Ethnoculturally-profiled care

Dementia caregiving targeted towards Middle Eastern immigrants living in Sweden

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Abstract

When social contexts have been taken into account in dementia studies, they have often been ascribed to the private surroundings of the person living with dementia, giving the illusion of dementia 'occurring in a vacuum'. Thus, there has been an inclination to disregard the importance possibly played by larger socio-cultural contexts, such as values, norms and beliefs, that will influence how one perceives, experiences – and responds – to the illness. This study was set out to explore the understanding of dementia as a culturally and socially shaped illness in order to illuminate such perceptions and experience in relation to ethnoculturally profiled dementia care in Sweden. The results indicate, contrary to many other studies (c.f. Conell et al 2009; Flaskerud 2009; Gray et al 2009; Hinton, Franz & Friend 2004) that the perception of dementia and the described meaning of the disease have little (or nothing) to do with decisions regarding formal care. However, cultural norms and traditions in relation to issues of filial piety seem to do. Thus, to understand how different ethnocultural groups might respond to dementia care within a migratory context, the current study illuminate the fact that it is crucial to realize that neither the individual person with dementia, nor larger ethnocultural groups can be placed within a vacuum that seemingly does not change or correlate with surrounding society. In order to achieve proper dementia care the issue of acculturation needs to be accounted for.

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> *Dementing illness does not respect cultural boundaries. However, persons from different*
> *ethnic groups may respond in culturally distinctive ways (Valle 1998:xix)*

Introduction

One question often raised regarding chronic diseases, in this case dementia diseases, is whether ethnic groups' responses vary. Although there is strong evidence that both genetics and environmental factors play significant roles in determining the risk of diseases like Alzheimer's (Larson and Imai 1996), the prevalence of dementia diseases has proven to be quite similar in different parts of the world (Marcusson, Blennow, Skoog and Wallin 2011). However (as the quote above by Ramón Valle indicates) how one *respond* to such diseases has proven to be quite diverse; the responses are often linked to how one understand and experience a disease such as dementia. In order to better understand such variation this article will explore the understanding of dementia as a culturally and socially shaped illness in relation to migratory contexts. More specifically, it will illuminate how persons with Middle Eastern background, employed within ethnoculturally profiled dementia care reflect upon these issues.

From a biomedical point of view, dementia disease is pathological. Dementia, being a generic term for a range of symptoms, is defined as a (irrevocably) cognitive decline. In the case of neuro-degenerative dementia diseases, such as for instance Alzheimer's, it is caused by microscopic changes of plaques and neurofibrillary tangles in the brain, affecting memory, executive abilities, language, intellect, as well as increasing difficulties in orienting oneself (Marcusson et al. 2011). By tradition this is also how most of the research concerning persons with dementia has been framed, as a progressive brain disease that occurs within a person's brain. Hence, research regarding persons with dementia has often focused upon individuals and their cognitive (declining) abilities. This, of course, is beneficial in terms of understanding dementia as a progressive brain disease, but not quite as helpful if we would like to try to understand how persons with dementia live and cope with their illness (Hydén 2014; Hydén and Antelius *fortcoming*). In other words, it tells us almost nothing about people's lived experience of the disease (Strandroos and Antelius, *forthcoming*; Toombs 1995, 2001).

For a number of years now, there has been a rapidly growing field of dementia studies that go beyond the individual's loss and instead view dementia not only as a biomedical disease, but also as a subjective experience that views both personhood and identity in complex terms of transformation and change. Significant in this approach is that the disease cannot solely be understood as *trapped* inside the brain of the person with dementia. Instead, it understands the transformations and changes brought about by the disease as collaborative (Hydén 2014; Hydén, Lindemann and Brockmeier 2014; Strandroos and Antelius, *forthcoming*) – where the persons with dementia always change with their disease in relation to other people.[i]

Hence, the importance of understanding that persons with dementia diseases are not isolated or sick individuals with non-functioning brains, but rather persons who belong to a social context, interacting

with other people, have been strongly stressed. (Hydén and Örulv 2009; Kitwood 1997; Lyman 1989; O'Connor et al. 2007; Örulv 2008).[ii] However when social contexts have been taken into account, they have often been ascribed to the immediate, private surroundings of the person living with dementia, giving the illusion of dementia 'occurring in a vacuum' (O'Connor et al. 2007; Antelius and Traphagan 2015). In other words, there has been an inclination to disregard the importance possibly played by larger socio-cultural contexts, such as values, norms and beliefs, that will influence how one perceives, experiences – and responds – to the illness (Antelius and Traphagan 2015; O'Connor et al. 2007; Innes 2001; Innes, Archibald and Murphy 2004).

Ethnocultural perceptions of dementia

International studies show us that such a *vacuum* is problematic, as different ethnocultural[iii] groups ascribe different meanings to the illness (see for instance Dilworth-Anderson and Gibson 2002; Leibing and Cohen 2006) and that such ascribed meaning seems to also affect not only if one is inclined to use formal services or not (Connell et al, 2009; Flaskerud 2009; Gray et al. 2009; Hinton, Franz and Friend 2004) but also how a person living with dementia diseases is perceived and what status is afforded to that person (Antelius and Traphagan 2015; Dilworth-Anderson, Williams and Gibson 2002; O'Connor et al. 2007). Hence, in order to more fully understand the complex social contexts in which a person with dementia is situated, more attention needs to be paid to the fact that the way one understand and explain health and illness is always culturally (and socially) shaped. To borrow a classical idea from anthropologist Arthur Kleinman, we need to understand that there are always 'normal ways of being ill' (Kleinman 1988:5) and that such normal ways most often result in very different health-maintenance and help-seeking behaviours (Antelius and Kiwi 2015; Mackenzie, Bartlett and Downs 2005).

