Living with and Caring for Patients with Alzheimer's Disease in Nursing Homes

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ARTICLE INFO	ABSTRACT
Article type: Original Article *Article History:* Received: 5 Nov. 2012 Accepted: 8 Feb. 2013 ePublished: 27 Agu. 2013 *Keywords:* Alzheimer disease Care experience patient Nursing homes	***Introduction:*** Many of the patients with Alzheimer disease are taken care of in nursing homes. However the literature on the experiences of Iranian formal caregivers of older adults with Alzheimer disease is scarce. This qualitative study explored the caring experiences of formal caregivers in nursing homes that can improve the quality of care and patient's quality of life. ***Methods:*** This qualitative study used the principles of descriptive content analysis to analyze these data. Our participants included 11 female and 3 male caregivers aged 25 to 38 years who were selected for interviewing based on a purposive sampling method. The data were analyzed with a content analysis method. ***Results:*** Nearly 900 initial codes were extracted and categorized into 6 main themes including "managing difficult behaviors", "dependence on familial care", "continuum of different feelings", "care for a child", "living with the patients" and "not understanding the patients", which was further analyzed in the two subcategories "caring without enough information" and " a dead man moving". ***Conclusion:*** The care provided by our informants was mainly influenced by attitudes, culture and religious beliefs of caregivers about family attachment and ample driven reward of helping and caring frail or old people in Islam. These cultural and religious beliefs could facilitate provision of care and confrontation with patients' child-like behaviors. It is suggested that employment of trained staff and plans for their continued education can improve the quality of care and the quality of the patient's life.

Introduction

Care is a multidimensional phenomenon, a cultural experience and a challenging domain in medical sciences, especially when it involves care for patients in nursing homes who have Alzheimer disease (AD) with cognitive deficits and behavioral disturbances. [1]

About 27 million people worldwide are affected by AD and this figure is expected to increase by up to one million annually.[2] In Iran there are 250 000 patients with AD.[3]

Given the rapid increase in the number of patients with AD in the world, the most important challenge faced by health services today is to build a comprehensive system of care for these patients.

In traditional Iranian society older adults are used to living with their families, and therefore the number of nursing homes is

limited. Moreover, there are no special units for patients with AD, who consequently receive care together with other older adults in nursing homes.

The State Welfare organization of Iran is responsible for supervising nursing homes in Iran. In recent years, due to changes in the nuclear family structure and the increasing number of working women, there is a growing tendency to transfer older patients to nursing homes. Also the evidence in other countries to date suggests that the risk of institutionalization increases during the course of AD,[4] particularly in relation to the level of cognitive impairment and abnormal behavior patterns.[5-8] In view of the rapidly increasing need in Iranian society for institutional care for patients with AD along with the increase in the number of patients with AD, it is essential to increase the number of nursing homes and improve the quality of care they provide.

Formal caregivers in nursing homes have an important role in providing suitable care and environment for AD patients. There are many challenges in their day-to-day work which can affect care [9] especially in the case of people with dementia; such challenges have been described as emotional and physical draining,[10] with heavy physical and psychological workloads.[11] Intense involvement with residents has been identified as a stressor which can lead to staff burnout.[12] These Issues affect the caregivers' ability to do their job and resident care quality.[13] However, our knowledge about the cultural experiences of caring is limited.[14] Particularly in Iran, to the best of our knowledge, there are no studies on the care of patients with AD. So we decided to explore the experiences of caregivers providing care for patients with AD in Iranian culture in the nursing home that can result in designing more effective caring programs and education based on our culture for caregivers to reduce their stress in caring these patients and result in suitable care for Alzheimer patients and improve the quality of their life.

Materials and methods

This qualitative study used the principles of descriptive content analysis to analyze the data. Qualitative method was chosen because the purpose was to elucidate Iranian caregivers' experiences in providing care to patients with AD in nursing homes, our study design sought to identify, describe and understand individuals' thoughts and experiences.

During data gathering (2009-2010), there were 5 nursing homes in Shiraz, of which only two admitted AD patients. In each nursing home, about 50 elderly people were taken care of and approximately 50% of them were AD patients. The informants for this study were 14 caregivers of residents with AD who attended in nursing homes in Shiraz (population approximately 1 500 000, southwestern Iran). They had 24 hour working shifts. Our 14 key informants (11 women and 3 men) were head nurses, supervisors and formal caregivers. Only one or two nurses were working at every nursing home as head nurse or supervisor and the other caregivers were mainly unprofessional without any education or training in gerontology or nursing. They were aged 25-38 years and had been working in nursing homes for older patients for about 1-12 years. They were selected by using purposive sampling. The main criteria for selection were experience in care giving and ability to communicate their experience.

