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Title: Experiences of living with dementia in Iran: qualitative content analysis of semi-structured interviews

Concise title: Living with dementia in Iran

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Conflict of interest

None reported.

ABSTRACT

Aim and objective: To describe people's experiences of living with dementia in Iran.

Background: A knowledge gap exists regarding the experiences of living with dementia in non-Western contexts. This gap may be especially apparent within the Iranian context, where dementia research is relatively new. Deeper understanding about context related experiences of dementia is a prerequisite for nurses' ability to provide adequate and meaningful care.

Design: Qualitative, cross-sectional design.

Methods: Qualitative content analysis of semi-structured interviews with people living with dementia in urban Iran (six women and nine men; 60 to 87 years old).

Findings: The participants experienced their condition as a state of forgetfulness that was accompanied by losses and dependency on others. They wanted to feel good about themselves and feel important, but they continually struggled with matters such as a loss of accountability, feelings of futility, and the frustration of others. Economic dependency and a lack of economic resources were sources of feelings of futility.

Conclusion: Experiences of living with dementia in Iran included a substantial struggle to stay connected to the social world and to deal with dramatic life changes, aspects of living with dementia that seem to be universal. However, the feelings of financial burden and the experience of being nagged for their shortfalls by family members have seldom been described in other studies and seem to represent a cultural aspect of their experience.

Relevance to clinical practice: The results of the study call for further nursing efforts in supporting people living with dementia in their struggle with their altered lives and in retaining their connections to everyday life. Furthermore, their family members might benefit of specific nursing interventions including information about dementia and advice on how to help the family members with dementia to interact with others while exercising their individual strengths.

Keywords: content analysis; dementia; gerontology nursing; Iran; life experiences; qualitative studies; semi-structured interview

INTRODUCTION

Current dementia research shows an increasing trend toward valuing and giving respect to people with dementia, especially with respect to their own experiences of the condition (Beard & Fox 2008, O'Connor *et al.* 2007, Roger 2006). However, as the latest published literature review on research of experiences of dementia (de Boer *et al.* 2007) pointed out, despite their comprehensive search, only articles from Western countries were found in the searched databases. This gap may be especially apparent within an Iranian context, where dementia research is relatively new (Fallahi Khoshknab *et al.* 2010), as is the case in many other developing countries (Prince 2004). Nurses meet people from various cultures and with a broad range of problems, beliefs, values, and lifestyles. If nurses' fail adjust their care to fit the patients' values and lifestyle, there is an increased risk that the patient will be uncooperative, noncompliant, and dissatisfied with the given care (Leininger & McFarland 2002).

BACKGROUND

A body of knowledge exists regarding the impact of culture on human experiences throughout life (Gilbert *et al.* 2007, Leininger & McFarland 2002, Thomas 2001). Culture shapes perceptions and behaviours and is therefore also assumed to shape responses to cognitive impairment and dementia. Culture impacts the actions that people take in response to symptoms of illness and how people interact with healthcare professionals. For example, conflicts between the cultural values of individualism and collectivism and regarding family values can arise in relation to decisions about treatment and care (Pierce 1999, Thomas 2001). Iranian collectivistic culture places a high value on older people, who

should be treated with respect, especially by their family members (Elizur *et al.* 2008).

Dementia might threaten the family's respect for their older family member because of the changes in the family member's behaviour and personality due to dementia.

Lawrence *et al.* (2011) have reported that the threats that commonly accompany dementia depend on people's own understanding of their condition, their attitudes toward support needs, and the perception of the disease's interference with their life values. Accordingly, any increase in the ability to help and support people with dementia and in providing individualised care and support plans, where the prevention of the threats accompanied with the disease are taken into account, requires a deeper knowledge of the affected person's understanding of and experiences of living with his or her disease.

