a somewhat diminished respect for elders. Where sayings such as “An old mind is worth more than the fountain of youth” were once held to be true, other, new sayings such as “Buy lame, buy blind, just don’t buy old” now arise. Despite all this, the elders remain at the top of the social class, as stated before.

Traditional Iranian views on care for the elderly

According to Riyahi (2009), the positive values associated with older people’s place in society are dependent on religion and tradition as part of the cultural conditions. In fact, the family traditionally had major responsibility for the care of elderly and less fortunate family members, wherein the vulnerability of the elderly as caused by declining physical strength should not mean that they lose importance. In many cases, advice would be sought from elderly family members in problem-solving, information-sharing and imparting of knowledge and experiences (ibid.). Indeed, taking care of their elderly would traditionally be a status marker strengthening the network of family prestige in friend and family circles. Islam, the predominant religion of Iran, conveys the message that young should treat older people well, pay tribute to them, show them respect and even support them (Riyahi, 2009). Although religion is woven into the lives of many and despite the traditional views of the family and the elderly, many older people have been caught in difficult and often isolated situations.

While Riyahi (2009) gives us a positive image of care for the ageing, Rostampoor (2012) holds a different view: that besides discrimination in the workplace, older people daily face different kinds of problems such as young people neglecting the problems older people face, and there is no time for caring. The younger society view the elderly as useless and frail. Nursing home residents in particular encounter stereotypes on a daily basis, and they are often compared to children and babies. Rostampoor (2012) believes that the consequence of the gradual withdrawal and isolation of the elderly makes their world smaller and smaller.

Rostampoor indicates that modern society is built by the young for the young, and as such considerations are not given to the old, sick, handicapped or incapable. The elderly, who were once young, helped to build the present society and now pay the price for their former neglect of the old. The previously strong desire to take care of the elderly, as well as the tradition of filial piety, has decreased. Sometimes this phenomenon is described as the children's acclimatization, or accumulation, into society (Rostampoor, 2012).

Elderly people living in nursing homes in Iran

Sheykhi (2004, 2012) emphasizes that the number of elderly people is on the rise in Iran. Out of the 65.6 million (as of 2002) people living in Iran, more than 5% of that total is made up of elderly people. The life expectancy is 69 for men and 71 for women. Both have increased and will continue to increase due to better medicine and practices. There are however also decreasing birth-rates, which combined with the increasing life expectancy has put Iran's elderly (above the age of 60) population at 6%.

With this rise in ageing population comes an increased demand for provision of care. Centres for the elderly in Tehran have experienced increased number of occupants. However, a huge part of Iran's population is made up of young people (those aged 0-24). Making up 60% of the population, the youth of Iran are given priority in matters of fiscal policy. This has resulted in sparse financing for the housing and health of the elderly. According to Kiani et al. (2010), approximately 31 million Iranians are middle-aged now, and they will form the elderly population of Iran in the future.

There is growing demand for nursing homes. But despite the increasing number of elderly people in Iran, the number of nursing homes has remained unchanged throughout the century (Mehr, 2011). Many of the elderly in the countryside of Iran are left to fend for themselves because of the lack of long-term care facilities.

One modern facility for elderly people in Iran is the Kahrizak Charity Foundation (KCF). Founded by the late Dr Mohammad Hakimzadeh in 1971, this flourishing establishment is designed for elderly people who no longer possess the ability to care for themselves. They are attended to and given personalized and professional care for free (KCF).

The care that is provided for the elderly in Iran has gone through many changes over the last few decades. According to Siam (2003), Iranian nursing homes are generally classified into four categories:

- 1). Nursing homes that work under the welfare state in every province in urban areas.
- 2). Nursing homes that provide care to the helpless and usually homeless elderly who have nowhere to go.
- 3). Some nursing homes are charitable organizations.
- 4). There are nursing homes that will provide care freely for people who cannot afford it, and at a subsidized rate for those who can afford it. The latter are the privately-run nursing homes with set fees.

The Chairman of the Pedagogy and Education Association at the University of Tehran, Mahajeri (2012), has claimed that sending children to preschool will directly and indirectly have an impact on individualism, which in turn is one of the reasons for people leaving the elderly in nursing homes. He added that those children who do not grow up with their grandparents and who spend their days in day care can feel a greater motivation to send their elderly family members to nursing homes later in their life. He further states that the number of nursing homes for the elderly in the country is increasing fast due to the present condition of Iranian society and family life.

Dementia in Iran

Azar and Dadvar (2008) emphasise that, in the Iranian culture, Alzheimer's disease is not generally viewed as a disease. It is rather considered to be a part of normal ageing. This might be the reason for the absence of any statistics for individuals living with dementia in Iran. According to Navab et al. (2012), there may be nearly 212 000 people living with dementia in Iran (Iran Alzheimer Association, Tehran, Iran). The Iran Alzheimer Association (IAA) is the only voice for people with various forms of dementia, most notably those with Alzheimer's disease and their caregivers. The association is engaged in the following activities: raising public awareness, clinical and rehabilitative activities and other activities such as counselling and education. It has not been possible to establish whether there are any nursing homes at all in Iran that are specifically for people with dementia.

The traditional name for dementia in Iran is *Nesyan*, meaning forgetfulness, amnesia or oblivion. There has been much (academic) debate about the "correct way" to name dementia, from *Zaval-Aghl*, meaning that it is not just forgetfulness, but a psychological problem that causes a noticeable reduction of intellect, to *Ekhtelal hafezeh* (paramnesia) and *Kherad zadegi* (intellect injury). Most experts, however, have rejected all

these suggestions due to their lack of respect. Finally, the Faculty of Philosophy and Medicine in Tehran committed to naming it *Demans* or *Dementia*, more commonly known in Iran in lay terms as Alzheimer's (NCST).

Iranians' emigration and immigration.

In 1980 (that is, the year after Ayatollah Khomeini's admission), a bloody and long war broke out between Iraq and Iran. It lasted for eight years and ended in August 1988. Elshtain (1987) reminds us, in a highly personal analysis, that war is political in its deepest sense. Furthermore, war is one of the social phenomena most associated with significant ups and downs (Bouthoul, 1968). It has catastrophic demographic consequences in the form of excess mortality and forced displacement of populations (Zimmer et al., 2006). The eight-year war between Iraq and Iran led to forced displacement, migration and emigration, which did indeed have serious consequences, forcing Iran to change socially, politically and economically (Rostamalizadeh et al., 2012).

During the war between Iraq and Iran, the whole world witnessed the huge refugee flow from these countries. According to Rostamalizadeh (2012), at the end of the war it was estimated that over a million people had lost their lives and millions of families had accepted forced internal migration (Rostamalizadeh, 2012). However, even before the war, forced or voluntary migration from Iran to other countries had started in connection with the Islamic Revolution in Iran. Migration due to the war followed this, and the third wave of migration saw relatives (often the parents) of those who had already left Iran move to live with their family members now settled in other countries all over the world.

Koochek (2008) notes that Iran is "the third largest refugee-hosting country in the world" (2008, p. 8); migrants leave, pass through, and arrive in the country. Modern emigration from Iran first began in the mid-1950s and was mostly made up of students studying abroad to cope with the country's rapid economic development (ibid.). According to Kamalkhani (1988) and Koochek (2008), the number of Iranian immigrants and refugees is hard to establish, given the differing definitions of such terms depending on the country, and no official data seems to have been collected in Iran regarding the emigration of Iranians.

Iranians in Sweden

Iranians are the fifth largest immigrant group residing in Sweden according to recent data from Statistics Sweden (SCB, 1991, 2017). Despite this, nothing is being done to problematize the issue facing Iranians with dementia.

Because of both the war and the Revolution in Iran, there are numerous Iranians in Sweden: from 3 348 in 1980 to 40 084 in 1990 (SCB, 1991). According to a census taken in 2016, the Iranian population then numbered 70 637 (Statistics Sweden, 2017).

Many of the Iranians who moved to Sweden have tried to bring their parents here. Proximity to their children in Sweden has not always been particularly successful, either for the parents or for the children.

According to Bahar (2007), Iranian generational identity is based on the distinction between three periods: the time pre-Revolution, the time of the Revolution and the war between Iraq and Iran, and the time after the war. Bahar emphasizes that the generation belonging to the pre-Revolution period is more event- and service-oriented, which means that they mostly want to keep busy with work. The generation from during the Revolution and the war is mostly idealistic, which means that self-culture is important to them. The new, third generation notes the world's new needs and is more flexible, regardless of place.

Klein (2001b), in her study of Iranians in Sweden, writes: "They are much more Swedish than we are", which is also a frequent comment from Swedes who have visited relatives or friends in the United States (2001b, p. 67). According to Klein (2001b), some Iranian families who visit those in Sweden claim that Iranians here are real Swedes (their food culture and social culture are not the same as Iranian ones, and most of them do not follow Iranian national traditions), while some claim that Iranians in Sweden are more Iranian than the Iranians in Iran. Klein (2001a) emphasizes that "Iranians" means those individuals born in Iran, and she underlines the importance of practicing folklore and different national traditions in maintaining their origin.

Swedish elderly care

Throughout history, people have tried to take care of their elderly family members, in different cultures, at different times and in different ways. Significant rises in birth rates in the transition between the 17th and 18th centuries, along with migration to the Americas, are thought to have increased the dual problems of financial support and providing care for the elderly (Odén, 2012).

Today's elderly care in Sweden can be said to have been instituted in 1947 by the then Social Minister Gustav Möller. The focus of elderly care at that time was on ensuring that the number of safe and professional retirement homes should be expanded (Edebalk, 2016).

Bygdell (2014), supported by Aboderin (2004), Daatland and Herlofson (2003), Hank (2007), Hjältn (2011) and Tornstam (2010), believes

that distances between generations have attracted much attention in research into elderly people's living conditions in general. Since the 1960s, social research has discussed whether the distances between urbanization and migration have meant that the contact between them has become worse. The so-called modernization theory explained that the working patterns and migratory behaviours involved in modern life emphasized the nuclear family, resulting in the elderly in society being excluded. These thoughts are largely dismissed in research today, but they can still be said to survive because the reasoning seems important when addressing certain areas of research.

Caring for aged parents in most traditional societies, including in Sweden before industrialization, was the children's responsibility, and in ancient agricultural society in particular, it was very common for children or other relatives to have ultimate responsibility for the health and care of the sick and old (Thullberg, 1990).

When pre-modern societies became modern and industrialized, however, the structure of society changed, including older people's social statuses. The really significant changes did not accelerate until the 1960s and 1970s, aligned as they were (like expanded childcare) with women's entry into the labour market. This meant that there was no longer the same option to care for family members in the home (Odén, 2012).

Changes in working conditions as well as social structure and housing during the 1900s led to the state taking on responsibility for and commitment to the care and maintenance of older people in society. This is the background to the design of today's healthcare and care systems in Sweden. Health and social care include assisted living, home care, day care, family status and home care allowance. Another type of intervention is support for relatives who care for an older family member (Thullberg, 1990). Taking care of the elderly was based on old traditions, particularly in relation to the extended family. In the wake of many factors, many social disagreements between generations in the contexts of understanding and care for the elderly should be noted (Odén, 2012).

Caregiving according to Swedish policy

Relatives' desire to take care of, and responsibility for, their elderly family members in their home or in the elderly person's own home is not a new phenomenon. According to the policy in different municipalities in Sweden, family caregivers have the right to be employed by the municipality to take care of the elderly family member in need of specific help. Individuals living with dementia are individuals who receive such help, albeit not often,

which – at least to begin with – helps cater for both psychological and emotional needs, when the family member in need is subsequently transferred to a nursing home (SNBHW, 2012).

Nursing homes for people with dementia in the past

To understand what SNBHW states, on which elderly care is based in part, one should review the history of care and caregiving.

People with dementia were previously cared for in almost all types of institutions within or belonging to local authorities and county councils. They were usually taken care of at nursing or psychiatric clinics, which were traditionally designed with large halls and long corridors. Generally speaking, they were cared for together with retired people and patients with other diseases, and so no specific dementia programme was available and in many regards these activities could be summarized as being a form of ‘storage’ (Asplund, 1998).