Qualitative interviews were conducted; the interview consisted of open-ended questions to allow respondents to fully explain their own opinions, perceptions and experiences. For instance, initially they were asked some general questions about their caring experience. The participants were asked to describe one of their own working shifts and then to explain their own perceptions and experiences of "caring AD patients". To further probe the informant's descriptions, explorative prompts were offered, such as "Could you please give an example?", "Could you please explain that more?", and "Do you

mean that [interviewer's paraphrasing of informant's words]?" Each interview lasted between 60 to 120 min. All the interviews were tape recorded. Interviewing closed when data saturation occurred.

In this study, the transcripts of the interviews with our informants were analyzed for themes and subthemes by qualitative content analysis. According to Burnard, the key feature of all content analysis is that the many words of the text are classified into much smaller content categories[14] as the first step in data analysis, the interview tapes were transcribed verbatim and reviewed with qualitative techniques to gain an overall impression. [15] In this research we used inductive content analysis. This process includes open coding; creating categories and abstraction.[16] The statements relevant to the goals of the study were marked, numbered, coded in the transcript of each interview, and then organized into conceptually relevant categories for the exploration of patterns and themes. The aim of grouping data was to reduce the number of categories by collapsing those that are similar or dissimilar in to broader higher order categories. [17] Each category is named using content-characteristic words. The research team met on a weekly basis to agree on the coding and categorization. When coding was completed, the research team examined the categories for conceptual overlap and emerging themes. All the comments and experiences were reviewed to identify and describe major themes related to each of the categories. The transcripts were checked to ensure that no relevant content was overlooked. The co-authors checked and discussed about the analysis and interpretations until consensus was reached.

The researchers accepted the perspective of Guba and Lincoln about trustworthiness.[18] To enhance the credibility and confirmability of our qualitative data and analysis, we used maximum variation sampling and member checks. For member checking, after the analysis, a full transcript of the participants' coded interviews with a summary of the emergent theme were given to the participants to ensure about a true representation of their experiences in providing care to Alzheimer patients. Also, prolonged engagement helped data credibility.[18] For further validity check, peer checking was done. Random samples of the interviews were analyzed by three expert supervisors and two independent researchers who were expert in qualitative research. There was an agreement between the different raters. The results were also checked with some of the caregivers who did not participate in the research and they confirmed the transferability of the results as well. The researcher tried to have precise documentation of the direction of research to help other researchers follow the direction of the participants' experience.

Ethical approval was obtained from the Ethics Committee of Shiraz University of Medical Sciences as the study was part of a PhD thesis at this university. Permission for the study was obtained from the Shiraz Welfare Organization and managers of the participating nursing homes. Printed information was given to the informants, who provided their signed, informed consent to take part in the research. Informed consent was voluntary and they could withdraw from the project at any time with no negative consequences. They were also informed that the tape-recorded interviews would be transcribed, and that their names and places of work would be replaced with fictitious names or symbols to ensure confidentiality. The tape-recorded material and transcripts were stored under secure conditions and only the authors had access to them.

Results

About 900 initial codes were gathered from the collection of interviews and categorized into six themes during the process of analysis. These themes were managing difficult behaviors, dependence on familial

care, living with patients, caring for a child, continuum of different feelings and not understanding the patients, which was further analyzed in the two subcategories caring without enough information and a dead man walking.

Managing difficult behaviors
One of the most challenging aspects of caring for patients with AD is managing their difficult behaviors. The caregivers noted that the control of behaviors is difficult and temporary, the patients are susceptible and fragile, the severity of disease and behaviors change, and the disease has a poor prognosis.

"Some swear a lot and they are very bad-tempered. We subconsciously keep a distance from them. Some don't even let us approach them to talk. Even when we want to give them their medications, they start yelling. They swear badly."

"If you don't have patience here, you won't last for even two months because of the patients' yelling and aggression."

"I try to control patients' aggression but my strategies are temporary. They start yelling and aggression again. Sometimes I don't know what I should do. I need more information about these patients"

Dependence on familial care
The participants pointed out the importance of care and attention, routine meetings and the family's participation in care in Iranian culture. In providing care, attention to familys' points of view was discussed by the participants within the nursing home framework.

"We should receive permission from their family for every work. Sometimes families ask us to restrain their patient for their patients' safety."

"Some people think because their patient has Alzheimer disease, it does not make much difference whether they visit them or not. But it shows in their behavior. They feel calm when they see their family, and when they don't visit they become agitated and swear."

"If we want to keep the patients calm, we should try to include their family in care because they are dependent to their family. The family can choose their patient's room and care."