Research on the experience of living with dementia shows great variations, from conceptions of living 'in a heteronomous existence in which they [people with dementia and their spouses] are lost and strangers in their own world' (Svanstrom & Dahlberg 2004, p. 671) or living on the threshold (de Witt *et al.* 2009) to having an intact manifestation of selfhood (Sabat & Collins 1999) and intact emotional and interpersonal responses (Evans-Roberts & Turnbull 2010). A systematic review has presented at least some evidence to support the notion of the persistence of self in all stages of dementia (Caddell & Clare 2010). Although a common theme in many studies is a sense of loss (see, for example, Harris and Keady 2004, Snyder 2001, and Steeman *et al.* 2006), the experience of dementia has also been reported as striving to incorporate a 'manageable disability' into an existing identity (Beard *et al.* 2009), with a view of a life that is not erased by the disease (Westius *et al.* 2009).

Studies reported from Asian contexts have shown that Japanese people were more afraid of the decline related to old age in general terms than they were specifically afraid of Alzheimer's disease (Traphagan 1998). Similarly, 'dementia in China did not evoke the kind of dread that was common among Americans', which is proposed to relate to Chinese people's 'beliefs about dementia, cultural values, and situational features of contemporary Chinese life', such as lifestyle and the lack of alternatives to family care (Ikels 1998, p. 257). No published studies regarding people's own experiences of dementia have yet been found that pertain to Middle Eastern countries.

The lack of research on the subjective experience of dementia in the Middle East and the necessity of studying the experience of dementia in various contexts in order to gain a broader image of the phenomenon prompted the present study. Deeper understanding about context related experiences of dementia is a prerequisite for nurses' ability to provide adequate and meaningful care and support to people with dementia and their relatives (Leininger & McFarland 2002). The specific aim was to describe people's experiences of living with dementia in Iran.

METHODS

The study had a cross-sectional design, and the methodological approach used was qualitative content analysis (Graneheim & Lundman 2004) of interviews with people having dementia.

Participants and setting

A convenient sample (Kvale & Brinkmann 2009) of 15 participants was recruited for the study. The inclusion criteria were that candidates had been diagnosed as having dementia (Alzheimer's disease or vascular dementia) at least one year before the interview, had the ability to communicate, and were willing to participate and talk about their experiences.

The participants were recruited through the Iran Alzheimer's Association (IAA), which is a non-governmental organization aimed at supporting people with dementia (not restricted to Alzheimer's disease) in Iran. The organization is located in Teheran and runs an outpatient clinic and a day care centre for people with dementia. None of the authors had any contact or relationships with the association or their centre prior to the planning of the study. The IAA employees asked the family caregivers of visiting clients with dementia whether they would allow their affected relatives to be approached and informed about the study. Upon accepting the invitation, the potential participants were given oral and written information about the study and, if informed consent was obtained, an appointment was scheduled for an interview.

All family members who were approached (15 families) by the first author allowed their relatives with dementia to be contacted and informed about the study. All 15 approached potential participants gave their informed consent and completed the study. The participants were from the urban population in Teheran: six women and nine men, ranging in age from 60 to 87 years (mean 72). One participant had no formal education, four had a post-secondary education, and ten had six to ten years of education. All were pensioners. Ten had held paid jobs, and five had been housewives. Three participants were living alone in separate flats close to their children, three were living with their spouses and children, two were living with their children only, and seven were living with their spouses

only. All participants had been diagnosed with dementia between one and six years prior to the interviews. Their Mini-Mental Status Exam (MMSE) scores varied between 14 and 19 points (mean 16.5) according to their medical records, which means that they all had moderate dementia.

Data collection

Data were collected through semi-structured interviews (Kvale & Brinkmann 2009) performed from 2008 to 2009 by the first author. The inclusion of new participants went on until no new content appeared in the interviews. Due to personal preferences, two interviews were carried out at the participants' homes, and the rest (13 interviews) were performed at the IAA facility. The interviewer asked the following main questions to generate a conversation about the participants' experiences of living with dementia:

- Could you please tell me about your experience of dementia?
- What changes have occurred in your life because of dementia?

More specific questions complemented the main questions (e.g., Can you recall more details of a specific incident? Do you have further examples of this? What do you mean by that?). The interview durations ranged from 23 to 51 minutes. The interviews were audio-recorded, transcribed verbatim, and validated by re-listening to the tapes.