Back in the 1980s, a group of anthropologists[iv] started a cross-cultural collaboration in order to shed light on how different socio-cultural settings come to shape the experience and meaning of (successful) ageing. Although criticized for having to strongly emphasized structural issues over cultural ones (see for instance Torres 2002) the group did bring a socio-cultural agenda into gerontology. This has since been further developed, in both practice (where both ethnogerontology and ethnogeriatrics are now common in many care education's curricula) as well as in gerontological research. Just recently, a special issue on '*Ageing and Ethnicity*' was published (in Ageing and Society, 2015, volume 35, issue 5) where current conceptualizations, representations and use of *ethnicity* within the field of social gerontology were explored and where the main emphasis was on highlighting how ethnic cultural homogeneity and *otherness* often are assumed in research involving older persons from ethnic minority backgrounds as well as discussing how wider societal inequalities often are reproduced within and through research itself (Zubair and Norris 2015). Likewise, ageing (and dementia) have also attained greater focus within anthropological research. In the mid-1990s, anthropologist Lawrence Cohen started researching issues related to elderly persons in India. He found that the symptoms we gather under the generic term *dementia* were not perceived or described at all as they were in his home country, the US. The elderly people he met, who experienced deteriorating memory, who had difficulties orienting in time and space and who had developed problems in communicating, were not considered to suffer from any (brain) disease. Instead, their *problems* were thought to be caused by bad family relations (Cohen 1995; 1998). Cohen's research was followed by that of a few other researchers[v] and in the early 2000s a special issue on intercultural perspectives on dementia was published in the *Journal of Cross-Cultural Gerontology* (number 17, volume 3) where it was argued that whatever kind of illness dementia is, it is multidimensional and in need of much more de-medicalized research in order to comprehend dementia also as a lived experience rather than just a biological fact. In 2015 another special issue *Ethnocultural Contextualization of Dementia Care: Cross-cultural Perceptions on the Notion of Self* (Care Management Journals, 16:2) expanded upon this

call, discussing issues regarding cross-cultural perceptions of dementia and how the notion of (dementia) care needs to be understood in relation to the perception of the illness, because the way care is conceptualized, how it is organized, seems to be closely connected to how the construction (and thus deconstruction) of the self is perceived (Antelius and Traphagan 2015).

Sweden: an ageing multicultural population

Sweden was one of the first nations to experience rapid population ageing and now has one of the highest population rates of those considered the oldest-old (85+). A great deal is known about ageing in Sweden, both in terms of the demographics of ageing (Sundström 2009) and how it (historically) has been uniquely shaped by its locally controlled services for older people (Davey, Malmberg and Sundström 2014). However, contemporary Sweden is also shaped by the fact that since World War II, due to migration patterns, Sweden has gone from being a relatively homogenous country (ethnoculturally speaking) to becoming a multicultural and multi-ethnic one (Hannertz 1983; Antelius and Kiwi 2015). As a consequence of both the refuges coming during WWII (many came as young children, especially from Finland) as well as labour-force migrants, who came mainly in the 1960s and 70s, now growing old, Sweden has experienced a rapid expansion in the numbers of elderly immigrants with culturally and linguistically diverse (CALD) backgrounds (Emami and Ekman 1998). In addition, one also needs to account for the fact that since the late 1960s and onwards, Sweden has been a receiving country of many asylum seekers and family-reuniting immigrants, who tend to be older than labour force migrants.

However, as people with CALD backgrounds are *not* a homogeneous population, it is crucial to questions *why* (or if?) certain groups should be regarded as ethnic or having cultural differences that call for a separate study of the group. In hindsight, the mere fact that groups are considered minorities has been a sufficient cause for a study of the group (cf. SBU172E/3:408; Antelius & Kiwi 2015).

The reason for singling out dementia study among persons with Middle Eastern[vi] backgrounds – as this study does – should be understood in regard to two facts. The first is that which has been described above, that previous research shows that different ethnocultural groups *do* ascribe different meanings to dementia, which has been shown to also have an effect on health-maintenance and help-seeking behaviour. This gives the second reason, which is that for the past few years, so-called ethnically-profiled dementia care has emerged in Sweden, pointing to the fact that in practice, ethnocultural groups are *already* being singled out, quite deliberately and purposefully in relation to dementia care.

Immigrants with Middle Eastern background (or the Arabic-speaking community, which it is often called) are of course a community consisting of many different ethnic groups having various cultures, traditions and beliefs. Although most speak Arabic, many also speak other languages (or dialects). To say the least, it is a very diverse and heterogeneous group, consisting of people from (among other countries) Lebanon, Palestine, Syria, Iraq and Egypt. Many are Muslims, but as we know there is also much diversity within Islam; there are Sunni, Shi'a, Alawi, Druze etc. Also, many are not Muslims, they may be practicing Catholics, or Chaldean, or Coptics, or they may not be religious at all. People with Middle Eastern backgrounds living in Sweden are thus not homogeneous even within the so-called group (or community). Thus, as with any other ethnocultural group, it is in itself quite heterogeneous; persons are of different class, gender, religion and so on. However, the choice to single out people with Middle Eastern backgrounds as a distinct ethnocultural immigrant group in Sweden – as this study does – should be understood in relation to the discussion above. Hence, the choice needs to be understood in relation to the facts that (a) there already exist Middle Eastern-oriented dementia care facilities in Sweden, which indicates that persons of these backgrounds are perceived (and/or perceive themselves) as an ethnocultural group with special needs for targeted care, (b) persons with Middle Eastern backgrounds

make up one of the largest immigrant groups in Sweden, with increasing numbers of people growing older (Mazaheri, 2013); and (c) hardly *any* studies exist regarding persons with dementia diseases and with Middle Eastern backgrounds (however see Mazaheri 2013; Antelius and Kiwi 2015; Næss and Moen, 2015). In our opinion this makes a separate study of the group valid, especially in order to be able to ask the question of whether it is still valid to conduct such a separation of groups in regards to dementia care.

Multicultural Care

The choice of singling out persons with Middle Eastern background also needs to be put in context of how Swedish elderly care policies have changed since the 1980s. Due to the change in the diversity of the population, with steadily growing numbers of immigrants growing old, the issue of multicultural (elderly) care gained high political priority in the 1980-90s. The former Swedish Committee of Immigration Policy concluded that when elderly care was to be planned, special consideration should be taken to 'each immigrant group's different ethnic, linguistic, and cultural characteristics' (SOU 1984:58, EA's translation). However, as research progressed, such a distinct and delimited definition of an immigrant group with a set type of characteristics came into question. Thus, following the progress of Swedish elderly care policies we find a much stronger focus upon individual characteristics and policies oriented towards providing *person-centred care* (often in relation to accessible care in native languages). However, at the same time it has also been concluded that because the progression of dementia diseases affects both language use and communicative ability as well as being linked to deteriorating memory and difficulties orienting in time and space (for instance believing that one is living in the society one grew up in, which might have quite different traditions and customs than contemporary Sweden does), *both* language and cultural differences might give rise to specific care needs (Ds 2003:47).