Living with patients
One of the outstanding features of the care provided by the facilities we studied is that the caregivers live with the patients, both physically and mentally. Most of the caregivers in this study noted that because of their 24-hour work shifts in the nursing homes, they felt at home. At the beginning of the caregivers' job in the nursing homes they had experienced lack of interest in working with the patients. With time and continued contact, however, they started to enjoy it and came to the point of adapting to their job, and to discussing and sharing their feelings about the patients with their families.

"It was really difficult in the beginning. I didn't even eat during the first few days. It is quite normal now though. We really are a family, because we sleep here at nights and feel at home with them."

"I am dependent on them now. They are the same as my family. Somehow being with and caring these patients is good, because there is purity here. It is not something related to financial matters and routines. This is the end of everyone's life."

Caring for a child
Infantilizing old adults is related to child-like behaviors in AD patients. [19] The participants compared taking care of the patients with caring for a baby, which made them felt better and enabled them to better tolerate the patients' behavior. Moreover, caregivers were tended to address patients as though they were children, and were mentioned to the features of caring for a child such as precise, consistent 24-hour care, preventive and limiting measures to restrict the patient's activity.

"Generally, patients with Alzheimer disease are more pleasant to provide care for, because their movements are like children. You feel you are taking care of a baby. I see them as babies. I enjoy feeding them. It is not

difficult for me at all, as if I were changing a baby's diapers or feeding a baby."

"Their movements and feeding have to be monitored like a baby. Sometimes they wander away and might even leave the nursing home, so the staff must be very careful. An Alzheimer patient must be monitored like a baby all the time so they don't fall and so that they eat their breakfast, and they must be kept clean. Since they don't inform us we must be alert all the time."

Continuum of different feelings
Formal caregivers experience different feelings during their care giving activities. Some feelings are negative, such as guilt for not providing suitable care, sorrow resulting from a patient's death, sadness over the behaviors of some patients. Other feelings are positive, such as capability, enjoying their work and satisfaction.

"We never thought he would die at this age. I was here till the afternoon. Everything he said and everything he did were in our minds for a week."

"I myself have had a good job opportunity, but I like it here. Their prayers have made many of my problems go away."

"Patients' repeated requests and remarks make me upset. But often I feel happy with caring the patients."

Not understanding the patients
The experience of caregivers in this study regarding the main theme of not understanding the patients was analyzed in two subcategories: "caring without enough information" and "a dead man walking". Caregiver attitudes and knowledge about the disease have a great influence on the method of care and the relationship with the older adults [20] and patients. Most caregivers in this study did not have a specialized background or training in this field, and they believed that the patients could not understand anything. As a result, patients might feel more isolated and their symptoms might intensify.

"It is really hard to communicate with people who don't recognize and understand anybody while not hurting them and following the rules. All of these factors are important."

"Patients with severe Alzheimer disease do not notice and are not aware of anything. He's a dead man walking. For him, there's nothing that can be done and nothing to say."

"It is necessary for a caregiver to have special training in the care of AD patients. There are so many problems in caring for these patients that we can't take care of them."

Discussion

The findings of this study show that caregiver's experiences reflect six main themes: managing difficult behaviors, dependence on familial care, living with the patients, caring for a child, continuum of different feelings and not understanding the patients, which were considered here in the two subcategories caring without enough information and "a dead man walking".

Caregivers' attitudes towards the patient and their disease have a substantial influence on care[21] Biomedical models of dementia were long associated with "therapeutic nihilism" and a pessimistic view of people with dementia, who were defined mainly in terms of their progressive brain disease.[22] This perspective broadly shaped professional and service paradigms, and spread to the public domain, where it led to (still-prevalent) fear and stigma associated with dementia. According to our personal experience, a defining characteristic of people in collectivist cultures such as the Iranian culture is their notable concern with relationships. When the patients cannot establish effective relationships with the caregivers, their presence as members of society becomes questionable. In the present study, caregivers generally believed that at advanced stages of the disease, patients had reduced communication abilities and were the same as "a dead man walking". This attitude can affect the quality of communication between caregivers and patients, and tends to

concentrate care on physical aspects at the expense of other aspects of care.