Asplund (1998) refers to Folsam (1968), who presented the reality orientation (RO) method, which promised both treatment and better care for individuals with dementia. Reality orientation described a way of reducing disorientation in elderly and confused patients. This confusion consisted of a loss of reality, and so the goal would be to reorient the patient by studying their confused perceptions of work, following which the caregiver would be informed of what needed to be corrected and then draw up a care plan.

Many caregivers found they finally had an instrument through which to respond to individuals with dementia. Reality orientation, along with memory training, often called “mental stimulation”, became popular. Time, date, name, day and week schedules were set up so that the disoriented patients could easily see them. Later, a so-called “validation theory” developed and was dominant in many instances in relation to the content and design of care. Eventually, the validation theory method faced some criticism, in that it was too structured and problematic; for example, each stage had its own specific treatment strategy.

The idea of building nursing homes for individuals with dementia in Sweden, according to Asplund (1998), went far beyond the idea of a nursing home for elderly people; however, it was believed that environmental factors should be taken into consideration for the sake of the person with dementia. The need for care – and at what level – varied between individuals in the early stages of dementia, so home care services arose to help these people live in their homes for as long as possible. Unlike those with advanced degrees of dementia, they were initially placed in special units.

However, as Sjöberg (2003) notes, it was in the late 1970s and the early 1980s that the situations of individuals with dementia came into focus. This was in connection with the restructuring of psychiatry during this time

whereby many people with dementia were staying in mental hospitals and, according to the Social Board's guidelines, their care did not require a mental hospital. The ÄDEL reform of 1992 and the psychiatric reform of 1995 mean that almost all people with dementia now receive care within municipalities (SNBHW, 2010, 2002).

Today's dementia care focuses on more constructive work whereby a person's needs are prioritized, which means collaboration between primary care and specialist care and between county council and municipality/private healthcare providers. According to Nägga et al. (2013), the most important factor is that we select the "right treatment" for the "right patient" at the "right time".

The Swedish care system and elderly care for minorities

In Sweden, as in most countries, the healthcare system is based on the belief in every person's right to receive care with equal conditions and with respect for the unique needs of each patient (e.g. SFS 2017). Specifically, elderly care in Sweden is based on providing support to the elderly so that they can live independently and with a high quality of life at home.

According to the SNBHW (2002), assistance services for the elderly offers security alarms, day centres, home care, various forms of senior housing, nursing homes and relief workers, respite care and other support for families or relatives.

Any person who is a permanent resident in Sweden is eligible for elderly care (Fukushima et al., 2010).

There may be some profiled nursing homes in the international landscape, and in Sweden there has been a long discussion about geriatric care for older people from minority cultures.

Elderly care for minorities has a relatively short history. The first instance documented in Sweden concerned the Sami (native people). According to Andersson (1996), public discussions on the issue of special governmental/public poor relief for the Sami began as early as 1851, with *lapphem*, or Sami retirement homes, being some of the first examples of Sweden's efforts and willingness to provide healthcare needs for a specific group. Gaunt (2002) notes that discussions took place in the early 1900s about retirement homes for Sami, because they had a different language and customs (*lappålderdomshem*), but since that time there have been a number of care facilities for different religious groups, such as for Jewish and Catholic people. Furthermore, during the 1980s, several municipalities opened ethnically oriented forms of care facilities and established service accommodation.

Swedish society is multicultural, and Heikkilä, Sarvimäki and Ekman (2007) highlight the need for a CPNH linked to contemporary health and

social care for older people with immigrant backgrounds. They state that in Sweden, many older Finnish immigrants wish to be provided with care in their own language. The immigrants also want to be cared for by members of their own ethnic group. The findings showed that being cared for by members of one's own ethnic group is beneficial for older patients (Heikkilä, Sarvimäki & Ekman, 2007).

The authors also state that there is a lack of knowledge about transcultural care and how to apply it to the healthcare system. Healthcare services need to adapt to the needs of culturally diverse patients. Furthermore, according to Ekman, working with culturally diverse populations requires specific knowledge, as well as sensitivity to cultural beliefs and needs. There is also a need for knowledge about which language and symbols a person uses to be able to adapt to specific communication patterns (Heikkilä, Sarvimäki & Ekman, 2007).

Studies of CPNHs providing services for individuals with dementia are extremely few in number; the study conducted by Ekman et al. (1994, 1996), for instance, of a Finnish nursing home only concentrated on the linguistic aspect of profiled residential care. We are aware that, in CPNHs, individuals with migrant backgrounds are heterogeneous, even in contemporary Swedish multicultural society. To provide care according to the SNBHW (2017) care model, it is important to consider needs that are related to people with a different cultural or linguistic background. Cultural considerations include, for example, giving the person the opportunity to practise their religion, eat culturally adapted foods and have access to staff who speak the same language as the person with dementia. In this regard, care is realized through such solutions.

Caldas and Berterö (2017) go further and describe the importance of caring for people, especially individuals living with dementia, who are already struggling with language and culture. The authors invite us to gain a deeper understanding of people living with dementia and in need of daily social life and care. The authors state that understanding facticity as a component of dementia care is very important. Facticity is a concept that has its roots in philosophy, and Caldas and Berterö say that: "facticity signifies all of the concrete details against the background of which human freedom exists and is limited. For example, these may include the family, the historical period, and the country where we were born, as well as the inevitable prospect of our death. There is a necessary connection with the person itself being in the world and its own past." (2017) As such, it can be seen as being in reality and the ability to understand the meaning of a situation, albeit every individual's life consists of his or her past.

According to Bahar (2007), Iranian generational identity and sociohistorical background are based on the distinction between three periods: pre-Revolution, the actual Revolution and the war between Iraq and Iran, and

after the war. This distinction may be one of the aspects of generational disagreement that have an impact on both the quality of communication and understanding the past of the elderly person with dementia.

THEORETICAL FRAMEWORK

People will enter a phase of transition between two relatively stable periods, during which time they move from one life phase, situation, health, illness, sickness, dementia culture or status to another (Meleis et al., 1994). Cultural and traditional modifications due to transition influences the dynamics of motivation in caregiving, family caregiving at home, or ceasing to provide care in this setting. These concepts of transition and culture were used as the theoretical framework in this thesis and are intertwined throughout the studies.

Transition

The concept of transition, according to epistemological and ontological convention, is found in both sociological and anthropological sciences and also has its roots in the health sciences (MacIntyre, 1977; Van Gennep, 1960, 2011; Meleis, 2010; Rex, 1968). This theoretical framework, as a unified theoretical framework about the individuals' crossing-over time, is supported and robust in this thesis.

Transitions are often precipitated by significant marker events or turning points that require new patterns of response and prompt the recognition that there is abnormality; as such, new strategies are needed to cope with daily life experience. The conception of transition is defined by different disciplines in different ways. While these differences may not be completely apparent, they do exist. So, for instance, Kralik, Visentin and Loon (2006) describe transition as “going across”, “crossing overtime”, “stage”, “subject” or “place to another”. Meleis (2010) states that the transition which entails several different experiences leads to a change in a person's health or their relationships with other people. It is also sometimes described by Meleis as “a passage from one fairly stable state to another fairly stable state, and it is a process triggered by a change” (Meleis, 2010, p. 11). Furthermore, transition is “inner reorientation and self-redefinition” that people go through in order to incorporate change into their life (Bridges, 2003, p. xii), and it is not just another word for change, but rather connotes the psychological processes involved in adapting to a change event or disruption (Bridges, 2003).

According to Golan (1983), transition can be defined as “movement or passage from one position, state, stage, subject, concept, etc., to another or a passage or change of this kind such as the transition from adolescence to

adulthood” (p. 11). According to a social psychologist’s point of view, Levinson (1981) believes that a transition is a bridge, a boundary zone between two stages of greater stability. Transition also involves an ending, a process of separation or loss. In the light of Levinson’s definition, the separation or loss can be a change of relationship; it can also be that one leaves the country or leaves the home. This also means that a transition period begins, where we leave the past and start a new phase in life.

These definitions denote that a transition period begins when we leave the past behind and start a new phase in life. Through the transition process, an individual may gain his or her integrity as well as a new point of view and perspective on life to accomplish, as Bridges puts it, “inner reorientation and self-redefinition” (Bridges, 2003, p. xii).

Migration as transition is defined more by the change of lifestyle, cultures and living conditions than by the change of physical location (De Anne et al., 2010). The transition of immigration adds to the effects of other transitions, such as transitions in family life, health, occupation and others. Factors that affect the degree to which the person is included in the type of society left and coming into are the age of the person and the person’s gender. There are also several patterns that affect how one reacts to the immigration transition: if the immigration was planned, unplanned, forced, voluntary, temporary, permanent, cyclical, return, regular, legal, undocumented or irregular. Changes and differences associated with migration transitions are immense. There are a variety of changes in social, political, economic and environmental conditions such as different modes of language, religious and cultural expression, but also different or changing educational and employment opportunities. These changes could also be levels of individual family, and community health, welfare and security (De Anne et al., 2010).

Culture and culture as transition

Culture is not a simple concept to define and understand. Shore (1996), for instance, writes: “Culture is not accurately conceived of as a neat packaging of traditions possessed equally by all members of a community. A distributive view of culture sees culture as a complex knowledge system unevenly appropriated in social and political time and space.” (1996, p. 209) According to Gilroy (1987), culture is the structure created by human activity and the life-world articulated by the people living there. Giddens (2003) considers culture in a similar way, related to values, norms, behavioural patterns and material resources.

Culture is not homogenous or static; it is an ongoing process (Giddens et al., 2014; Kleinman et al., 2006; Hannerz, 1992). According to Kleinman's study, the cultural and traditional views of depression in Chinese society do not relate to feeling sad but rather to a feeling of inner pressure, symptoms of pain and discomfort, though this cultural and traditional pattern among Chinese migrants in the United States has changed over time (2004).

Cultural transition could be a self-motivated and active construction performed by individuals, and negotiation as an ongoing process (Gelfand & Brett, 2004). Understanding cultural transition is a central requirement in understanding negotiation, as it may indicate a negotiator's tendency to think that negotiation is primarily a process of building, reconstructing and maintaining relationships, or a process of distributing resources.

Individuals do not always follow traditions (O'Dell, 2002), meaning that traditions gradually become less relevant, while new traditions can be developed or incorporated. From this perspective, "culture" is not a standalone phenomenon; it is not bound and is not a thing one can own. It is a process, something that happens, and it is constantly evolving (O'Dell, 2002). This cultural transition may be a nonstop transition; deep experiences leading to encounters evolving when meeting other cultures (Adler, 1975). Gaunt (2002) argues against the assumption that, within medical anthropology, the person who is once socialized into a particular cultural health system will always prefer medicine and medication within that health system.

Describing immigrants purely through different cultural backgrounds and cultural needs relating to care deprives the different cultures of indigenous peoples, because they (the staff) consider the culture of indigenous people to be self-evident or, as Kamali (2002) notes, universal Western cultures. Such insight and comprehension can go against the values we apply to healthcare and nursing in Sweden.

RATIONALE

The term dementia is an unhelpful term to use since it is not a definition of a disease in itself and does not define the cause of the condition or even the exact nature of the symptoms.

Knowledge about dementia may differ among people moving from their original community (or country) who emigrate to another community (or country), where for instance the Western biomedical system plays a dominant role. Due to a lack of knowledge about dementia, people with dementia may be stigmatized.

Much of the research on cultural aspects of dementia is based on and clarifies the unitary and mono-cultural values, beliefs and traditions set within different societies and countries. The mono-cultural norms and traditions that affect and influence people's views of social welfare, faith, healthcare and ageing are highlighted. The cultural studies on dementia point out the importance of these norms in understanding and dealing with people with dementia or "senility".

According to the SNBHW (2010), coming from same country, sharing the same culture and speaking the same language indicate staff's skills in caregiving for people with dementia.

There is sparse research on how any kind of transition can impact on people's perceptions of ageing, sickness, illness and specifically dementia. Therefore, the reflection and thought patterns of elderly Iranians with dementia in Sweden, their relatives and the staff at a CPNH are the focus of this thesis.

AIMS

The overall aim of the thesis is to study dementia across cultural borders, and the experiences and perceptions of dementia among staff with Iranian origins and backgrounds. Further, the aim is to explore the family caregivers and the family member with dementia's experiences and perceptions of caregiving and the encounter with the Swedish healthcare systems. There is a particular focus on illuminating issues related to so-called culturally profiled caregiving.