Data analysis

The transcripts of the participants' interviews were analysed using latent qualitative content analysis (Graneheim & Lundman 2004). During the analysis, (*i*) the interviews were read in

order to acquire an overall understanding of content related to the aim of the study; *(ii)* the interviews were repeatedly read and discussed in order to achieve immersion and gain a sense of the whole; *(iii)* the interviews were read again (word for word) while jotting down the reflections (e.g., the participants have not given up) and impressions (e.g., similarities and differences among participants); *(iv)* each interview text was divided into meaning units; and *(v)* condensed meaning units were extracted out of meaning units with regard to the context. Those condensed meaning units which were related in terms of their meaning and content, were merged and abstracted into subthemes. These subthemes were then related to an overall theme. (See Table 1 for an example of the process.)

<Insert Table 1 about here>

The research team had expertise in the field of dementia and in qualitative content analysis, and team members were well-engaged in constructing themes and subthemes. Two of the authors analysed the interviews separately in parallel. Then, the results were compared and discussed with the other authors to reach an agreement on the themes and subthemes.

Ethical considerations

The Karolinska Institutet's Regional Ethical Research Committee (record number 111/05) and the National Ethical Committee in Iran (record number 391/05) reviewed and approved the study. The principles of World Medical Association Declaration of Helsinki (1964) were carefully considered. Participants and their family caregivers were informed that the study was voluntary and that they could withdraw at any time without cause or notice. All participants provided informed consent. During data collection, every possible effort was

made to detect non-verbal signs of inconvenience or any indication of a wish to withdraw from the interviews. All participants were assured of the confidentiality and anonymity of their interviews. Participants' personal information has been kept in a locked filing cabinet at the university. Participants' names were replaced with numbers before anyone was granted access to the transcripts. When data from the study were presented, care was taken to describe the participants in a way that maintained confidentiality (i.e., efforts were made to *not* disclose information that could be traceable to a specific participant—particularly in the quotations).

FINDINGS

The participants were able to give concrete examples of their experiences of living with dementia, and they recalled conversations with relatives and family caregivers in relation to the interview questions, thereby demonstrating their ability to describe their life experiences.

Some participants regarded dementia as 'a normal stage of life' that everyone might experience, but most perceived it as a 'medical disease' that was not a part of the natural ageing process. Certain participants believed that their disease had no particular cause; others tried to explain it as being a result of having had a hard life.

Struggling with an altered life

The content analysis revealed one main theme and five associated subthemes (see Figure 1). Living with dementia for the participants meant 'struggling with an altered life'

which included the subthemes of ‘in the eyes of others—an altered self’, ‘forgetfulness as an irritating condition’, ‘being a burden on others’, ‘longing to be a valued person and ‘finding strategies to deal with the disease’.

<Insert Figure 1 about here>

In the eyes of others—an altered self

The participants described how they, even prior to being told of their dementia diagnosis, gradually found themselves different, mainly through others’ eyes. Through a combination of their own insights into their increasing shortcomings and the many comments they received from family members, relatives, and friends, they had become aware of the deterioration of their memory and cognitive skills. They recalled their families’ or friends’ reactions when they could not recognise common events and friends, remember a special event or occasion, or remember details, such as closing the water tap.

It is not good to forget things. I ask myself why I forget things that make my wife and daughter get so upset... I don’t close the car door properly; she gets out, comes over, and closes the door... My wife says I have dementia... (male living with his wife and daughter).

The reactions and reflections of others made them feel as though they were some other person. In their own view, however, they were still the same person they had always been, although with some new problems.

Forgetfulness as an irritating condition

When the participants described their experiences of the illness, they used the term ‘forgetfulness’ to describe their condition. They said their forgetfulness was the cause of all

their problems. They mentioned how badly they felt when they discovered they repeatedly forgot things and how troublesome it was to live with the condition.

...[It] is a teasing disease. It teases you a lot. For example, you no longer recognise your childhood classmates. Your friends' faces look strange. It's like typhus—it breaks you down. /.../ It is very troublesome; it's very bad (male living with his wife and two young children).

Being a burden on others

Participants were well aware of the difficulties their forgetfulness and distractibility caused, and they stressed how futile their lives as individuals felt.

If we go to our relative's house, I see how others are active. This breaks my heart ...[crying]...I don't act like an active person: I who could move mountains! When I was employed, I worked from 8 am until 12 midnight; now, why should I be like this? Why? (female living with her teenage daughter).