Thus in 2010 The Swedish National Board of Health and Welfare concluded that 'person-centred care means to especially consider needs related to people having different cultural or linguistic background'. Cultural needs are defined here as 'giving persons with dementia disease the opportunity to practice their religion, being served culturally appropriate food, keeping their cultural traditions and customs, and having access to nursing staff that communicate in the same native tongue as the person with dementia'. On the subject of linguistic needs, they state 'to be cared for by nursing staff who communicate in the native tongue and who also have cultural competence could give the person with a dementia disease who has a different ethnic background a sense of security, increased well-being, and a sense of feeling 'at home'' (2010:21, EA's translation).

Ethnoculturally-Profiled Dementia Care

The development of dementia care policies discussed above, with its *end result* being the guidelines published by the Swedish National Board of Health and Welfare in 2010[vii], has been greatly influenced by research conducted by Sirkka-Liisa Ekman (1993; 1996) and colleagues (Ekman et al. 1993; 1994; Heikkilä 2004; Heikkilä and Ekman 2003, 2000). They have been able to show that Finnish immigrants living in Sweden with a dementia disease acted on a level of apparent competence that seemed far below their level of actual competence.

For instance, when the Finnish immigrants (who used to be fluent in Swedish) communicated with Finnish-speaking caregivers they were much more *successful* in their communication than when they communicated with monolingual, Swedish-speaking staff. When they were able to use their native tongue, the residents showed latent abilities when participating in activities requiring abilities thought to be long lost. Additionally, the relationships between residents and staff seemed more positive and the

Finnish immigrants seemed to be more aware of both themselves and their surroundings when communicating with the bilingual personnel (Strandroos and Antelius, *forthcoming*). As a result of these research findings, Finnish-speaking dementia care has been well established in almost all parts of Sweden.

However, Ekman and colleagues' studies revolved solely around the ability to share (native) language with care staff. The so-called ethnically profiled dementia care facilities that we now see emerging in Sweden are residential care facilities that state that they are different from ordinary municipal care facilities in that they offer something more – or else – by being targeted at specific ethnocultural groups. For instance, *The Agora* (one of the ethnoculturally-profiled care homes presented in our data further on) profiled itself as a nursing home with Oriental inspiration for those wanting to live in a safe environment; it is a lodging with respect for traditions, where one can speak one's native tongue and thus feel at home. *The Agora* is based upon 'Oriental colours, tastes and traditions'.

Thus, there are dementia care policies – and actual residential dementia care facilities – already in place in Sweden, targeted at specific ethnocultural groups. However, we know very little about how staff, relatives or the person with dementia in these specific ethnocultural groups themselves understand, explain, and experience a disease such as dementia and how that might affect health-maintenance and help-seeking behaviour. Or if *specific care* based upon ethnocultural grouping and different *needs* is even desired.

Hence, the aim of this article is to further elaborate on how a disease such as dementia, which seems to affect people all over the world with similar prevalence and incidence, needs to be understood outside of the social *vacuum* it *still* seems so often to be placed within. Hence, in this article we will explore the understanding of dementia as a culturally and socially shaped illness in order to illuminate perceptions as well as experiences of – and responses to – both dementia as an illness as well as dementia care. The case in point will be to illuminate this in regard to persons with Middle Eastern backgrounds involved in ethnoculturally-profiled dementia care in Sweden.[viii]

The Setting

This article is based upon interview data and (some) fieldwork data gathered in Sweden, in three separate settings, including (1) a residential dementia care facility with Arab focus, (2) a residential dementia care facility with (so-called) Oriental focus, and (3) a day centre for persons with dementia diseases who have Middle Eastern backgrounds. Thus, all settings have a specific ethnocultural profiles, offering dementia care with a Middle Eastern, Arab and/or Oriental profile.[ix] All names of locations, places and persons are of course fictitious.

The first setting, here called *Manazel,* is a so-called ethnically profiled residential dementia care facility and specializes in what they themselves call *care with an Arab focus*. In the residential care building to which *Manazel* belongs there are five floors with nine separate apartments and one communal living room/dining hall with dining tables, sofas, reclining chairs and a TV on each floor. One floor – simply named after the number of the floor it is located on in the building – is for younger persons with dementia (under the age of 65 and with no specific ethnic profile). One floor – the one in focus in this paper, here called *Manazel* – is targeted towards Arab-profiled (dementia) care and three of the floors are targeted towards Persian-oriented care[x], of which two of the three floors are dedicated to dementia care. Except for the one on the floor for younger persons with dementia, the others have nursing staff fluent in Persian, Arabic, Armenian, Azerbaijani and/or Kurdish, and all also speak Swedish as a second language. The second setting, here called *the Agora,* is also a residential dementia care facility with what they called an

Oriental focus, with staff speaking Swedish, Arabic, Kurdish, Persian and Syrian. Just as *Manazel*, it had decorations, food and TV shows/radio reminiscent of the Middle East (the building was built around a large, indoor plaza (hence the name) where tea, coffee and typical 'Swedish', 'Turkish', and 'Persian' pastries were always available). The third setting, here called *the Fig,* is a day centre for persons with dementia diseases who have a Middle Eastern backgrounds. All staff speak both Swedish and Arabic, some also speak Kurdish, Turkish, Syrian or Assyrian. In order to attend the day centre one needs to have attained a formal decision on care service (provided by the municipality at special assessment meetings).

