Self-appraisal of caregiving in family caregivers of older adults with dementia in Iran: a content analysis study

Akram Farhadi

Bushehr University of Medical Sciences

Farahnaz Mohammadi

The University of Social Welfare and rehabilitation

Mahshid Foroughan

University of Social Welfare and Rehabilitation

Leila Sadeghmoghadam

Gonabad University of Medical Sciences

Shima Nazari

Tehran University of Medical Sciences

Seyede Salehe Mortazavi (✉ salehe.mortazavi@gmail.com)

Iran University of Medical Sciences <https://orcid.org/0000-0003-4565-9688>

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Abstract

Background The concept of caring appraisal, which includes positive and negative aspects of care, has been considered as one of the key concepts in caregivers' studies. The aim of the present study was to investigate the self-appraisal concept of caring from the viewpoint of family caregivers in the elderly with dementia in Iran.

Methods This study was based on qualitative analysis. Data were collected through in-depth and semi-structured interviews. Twelve participants (family caregivers of elderly people with dementia) were interviewed between January and September 2016. They were selected from visitors to the Alzheimer's Association of Iran and Yadman Memorial Clinic (Tehran- Iran). The interviews were recorded and transcribed. The transcribed texts were analyzed using inductive qualitative content analysis recommended by Graneheim and Lundman (2004).

Results The study explored two main categories include "perceived burden", "Losses and Threats," "satisfaction with care", "Personal growth", "caregiving gains", "philosophy of care" and 22 subcategories.

Conclusion According to the results of this study, the family caregivers' appraisal of their care not only does not have negative aspects but also covers a large number of positive aspects, in which the cultural and social conditions prevailing in the Iranian society play a significant role in the formation of these positive aspects.

Background

The increasing growth of the aging population in the whole world will have consequences such as a higher incidence of disabling diseases such as dementia [1]. Thus, it is estimated that the population of 50 million in 2018 will reach 131.5 million by 2050. This increase will occur in developing countries such as Iran more quickly [2]. It is expected that the percentage of the elderly population in Iran will increase from the current 9.3% to 21% by 2050[3]. With the absence of a national program for the prevention of dementia, the incidence of illnesses in Iran will increasingly increase [4].

Dementia is one of the most challenging diseases of the old age, which puts a heavy burden on the health systems of communities and families. As expected, it will cost a trillion dollar in 2018 [2].

Because of the disabling feature of the disease, the loss of autonomy of the elderly and the need for care in these people are more vulnerable than other elderly groups, and family caregivers in these people suffer a lot during their role of caring [5–7]. Sometimes these pressures lead to issues such as elder Abuse or end-of-care and ultimately admission of the elderly to the nursing home [8]. The majority of these people are cared informally and by family members [6], which is higher in developing countries such as Iran with the lack of adequate formal systems for people suffering from dementia. Despite all these disadvantages in terms of official government support from family caregivers, these people are still reluctant to bring their elderly to a nursing home [4].

Several studies have shown that caregivers of people with dementia experience more physical and psychological problems than those without a caring role. In general, the study of caregivers have focused on the negative aspects of care, and although several decades have passed from the introduction of positive aspects of care, the prevailing view in these studies are still based on negative aspects [9, 10]. In some studies,

positive aspects such as satisfaction with care rewards received through care, personal development, etc. have been introduced. The concept of caring appraisal, which includes positive and negative aspects of care, has been considered as one of the key concepts in caregivers' studies [11], even with respect to objective indicators such as dependence and patient symptoms, is a more important determinant of the outcomes of care [12, 13].

Deep and intercultural studies indicate that the caring issues are affected by the cultural and social conditions governing each country, which makes it possible to take care of particular value. In general, the conditions governing the acceptance of care, the quality of care provided and even the decision to end care can be effective. Having special cultural and ethnic backgrounds regarding the elderly and taking care of them in the family environment, with the lack of appropriate social structures and supportive systems to facilitate home care, Iran country can provide different experiences for these caregivers that are not considered in the studies. The remained question is what the experiences of family caregivers caring are for the elderly with dementia [4, 14]. What do they think of their care with the lack of support and insurance facilities for these patients and their families, and the existence of culture and background for accepting this role by the family and recent changes in Iranian society in the direction of modernity [12]. By knowing these experiences and explaining the concept of self-appraisal of care provided by one, it is possible to provide a way for effective interventions based on the experiences of caregivers within the same social context. The aim of the present study was to investigate the self-appraisal concept of caring from the viewpoint of family caregivers in the elderly with dementia in Iran.