Specific aims

- The aim was to explore how dementia and caregiving for dementia are described and viewed among Iranian immigrants living in Sweden. (I)
- The aim was to identify and describe why the family caregivers cease caregiving at home and transfer the family member with dementia to a nursing home instead. (II)
- The aim was to explore the family caregiver's perceptions and experiences of the culturally-profiled nursing home. It is also to explore how they view the culturally profiled nursing home and the formal caregiving provided there. (III)
- The aim was to identify and describe how Iranian residents with dementia perceive living at a culturally profiled nursing home in Sweden. (IV)

METHOD

Design

The design was inspired by an ethnographic approach with interviews and observations (Corbin & Mors, 2003). This approach included interviews with healthcare staff, relatives of the people with dementia and interviews with people with dementia. The design was mostly descriptive. A comprehensive view of the four studies making up this thesis is presented in Table 1.

Table 1. Overview of the design, method and analysis for the four studies

	Study I	Study II	Study III	Study IV
Design	Qualitative interview study	Qualitative interview study	Qualitative interview study	Qualitative interview and observation study
Sample	34 staff members	20 family caregivers	20 family caregivers	10 people with dementia
Data collection	Semi-structured interview	Semi-structured interview	Semi-structured interview	Dementia-friendly interviews, “photovoice”
Data analysis	A blend of content analysis and ethnographic analysis (Elo & Kyngäs, 2008)	A blend of content analysis and ethnographic analysis (Elo & Kyngäs, 2008)	A blend of content analysis and ethnographic analysis (Elo & Kyngäs, 2008)	A blend of content analysis and ethnographic analysis (Elo & Kyngäs, 2008)

Setting and sample

Studies I-IV

The studies were performed in two different Swedish cities, one larger, one smaller. The main source of data (both participant observations and informal interviews) was gathered from a residential care facility (Anahita) targeting people with dementia and who speak Persian, Arabic, Kurdish, Azerbaijani or Armenian. All the names of care facilities, interviewees and participants given in the text are fictitious.

The CPNH, Anahita, is a “culturally-profiled” care unit that specializes in what they call “care with a Persian focus”. This includes the ability to speak Persian with staff, and everything about Anahita should remind the resident of “being at home in Iran”. Hence, furniture, carpets, paintings, smells, food, etc. are all chosen to create this feeling. Things that influence people in their environments during the day are the colours and styles of things that exist within the environment in which they live. The placement of colour, paintings, mirrors and drapes, as well as mats, has meaning in the traditional Iranian home.

Most of the residents’ rooms were decorated with family pictures as well as the person’s old furniture and old mats. The only thing the individual received from the care facility was a bed. In some cases, even different types of perfume had the scent that they used to have before, but not everyone was able to maintain their previous home style.

Paintings by various Iranian artists hung in the corridors. Even though there were small Persian mats, the entire hall was decorated with comfortable furniture and dining tables. There were, however, TVs that only broadcast Persian programmes from Iran, the UK and the US. The smell of Iranian food, especially Iranian cupcakes, grabbed the attention of many residents. The nursing home had organized a prayer room for any resident who would like to perform daily prayers, but this room was never used for its intended purpose, as there was simply no interest in having a prayer room.

At Anahita, each floor has trained nursing staff who are fluent in Persian, Arabic and Swedish. In addition, there is a service that oversees cleaning, breakfast and storage. People living at the nursing home mainly come from the Middle East. Professional staff oversee leisure activities at the care home, and a member of staff is tasked with keeping the older residents both physically and mentally active. There was also a chef who prepared culturally appropriate food.

The other research site, Aphrodite, is a company that provides home care services. It is tailored for people who find care in a home the best solution for maintaining a healthy lifestyle. Its multicultural care initiative consists of various professionals such as social workers, nurses and nursing assistants with a mission to conduct home, social and respite care.

Aphrodite Healthcare is a multicultural company, and its staff speak several languages, including Arabic, Kurdish, Persian, Finnish, Russian, English and Swedish. Some of their clients have been diagnosed with dementia. When a caregiver starts working for the company, they go through an orientation process to learn the company's policies and procedures, CPR (cardiopulmonary resuscitation), cooking and nutrition, communication skills (to strengthen the relationship with the client), safety/risk management, understanding the specific health needs of people with specific diseases or disorders and various other courses.

There were a total of 34 members of staff at Anahita: 27 assistant nurses, 3 certified nurses, 2 managers, 1 director and 1 activity leader.

Of the relatives and informal carers of people with dementia 20 were eligible, and there were 17 eligible people with dementia.

On the ward that catered for advanced dementia, the residents came from various social and professional backgrounds. Their ages were 40+, with residence in Sweden spanning from 10 to 30 years.

Regarding religion, the majority were of the Islamic faith, but there were also several Christians.

Data collection

Through contact with Iranian associations, cultural associations and national federations, contact was established with companies and individuals involved in Persian-targeted healthcare. Based on agreements with the associations and the care companies, designated staff members and I met at pre-planned locations. Before meeting with these participants, translated information sheets in Persian and Arabic had already been prepared.

Interviews

Before interviews were initiated, knowledge was collected by reading several texts in different languages within the subject area. One-to-one chats with staff, family caregivers and residents were performed at different times and recorded as field notes. A semi-structured interview guide was developed based on this knowledge. This thorough preparation meant that no pilot study was needed.

A research interview is a conversation with a purpose (Silverman, 2006). An interview is a way of collecting information or generating data. The question is, as Nunkoosing (2005) notes, why do we interview? What do we want to know? And how can we know? Bryman (2001) made an impassioned plea for the “in-depth interview not to be regarded as a poor cousin of participant observation” (2001, p. XXIII). Bryman argues that an interview contains many of its own outstanding strengths. There are many different types of interviews, but there are four main approaches, namely structured interview, semi-structured interview, thematic open interview and completely open interview (Gubrium & Holstein, 2002; Kvale, 2008). The choice for this research was the semi-structured interview whereby the researcher asks a number of questions which have been chosen in advance, but the interview is not bound to keep to the same questions. The interviewer can follow up an answer with supplementary questions, to clarify issues. Most of the interviews took place at the nursing home. Interviewees were welcome to choose the language for the interview.

Interviews were conducted with three different groups of people: staff, family members/relatives and people living with dementia. As these three groups of people posed different demands in terms of interview techniques, they will be presented under the separate studies.

Observations

Observation is a form of qualitative data collection based on the researcher’s personal experience and understanding. Observations generate most of our “common sense” and cultural knowledge (Johnson, 1975, p. 377). Observing can be an invaluable way of collecting data, because what you see with your own eyes and perceive with your own senses is not filtered by what others might have (self-)reported to you or what the author of some document might have seen.

The fieldwork began in November 2012 and continued until May 2014. The observations were performed on weekdays, weekends, holidays and evenings, and these continued during the summer when most of the regular staff were away on holiday and when temporary replacements began their employment.

During the first visit, I was familiarized with all levels of the nursing home and with the assigned staff for each department. While greeting the residents, my thoughts turned to Spradley’s (1979a) very serious, emotional and lyrical expression when he conceptualized the bond between interviewer and interviewee: “I want to understand the world from your point of view. I want to know what you know in the way that you know it. I want to understand the meaning of your experience, to walk in your shoes, to feel

things as you feel them. Will you become my teacher and help me understand?" (Spradley, 1979a, p. 34)

The central aim of ethnography, as Spradley (1979b) and Skinner (2012) state, is to understand human beings' different ways of life, life patterns and social situations. The resident's everyday life was based on institutionalized life with certain routines and activities.

Every morning, when the night staff gave their nightly report to the day staff, I sat in on their meeting. Afterwards, I followed the day staff as they began their routine work with the residents. The schedule often involved bathing them, dressing them and taking them to the dining room for breakfast. I assisted the staff whenever my help was asked for or required. I often sat with the residents and helped those in need to eat their food. Sitting with the residents was a great opportunity to get closer to them and to give them the time needed to express themselves adequately. After breakfast, those medical staff who were authorized to distribute medication to residents would do so.

Once a week, all sections would come together and play bingo. Another weekly activity was a gymnastics class led by one of the task managers, who had been a professional and spoke several languages. The added benefit of being able to speak several languages was that everyone was able to understand and participate. When the summer heat arrived, it was common for residents from most of the sections to visit the nursing home's ground-level gardens to eat.

Residents' daily routines in the morning (07:00) consisted of waking up, eating breakfast, taking medication and then bathing. (Some would bathe before breakfast, while other preferred to do so after.) Lunchtime began at 12:00. Some individuals required help eating and were assisted by the staff. Again, I often sat with the residents and helped them eat their food. After lunch, residents were accompanied to their own rooms for rest. Those with wheelchairs were walked, with the help of staff, into their rooms. Residents did not always want rest and some preferred to stay in the communal room. Supper was served from 18:00 to 19:00 and, as usual, all residents gathered to eat their supper. During dinner, some residents would complain about their lack of appetite and would refuse to eat the food. Their meal would therefore be replaced with a nutritional drink (Spradley, 1979a; Skinner, 2012).

Study I

Before the interviews with staff, a semi-structured interview guide was developed. Interviews with staff members were challenging. Staff with different knowledge of managing the task, shifting work in uncomfortable times, and facing different kinds of daily challenges both in private and at the

workplace, resulted in long “conversations”. I adjusted my schedule according to when the staff wanted to give me an interview. 34 members of staff were interviewed at the CPNH. Interviews with staff members varied from two to three and a half hours. All interviews were recorded.

The interviews were supplemented during the fieldwork through interaction with the residents as well as observations of the staff at the nursing home. These field notes were written in a diary and recorded.

Studies II-III

In these studies, there were 20 eligible participants and all of them agreed to participate. Before the interviews with family members/relatives, a semi-structured interview guide was developed. In an interview situation, (Study III) there was an interest in the interviewee’s opinions and reasoning on certain topics regarding care, the choice of nursing home, and their views on a CPNH before and after transferring the family member with dementia. Although the checklist was prepared for semi-structured questions, it was the participants themselves who began to tell their “story” or experiences. Often the question began with a request: “Can you tell me about how you found out that your mother/father/spouse was living with dementia?” “Can you tell me about your work?” All interviews were performed at the nursing home. The length of the interviews with family members mainly varied between two and three hours. All interviews were recorded.

The interviews were supplemented during the fieldwork through interaction with the residents as well as observations of the relatives at the nursing home. These field notes were written in a diary and recorded.

Study IV

In study IV, 10 participants were interviewed. They were selected due to their ability to engage in conversation. Interviews with people with dementia require time, patience and flexibility, because they may face some challenges in communicating. People with dementia have difficulties managing discourse topics and will suddenly make topical shifts without advance warning and may also introduce new topics (Ekström, Lindholm, Majlesi & Samuelsson, 2017).

Dementia-friendly interviews were performed. To help people with dementia remember and include them in a conversation, and in order to unravel hidden knowledge, a photo may be the simplest tool, as pictures can help the interviewer gain an unexpected answer. One of the effective visual methodologies that can be used in health research is photo elicitation: using photographs or other visual mediums in an interview to generate verbal

discussion to create data and knowledge (Glaw et al., 2017; Benninger & Savahl 2017).

Photos from the person's own family album were used, and sometimes different pictures, to help the interviewee continue and provide a more detailed conversation, without feeling tense or worried. In addition, we were able to fill in the conversation with new subjects. With the help of photos and pictures, individuals with dementia could describe and discuss their perceptions, experiences and understandings related to the questions, people, times, places, other facts and events in the person's life. Most of the individuals with dementia who were interviewed had gradually forgotten their second language, and it was a precondition that I could adjust myself to their shifts in languages as well as the selected appropriate language during our conversations. Therefore, the interview could be half in Persian and half in Azerbaijani, for instance. Further, because of the progressively decreasing ability to communicate, facial expressions, gestures, touch, eye contact, nearness and voice volume/tone all became more important in interpreting their thoughts. An attentive and active listener can "hear" a lot. As Frank stated (1995, p. 24), "People with dementia can communicate properly – if we are able to hear".

Most of the interviews were carried out in the interviewees' rooms, and this would sometimes be with one of the person's favourite staff members, sometimes with a relative or sometimes just the two of us.