Gathering data

Data collection included mainly in-depth interviews with care staff at the three different settings. One of the authors (EA) gathered most of the data. At times she conducted the interviews alone, and sometimes in collaboration with author CP. Some observations were also the bases for the interviews as both authors visited the different care facilities prior to interviewing. This also included some work by a third researcher, PhD student MK, who conducted a year-long fieldwork period at a residential dementia care facility with Persian focus. As this residential home was in the same building as the Arab-profiled one, i.e. *Manazel*, she also came to observe and keep some field notes of *Manazel*. MK has kindly allowed us to use them as preparations for this paper. The interviews conducted by author EA at *Manazel* were done in collaboration with MK. As the gathered data includes different settings and to some extent different research projects the time span on gathering the data has been quite wide, and in some instances, is a still on-going mater. Some of the interviews were conducted in 2013 and some much more recent. The length of each interview has been approx. one hour.

Interviews were based upon the fact that all interviewees knew that we were interested in issues related to ethnoculturally-profiled dementia care. We used an unstructured interview guide; i.e. we had some main topics we wished to introduce/ask about and the interviews consisted of mainly open-ended questions. Quite often the interview would start with questions such as 'can you tell me about your work?' or 'could you tell me about your day?' and most interviewees took it from there, talking freely about their experiences and perceptions regarding dementia and dementia care. Thus, in most cases the interviews became more informal conversations rather than interviews (Briggs 1986). All interviews/conversations were audio recorded and transcribed verbatim; the total number of interviews conducted was ten.

Participants

The persons interviewed consisted of three certified nurses, three assistant nurses, two head managers, one vice manager and one head of marketing. These persons were chosen as they comprised the entire staff at the day centre (*the Fig*) as well as the management of the Oriental-profiled residential care facility (*the Agora*) and the head nurses (certified) at the Arab-profiled residential care facility (*Manazel*). We had also hoped to interview nurses/assistant nurses at *the Agora* but due to circumstances beyond our control, this could not be done. As our study sample is quite small (and there are not that many ethnoculturally profiled dementia care units within Sweden) we wish not to be al too specific regarding personal details (since our informants could then be too easily recognised). However, some data is needed: the staff at *the Fig* all had Middle Eastern backgrounds, coming from the countries Iraq, Kurdistan, Turkey and Syria. All of them had lived in Sweden for several years and had worked within mainstream dementia care before working at *the Fig*. They ranged in age between 35-50, being of both female and male gender. The staff interviewed at *the Agora* consisted of persons with both Middle Eastern (Iraqi) background, but also one with Swedish background. They were of both sexes and ranged in ages

40-50. The staff interviewed at *Manazel* were all women, all of Middle Eastern backgrounds, ranging from countries such as Iraq, Kurdistan, Turkey, Syria and Iran. They tended to be younger than the other interviewees, all being in their 30s, all of them had lived in Sweden for many years. Most of them had work within mainstream, municipal care before working at *Manazel*. As *Manazel* is located in the same building as a Persian-oriented facility, the nurses sometimes work alternately at the different floors and thus one of the nurses interviewed spoke Persian as first-language, but also knew some Arabic.

The main aim of this article is to explore the understanding of dementia as a culturally and socially shaped illness in order to illuminate perceptions as well as experiences of dementia and dementia care among persons with Middle Eastern background partaking in ethnoculturally-profiled dementia care in Swede. Therefore, we base our analysis (mainly) on care staff working in such settings. We wish to point out that this paper's particular focus should not be perceived as an act of negligence or dismissal of the persons with dementia and their experiences and perceptions. Our intent is *not* to strip persons with dementia of their agency by conducting research about them rather than with them. This choice simply means that for this article, we have placed our focus upon those who work in such a specific care setting as an ethnoculturally-based one constitutes, and what they have to say in regard to that. The voices of the persons with dementia and their perceptions in all of this – as well as those of their relatives – have been reported elsewhere.[xi]

Analyzing the Data

This article is empirically driven as we take our starting point in the interviews conducted. Data analysis has thus mainly been ethnographic. Although ethnographic analysis perhaps is more selective and limited rather than always being comprehensive, it aims at contextualizing details and interpreting human behaviour from the *actors*' point of view (Kovarsky and Crago 1990-1991) in order to describe these experiences as *thickly* as possible. We must not forget that 'thick description' of course stems from Geertz's (1973) idea that ethnographic analysis needs not only to be rich in detail and context, but also in meaning and interpretation – interpretations that include finding a stratified hierarchy of meaningful structures. We have thus analysed our data in this article by identifying (recurrent) instances and *meaningful structures* across the data set in order to achieve that thick description of hierarchy among the details (Antelius, 2009; Geertz 1973).

Having said that, it also becomes important to show how data has been produced *within* the interviews. It is not as if they stand on their own. Interviews are interactional collaborative accomplishments, and respondents (interviewees) are not so much repositories of knowledge as they are constructors of knowledge in association with interviewers (Holstein and Gubrium 2004; Mishler 1986; Riessman 2008; Antelius 2009). The themes presented under *Results* should thus be understood as introduced by the interviewees themselves, however in response to the fact that we as researchers/interviewers have asked about specific topics. It should also be stated that after conducting one interview, it was transcribed and systematized (in terms of finding a stratified hierarchy of meaningful structures in recurring themes) and themes/questions from one interview thus led us as interviewers to ask about that particular theme in the following interviews.

Ethical Consideration

The study has been carried out in accordance with the standards of the Swedish Research Council's ethical principles for research in the humanities and social sciences as well as the responsible

committee of human experimentation and with the Helsinki Declaration of 1975, as revised in 1983. All participants in the study have been asked for – and have given – informed consent; this included the participant's right to refuse to answer a question, to stop an interview at any time, to reschedule, or to withdraw from the study altogether at any time, without personal consequences (Corbin and Morse 2003). The study is approved by the Central Ethical Review Board, Linköping (Dnr: 2012/180-31).

Results

Dementia: something other than a disease?

In line with the background described above, in regard to both the fact that quite a few studies have shown that dementia is a culturally-shaped complex of experiences, and that there exists ethnoculturally-profiled dementia care in Sweden, we wish to further develop the understanding of dementia and dementia care among persons with Middle Eastern backgrounds living in Sweden. Hence, in the interviews we conducted we asked about this, how they – the staff who worked in profiled care and also had Middle Eastern background – would describe dementia.