Methods

Study design

This study was carried out using qualitative content analysis method with conventional type.

Participants and Sample

The purposeful sampling method was used in this study. Participants in this study include family caregivers of elderly people with dementia who have played a major role in caring for them and called themselves "the main caregivers". These caregivers were selected from visitors to the Alzheimer's Association of Iran and Yadman Memorial Clinic. These two centers are considered as important referral centers for the diagnosis and treatment of dementia in Iran. The inclusion criteria that were considered for caregivers of the study were the willingness to volunteer in the study, having a family relationship with the elderly receiving care, providing care at least 5 hours a week regularly [15], non-receipt of money and salary for providing care, providing care at least six months, and helping the elderly do one or more daily tasks of life [15]. The type of dementia was not considered as an inclusion criterion. In addition, all elderly people were certified by a neurologist with 15 years experience in the field of dementia.

Data collection

Data collection was conducted through open-ended and semi-structured interviews with family caregivers between January and September 2016 and continued as other qualitative studies until data saturation and as long as the code or new concept could not be obtained. All participants in this study had good communication skills to express experiences and were interested in participating in this study to share these experiences.

In order to gain access to caregivers with more and richer experience, the researcher attended the Yadman Memorial Clinic on odd days and the Alzheimer's Association in even days. In addition, the information of the experienced staff of both centers who knew enough about caregivers in addition to attending the classes related to caregivers such as advocacy groups. In order to achieve maximum variability, caregivers were selected from groups with different socioeconomic characteristics with different time periods and severity for caregivers in addition to the different diagnosis of dementia. The location of the interview was based on the opinion of the caregivers and in a relaxed, non-commuting environment. Due to the conditions of the patients under care, some caregivers chose their home for this interview.

In all interviews, the data was provided by the first author (AF) who had sufficient experience in the field of elderly research, and was also trained in conducting qualitative studies. Initially, the caregivers also requested a general description of their care in order to create an intimate atmosphere based on the trust of the researchers, while introducing themselves and describing the purpose of the research. Subsequently, the question was opened based on the purpose of the research and then, deep and consistent questions were used with an analysis of their conversations during the interview. The main question of this study was that how do you describe the care you provide to the elderly with dementia? What was the effect of this care on you? What were the positive and negative points of this care for you? What were the positive and negative changes in your life for caring for the elderly with dementia? Throughout the interview, participants' statements are based on profound questions such as when you say ... what do you mean. Do you have any specific memories in this regard to tell? Please explain more about this; please give an example in this case, etc. More detailed information on the subject of the research has been asked. The duration of the interviews lasted between 30 and 65 minutes, depending on the circumstances and desire of the caregiver. Two of the caregivers at their next visits showed a willingness to conduct a second interview. All interviews were recorded on an MP3 device, the need for the action was described before the use of this device, and they agreed. All interviews were implemented and typed by the first researcher in Word software in the shortest possible time. Interviews were carried out, they were repeatedly and repeatedly listened, and the accuracy of the material was confirmed by typing. Data coding and parsing were also carried out, so that data was collected simultaneously and continuously.

Data analysis

Data analysis was performed using the Graneheim and Lundman (2004) method simultaneously with data collection, which includes the following steps including 1- Implementation and preparation of the data immediately after the interview. 2- Reading the text repeatedly to understand it comprehensively and define the meaning units. 3- Identifying the appropriate label for the meaning units (text coding). 4- Reviewing the codes by comparison with the text. 5- Determining subcategories and categories through the similarities and differences between the codes and combination of the same codes. 6- Subcategories and categories review. 7- Determination of the implicit content by comparing the categories with each other, and finally. 8- Translating the explored concepts into English, which are presented in the data analysis table [16].

Rigor

The Lincoln and Guba criteria included credibility; audit capability, confirmability, and transfer capability for reliability and reliability of data were used [17]. For this purpose, the main researcher involved continuously

with data and research subject with duration of nearly one year to collect and analyze data and used all possible ways to gain experience in the field, such as attending caregiver meetings and support groups, attending the memory clinic, participating in congresses. In order to ensure the accuracy of the data, knowledgeable and experienced people in the field of qualitative research were asked to review the text of interviews, codes, and classes. Meanwhile, the review of the text and codes by contributors and their understanding of the true meaning of their conversations were also used. In order to provide audit functionality, all stages of work were carefully recorded and reported so other researchers interested in this field could follow it. Data transfer capabilities were conducted through interviewing various contributors, providing their direct quotes, and richly explanatory data.