Almost all participants stated that they received too many reminders and comments about their mistakes, shortcomings, and failures. Such failures were challenging to their understanding of themselves as competent people. One of the participants, a male living with his wife said:

People say, 'You are of no benefit. You don't work, and why don't you have a job?' People don't deal well with me.

Such comments made them feel deeply unfulfilled in their own personal lives. Some even believed that their intellect had been disrespected because of their altered condition and felt that they were treated harshly.

The participants experienced greater dependence on others (e.g., family members) in carrying out daily tasks and life routines. The participants acknowledged the difficulty that

others had in approaching them, and they regretted that they were bothersome and caused discomfort for family members.

My daughter does the entire job for me./.../ My daughter is very tired—I know that [crying]. She is forced to live this way (female living with her daughters).

The participants also talked about financial difficulties as a source of feelings of futility and the fact that they created feelings of deprivation and hopelessness. The participants pointed out that the financial help that had been provided was inadequate. Those who had lost their jobs had become financially dependent on others, which they found miserable.

Financially, we depend on my wife's salary. I've not worked for the past five years. I don't earn even one rial [Iranian currency]. My wife works/.../and our life depends on her money. We have three daughters, and they are all university students. They all need help (male living with his wife and three children).

Longing to be a valued person

Participants longed to re-establish their own lives and to be valued members of their families and communities. Most of them felt that their family members had discarded them because they were no longer involved in decision-making or their former activities. Furthermore, the participants complained about the ways others approached them and met their needs.

My children and relatives are not behaving politely and show a lack of respect. They ignore me (male living with his wife).

They said they needed to be shown respect, which involves recognition, acceptance, and appreciation.

The participants were concerned with having nothing special to occupy their time and gave several examples of how close relatives did all the tasks themselves, not allocating any responsibilities to them or sharing problems, as they had once done.

I say to them [her daughters], 'Let me help wash the curtains and put them up again'. They say 'No, no. It is better you stand and watch. We'll do the entire job ourselves'. I don't know what to do during the day (female living with her daughters).

Another example was reported by one participant, a former health professional, who had been accustomed to being asked for advice by his relatives and friends when they had health issues. Now, after developing dementia, his role and social network had dramatically decreased, and his relatives and friends no longer asked for his advice. He believed that even though he could not practice his profession due to his condition, his knowledge and skills should not be disregarded. He had suggested to his day care centre that he could give speeches regarding general medical conditions and health promotion to those attending the centre, but he said that his suggestion had not earned any response at all.

Many participants, like the two above, described how they were observers of ongoing events, rather than active participants, and this was weighing them down. They were no longer relied upon. Instead of being involved in everyday issues, they felt restricted by their environment, and many complained of being left alone. Altogether, this led to a sense of discontent regarding their dire situation.

They [family members] don't let me go out, walk, and do things./.../ they think they are in charge of me [angry and with tears in his eyes] (male living with his son's family).

Finding strategies to deal with the disease

Even though some participants believed that no cure existed, most described how they searched for strategies to deal with forgetfulness and other problems related to their dementia. They used various strategies, such as humour, trying to ignore or normalise their difficulties, or highlighting their life achievements, and they made efforts to put their failures and forgetfulness into the background. Some participants searched for medical treatment to improve their condition, made extra efforts to behave according to the norms to avoid problems, or attempted to improve their memory by spending more time reading and memorising poems. Some participants tried to find meaning in their dementia experiences by dealing with their dementia through their faith.

DISCUSSION

In the present study, we interviewed people in Iran who live with dementia. We did so in order to access first-hand experiences of living with dementia. The results of the present study support earlier research that indicates that despite considerable memory loss and functional deterioration, interviewing people with dementia is still possible (Beard *et al.* 2009, Clare *et al.* 2008, Westius *et al.* 2009). The interviewed people described how they began their life with dementia by recognising how they had changed in others' eyes. They experienced dementia as a state of forgetfulness that was accompanied by losses and by dependency on others. They wanted to be recognised as individuals, i.e., they wanted to feel good about themselves and to feel important. The participants underwent a continuous struggle with matters such as loss of accountability, feelings of futility, and the frustration of others.