> Laleh: They don't have good knowledge about this disease (.) uhm, what can I say (.) it's rare to hear about someone becoming demented[xii] in our countries, rare. Like (.) I lived in my country 22 years and I never heard about anyone being demented when they got old.

> EA: Is it called something else then, other than dementia? Or (.) does one not speak about it at all or are there other words for it?

> Laleh: Uhm, our culture it (.) well (.) one goes crazy (.) uhm it feels, we don't have (.) use proper words like dementia [we say] aa he's crazy.

Laleh tells that within her culture (as she herself puts it) dementia is not a term commonly used to describe what we would describe as cognitive decline. Instead one would rather describe someone showing such symptoms as *crazy*. The biomedical term *dementia* does not seem to be valid in her description of the culture she was brought up in before moving to Sweden. However, when asking Hadya about the same topic she says:

> Hadya: The most difficult thing about demented people is that they (.) they don't know about this thing, their relatives or their wives, or husbands, this disease, <u>what</u> it means.

> EA: One still talks about it as a disease then?
> Hadya: Yes, a disease, yes, but uhm (.) here in Sweden one says dementia but there one does not, they say Alzheimer, she's got Alzheimer uhm.

> EA: And if one does not talk about Alzheimer and not dementia, is there another way to talk about it, like it's

> Hadya: No. They only say it is a disease (.) they don't have (.) they don't have as much [knowledge] so I explain that I work with such things so it doesn't become (.) but they don't have a proper picture…

> EA: Ok (.) I was thinking (.) I have heard others say that well (.) one goes crazy or that people are strange or

Hadya: They, they say this (.) forgetful (.) they don't say crazy, no, it's forgetful and that it's normal to be forgetful for older people

Shila continues:

Shila: I have thought about it a lot and I think that in the old days we didn't have anything called dementia. The old were either healthy or sick, and died of their diseases (.) maybe it's because of that that relatives with immigrant backgrounds don't understand. During my parents time there wasn't the same source of information we have today and that's why they have difficulties accepting what we today call dementia. Maybe the younger generation will accept it.

EA: So the relatives do not see it as a disease or?

Shila: No they don't. They don't think about it as something that has occurred in one's brain. They deny it all the time. And their denial is a problem.

Arif elaborates:

Arif: So it is (.) a little bit of bad knowledge about dementia diseases among our people from the Middle East, really bad knowledge.

EA: You mean generally speaking?

Arif: Yes, in general, they connect this disease with old age, if you're old, of course you forget.

EA: Ok, so it becomes natural when one

Arif: You know, it's natural but it's not at all natural, we have young people with dementia, under the age of 65 here at the Fig, that's not natural, it's a disease really, but for them it's connected to well, being old they say.

As it turned out, there seemed to be no clear-cut definitions of dementia. If saying anything they usually described it as Hadya and Shila and Arif do here, that people from *their* culture usually viewed dementia as normal ageing and forgetfulness, or did not think about it at all. This implies that according to our interviewees, there are different perceptions and ascribed meanings of dementia but people with Middle Eastern backgrounds might not medicalize *forgetfulness* in the same manner as people of a Western, biomedically-influenced culture might do. It is thus interesting to ask whether this may affect health-seeking and health-maintenance behaviours, as other studies have showed such a link (if it is not a disease, why would one seek care? Or, if it is perceived as stigmatizing, one hides the person affected). And what we found was that our questions regarding perceptions of dementia quite often turned into discussions about (dementia) care instead.

Filial piety and senses of guilt and shame

Many studies have shown that a stronger sense of filial piety is more prominent among some ethnocultural groups than others, and hence caring for one's elderly (and sick) is something relatives take care of themselves as opposed to using formal care services (if such are at all available).[xiii] As our attempts to talk about perceptions of dementia so often turned into discussions about (dementia) care instead, we became curious to see if this notion of filial piety was (a) valid among our interviewees and (b) if so, could

it be viewed as somehow linked to the perception of dementia, as other studies have suggested (cf. Connell et al. 2009; Flaskeru 2009; Gray et al. 2009; Hinton, Franz and Friend 2004).

> EA: If one does not see it as a disease, either its ageing or craziness or something else (.) according to studies it is more unusual to leave one's elderly at a residential home. Do you notice that here?

> Shila: Yes, I see that many have difficulties leaving their elderly to formal care and even if they did, they have feelings of guilt [.] It's unusual to leave one's old and dear to a nursing home.

> Noor: I agree with Shila and I understand that in our countries it is different. In our culture we have never had anything called nursing homes or residential care. When mum and dad get old it's a necessity to care for them.

> Mitra points to the same issue in her interview:

> Mitra: I believe, through my own experience and by talking to others who also feel the same way (.) that Arabic-speaking people are more willing to take care of their elderly at home by themselves (.) and that's part of the culture.

> And so do Arif and Laleh:

> Arif: We have several who would like to have their (.) demented in a residential care home but they don't dare, they don't want to, they (.) something rests in here [points to his heart] (1s) shame you know, it, uhm evil, God will punish them.

> Laleh: Because, one can say, ashamed, people bad-mouth about you. It's like you throw away your mum and dad at the nursing home because in our culture one takes care of mum and dad, at home until they die.

> Mona elaborates:

> Mona: These people, they fight until the end (.) I can see that, one understands that of course

> EA: Fighting to keep them at home?

> Mona: uum, but you know, younger daughters and, and sons who are, who have their jobs

> CP: Right

> Mona: and that's not easy to combine

> EA: Right

> Mona: and that's why it is so hard (.) because they come to harm because of it

> CP: That's true

> Mona: and that's why I think one needs, one needs to be informed about what's available instead of going around seven days a week feeling bad

> EA: Uhm, because one doesn't see an option?

Mona: Exactly (.) because one doesn't know or one might not (.) one's relatives don't <u>allow</u> one to abandon or (.) that's also, it's very much cul (.) cultures colliding, all the time.