The interviews with people with dementia varied between half an hour and an hour and were completed at different times, since I used to spend a good deal of time with them daily, weekly and monthly. All interviews were recorded. The interviews were supplemented during the fieldwork through interaction with the residents as well as observations of the nursing home. These field notes from observations were also recorded.

Data analysis

Content analysis is a research method for making replicable and valid inferences from data in relation to their context, with the purpose of providing knowledge, new insights, a representation of facts and a practical guide to action (Krippendorff, 1980). An inductive design/approach was chosen. As Patton (2002) noted, the strategy behind inductive designs is to allow important analysis dimensions to emerge from patterns found in the studied cases, without presupposing in advance what the important dimensions will be.

The content in this type of analysis is the text being analysed, while ethnographic analysis, on the other hand, frequently emphasizes cultural and traditional phenomena such as ideas, mindsets, symbols or meanings.

Sometimes in the form of cultural symbols, behavioural patterns and material conditions, ethnographic work is characterized by continuous feedback between theory and empirical theory, where theories are more likely to provide direction (Thorne, 2000). The analysis here was combined with ethnography, aiming for understanding, social contexts, activities, environments, people and actions in this specific field of culturally profiled nursing homes (Brewer, 2000).

Studies I-IV

The collected data consisted of verbatim transcribed audio-recorded interviews with staff, relatives and residents, audio-recorded field notes such as passive observation aligned with watching, listening and learning, and all kinds of field notes. Data was analysed using the four steps presented by Elo and Kyngäs (2008):

- 1). Each individual interview was read in each group several times, to get a clear picture of the interview.
- 2). Each interview with collected observations as field notes related to the respective interview was coded within each group. Encoding is part of the analysis and coded material is necessary for a deeper and more detailed analysis. Coding involves paying attention to keywords that repeatedly come up and represent what the informant says. Codes were compared in terms of similarities and differences, to be grouped and categorized into categories and subcategories. Such examples from the interviews included material related to “move my mother”, “transfer my mother”, “locate my mother” or “I had problem with caring”, “lots of the problems with caring were because of...”, “the main problem in caring...”
- 3). Categorizing. After coding, there was categorization. The category represents the fundamental meaning of the subject in terms of what the interviewee narrates, not only bringing together similar categories, but also classifying them according to where they belong in their content. The category was designated after discovering what the interviewee was taking about.
- 4). Abstraction. The next step was to go through each category and code them into a category or a subcategory, where general descriptions are formulated. Each category was labelled with some content characteristics (Elo & Kyngäs, 2008).

The analysis has been discussed as a source for further processing with other researchers.

Ethical considerations

The study has undergone ethical vetting by the Ethical Review Board (EPN) and has been approved (Rec. No.: 2012/180-31). All studies have been performed in accordance with the Declaration of Helsinki (World Medical Association, 2013). All participants, the people with dementia, their relatives as well as all staff, were given verbal and written information about the study and all people included in the study gave their written consent. As in all studies concerning humans one should be observant and in tune with one's informants, but perhaps even more so in studies that concern people with dementia diseases, which can leave them uncertain about what is going on in what context (McKillop & Wilkinson, 2004). Therefore, I have been particularly aware of the daily moods of the people with dementia; if they did not seem to remember me or seemed particularly tired or anxious that day, I either tried to be there for them, as a fellow human being rather than a researcher, or I would let them be until they felt better. In many situations when it was not easy to interpret the signals, I was more observant. When the person with dementia had difficulties expressing their need I tried to help and support in best way. This study did not use the names of the informants; instead, a pseudonym was applied. Providing a fair image/picture of the informants, without taking note of others' portrayals, is an important aspect that should be included with the ethical ruleset. In addition, using a language with which an informant is comfortable is the right of that person.

When I, together with the principal of the nursing home, visited departments in the unit, one person said: "On this ward, people with advanced dementia live, and there is nothing for a researcher to study." I had to consider this as an ethical challenge. I chose this ward to start with, first with a view to respecting the person's human rights (World Medical Association, 2013) and allowing them to express themselves and use their own voice to articulate their thoughts, not to use someone else's assessment. Second, I was very interested in meeting these people, talking with them and communicating with them without any assessment or valuation of an individual with dementia made by others. When the staff do not relate to the person in front of them, but to the constructed image of the person before I meet them, this is a case of stigmatization. I believe that it is unethical to see people with dementia as their diagnosis. An ethical approach should be distinctive, for all staff in healthcare, to eliminate every kind of stigmatization towards people with dementia.

Trustworthiness

Lincoln and Guba (1985) suggest four criteria for establishing trustworthiness: credibility, dependability, confirmability and transferability. In these four studies (I-IV), using qualitative content analysis according to Elo and Kyngäs (2008), the term ‘trustworthiness’ includes the terms mentioned above.

When establishing credibility, researchers must ensure that those participating in the research are identified and described accurately. The purpose of credibility in a qualitative study is to support the argument that the results of the request for information are “worth mentioning” (Lincoln & Guba, 1985). As Elo et al. (2014) point out, this is especially important when using inductive content analysis as categories are created.

Lincoln and Guba (1985) further emphasize that what is needed in order to increase credible findings is prolonged engagement, persistent observation and triangulation. They also note that “prolonged engagement is the investment of sufficient time to achieve certain purposes: learning the ‘culture’, testing for misinformation introduced by distortions either of the self or of the respondents, and building trust” (Lincoln & Guba, 1985, p. 301). As mentioned earlier, data was collected by being in the field for years and establishing trust has been a central part of the research.

Dependability is one of the terms Lincoln and Guba (1985) highlight, in that dependability and credibility are involved together, and without one, the other would not exist. Dependability is an important criterion to consider, and the social reality of the participants should be explained correctly and accurately. In this regard the researcher is responsible, and it is his or her task to describe the reality that the participants experience and deliver. Time was spent, both during day and at night, with those participants living in the nursing home. They were interviewed, observed, taken for walks and had “fika” (a Swedish social gathering). Furthermore, time was spent together with residents at their relatives’/family members’ home, involving several hours of listening to conversations and observing. In addition to the interviews, all observations were recorded and written in a diary, based purely on what these people said, without introducing my own or other people’s opinions and interpretations. All interviews and translations thereof were checked by native speakers of the relevant language.

Confirmability refers to data accuracy by checking the relevance or meaning with at least two independent people. The most essential element is the responsibility the researcher carries concerning credibility and confirmability. As Elo et al. (2014) note, all researchers must consider how to confirm the credibility and conformability of the organization phase.

Confirmability of findings means that the data accurately represents the information that the participants provided and that interpretations of this data are not invented by the researcher.

Although all the questions were well designed, they were discussed with two other experienced researchers. Communicating with the individual with dementia involved understanding the participant correctly, but this does not mean there were no errors. Confirmability is also strengthened by using quotations to show what the participants stated, and these have been used in these studies.

Transferability refers to the extent to which the findings can be transferred to other settings or groups, often similar groups (Graneheim & Lundman 2004; Lincoln & Guba, 1985). One strategy to establish transferability is a clear description of data collection and the process of data analysis, and as Thomas and Magilvy (2011) state, a vigorous presentation of the findings together with appropriate quotations will also enhance transferability. These strategies were used throughout the whole research process.

RESULTS

The most essential finding of each study is presented separately below, and the theoretical framework is applied to reach a deeper understanding of the phenomenon being studied.

What is dementia according to the staff? (Study I)

Dementia is not only a medical term – it also has societal and sociological as well as cultural and human contexts, and yet some still wrestle with the syndrome now known as *dementia*. The notion of dementia during human history has undergone transition, and there may be further transition in future.

Study I identified three main findings and contributes to establishing how dementia can be understood and experienced by Iranian staff at a CPNH in Sweden. People from different cultures have different preconceptions of what constitutes dementia, and these preconceptions influence health maintenance, health-seeking and caregiving behaviour. These perceptions may lead to misunderstandings regarding health-seeking and caregiving.

The second finding is that the view of dementia and its perception can have a decisive impact on how to manage the caregiving and well-being of people with the condition. Individual assessments as a sign of ageing or other psychosocial factors are widespread in many different societies. The knowledge deficiency in perceiving dementia and caregiving in dementia among staff has been emphasized differently in different countries. In order to increase or maintain the quality of life of a person with dementia living at a CPNH, the formal caregiver's knowledge and competence is an essential requirement. It is often argued that staff with good knowledge provide better care and show better attitudes towards people with dementia.

Even though some of the Iranian staff have had longer experience of working within the area, they felt uncomfortable with their primary knowledge. Knowledge about dementia among the interviewees varied. Although many of them had undergone nursing training in Sweden, they claimed not to have much knowledge about dementia. Sometimes the staff interpreted dementia as delirium, and why a person with depression should live here in nursing home was a constant question. Perceptions of

dementia can be based on cultural and traditional understanding and beliefs, but this understanding can shift and transition by accumulating knowledge. In many cases, culture can be described through processes or facts about the person's personal endeavours and accomplishments. In all countries, regardless of culture, there are different views on human behaviour, especially dementia. What we all know is that culture itself is not static. This means that culture is changing. The person's view is changed and transformed through experiences, social learning and education.

The third finding that study I identified was that culturally profiled dementia care strives to live up to the ideals of so-called "Iranian culture". Regardless of how culture can be exercised, it may be linked or closely related to several conditions. For some, culture may appear as a well-ordered packaging of traditions that may influence all members of a community equally.

The CPNH aimed to be Iranian, by offering residents a diet that was familiar and more essentially by speaking the same language which facilitated togetherness, and considered cultural matters and possibilities that in one way or another was expressive. After all, the presence of such an institution for Iranians in Sweden is an indication of cultural transition influenced by other transitions.

Regardless of whether or not a nursing home is profiled culturally, institutions still follow the healthcare guidelines in Sweden. Transition in the forms of cultural, social, political or economic aspects is an ongoing process, irrespective of how much one would like to maintain the culture.

Why do Iranian family caregivers living in Sweden cease caregiving at home? (Study II)

In Iranian society, as in many other societies, families' expectations surrounding being cared for during old age by their own children varied, but many had high expectations. Some believed the family has a major responsibility to take care of their elderly and less fortunate family members.

Within the family network, people have had their own roles and duties in relation to the elderly. In different times, family caregiving has radically changed in Iranian families. The interviews with former caregiving relatives presented and analysed here reveal the main reason for the transition to residential care: namely "sheer exhaustion". In other words, the existing lifestyle in Sweden was incompatible with caring for elderly relatives.

Irrespective of other facts that require family caregivers to take a step back, different social transitions meant moving family members with dementia to nursing homes.

In this study, the analysis led to the transition process. This transition process was presented as four categories: Pre-decision, Decision, Transition and New life. Several sub-categories made up these categories.

Pre-decision is one of the main categories in the transition process, built upon several merged subcategories, namely intra-familial process, lack of physical skill, and lack of social constraints.

The pre-decision phase in caregiving is highly dependent on cultural and personal perceptions of dementia. As the symptoms become more evident and start to affect everyday life in a family, the need to understand the syndrome and the provisions becomes obvious. Transition therefore involves several different experiences.

The family ceased caregiving at home, not only due to different physical and psychosocial issues, but also because of the transition into the new society in which they live. The mere fact that a nursing home is a *culturally profiled residential care home* proved to be crucial in making the decision to cease caregiving at home. It also seemed to ease the guilt that family members felt about not fulfilling their duty of filial piety. According to several of the interviewees in the study, moving the person with dementia to a culturally profiled nursing home was part of “lovingly deceiving” their relatives that they were, somehow, back home in Iran.

Migration as part of transition involves changes in lifestyle and culture rather than physical location. This can give rise to different challenges and opportunities. Family caregiving may be culturally divorced, but nevertheless the motivation of someone, and a different lifestyle in terms of being culturally transited, may decrease the obligation of family caregiving. Intra-family conflict is often caused by the cultural transition and adaption to a new lifestyle, rather than to traditional norms and expectations.

A lack of physical skills and social constraints can inhibit family caregiving, because being able to take care of a family member with dementia requires both physical and mental strength, and there is a clear need for professional care. These effects could be seen in Swedish caregivers as well as immigrant caregivers, but giving up the obligations to end caregiving at home as cultural and traditional demands is a form of transition.