Many experiences of living with dementia in urban Iran seem to be shared with participants living with dementia in other contexts. The study mostly confirms results from other studies and therefore points out that the core experience of people with dementia is to some extent universal, despite differences in cultural and political contexts and with different religious beliefs or confessions. Steeman *et al.* (2006) showed that losses were present in the post-diagnostic phase of dementia, a finding confirmed in our study. Furthermore, although participants in the present study had to face many problems because of their illness, their primary concern was the desire to be viewed as a valued person who should be respected and understood. This finding is consistent with that of Steeman *et al.* (2007), who also found that individuals with dementia were less concerned with cognitive decline than with remaining someone of value. Svanstrom and Dahlberg (2004) found feelings of futility among Swedish couples in which one partner had dementia. They also reported that feelings of loneliness intensified and amplified a couple's sense of futility. This finding is aligned with the feelings reported by the participants in the present study, who also expressed feelings of loneliness and futility.

The participants in the present study showed examples that indicated their awareness of and concern over the discomfort and burden they caused their family caregivers. Similarly, Wolverson *et al.* (2010) showed that people with dementia could recognise their caregivers' levels of anxiety and psychological health. Studies from Canada, the United Kingdom, and Sweden have shown that people with dementia felt guilt and shame for being a burden on their loved ones (Gillies 2000, Robinson *et al.* 2000, Ward-Griffin *et al.* 2007). Wolverson *et al.* (2010) explained the presence of such feelings through the claim that people with dementia have enhanced memories of emotionally-related issues or events that

enable them to remain aware of their caregivers' levels of psychological health, irrespective of their general memory difficulties. In the same way, Kitwood (1997) argued that certain aspects of the self (e.g., feelings, emotions, and reactions) could be sustained in relationships with others because they are not bound to the preservation of memory. These findings could alert nurses and family members to be cautious about their own behaviour and reactions related to the performance of people with dementia in order to not trigger their sense of futility and burden.

Some strategies that participants applied in dealing with their condition have also been found in other studies of various contexts, e.g., adopting a fatalistic attitude (Clare 2003), normalising their forgetfulness and associated problems in various ways (Clare 2002, Shakespeare 2004, MacQuarrie 2005), working harder to perform at previous levels, trying to overcome task difficulties by using cognitive or practical strategies, repetitive reading to improve retention, relying on others for practical help (Beard *et al.* 2009, Clare 2002, Pearce *et al.* 2002), using humour (Werezak & Stewart 2009), concealing the inability to remember or respond satisfactorily (Burgener & Dickerson-Putman 1999), and using medication (see, for example, Clare 2002 and Pearce *et al.* 2002). As care providers, nurses can support and empower constructive strategies and help the people with dementia in accepting their own limitations due to dementia. Furthermore, nurses can also contribute in educating family members about the dementia and the difficulties in living with dementia in order to increase their ability to cope and understand their relatives with dementia.

However, unlike the reports of previous Western studies, financial problems and being financially dependent on others were expressed as sources for feelings of futility and vulnerability in the present study, and in some participants, these were thought of as a

source of hopelessness. Contributing factors for these differences could be the lack of insurance and support services for older people in Iran and economic inequities in line with those reported by Prince (2004), who found much greater economic hardships for people with dementia in developing countries as compared to similar people in the developed world. Darvishpour Kakhaki *et al.* (2010) drew attention to the special cultural position of older people in Iran where they, as the senior members of extended families, are expected to host traditional ceremonies. Although not explicitly expressed by participants in the present study, the demands of hosting such ceremonies could contribute to increased expenses and add to the financial constraints related to their health problems.

Another issue that might be special in this Iranian context was the participants' intense feelings about the many comments and corrections that they received from their families regarding their forgetfulness and its consequences. Such reactions of families and friends might be due to the general population's lack of knowledge and insight regarding dementia in Iran. Furthermore, we draw parallels to Ikels (1998), who speculates about an East Asian collectivistic culture in which the family is morally obligated to care for their ageing members, who, in turn, are expected not to interfere; that study found that Chinese society encouraged its older people, especially those not contributing economically, to withdraw and not interfere with significant aspects of family life. Since people with dementia in Iran usually do not get diagnosed as early as in Western countries due to lack of public knowledge about dementia (Fallahi Khoshknab *et al.* 2010.), they might struggle with memory problems and accompanied complications longer, which is another context-specific issue.