These examples show that there does seem to exist a perception of persons with Middle Eastern (or Arab) backgrounds showing a stronger sense of filial piety. However, when discussing why this is so, we see some different explanations from the interviewees. Arif, Shila, Noor, Laleh and Mitra, who all have Middle Eastern backgrounds themselves, raise the issue of guilt; it is one's obligation, a *necessity* to do so. Otherwise one will be punished (by, for instance, God). Mona on the other hand, who does not have a Middle Eastern background, perceives it more as a combination of not knowing that other options exist, or that one is forced by relatives to take on this obligation. Laleh somewhat confirms this as she also speaks about how people, in general, from *her* culture are ashamed to *throw* their elderly into formal care as others will speak ill of you if you do.

We see then that very few of the interviewees say anything about the ascribed meaning of dementia causing people of Middle eastern backgrounds not to seek formal care (such as for instance perceiving dementia as normal ageing and thus presenting no need for care). However, two interviewees, Sadira and Joakim, raise the issue of how perceiving dementia as shameful influences decisions on formal care:

EA: Do you notice this about the dementia, those who have dementia, uhm, (1s) that one doesn't really talk about it, because we have come across that, that one doesn't even use the term dementia when

Sadira: No, one doesn't (.) one doesn't.

Joakim: Do you experience that there is guilt

Sadira: of course

Joakim: or something <u>shameful </u>about the disease?

Sadira: Umm

EA: In what way?

Sadira: Well (.) yes exactly (.) exactly, it is like if they were on the same level as a handicapped (1s) it is exactly the same level, one doesn't talk about such persons so one becomes a bit isolated from others around um, family so they don't want to be near or visit someone else (.) with mum or dad because of their state (.) it is such (.) it is a <u>shame </u>it is a shame, one doesn't do that (.) it is exactly the same as with a handicapped (.) child that you have at home and don't want to show off (.) in foreign countries if you have a mum or dad that is demented then you are usually an isolated family, you don't want to visit anyone, you don't want anyone to visit (.) it's expressed as a shame.

What Sadira states here is that people of Middle eastern background *do* reject formal care on the basis of how dementia is perceived and what meaning is ascribed to the disease; as it is perceived as shameful, one is kept hidden, away not only from formal care but also from other family and friends. Sadira's experiences of course need to be acknowledged, however the main reason discussed among our interviewees regarding not seeking formal care seems to be based more upon guilt associated with not fulfilling one's filial piety responsibilities than upon shame for the actual disease.

Ethnoculturally profiled care: a way to ease the burden of guilt?

Researchers Antelius and Kiwi have in their study of dementia caregiving among Iranian immigrants living in Sweden showed similar results to the ones described above, i.e. that the perception of dementia and ascribed meaning of the disease have little to do with decisions regarding formal care, but 'more to do with living up to standards of *Iranian culture'* (2015:88). However, as they were also able to show that the choice to at least pick an ethnoculturally-profiled residential facility could in some sense ease this sense of guilt, it becomes interesting to see if such a connection could also be detected within this study. Arif says: It's hard for them, really hard actually but I know that it is (.) in the tradition or (.) with these people who come from Syria, Iraq or Turkey, it's just a habit that we need to take care of mum and dad as long as they are alive (1s) it is a bit shameful to send them to a retirement home [...] relatives do send their demented here [to the day centre] more than willingly, they do, because they come home again, they sleep at home.

Arif discusses the idea that tradition is still strong, that *we* (i.e. people with Middle Eastern backgrounds) feel the need to take care of one's own as long as they are alive. However, Arif works in a day centre, *the Fig*, not a residential care home, and because of that he was also able to discuss why that might be easier to *accept* than residential care as the person with dementia will return home, they will sleep at home. It is thus *not* as if one has *thrown away* one's elderly or sick. When talking to Sadira and Joakim, who worked in the 'Oriental' residential care facility, they said:

> Joakim: Well, yes, we have utilization problems and we suspect that we have been too premature, I mean we have an ambition to work with integration and so on (EA: mm) but, well it is possible that it isn't ready. What we have experienced and what you [referring to Sadira] can tell about is, well (.) families and (.) uhm, these cultural associations influence (EA: uum) well, they create a lot of pressure 'you shouldn't really, should you' even if the family (EA: um. Ok) daughter or whoever takes care in the home feels that 'no, now I'm fed up, this doesn't work anymore' and and they have come to this insight and the step were you can't take it anymore and then there is all this pressure from outside (EA: um) uhm, well which perhaps we didn't take into account.

> Sadira: Mm, for example, these mosques, since they go to mosques, it is the mosques that affect this 'how could you?' this imam that sits and 'how do you allow?' (.) you know, in Islam the children are supposed to take care of their parents and things like that and 'it is not good that you leave them, you will go to hell' and stuff like that. Then there are associations they go to and what they say about it and they feel it's not ok (.) so there is a lot of pressure going on and distant family is strong (.) they don't allow (.) it's not ok in their world that they should end up in nursing homes (CP: umh) and they don't have the knowledge about nursing homes, how they are kept and what resources there are and staff 24/7 and so

> EA: And that doesn't help?

> Sadira: Because of the culture, definitely, it doesn't help even if the family is ok with it, but the mosques around them, and the churches, and associations, distant family, neighbours who think this is (.) uhm, shame and guilt for relatives who leave their parents here.

> Joakim: So, there we have (.) that resistance we didn't really (.) account for, that it would be that (.) strong

> EA: No, did you check, I mean with associations and such before or how (J: no:o) the idea to

build this in the first place?

Joakim: Actually, very little (EA: aa) uhm we (.) were rather convinced in our own belief that this [profiled residential care] would be

EA: Be something one wanted?
Joakim: Exactly.

According to Sadira and Joakim, who worked in a facility that suffered great problems with filling their capacity (at the time of the interview, *the Agora* had been open for about a year and 18 out of 54 rooms were occupied), the resistance towards formal care was much tougher than they had expected. According to Sadira, this is most definitely due to the pressure from outside to adhere to cultural norms of filial piety. It does not help that it is an ethnoculturally-profiled care facility; the (perceived) guilt of not fulfilling one's obligation of filial piety seems to outweigh this. In the quote above by Mitra we could see the same explanation when she said: 'I believe, through my own experience and by talking to others who also feel the same way that Arabic-speaking people are more willing to take care of their elderly at home by themselves and it is part of the culture.' However, Mitra also expanded on that statement and went on to say: 'Still, such is indeed the case for us Iranians as well but I think that it's, in Sweden perhaps we Iranians have adapted us more.'