Making the decision, the second main category, is based on finding and collecting information and excluding the family member with dementia. Culturally, Iranians, just like many other nationalities, have deep respect for their elders and they take on the responsibility of caring for elderly family members in their own homes.

Almost all participants initially cared for a family member with dementia at home. According to Iranian family traditions, children make decisions for elderly family members in need of help; however, in the presence of progressive dementia, the subsequent crisis the family faces intensifies

the unavoidable decision to transfer the elderly family member to a nursing home. Ensuring the care of a family member with dementia is a process of transition. Such an institution, a nursing home, is a clear indication of cultural transition, which is caused by significant turning points that require new responses and prompt new strategies to cope with daily life experiences.

Regardless of how family caregiving is a traditionally and culturally negotiated subject between culturally different families, they face another aspect of traditional or cultural negotiation in the form of roles and duties. Family caregivers' positive attitudes towards nursing homes made it easier for them to make the decision to admit their relative. There is no indication that any of these family caregivers aimed to shirk responsibility, but family caregiving was no longer a strong and vital cultural or traditional calling and was not viewed as an essential part of the female role. "Once you've resigned yourself to losing gracefully, it doesn't mean you're totally off the hook. You still have a responsibility for your parent's health and welfare issues. You still want to help them and protect them. There are certain battles that are important for you to win." The CPNH is crucial in the decision to cease looking after a relative at home. To some extent, a CPNH seems to make sure that a mother or father is taken care of by someone who speaks the same language and has a connected cultural background. It feels safe and secure. Therefore, this must be a cultural transition.

Despite the cultural transition, the family member with dementia was almost always excluded from the decision to be transferred to the nursing home. Furthermore, family caregivers generally did not exclude their family member from the decision out of carelessness or a lack of concern, but were rather focused on their well-being.

Transitions from home to nursing home showed various reactions and strategies. Falsehoods and loving deceptions were used to persuade the elderly family member to move. Regardless of how family caregivers were concerned about the well-being of their relatives, there were several barriers to transferring them to the CPNH because of different legal restrictions. Those families living within certain municipalities/district boundaries must deal with the respective municipal rules, which complicate the process of enrolling in the new nursing home. They are required to meet with various responsible authorities to obtain permission to move into the chosen facility, and this often takes longer than one might have originally anticipated.

New life for family caregivers and a new life for the family members with dementia is the fourth category of the identified findings. Despite the duration of caregiving at home, the family caregivers were relieved and satisfied. The decision, and the result of the move, is understood as being ben-

eficial for all concerned, i.e. for both the person with dementia and the family caregiver. They are still able to provide for their loved ones, and they frequently visit the nursing home and help their mothers and fathers (or sometimes husbands and wives) with many things, but the main responsibility has gone and almost all of them express a sense of relief at being able to live their own life.

Iranian relatives' attitudes towards culturally profiled nursing homes for individuals living with dementia (Study III)

Three main categories were identified. The first category is about nursing homes in Iran.

Iranian nursing homes are generally based on peoples' economic and social status. Nursing homes operating under the welfare state in every province in urban areas provide care for the helpless and usually homeless elderly people who have nowhere to go. Many of these nursing homes are charitable organizations. There are also nursing homes that will provide care free of charge for people who cannot afford the fees, and a subsidized fee for those who can afford it. The latter examples are privately run nursing homes with set fees. As people go through different types of sociocultural, socio-structural and economically negotiated transitions, different cultural, traditional, structural, social and economic modifications will arise. Culture is an ongoing process, and it is constantly evolving. It never stands still, and it will never be finished. Varieties of social changes are a result of different transitions, and certain factors contribute to the rise of nursing homes in Iran. These different factors are clear indications of cultural transition, that is an active construction performed by people, and negotiation is an ongoing process.

The experiences of living in another country may change a person's perceptions about his or her former society, depending on the motivation behind the person's migration. Transition is an "inner reorientation and self-redefinition" that people go through to incorporate change into their life (Bridges, 2003). None of the interviewees had personal experiences of any nursing home in Iran, and yet they had negative views about these facilities. Positive views of the cultural nursing home were evaluated alongside participants' perceptions of Iranian examples, despite having no direct personal experience of them. Problems with Iranian nursing homes were described in terms of defective hygiene, high costs, shared facilities and difficulties for the patient in adapting to collective life.

However, while many of the elderly people with modest incomes need immediate care in a nursing home, they cannot easily afford to be admitted to a private one, and their admission to a public home is not particularly easy, due to limited beds.

Many of the interviewees admitted that they would never be able to afford the high cost of private nursing homes in Iran.

Nursing homes in the new homeland is the second identified category.

Swedish nursing homes have also undergone transitions as Sweden has become more multicultural. Nursing homes with only Swedish-speaking staff have not been without problems for some residents/patients. Language is important when communicating, and enhances daily engagement with residents and relatives. People undergo a transition when they need to adapt to new situations or circumstances to incorporate the change event into their lives. As we know, people with dementia gradually forget the second and third languages they may have learned during their lifetime to adjust themselves to the society they live in. The only language they are left with is their mother tongue. Memory loss should be considered as a transition, and transition accommodates both the continuities and the discontinuities in the life processes of human beings.

Negative views of Swedish nursing homes were evaluated alongside what the participants considered to be 'typically' Swedish. Despite gratitude to the nursing home and positive views of the work style and structure, there were complaints regarding communication between staff and residents, due to language difficulties.

As a result, staff often contacted the family to try to resolve any issues that might arise, and this disturbed the family badly. The third and last category is the current CPNH.

Family members differed in their views about the CPNH, due to underlying factors such as a perceived lack of care, of genuine engagement with patients, of cooperation between staff and family, and of good staff behaviour. A sense of stigma towards the person with dementia and a lack of deeper care (as can only be provided by family members) were also sources of dissatisfaction.

Regardless of how much one displays fluency in one's own language, a lack of knowledge about dementia and caregiving can give rise to uncertainty in the roles undertaken by nurses and nursing assistants. Comparing Persian-speaking staff's moral standing with that of Swedish speakers gave rise to negative views about the CPNH, while stigmatizing residents affected family caregivers emotionally. One of the indicating factors of transition is education. Accumulating knowledge is personal and is based on personal situations and motivation as well as definitions and re-definitions

of self and situations. Accumulated knowledge can enable staff to act with competence.

The generation gap and generational incoherence, and a lack of knowledge among staff about the standard of living of residents in Iran before the Revolution and the war, led to an extremely negative picture of the CPNH.

When people leave the past and start a new phase in life, a transition period begins. Generational confusion may, in some cases, be the result of cultural transition. Separation as a transition is not only manifested in physical form; separation from the generation is in many respects an ongoing process and transition. The alteration of people's lifestyle or significant efforts to improve their life, adaptation or participation in society and social order, involves "going across". Generational incoherence may be subject to many different transitions, which structure their lifestyle and view.

Additionally, several family members had a sense of pride and even social status for their family member with dementia after moving to the CPNH. They were pleased to inform their relatives and friends in Iran, in Sweden and overseas that their relatives were residing in a home as good as a luxury hotel, complete with a separate room, shower, toilet, Iranian food and Persian-speaking staff as nurses, assistant nurses and doctors. The CPNH became a desired contingency approach that suited their purpose. This is a transition; the way people respond to change over time.

How Iranian residents living with dementia feel at home at a CPNH in Sweden (Study IV)

This study contributes to understanding the feelings and perceptions of residents with dementia who moved to Sweden to be with their children, or at least to live close to their children, but who ultimately and unexpectedly preferred to live without their children's help and support.

This study identified the category 'home is a place to **escape to** – from the former homeland'.

'A place to escape to' is based on the participant's background in their former homeland, since the place a person has grown up in is the foundation of their memories. The identified results of the consequence of escaping from the place include the family as an institution, transition and oppression, national occurrences/changes. Transformation of the traditional family structure, i.e. treating the family as an institution, was demanding for almost all of the female participants in Iran. Gender inequality is widespread in many countries and societies. A traditional society's demands placed on women or wives are oppressive, distressing and demoralizing,

and leave many sad memories for those who faced physical and psychological violence. The war and the Revolution were major examples of national transition. Transitions involve making sense of life's changes, and change is situational. Transition is not just another word for change, but change prepares the person for the transition. All the participants moved to Sweden due to family reunification, although this did come with several problems.

The greatest cause of feeling secure was being together with family members in Sweden, and the participants chose to move their lives to Sweden mostly as "a place to escape to".

Family members' new lives gave rise to cultural and traditional perceptions of family construction, family relations and family obligation. Despite family conflict, however, family cohesion was still strong within the family and between the relatives. This sense of community and unity was shown in the replacement of certain features such as being the family caregiver for some years, and ultimately the final decision to transfer the person to a CPNH was made by family caregivers. Transition here includes disconnectedness, perception and response. Transition denotes a process of changes in role, relationships and expectations; it is variations in a person's life journey such as changes in health and abilities.

The second main category of identified finding is 'Home is a place to **be at** – a new homeland'.

Participants had left their previous established network back in Iran. Participants' new homes and lives in Sweden represent a transition. A pivotal transition is a transition that changes everything in a person's life. It is a transition that all other parts of a person's life depend upon.

The significance of the reunification was that the family – according to the elderly family member's expectations – live together or live close to each other.

Participants had left their previous established network in Iran, and the lack of a new network and their children's new lifestyles sometimes intensified the feeling of solitude. A transition from an ordinary life to an extraordinary life with dementia can be demanding and confounding. This separation transition, as well as the transition process with variations in a person's life journey such as changes in health and abilities, may intensify the feeling of solitude for the time being.

Family conflict concerning caring for an elderly family member arose due to the present lifestyles of family caregivers in Sweden. The traditional ambition and aspiration to take care of an elderly family member loses its sincerity, and seeing the caregiving as his or her personal responsibility is exchanged for other options, in this case placing the family member with dementia in a CPNH.

The third identified main category is 'Home is a place to **live in** – a nursing home'.

Home is not a secure place, sanctuary or refuge for all people. Taking the feeling of home into account, the person's personal experiences played a key role, and all of them stated that the CPNH was a place in which to live. Family conflict concerning caring for an elderly family member arose due to the present lifestyles of family caregivers in Sweden. Any change in someone's lifestyle is a transition. The traditional ambition and aspiration to take care of an elderly family member changed. Regardless of the family caregivers' suggestions and decisions, various aspects that affect the transitional process for a person with dementia may be the relocation; moving from one environment to another, for various reasons. Transition also involves an ending, a process of separation or losses. Perceptions of separation as a transition vary, and managing separation as a transition can be personal.

Residents' life changes as a transition also have an impact on their points of view and their expectations of their children, and a transition away from the traditional way of valuing children's presence.

Many of the participants' memories of their homes in Iran were often very unfortunate and sorrowful, while some described their former lives with longing and said that their feeling of insecurity in Sweden and not having family members around them in the country meant that they did not have a feeling or a sense of home. How people respond to changes over time is a transition.

Almost all the participants had difficulties understanding staff's social and national knowledge, and were therefore often lonely. Life in the nursing home, however, was tolerable, as it afforded them a sense of privacy and independence from their children. However, the feeling of autonomy and satisfaction in a CPNH, the feeling of being independent of their children's help, meditating the way they want without being criticized and receiving medical help all gave them a sense of security and encouraged them to stay in the nursing home. People undergo a transition when they need to adapt to new situations or circumstances to incorporate the change event into their lives. By being able to speak their native language and having a familiar diet, these participants went through a kind of repatriation transition or mental domestic and geographic transitions.

DISCUSSION

Discussion of results

The focus in this thesis is on exploring how dementia can be understood by Iranian staff working at the CPNH, why family caregivers end caregiving at home, how family caregivers perceive the CPNH and how residents with dementia feel at home in the CPNH.

What is dementia according to the staff?

Views and knowledge about dementia can have a decisive impact on how to manage the caregiving and well-being of people with the condition.