Methodological considerations

The study was conducted by researchers from both Sweden and Iran, which provided possibilities of looking at data from different cultural standpoints. The authors became very aware of their pre-understanding in different phases of the analysis process. Having several authors helped to minimize the bias that the pre-understanding might cause, as all the authors participated in the analysis process and discussed the emerging results.

Issues of trustworthiness were carefully followed by criteria mentioned by Graneheim & Lundman (2004) including credibility, dependability and transferability. To achieve credibility, the participants were selected to have different gender, age, and education characteristics in order to get varied experiences. All the interviews were recorded and transcribed verbatim. During the analysis, the authors discussed the different steps of the analysis process back and forth to reach agreement. Careful efforts were made to choose the most suitable meaning units and the process of developing the theme and subthemes were documented. Efforts were also made to select representative quotations from the transcribed text to illustrate the theme and subthemes. Among the authors, there was expertise both in the field of dementia diseases and in qualitative content analysis. This helped the authors be more cautious about whether the final themes covered all data and decreased the risk of excluding some data because of misidentification as irrelevant. The results of the study have also been shared with other researchers in research seminars in order to discover potential blind spots and less obvious points. Dependability was dealt with by asking the same areas among all interviewees and having an open dialogue within the research team. To address transferability, efforts were made to give clear descriptions of the context, participants and participants' recruitment, data collection and process of analysis

followed by a presentation of the findings together with appropriate quotations. Also, some suggestions on how our findings may be transferred to other contexts are provided in the Discussion and Implication for practice sections.

CONCLUSION AND IMPLICATIONS TO PRACTICE

Many aspects of the experience of living with dementia seem to be universal. However, the feelings of financial burden and the experience of being nagged for their shortfalls by family members represents a specific contextual aspect of living with dementia in Iran. It seems that these people with dementia in Iran suffer from losing their role as financial provider, which can cause problems for their family role and damage their self-dignity concerning their senior position in the extended family structure. This calls for further efforts in supporting people living with dementia in their struggles with their altered lives and their struggles to retain their connections to everyday life.

Our study's findings can contribute to the development of appropriate dementia care plans based on the specific contextual situation of people with dementia. There seems to be a need of nursing interventions to help people with dementia and their relatives to accept problems associated with forgetfulness and losses. As pointed out by Day *et al.* (2000), nurses can help improve the lives of those living with dementia by facilitating a social environment that allows people with dementia to engage in various activities and decisions, all of which promote self-dignity and the individual's worth. Furthermore, nurses could support family members by giving information about dementia and advice on how to help the family member with dementia interact with others while exercising his or her individual strengths.

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Table 1. Content analysis of transcribed data from interviews with 15 people with dementia.

Examples of meaning units, condensed meaning units, subthemes, and themes.

| Meaning unit | Condensed meaning unit | Subtheme | Theme |
|---|---|--|---|
| <p>“They asked me to go somewhere but I forget to go, and they ask me why I haven’t done that, and I say ‘oh sorry! I have forgotten that...’ It is not good to forget things. I ask myself why I forget things that make my wife and daughter get so upset... I don’t close the car door properly; she gets out, comes over, and closes the door... My wife says I have dementia...”</p> | <p>Noticing his forgetfulness and mistakes, getting to know about his dementia diagnosis via his wife</p> | <p><i>In the eyes of others— an altered self</i></p> | <p>Struggling with an altered life</p> |
| <p>“I say to them [her daughters], ‘Let me help wash the curtains and put them up again’. They say ‘No, no. It is better you stand and watch. We’ll do the entire job ourselves’. I don’t know what to do during the day.”</p> | <p>Rejected when trying to be involved in house chores</p> | <p><i>Longing to be a valued person</i></p> | |

Figure 1. Theme and subthemes revealed by the qualitative content analysis of interviews with 15 people living with dementia in Iran.