Discussion

As discussed in the introduction, earlier research has demonstrated how different socio-/ethnocultural settings come to shape the experience and meaning of both ageing and dementia diseases. Research has also shown how different perceptions and ascribed meanings of a disease such as dementia can have an impact on health-maintenance and health-seeking behaviour. And still, most studies regarding dementia place the person with dementia within a so-called *personal vacuum*, i.e. disregarding the fact that all people, even those with dementia diseases, are part of larger socio-cultural contexts, where values, norms and beliefs will come to influence how one perceives, experiences – and responds to – the illness.

Thus, in this article we have explored the understanding of dementia as a culturally and socially shaped illness in order to illuminate perceptions as well as experiences of, and responses to, both dementia as an illness and dementia care. The case in point has been to do so in regard to persons with Middle Eastern backgrounds partaking in ethnoculturally-profiled dementia care in Sweden because of the facts that, (a) there already exist Middle Eastern-oriented dementia care facilities in Sweden, which indicates that people of this background are perceived (and/or perceive themselves) as an ethnocultural group with special needs for targeted care, (b) people with Middle Eastern backgrounds make up one of the largest immigrant *groups* in Sweden, with increasing numbers of people growing older; and (c) hardly *any* studies exist regarding persons with dementia diseases and with Middle Eastern backgrounds.
As presented above, our results in this paper indicate that the perception of dementia and the described meaning of the disease have little (or nothing) to do with decisions regarding formal care. Our interviewees did discuss different perception of the disease, however very few of them seemed to connect such perceptions to the use (or non-use) of formal care. Instead, the fact that almost all our interviewees had Middle Eastern background themselves and worked within ethnoculturally profiled care, seemed to make them explain – and contrast – their own perceptions and experiences not only as "opposed" to people of Swedish background but sometimes also with those from "their own culture", as for instance Arif did in clearly stating that he, as an educated healthcare worker, had "better" knowledge than others

from "his own culture" did. This of course needs to be clearly stated: that our informants in this study consist of people of Middle eastern background whom all have had (at least some) training within health care and as such the positionality of the care staff cannot be extended to represent the so called wider community of Middle Eastern immigrants living in Sweden. However, as we have presented in our results, most of our interviewees tend to speak "on behalf of the culture" and as such it could still be interesting to analyse their discussions in regards to cultural assumptions concerning profiled care.

We thus suggest that in order to better illuminate issues regarding ethnoculturally-profiled care, we might be helped by introducing the concept of acculturation. Acculturation is the theory surrounding changes that come about when persons come in contact with other cultures (first introduced by Redfield, Linton, and Herskovits as early as 1936). This theory is of course linked to *the acculturation continuum* – a means of trying to explain one's degree of ethnic identification. This model was developed in order to try to help practitioners to respond to cultural variations encountered when working with ethnoculturally diverse groups (Valle 1998). In short, the acculturation continuum goes from a traditional position, characterized by strong orientation towards 'the homeland' and the retention of cultural origins, to bicultural positions marked by persons moving with relative ease between both cultures, to the end of the continuum – acculturation[xiv] – where one almost completely identifies with the culture of the new society in which one lives (Valle 1998; Yeo and Gallagher-Thompson 1996). Studies have thus shown that acculturation may be linked to changes in health behaviours as well as changes in knowledge and beliefs (see for instance Landrine and Klonoff 2004).

One might say that some of the participants in this study show tendencies of being acculturated; that they have started to reject their culture (which they explain do not necessarily understand what dementia "really" is) and instead adopt the Swedish cultural definition of dementia as a disease. As Arif puts it in the quote above, dementia is *not* something natural, it *is* a disease and according to him people from the Middle East need to understand that (which Arif and several of the other interviewees suggest they do not). However, our results also show that the interviewees describe certain cultural differences among persons with Middle Eastern backgrounds, that some are being more traditional in regard to retaining cultural origins in comparison to *other* Middle Eastern immigrants. As Mitra said:

"I believe, through my own experience and by talking to others who also feel the same way that Arabic-speaking people are more willing to take care of their elderly at home by themselves and it is part of the culture. Yet, such is indeed the case for us Iranians as well but I think that it's, in Sweden perhaps we Iranians have adapted us more."

What Mitra thus points out is that it seems hard to believe that immigrants with Middle Eastern backgrounds now living in Sweden will automatically have the same attitude towards residential formal care as immigrants with Middle Eastern backgrounds in other societies will have, simply based upon the fact that they have migrated from the same area and might (or might not) have had similar perceptions and experiences of dementia (and dementia care) in their home countries. Because, as Mitra states, and the acculturation theory suggests, people adapt and change in relation to surrounding society. Otherwise it is almost as if the whole Middle Eastern community also existed in a vacuum, with no regard to the fact that cultural ideas, norms and tradition also change over time and in correlation to surrounding society. In order to understand ethnoculturally-profiled (dementia) care in Sweden this study has thus shown that to understand more about persons from the Middle East with dementia who are living in Sweden, it is crucial to understand how one relates to dementia care *in Sweden* rather than trying to conceptualize it in relation to (preconceived) perceptions of the disease itself. This result is similar to what was recently found in a study exploring response processes surrounding signs and symptoms of dementia among Pakistani

immigrants living in Norway (Næss and Moen, 2015). Although the result of that study has a reverse line of argumentation and showed how norms and traditions regarding the centrality of *the traditional family* has profound influence on how cognitive changes at old age are explained and dealt with (which this study does not), it comes to the same conclusion that dementia care – in a migratory context – needs to be understood more in relation to the health-care system/health-care culture in the *new* society. General assumptions based upon some notion of cultural perceptions of the disease will help very little. Thus, as our results show, and as is confirmed by Næss and Moen's study, cultural norms and traditions in regards to issues of care might need to be further highlighted in regards to (dementia) care within a migratory context.