The staff who handled daily work had different views about dementia, but after studying in Sweden they began to understand what it involves. This lack of knowledge is not unique to Iranian staff. Several studies that have been conducted in the UK and Scandinavia have identified that there are still staff who have a poor understanding of and knowledge about dementia; for instance, a recent survey by the Royal College of Nursing (RCN) (2011) emphasized that poor levels of awareness, insufficient communication and a lack of understanding in terms of dementia are noticeable. The staff in the present thesis stated that ongoing training, to respond appropriately to the needs of residents with dementia, is a necessity. As Dewing and Dijk (2016) state, a lack of dementia education affects the quality of care. It was noteworthy that the results showed that doctors felt more adequately trained in dementia care than nurses and healthcare assistants, even though the latter two groups are most involved in direct care (Dewing & Dijk, 2016). Similar results regarding a general lack of knowledge about dementia were observed, in that there were no individual development plans for the staff and almost everyone felt that there was insufficient continued education where they worked (Albinsson & Strang, 2002). The authors stated that knowledge at all levels was poor with respect to dementia care. Another example that is a clear indication of a lack of knowledge about dementia can be found in Evripidou et al. (2018), who identified significant deficits relating to the care of people with dementia among nurses and stated that these findings have been consistent over time. Another study (Kada, Sundaran et al., 2009) showed significant attitudinal differences among staff according to varying levels of education, different age groups, lengths of work experience, staff who work in nursing homes of differing sizes and nurses with and without further specialized training. The authors proposed that the knowledge should effectively increase and improve attitudes towards people with dementia if there was training and education at

the worksite (Sundaran Kada et al., 2009). Similar reflections are to be found in Lintern et al.'s (2000) study, stating that education and training may result in improved staff attitudes and skills, but residents only benefit if management is determined to change and overcome the barriers to person-centred care. This kind of care requires principled communication and interaction. Another reflection on knowledge comes from Jonasson et al. (2017, p. 438): "knowledge not only builds on an observant and responsive attitude but also includes the wish to understand the patient's needs as a starting point for care improvement together with colleagues."

The multicultural societies of today will continue long into the future, so it is important to overcome several deficiencies that may be spatially disturbing within healthcare services. The influence of cultural expectations regarding care may be demanding, and consequently care results will become important. However, Ekman (2007, p. 417) stated that: "there is a lack of knowledge about how culturally transited care should be understood and implemented in the healthcare system. Healthcare services need to be adjusted to the needs of the culturally diverse patients instead of the other way around." In this thesis, the CPNH strives to live up to the ideals of so-called "Iranian culture" as a way of meeting these demands.

According to Ekman (2007), working with culturally diverse populations requires sensitivity to cultural beliefs and needs, as well as specific knowledge, skills and awareness of a person's world. Having knowledge about which language and symbols a person uses "informs the caregivers of specific communication patterns" (ibid.), a notion with which I agree to some extent, along with Ekman.

Studies conducted by Ekman et al. (1994, 1996) in Sweden at a Finnish nursing home focused only on the linguistic aspect of the profiled residential care. There is an awareness that, not only culturally but also linguistically, people with migrant backgrounds are heterogeneous, even in contemporary Swedish multicultural society. The need for a CPNH linked to contemporary health and social care for older people with immigrant backgrounds was highlighted by Heikkilä, Sarvimäki and Ekman (2007). They stated that many older Finnish immigrants wish to be provided with care in their own language, and by members of their own ethnic group, and this has been shown to be "beneficial for the older patients" (Heikkilä, Sarvimäki & Ekman, 2007).

Swedish society is multicultural. As Kleinman et al. (2006) emphasize, for instance, culture is not homogenous or static, and in many cases, it can be described through processes or facts pertinent to an individual's personal endeavours and accomplishments. Across the globe, regardless of culture, there are different views on human behaviours, especially dementia. What we all know, however, is that culture itself is not static, which by definition means it is constantly changing. A person's view is changed and

transformed through experiences, otherwise known as ‘social learning’, especially in the light of socio-economic, sociocultural and socio-political transitions. There may be signs in this thesis indicating that the perception of dementia may be based on cultural understanding, but a lack of knowledge is also an essential factor that should be taken into consideration.

In order to provide care according to the SNBHW (2017) care model, it is important to consider needs that are related to people with a different cultural or linguistic background. Cultural considerations include giving the person the opportunity to practice their religion, eat culturally adapted foods and have access to staff who speak the same language. In this regard, care is realized through such solutions, and this was shown in the results of this thesis. One may certainly understand that it is a holistic truth that a common language may be one of the essential tools for communicating and maintaining a connection with a person living with dementia in a nursing home. Nevertheless, when discussing care in this setting, they (SNBHW, 2017) do not mention the quality of *communication*, *understanding* and *relationships*. To assure well-being when there is a lack of quality in communication and understanding would not be truthful and realistic. One of the lacking qualities of communication and understanding can be the result of generational, sociohistorical experiences among the staff.

“Iranian culture”, as with many other cultures, is of course not *one* static thing or a psychological state. One interviewee in this thesis mentioned this in a meeting she had with her manager, who told her: “Please act like an Iranian.” This agrees with what Shore (1996) stated; it seems for some that culture appears as a well-ordered packaging of traditions that influences all members of a community equally.

Some of the younger staff at the CPNH not only failed to forge a relationship with the older generation, they totally missed the experience of living in Iran. One should not expect that they would be able to communicate with a person with dementia without facing any challenges. This is what Levinson (1981) calls the ‘generation gap’. In the present thesis, difficulties that the residents encountered with members of staff included managing sociocultural understanding. Staff mentioned on many occasions that the pictures residents had in their rooms were of American Hollywood stars, but the truth was that they belonged to the residents, regardless of the subject matter. This is an issue of generation differences, bringing forth different knowledge and understanding, which could be explained by Pilcher (1994). Apart from society, cultures and traditions, ‘generation’ often defines the differences between ‘my generation’ and ‘the older generation’.

Iran has gone through many transitions, such as revolution and war, resulting in many kinds of social and economic alterations that have had

an impact on all generations. According to the Iranian Sociological Association (2004), an increasing age gap between parents and children makes each cohort stick to its own generation, with each one searching for different sets of values. If such values have very significant differences, and each generation fails to comply with the values of another generation, a gap will be created.

I believe that, as people, we all belong to a chain of different living styles, patterns, principles, characters, patterns of thought and social and psychological tests that make up so-called 'personal culture'. The focus, therefore, should be based on people's conditions and circumstances. Our experience of illness and our subsequent reactions have been and are different overtime. Culture may affect all areas of life, and its impact on health may be considered great; for example, it plays a crucial role in identifying what we consider to be mental disease, in what guise such a disease occurs and how we are expected to care for someone in this situation. Every person's culture has a strong impact on perceptions, feelings and the like, as well as on diagnostic processes and treatment decisions (Meleis, 2010). Better awareness about these aspects will improve care.

Caring for people does not always depend purely on medical science. One essential fact in this regard is the elementary and very simple need for feelings of safety, security, joy and hope in a healthcare setting. This may be achieved by sharing one's feelings, ideas, beliefs and values with a patient and seeking to understand why they feel the way they feel. It is important to have the competence to meet these people's unique and complex needs (i.e. people with dementia). As Meranius, MS and Josefsson, K. (2016) point out, increased staff competence in this regard may lead to improved understanding and a willingness to promote cooperation, availability and continuity (Meranius, MS. & Josefsson, K. 2016).

The Iranian staff genuinely wanted to learn more about dementia, to help manage daily communication with the residents. On another point, the staff admitted that simply being able to speak a person's native language was not good enough to claim that they were actually communicating: "No matter how good anyone is at speaking Persian with residents with dementia, we still do not know how to speak to them."

Despite the staff members' ambitions and desires to learn about dementia and to communicate with residents, there was another obstacle, namely speaking understandable Farsi/Persian without knowing the part of Iran in which the resident had lived before migration. Furthermore, without any knowledge about the resident's background, contextual experiences led to social isolation and a sense of loneliness and friendlessness. Having knowledge about a person with dementia's early life was highlighted by Söderman et al. (2018), who stated that knowing their language and details of their early life could be a way of understanding those with

dementia; otherwise, this could present a challenge for residents and healthcare professionals in their daily work.

I believe that regardless of any cultural understanding or perception of dementia, stigmatization is a severe issue that many – and at the very least those within the care service – should take seriously, since it can lead to aggravation and the weakening of family and staff cooperation as well as diminishing the quality of caregiving/nursing. According to the participants and interviewees in this thesis, the generation gap, i.e. a generational disconnection aligned with a lack of knowledge, has led to many misunderstandings and misinterpretations of the residents as the people they are. Labelling and stigma often reflect a lack of knowledge, and their purpose and intention can consciously or unconsciously degrade or dishonour people. Targeting people with dementia by stigmatizing them can certainly affect both the quality of caregiving and family caregivers emotionally. Furthermore, from my viewpoint, stigmatization means excluding a person from all kinds of social relations and gatherings.

Why do Iranian family caregivers living in Sweden cease caregiving at home and Iranian relatives' attitudes towards culturally profiled nursing homes for individuals living with dementia

Iranian families in this thesis had often been carers for a long period in their new Swedish homeland, before finally transferring family members to a nursing home. Relatives' desire to take care of and take responsibility for their elderly family members in their own home or in the elderly person's abode is not a new phenomenon. According to policies in different Swedish municipalities, family caregivers have the right to be employed by the municipality to take care of an elderly family member in need of specific help (SNBHW, 2012).

Ceasing family caregiving is the outcome of several elements, but among nationally and culturally transited families, the main reason is the character of advanced dementia.

The cognitive challenges experienced by the person with dementia became so obvious that, over time, the everyday life of the caregiver became hindered by various demands and, regardless of intra-family conflicts, the need for professional help for the family member with dementia grew. The family caregivers had different experiences. Multiple difficulties led the family caregivers to the decision to transfer their beloved relatives with dementia to a culturally profiled nursing home. Sometimes, the difficulty was due to the person with dementia's life-world, which differed from that of their children and others in the surrounding area, making it difficult for families to cope. One interviewee even described the time of her life when she cared for her mother with dementia as a nightmare, involving dealing

with many traumatizing events. One example in particular was when her mother had set the house on fire while smoking. Family caregivers providing care at home for the family member with dementia carry a so-called caregiver burden, which is in agreement with Etters et al. (2008). Many family caregivers dealt with social pressure, as they could potentially be blamed by other relatives if their loved one with dementia were to come to any harm while under their care. Omeri (1997) states that Iranians are not willing to transfer their own family members to a nursing home. Family caregivers in this thesis face many different hurdles, but nonetheless the notions of capacity, ability and management, as outlined in McGrew and Hirschfeld's theory (McGrew, 1995 & Hirschfeld, 1978), make it easier to understand why culturally and nationally transited family caregivers cease to provide care at home and instead choose a nursing home for family members with dementia. Those family members who experienced physical and social problems due to exhausting tasks and a lack of informal and formal support from the outset came to the conclusion that it would be safer to transfer the family member with dementia to a nursing home.

Some family caregivers intended to give themselves a break from caregiving, to provide them with time for life together with their children who lived outside of Sweden. This break, however, was only partial, as the family caregiver still assumed responsibility for the family member with dementia. Another essential conclusion concerning family caregiving was not only for how long they continued to care for a family member; the most vital change was the change of traditional structure and the structure of family caregiving within the family through transition in Sweden.

Moreover, according to Omeri (1997), the reason why Iranians are reluctant to accept formal institutional care is due to cultural differences, but my findings are quite to the contrary in this regard. Iranians in this thesis live under the influence of great ongoing process, depending on their social resources, social principles, values, attitudes, beliefs and experiences of current and historical developments in Iran. Such an ongoing process includes the current rise of distinctiveness in Iran, the increased number of elderly people cared for by a growing group of individualistic, young people and a clash between the increased need for nursing home places for the elderly, different private nursing homes and the transition of cultural traditions of elderly people being cared for by the extended family at home. Iranian family caregivers may be more willing to turn to institutions for assistance, even though these services are culturally considered a private duty. Iranians seem to be disconnecting from extended families and moving towards a tighter nuclear family unit. In modern society, the tradition of the extended family is challenged by the fact that it is not always possible for individuals to follow traditional guidelines as they were expected to in the past.

Furthermore, Hajighasemi (1994), in contrast to Omeri, states that children have ended the tradition of caregiving at home because of acclimatization or acculturation into society. One reflection here is that the suitability of caregiving may change for many reasons, and ceasing it may be the outcome of several elements rather than acclimatization or acculturation. Presumably, Hajighasemi and Omeri may not have taken into consideration the impact of numbers of actualities and above all transition.