To test this view, we used the analysis of nurses' attitudes towards patients with dementia in 11 nursing homes by Norbergh et al. Although their study was done in a different context, their results also show that the staff had a negative attitude towards the patients, leading to job dissatisfaction.[20] Other studies suggested that having a positive attitude towards patients could contribute to good care.[23] Accompanying these neutral to negative attitudes among practitioners is a general deficit in gerontological knowledge.[24-25] The gerontological knowledge base of many professionals is limited and their attitudes toward AD patients are not positive; consequently, their knowledge of dementia and attitudes toward older people with AD are of potentially great concern.[25]

Caregivers must often deal with a variety of long-term and disabling physical and behavioral problems associated with dementia. The typical cognitive changes of dementia are frequently accompanied by equally disturbing behavioral dysfunctions. Caregivers are frequently unprepared to cope with the trauma of care giving because of their lack of knowledge and "potential negative appraisal of the stresses associated with the care giving process".[26]

An important theme in the present study is dependence on familial care. In Iran, the individual's life is dominated by family and family relationships: people rely on family connections for positions, security, influence and power.[27] The participants of this research emphasized that establishing a relationship between family members and involving them in patient care improve patients' mental status and can assuage their feelings of isolation and depression. Although studies in other countries also support this theme, it seems that due to the cultural effects of the familiar relationship, it is more highlighted in this research by the participants. The caregivers should take permission from family for providing care. It seems that

family has the main responsibility of care in the nursing home. In this regard, Voutilainen et al. demonstrated the need for ward policies and staff training makes enhanced, appropriate family involvement possible in the care and support of residents with AD.[28,29] Tickle and Hull, in a qualitative study with participation-observation methodology, determined the role and function of family member visits in long-term care settings. They found that some family members wanted and needed to be involved in caring for their relatives in long-term care. When they participate in caring, the residents may be more satisfied.[30] Feeling unsafe and insecure may be a common feature of the dementia process, so the presence of family members may help the patients with dementia to feel more satisfied and have less frustration.[31]

The participants also mentioned the gradual increase in their interest in caring for and working with patients. Although many studies emphasize the burden on the caregivers of AD patients, [10,11,13] it seems that 24 hour shifts, living and caring with AD patients for the participants in this research was effective on their dependence on the patients and it could increase their interest in caring. Also in Iranian caregivers, helping and caring frail or old people, apart from the social approbation, is considered a labor of love that, in Islam, attracts ample driven reward. Similarly, a study of Drebing et al. showed that internal and external factors are involved in caring for elderly people with AD in nursing homes. Rather than external factors, internal factors such as self-actualization and dependence on the patients and their families were more effective in favoring the continuity of staff work.[32]

Another theme of this study is taking care of a baby. Viewing individuals with AD as children makes the participants in this study more able to tolerate their patients' behavior. Along with other results obtained in this research, continuum of different feelings was observed; most of the caregivers in this study

experienced positive feelings with caring AD patients. In contrast, Sanders et al. reported feelings of depression, grief, isolation and restriction among staff workers .[33] According to subjective theory of hedonism, which emphasizes the pleasure and relief of pain for a good life, [34] maybe considering AD patients as a baby is a good mechanism for promoting pleasure and protecting caregivers against their patient's behaviors and preventing burden. However, Thornbury in this regard states that treating older adults like children is antithetical to the goals of care for persons with AD. Rather than infantilizing older adults, it may be useful to apply a developmental model to facilitate understanding of child-like characteristics in patients with AD, as a way to provide insights into the nature of their impaired thought processes. This understanding can enable caregivers to respond to the AD patient's needs rather than to their behavior.[19] More research should be done in this field to find out useful mechanisms which help caregivers of AD patients to decrease their feeling of burden.

Conclusion

To optimize the quality of care for patients with AD, more surveys are recommended on different aspects of care in the context of religious and cultural beliefs. Potential areas for research among the themes we identified in the present study are the assessment of patients based on their cognitive disorders, the development of communication skills with patients, to find out useful mechanisms for reducing burden in caregivers and improving the care environment and other themes. We hope that the results of this research will be useful for efforts to enhance care provided by specially trained caregivers in physical, psychological, spiritual, cognitive, familial and socio-cultural dimensions, in a manner appropriate for individual patients' level of cognitive functioning and cultural context. Nurses' experience, knowledge, and skill level can

directly affect the quality of nursing care.[35] A priority should be to find innovative ways to support nurses in their experiences of role stress.[36] Improving the care provided by nursing homes specialized for patients with AD, together with continuous work training for caregivers, can enhance the quality of life of patients with Alzheimer disease.

Ethical issues

None to be declared

Study limitations

One of the limitations of the present study was the lack of specialized nursing homes for patients with AD. This sometimes led to informants' not distinguishing between patients with AD and other patients during their interviews. The authors used focusing techniques to avoid interference by information about non-AD residents. In addition, observing informants during their normal working hours and tape recording their interviews may have influenced their behavior. [36]

Conflict of interest

The authors declare no conflict of interest in this study.

Acknowledgments

Contributions

Study Design: SY, FS, MHK, MFK, Data Collection and Analysis: SY, FS, MHK, MFK, PP Manuscript.

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