The fact that the data, which this study is based upon, is a still ongoing matter (some data was gathered almost three years ago, some much more recently) points to this need of contextualization. When preparing this particular paper, we of course went back, looking over the data yet again, checking out the different care facilities yet again, we soon realized that things had already changed. *The Agora*, which profiled itself as an *Oriental* facility no longer has such a profile. It still exists with the same name, but has a much wider focus upon (all) elderly with somatic and dementia diseases (however still offering staff who all speak Swedish and 'many other languages'). Remember Sadira's and Joakim's discussion above? Where they said: 'we were rather convinced *in our own belief* that this would be something one wanted'. However, it was never checked with the so-called *target group* to see if it really was. We believe that this is crucial, because it points to the fact of how people relate to issues of formal care needs to be studied in context – to offer ethnoculturally-profiled (dementia) care to persons who might not even consider formal care an option, however adapted it is in terms of cultural traditions and customs, foods and religion – might be a waste of both time and resources. What we argue is thus that to underestimate the impact cultural norms and traditions might have in regard to care and care-seeking behaviours, neither the individual person with dementia, nor larger ethnocultural groups can be placed within a vacuum that seemingly does not change or correlate with surrounding society. It is thus crucial to remember that in regards to the acculturation continuum people are complex, and it is almost impossible to be *pinpointed* at one particular position in the acculturation continuum. It is a sliding scale and who can say in which ways it slides? Is it always towards the acculturated position and away from the traditional one? Of course not, because it might also be the case that ethnocultural continuity is regarded as extra valuable to try to *keep* as intact as possible, and to not let it change all too much.[xv] As Hadya, who herself works with formal dementia care, says:

> There are pros and cons about both cultures (.) but that someone else will take care of me, I think about when I get old, yikes what a pain, even if I am treated fine but still, it feels better if my daughters or sons would do it because I have worked many years for them (.) I did everything for them, and then, when I don't have more strength, they throw me away. (…) There [back in Iraq] one is always with one's children, with one's grandchildren. You don't die alone.

Thus, ways of being and ways of belonging might need to be distinguished in relation to a migratory context (Levitt & Schiller 2004), especially so in relation to migrant life trajectories (Boccagni 2012) and how diseases – such as for instance dementia – needs to be much more understood outside of the social vacuum it so often seems to be placed within.

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NOTES

[i] This is not to suggest that dementia is nothing but a social construction (i.e. if all people and all contexts were adjusted towards facilitating people with symptoms related to dementia disease, the disease would magically *disappear*). It is however an approach that understands dementia as a complex collection of conditions, occuring in relation to surrounding social environment, rather than being an attribute of a single individual (Antelius 2009; Kitwood 1997).

[ii] Relevant to this progression of understanding dementia and the people affected is that the term *demented* points to the idea of someone *being* one's disease and should preferably be replaced by the more active/agentive approach of saying *persons with dementia diseases*. However, as the readers will notice throughout the paper, the term demented is still used, but ONLY when directly quoted from interviewees. We have thus not gone into correcting people's statements, but as researchers within dementia studies we only use the term persons with dementia diseases in our own analyses.

[iii] In the paper concepts such as *culture, ethnicity* and *ethnocultural* are used throughout the discussion. A clarification regarding these concepts is necessary, however any clear-cut definition is (almost) impossible to give, simply because the literature does not provide such a definition. Multiple definitions are to be found as well as the fact that the two concepts of *culture* and *ethnicity* are often used interchangeably (Valle 1998). We will not try to resolve these definition issues here, but instead take on a more practical approach. We will try to use the concepts as our informants give meaning to them. However, a note should be made that there are differences between the concepts, where *culture* is often understood as the values, traditions and beliefs of a group while *ethnicity* is the active expression of such culture (ibid: 10). Thus, *culture* could be understood as the forms of behaviour a person has acquired in being a member of (a certain) society while *ethnicity* has more to do with the social relations between such members. The fact that two groups could be said to be culturally distinctive does not create ethnicity. Ethnicity only occurs when cultural differences are made relevant through interaction (Eriksen 1993). Our use of the concept *ethnocultural* thus points to the fact that people can never really belong to *a culture* and ethnicity concerns what is socially relevant, not which cultural differences that are *actually there*. Hence, ethnicity *and* culture need to be understood as intertwined.

[iv] For more information regarding the AGE project, and its results, see for instance Fry et al. 1997.

[v] See Dilworth-Anderson and Gibson 2002; Leibing 2002; Leibing and Cohen 2006; Henderson 2002; Henderson and Henderson 2002; Henderson and Traphagan 2005; Traphagan 2002, 2005, 2009.

[vi] The naming of profiled care groups in this study range from Arab, to Oriental, to Middle Eastern. However, when talking to the informants most of them use the term Middle Eastern (or sometime Arab), thus we have chosen to use the most common name/term that the interviews themselves use.

[vii] These guidelines are now being audited and new guidelines are to be published in the fall of 2016.

[viii] For other examples, see for instance the special issue 'Ethnocultural contextualization of dementia care: cross-cultural perceptions on the notion of self' in *Care Management Journals 16*(2), 62-120.

[ix] All naming of cultural *groups* are the care providers' own.

[x] For studies from this Persian-oriented dementia care facility, please see Antelius and Kiwi 2015; Kiwi, Hydén and Antelius, *forthcoming.*

[xi] See for instance Antelius & Kiwi 2015; Kiwi, Antelius & Hydén, *forthcoming*.

[xii] The word 'demented' implies that someone is their disease, a term nowadays seldom used in dementia studies. In order to put forward an agentive approach the term person with dementia should instead be used (as we do in this article). However, in the instances an interviewee has used the word 'demented' we have of course not changed this.

[xiii] In regards to dementia care, several research reviews touch upon this subject, see for instance Botsford, Clarke and Gibb 2011; Daker-White, Beattie, Gilliard and Means 2002; Janevic and Connell 2001; Mukadam, Cooper and Livingston 2011; Connell and Gibson 1997.

[xiv] It is important to emphasize that acculturation is not the same as assimilation. The lessening of cultural distance (acculturation) does not necessarily mean that a symmetrical lessening of social distance (assimilation) will occur.

[xv] This ambiguity is in fact something that the acculturation theory does not seem to fully account for and a forthcoming article, *Dementia in the age of migration: the disruption of cultural continuity as a cause of illness?* will elaborate further on this subject and discuss healthcare in migratory contexts in relation to issues of transnationalism and simultaity.