Family caregivers in this thesis ended caregiving at home, not only due to different physical and psychosocial issues, but also because of transition into the society in which they live. This is in agreement with a study by Lee et al. (2004), who emphasized that Korean families face difficulties in following traditional family caregiving and a belief in traditional filial piety in Canada. There is no indication in Lee et al. (2004) that any of these family caregivers' aims were to shirk responsibility. However, family caregiving is or was no longer a strong and vital cultural or traditional calling.

According to my point of view, cultural transition can influence some people because they lose their former role. Many elements, such as changes in family structure and social relationships, affect nationally and culturally transited family caregiving. Furthermore, changes in gender roles, such as women's traditional caring roles and cultural transformation, may be clear indications of transition. This means that families must renegotiate their roles and duties. As such, culturally and nationally transited family caregiving, as well as cultural and traditional legacy issues, may need to be viewed and addressed through the influence of transition.

Choosing a CPNH to end caregiving at home seems to relate to being able to "live up to an ideal". Regardless of burden and stress, the most essential reason is the person's safety and well-being.

The mere fact that a nursing home is *culturally profiled* has been shown to be crucial in making the decision. The CPNH still follows the Swedish SNBHWN (2017) guidelines, which in turn gives the family caregivers a sense of security. It also seems to ease the guilt that family members feel at not fulfilling their duty of filial piety. Iranian relatives' and family caregivers' experience of transferring their family member with dementia to the CPNH was satisfactory.

Family caregivers' views on the CPNH were both positive and negative. Nursing homes were not familiar to most Iranians before the Revolution, but they were after the war between Iraq and Iran. However, family members differed in their views of the CPNH, due to underlying factors such as a perceived lack of care, a lack of genuine engagement with residents, a lack of cooperation between staff and family and a lack of good staff behaviour. Similar findings were reported by Linn and Gurel (1972) regarding family attitudes towards nursing homes, where wives' attitudes were affected by

the characteristics of nursing homes and the quality of the care. According to Lau et al. (2008), families who use what they refer to as institutional social penetration, including self-disclosure, evaluation of care, and multiple penetration strategies, achieve a harmonious collaborative relationship with nursing home staff. A more recent study by Reid et al. (2017) states that positive communication between family and staff is essential for the development of relationships and subsequent desired outcomes such as opportunities to share information about the resident with staff (e.g., life histories/backgrounds) and, ultimately, the best possible care for their relative. Communication and interaction may build a bridge of honesty and trust. In my opinion, ceasing family caregiving and choosing a CPNH requires a mutual understanding of all involved parties, which agrees with Mirowsky and Ross' (2003) and Rotter's (1980) ideas about trust as a belief in the integrity of other people. Trusting people expect that they can depend on others, and they have faith and confidence in other people.

Family caregivers' perceptions and understandings regarding the staff's caregiving and attitudes towards residents increase their hesitation. According to family caregivers, the residents feeling isolated, due to cultural and generational gaps and breaches, generally gave them a sense of dissatisfaction. However, a sense of stigma (Swaffer, 2014) towards the person with dementia and the absence of deeper care were also sources of disappointment and distress. A lack of compliance with confidentiality that involves a set of rules in such institutions in Sweden was also a great cause of displeasure, which the family caregivers validated by accusing the CPNH of being too much like Iran. Some of the interviewees hoped that organizational willpower would be able to conquer some essential concerns, which is crucial. An institutional establishment such as a culturally profiled nursing home has had its own internal family support arrangements, as other nursing homes in Sweden are under the direction of SNBHW (2017). Stigma and the role it plays in defining the experience of people with dementia is well documented (Swaffer, 2014). Stigmatizing attitudes toward dementia are still a constant question. I believe that organizational willpower may be able to conquer these essential concerns through appropriate, adequate staff education, and a campaign to combat the stigmatization of people with dementia should be considered.

Nursing and caring entail a human relationship between people who need help, care or health services, and require a nurse who has been specifically trained to recognise and respond to the need for help (Peplau, 1991). Involvement, essentially, involves caring deeply about what is happening and what might happen to a person, and then doing something with and for that person. It is a matter of reaching out and touching and hearing the inner being of another. Understanding and the effective use of commu-

nication skills are only part of building a relationship. One reflection offered by Jonasson et al. (2017) is that caring for people living with dementia also requires the ability to meet the person with deficiencies in linguistic ability.

However, Caldas and Berterö (2017) go further and describe the importance of caring for people, especially people living with dementia who are already struggling with language and culture. Gaining a deeper understanding of humans living with dementia and in need of daily social life and care is the caregiver's significant duty. The authors' notion of 'facticity' as a component of dementia care is very important, as it "signifies all of the concrete details against the background of which human freedom exists and is limited. For example, these may include the family, the historical period, and the country where they were born, as well as the inevitable prospect of our death. There is a necessary connection with the person itself being in the world and its own past." (2017) As such, there is a sense of reality and the ability to understand the meaning of a situation, and that every person's life consists of his or her past.

How Iranian residents with dementia feel at home at a CPNH

The perception of the Iranian residents with dementia who moved to Sweden to be with their children, or at least to live close to their children, but who ultimately and unexpectedly preferred to live without their children's help and support, is that home is a place to escape to, a place to be at and a place to live in.

The idea that home is a place to escape to exposes a fundamental circumstance based on the migration. The participants did not have the advantages of living in their own home country. They were forced to escape, while others moved to Sweden because of family reunions, to be close to their children.

Regardless of national events and changes causing migration, escaping from home was also based on the family as an institution. This migration is similar to the way De Anne et al. (2010) define migration as a transition through a change in lifestyle and living conditions rather than a change in physical location.

According to most of the participants in this thesis, one's place of birth does not automatically denote one's home and the most essential aspect of feeling at home. Most of the residents' memories of their homes in Iran very often involved misfortune and sorrow, while very few informants described their former lives with a sense of longing.

The participants' stories illustrate their lives and destinies, which in turn reveal how they lived in Iran and Sweden, their perceptions of social life and of being independent, and their views on caregiving, the family's

role, dementia and feeling at home. In almost same path as De Anne et al. (2010), Meleis (2010) describes migration as a transition, as something that happens to someone migrating – not just the physical movement from one area to the other, but also how one moves and adjusts between different life conditions, statuses and phases that result in an evolving redefinition of oneself, which makes migration a life transition.

Home is a place to be

Many of the participants lived in close family relationships, with all the support they required. The feeling of loneliness was also linked to the participants' former homeland. In Iran, friendships were established earlier in life, but they had disappeared one by one, due partly to either war and revolution or migration. Participants' desire to be close to their children was a cardinal fact, but according to Hajighasemi (1994), and in agreement with the results in this thesis, the family reunification was not without its challenges and presented many different problems. However, "leaving the past" behind in Iran to live in Sweden with a new family structure may lead to different socio-physical conditions. Life in Sweden made most residents feel content, because they were given the attention they needed. Almost all of the participants had their own apartment and lived with their spouse(s) or alone. Overall, almost all of them had developed emotional attachments to where they found themselves. What participants' lives in Sweden had given them was the feeling of pride at being independent of their children, even if they were dependent on help from home care staff. Despite their immense disappointment and many questions about forgetfulness and confusion, they talked about happiness after migration. Although some participants grew to desire a place to be, they nevertheless lamented the loss of the life they had previously built up. As we can comprehend from the participants' versions, the significance of home varies among different people. Home is not always experienced as a safe and stable foundation in life. According to most of the participants in this thesis, one's place of birth does not automatically denote one's home and the most essential aspect of feeling at home. Most of the residents' memories of their homes in Iran very often involved misfortune and sorrow, while very few informants described their former lives with a sense of longing.

As a matter of fact, the home described was very close to what Freud (1971) named "uncanny", the name given to everything that ought to have remained secret and hidden but has come to light. Freud used this definition when explaining things that are "secretly familiar" or things that we have done or have been done to us that we have, through the process of repression, forgotten and that is returned to us.

All kinds of life alterations and variations are a transition.

Home is a place to live in

After initial difficulties transferring to the culturally profiled nursing home, most participants felt a sense of relief that they were not a burden to their families. Some also thanked the Swedish government for promoting the possibility to experience a feeling of autonomy and self-respect, which gave them a feeling of strength. This is in agreement with what Nordenfelt (2007) states about dignity: that personal identity relates to a person's integrity, autonomy, life history and relationships with other people (p. 5).

However, in this thesis, giving the family member a choice in terms of relocation was never an option, since the condition demands 24-hour care that only a nursing home can offer. Walker and McNamara (2013) highlight that it is important that every person chooses his or her *own* relocation options, and without a doubt, *everybody* should have the right to do so. According to family caregivers, however, it may often be extremely difficult for significant others to follow their wishes in this regard.

Another person's choice of relocation or displacement is a transition, which is complex, since the situation consists of both disruption of the person's life and the person's responses to this disruption (Rossen & Knafl 2003, 2008). Choi et al. (2008) suggest that transition into a nursing home is often a traumatic event in later life, since the loss of independence and freedom is accompanied by the notion that nursing homes require significant adaptation to new environmental stressors (2008). This is partly understandable, but the participants in this thesis grew to accept that the nursing home is a place to live in. In contrast to Choi et al. (2008), Peace et al. (1997) suggest that a nursing home provides care, continuity and opportunities for living in ways that should be culturally and spatially affordable. This assumption, however, according to the present thesis, is not always consistent with people living with dementia, as living in a nursing home is a transition.

Participants faced different 'cultural' and social disruptions. While some felt that being able to speak their native language and having a familiar diet was good, others felt totally isolated, due to the generation gap and staff's lack of knowledge about their sociocultural background, thus making them feel like strangers. This highlights the importance of what Jonasson et al. (2017) stated, in that understanding someone's life story can be a guide for developing a caring relationship.

The CPNH was decorated to remind the residents of Iran, and of their bedrooms before life with dementia. However, objects such as old pictures, photos and names seemed to affect them detrimentally. In my view, almost all attributes represent our distinct past memories, which may remind us of unforgettable events. As Zerubavel (1997) indicated in Bassett et al.

(2007), the social environment plays a major role in defining what is memorable and what is forgettable.

The SNBHW (2017) states that staff should share the same language and culture as their residents, but this is somewhat ambiguous, since many people have tragic memories of home, or their lives were much better and more comfortable than at the nursing home. Dementia sufferers are very often aware of their forgetfulness and confusion: “I want to remember the present. It gives me nothing to remember my youth and my life in Iran. What I want to remember is what I am doing now, here. My problem is the time that passes.”

However, some residents felt secure at the CPNH, because they trusted the staff. This agrees with Tryselius et al. (2018), who saw the home as existing only as an attribute and an emotional environment. These emotions are related to safety and security, though the authors do not embellish on this point.

Despite the cognitive challenges that dementia causes, the residents explained what home means to them. On the meaning of “home”, Gurney (1997) stated that it is an ideological construction, the product of people’s lived experiences. Considering this notion, one can understand the connection between a person’s emotion and his or her lived experience. Past memories of Iran create distaste and an increased rejection of the country. Nevertheless, the nursing home was a place in which to be and to live. The capacity and ability to remember personal experiences from the past is unique to humans.

Budson et al. (2016) posit that memory is thought of in two different forms: short term and long term. It is not just one process in the brain but a collection of different systems. Those with dementia may have short-term memory issues, but remote memory can be left relatively intact. They will be able to remember public and personal events many decades previously but unable to recall what happened earlier that day. However, as the disease progresses, they may gradually experience more long-term memory loss, also called amnesia.

Method discussion

The studies were performed in two different Swedish cities, one larger than the other. The main source of data (both participant observations and informal interviews) used in this dissertation was gathered from a CPNH (Anahita) targeting people with dementia and who speak Persian, Arabic, Kurdish, Azerbaijani or Armenian. Leaving out all surveys and questionnaires, the approach was based on face-to-face interviews in combination

with observations of Iranian-Swedish elderly people living with the syndrome at the CPNH, as well as their relatives and staff. It is generally known that people with dementia often revert to their first language. This commonly begins with utterances from the first language appearing in conversations in the second language. When interviewing a person living with dementia it is extremely important to speak the language he or she is able to speak and express himself or herself in. Using an interpreter who only speaks the common language, without knowing the person's first language and how to communicate with a person with dementia, may result to ineffective interview results. A clear indication of my statement is found in the study by Adamson (2001, p. 393), who writes: "interviews conducted with the help of an interpreter tended to result in a more stilted exchange. This probably resulted in data less rich than might be achieved by researchers who could interact in the language of the interviewee."

Without doubt, sharing a mutual language may play a key role. Spradley (1979a, p. 17) makes this clear: "Language is more than a means of communication about reality: It is a tool for constructing reality."

Obviously, all interviews and data collection should be carried out in such a way that the information will be accurate, correct and reliable. An interview's compatibility, strength, dignity and correctness can be damaged if one uses the wrong procedures like using a close relative of the participant as an interpreter. Close relatives' participation in the interpretation undermines the accuracy of the answers to the questions. Every interview situation is based on mutual trust. The individual's trustworthiness is crucial for progress, growth and successful interactions.

What is latent or hidden in each participant can only be detected by the interviewer's "subtle" way of questioning. Using an interpreter who is impartial and bound by professional confidentiality under Swedish law is preferable to using family members or close relatives.

Regardless of whether one is culturally an insider or in-between, it is important to understand that one is an interviewer and collecting data to explore an unexplored subject and to be the interviewee's voice. In some studies, researchers highlight the concepts of the cultural insider-outsider (Al-Makhamreh et al., 2008) and the in-between, a 'researcher, neither entirely inside or outside' (Milligan, 2014), which could play a positive or a negative role. I can agree with them to some extent, but I believe that if I, as a researcher, due to having the same nationality and sharing the same language, religion and traditions, assume that I already know the interviewees' cultural and traditional codes and rulings (or if there were concerns about the question being interpreted negatively according to our common culture), this is a very serious error. Regardless of how much we as researchers know before conducting interviews, it is essential to ask participants about their version of the given topic. What they say in return, as

well as their perceptions and understanding, is important. It is essential as an interviewer to be perceptible, distinguishable and comprehensible and always to act according to the Declaration of Helsinki (2013).

It is not easy approaching people living with dementia and with a past in Iran and later in Sweden. Efforts must be made to understand or at least catch glimpses of the existing reality these people live, and although interviewing them and observing their everyday lives were necessary for the studies, these processes were nevertheless time-consuming and yet at the same time rewarding (Spradley, 1979a, 2017, 1996, 2016).

Without taking this approach, it would have been impossible to uncover the experiences and feelings associated with being assisted and relying on help or becoming autonomous, alongside all other emotions.

According to my experiences, knowledge and beliefs, being close to a person and conversing with them, seeing them in reality and imagining their invisible desires, pain, sorrow and loss means that a researcher's understanding must go beyond what one might consider 'normal' cognition and understanding. All this data has been analysed with qualitative content analysis as presented by Elo and Kynges (2008), and blended with ethnographic analysis (Brewer, 2000), in order to grasp this reality.

Content analysis is used to investigate, explore and evaluate the phenomenon that is being studied. According to Downe-Wamboldt (1992), its aim is to provide knowledge and understanding of the studied phenomenon. As a key fact, content analysis sets out to specify what needs to be captured in the material (Krippendorff, 2004, 2012). By combining content analysis with ethnography there could be an understanding of social meanings and activities of people in a given field or setting (Brewer, 2000).

The data collection methods – using interviews and observation as well as the analysis – are similar to grounded theory. One might ask: Why not use grounded theory instead? The focus of the studies in this thesis was not on basic social processes or on interactions. Data was also collected in a more ethnographical way and the analysis was performed after data collection (Denzin & Lincoln, 2000; Silverman, 2006; Glaser & Strauss, 1979, 2017).

Content analysis, according to Krippendorff (2004), is mediated between people-textual matter, symbols, messages and information, without perturbing or affecting those who handle that textual matter. An interview is not only the text or description, it is a person's life experiences, life history and how time has gone for the person. So, blended with ethnography, ethnographic analysis uses cultural ideas that arise during involvement "in the field", being transformed, translated or represented in a written document. It involves shifting and sorting through pieces of data to detect and

interpret thematic categorizations, search for inconsistencies and contradictions, and generate conclusions about what is happening and why (Thorne, 2000; Brewer, 2000). Content analysis sets out to specify what needs to be captured in the material. What is more significant and vital for the choice is that content analysis as a method concentrates mainly on human beings (Krippendorff, 2004, 2012), not ostensibly on concepts or social processes ending in a theoretical construction as in grounded theory (Glaser & Strauss, 2017).

All four studies have been conducted within a particular area, and almost the same method was used for the four studies. This could be interpreted as a limitation.

Every research technique has its powers and limitations, and content analysis is no exception in this regard. Certainly, it is not the only research method that takes meanings seriously, but it is a method that is both powerful and unobtrusive (Krippendorff 2004, p. xiii).

Regarding using the same method, some modifications were added in the study with the people with dementia, so it became what I would call a “dementia-friendly interview”. These people are very fragile, and regarding their sometimes hazy and ‘sunshiny’ emotions, one should understand that their emotional reactions can be a contrary mix of modesty, depression, sadness and happiness. Therefore, interviews with people with dementia are beyond extraordinary. To help residents with dementia develop their creative talents and the ability to retrieve memories and thoughts, one should be patient and tolerant, showing respect, and give them the time and tools to do so, such as pictures, photos and the like (Benninger & Savahl 2017). In my opinion, a successful interview technique involves connecting with another person on a very profound level, even more so when interviewing a person with dementia. I believe that the giving of one’s life story is a deeply valued gift, and so the researcher has a responsibility to care for and respect that gift and to use it as it was intended, so that others may benefit from the participant’s story. Research interviews often involve the exploration of sensitive material, and I was particularly aware of ethical issues in this regard.

In content analysis, “reliability and validity” (Krippendorff 2004; 2012) are the terms used for showing reliable methodology, but according to Lincoln and Guba (1985), trustworthiness is used for qualitative research. Trustworthiness is presented by the components *credibility*, *dependability*, *conformability* and *transferability*.

Dependability is the one of the terms Lincoln and Guba (1985) highlight, in that dependability and credibility are involved with each other, and without one, the other would not exist. Dependability is an important criterion to consider.

In this thesis, data was collected using different tools, namely fieldwork with semi-structured interviews with family caregivers and staff, aligned with dementia-friendly interviews with and observations of residents with dementia. Credibility was ensured by following the rules that should be applied throughout the work process. Before the research began, time was spent in the culturally profiled nursing home, purely to gain an understanding of such an organization, to *develop knowledge about its culture* and to establish a relationship of trust between the staff, residents and family caregivers before the first data collection took place. This is in agreement with what Lincoln and Guba (1985) recommend, i.e. *prolonged engagement involves daily contact and building trust*. Some of the literature has stressed that the ability to obtain reliable data depends on how the respondent defines the interviewer as a person, i.e. what social role he or she is assigned. Johnson (1975) states that the interviewer should behave honestly, openly, nicely and as an ordinary person. But what does it mean to be “nice” in this regard? Johnson (1975) gives no direct clues but refers to Dean (1958, 1967) and his ideas about morality and trust-building. Dean believes that the interviewer’s personality and morality are crucial when building trusting contact.

I spent more than a year carrying out fieldwork, which is in accordance with Lincoln and Guba’s (1985) recommendation about prolonged engagement. I was honest, respectful, sociable, curious, eager to learn and curious about how others perceive daily life with its advantages and disadvantages, which is in agreement about Lincoln and Guba’s statement about engagement involving daily contact and building trust. Additionally, I was open with everyone, in order to understand family caregivers, staff members’ ambitions and struggles, and what lay behind dementia in general, and thus I managed to establish trust with my interviewees.

Credibility was strengthened by adopting the correct research methods for a qualitative study and by detailing how the method and analyses were conducted (Lincoln and Guba, 1985). To promote and strengthen credibility, I strived to provide detailed descriptions of the field and the contexts that surround it. Furthermore, I recorded usable operational details of what was done in the field in terms of data collection. In addition, I attempted to provide comprehensive methodological descriptions, to allow the integrity of the study results to come through clearly.

In addition to the interviews, I wrote all my observations in a diary, based purely on what these people said, without aligning my own or other people’s opinions and interpretations. All the interviews and translations were checked by native speakers of the relevant language. I employed different tactics to help and ensure interaction with participants when contributing data. Interviewing a person with dementia is in many ways an extraordinary experience – sometimes it may need an “overlapping method”,

such as a “personal” interview while walking together, or a discrete interview with the person using photos, pictures and sometimes watching a family’s video film (Benninger & Savahl, 2017).

To obtain conformability, I strived to be neutral. Although all my questions were well designed, I discussed them with several other experienced researchers. I believe that communicating with a person with dementia involves understanding the respondent correctly; this does not mean there are no errors, since there are many cases in research where the reporter and/or the respondent is wrong. Many of these cases we will never discover, but even if the errors are obvious, the participants’ versions are detailed, and no one else corrected statements.

Transferability involves establishing whether a result can be transferred to another group of people or another context. I have described the research field through its cultural character, sampling, interviewee selection, and where and how the data collection was conducted (Lincoln & Guba, 1985). The findings of this study may therefore be transferred to other similar settings.

CONCLUSIONS

Perceptions of dementia can be based on cultural and traditional understanding, although this can shift through transition and knowledge accumulation.

Family caregivers' decisions to end caregiving at home involve mutuality, capability and management, but decision-making sometimes has nothing to do with violating a person's autonomy and is more about protecting the person. Family caregivers certainly care for their elders, but transition changes the structure and construction of this practice. They concluded that moving their loved ones to a residential care facility was for the best – for everyone.

Family members had differing views about the CPNH, due to underlying factors such as a perceived lack of care, engagement with patients, cooperation and good staff behaviour. Stigma was also a source of dissatisfaction, so some moved their relatives to a Swedish-speaking nursing home. Overall, many felt that culturally profiled nursing homes resembled Iran too much, which disturbed them in some ways.

The residents thought of home as a geographical location but also connected it with both positive and negative feelings. However, following emigration, they developed an emotional attachment to their new country of residence. After being transferred to the CPNH, most of them felt a sense of relief at being independent of their children. Furthermore, this new autonomy and self-respect gave them almost a kind of mental repatriation. Aside from the various challenges, some were happy being able to speak their native language and eat their own food, but some felt totally isolated, due to the staff's lack of knowledge about Iran before the Revolution and the war. Generational differences and incoherence, aligned with staff members' different sociocultural backgrounds, made them feel like strangers. Nevertheless, the nursing home, due to memories and experiences of life in Iran, "home", was a place to be and to live.

CLINICAL IMPLICATIONS

Presently, there are no statistics on how many elderly Iranians have been diagnosed with dementia, but the fact is that the many people who need professional care are also in need of a nursing home.

The SNBHW (2014) emphasizes the importance of fulfilling people's cultural and linguistic needs (2010:21) in dementia care. Cultural considerations include giving the person the opportunity to practice their religion, eat culturally adapted foods and have access to staff who speak the same language as them. In this regard, care is realized through such solutions. "Iranian culture", as with many other cultures, is of course not *one* static thing or a psychological state. Culture is not homogenous, and culture is not static. For some, including the SNBHW, culture appears as a well-ordered packaging of traditions that influences all members of a community equally.

Iranians in this dissertation come with different linguistic, socio-economic and social backgrounds, and they have lived in Sweden for more than 20 or 30 years. These years mean going through numerous transitions that, in turn, have had an impact on their life in Sweden. Without seeing different influencing factors, describing people with the same cultures and traditions will possibly damage the face of science.

The results presented in this thesis will hopefully contribute to the future development of culturally profiled nursing homes by addressing the variety of culture and all the affecting aspects of transition.

The generation gap and generation "disruption" need to be addressed. Using a person-centred approach may facilitate these issues.

FUTURE RESEARCH

Culturally profiled nursing homes is a very exciting theme and a challenging issue for future research.

- The family's view of culturally profiled nursing homes for people with dementia.
- Dementia care targeted at culturalization, for example in a culturally profiled nursing home or care facility, could be based on the idea that different peoples need different forms of care.
- The cultural contextualization of dementia needs to be revealed and understood. Culture, however, needs to be clarified in context.
- To what extent can the new national guidelines for dementia care in culturally profiled nursing homes be beneficial?

My humble wish is for continued interaction between the people and practice involved and forthcoming research which by necessity needs to be interdisciplinary.

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