Ethical consideration

Prior to the beginning of the study and the interviews, ethical considerations in this study were approved by the Ethics Committee of the University of Welfare and Rehabilitation Sciences (USWR, REC1393.187). Items such as knowingly entering the study, obtaining written permission to record all interviews, the right to withdraw at any time that the contributor was inclined, maintaining anonymity, and observing the secrecy principle were considered throughout the study.

Results

In this study, 12 family caregivers (8 females, 4 males) who were responsible for the care of the elderly with dementia participated in 14 interviews. The mean and standard deviation of these age groups was 61.8 ± 8.94 in the age range of 47 to 74 years old. The demographic characteristics of the participants in this section of the study are shown in Table 1.

The results of the qualitative analysis of the six main categories include "perceived burden", "Losses and Threats" "satisfaction with care" "Personal growth" "caregiving gains" "philosophy of care" and 22 subcategories (Table 2). These subcategories and categories result from the experience and understanding of family caregivers of the care provided. We will continue to explain and provide quotes for each of these categories.

Perceived burden

The perceived burden of care is as one of the most important negative aspects of the caregivers' caregiving of the elderly with dementia in Iran so that there were some aspects in all of them and the caregiver's experience of caring for various physical, emotional, financial, and occupational fields was experienced. Caregivers expressed their physical and emotional experiences with physical problems, such as back pain, headache, knee pain, blood pressure, heart disease, and obsessive-compulsive disorder, as well as feeling tired or weak, taking medication or increasing the dose of medication.

"I cannot do it like before, now my neck aches, my back aches, I got a neck disc. My forgetfulness is too much. This forgetfulness is annoying me so much." (P7)

In addition to physical burden, the emotional burden of care, which was considerable for on caregivers, expressed their experiences with such things as feelings of grief, depression, feelings of isolation, feelings of

intrusion and imprisonment, and inability to persevere care by family caregivers.

"Now I have reached a stage where I don't have the power. I feel very tired mentally; sometimes I feel I cannot continue." (P1)

Caregivers believed that care limited their social relationships and reduced their social and recreational activities, and had a negative assessment of their care.

"The other impact is that I cannot use the social, greetings, and other things that one uses when he\she is free. I can't be in touch with my previous colleagues. I'm an isolated person away from the community now, but I was always in the society before and I was dealing with everyone "(P8)

Caregivers described financial burdens caused by the care with financial problems, such as reduced income and increased living expenses, such as the cost of drugs and patient care expenditure, which was seen this time for most of these people.

"Since my wife's been so, I have to stay at home more often and less to work. I left the work to the rest, but nobody pays attention to the work like me. The expense of this illness is also very high, especially the nurse's money that cares for her, I had to sell whatever I had and spend for all these years. My income is reduced and our living costs are also increased. The government also does not support us."(P2)

Other negative experiences of caregivers were the burden of occupational care, which was shown as a loss of the full-time job in a form such as reducing working hours, leaving the service.

"The odd days are allocated to her physiotherapy, I have to stay home more and go to work later, I can only stay at work for only a few hours, I must go back home so my mother is not alone." (P6)

Losses and Threats

Most caregivers, especially those caring their spouse experienced a kind of loss and threat in their care and assessment of the caring role. These deficiencies and threats are categorized in various fields related to the caregiver and the caregiver, who have subclasses such as familial affairs, lack of opportunity, and gradual loss of the patient.

Internal conflicts arose between caregivers and other family members for various reasons. Some of the reasons for these conflicts were the interference that had taken care of the home, the unwillingness of the children to the patient, and the continued caring of other caregivers to the main caregiver over their duties.

"My kids always complain. They are so upset. They say became old. Give a little to us, and our kids. They are always grumbling about the house and keeping the grandmothers here."(P7)

The caregivers' experiences showed that there is no opportunity for them to meet their needs because of caregiving. This was the loss and threat to lose their calm and to think that they had lost their calm. They had somehow lost their privacy and were always under pressure to play this role. In expressing this experience, they claimed that the individual liberty was taken from them with this care, so that they did not have time for themselves and their desires, and over time, they lost their identity.

"I cannot lie down at my house, because whenever he\she is not in my sight, he\she is sabotaging. I have no time for myself to say now I can go to do my work now" (P10).

In addition to these deficiencies, the participants in this study talked about the experience of a sense of sadness caused by the gradual loss of their dear. As if, they are mourning before their death. Some caregivers said that despite the physical presence of the patient, they could not grasp the true nature of the patient and have lost the ability to communicate and talk with the caregiver. They also said that they felt that they had lost their lives, which was a painful experience for them; such experiences were seen in the care of spouses.

"Every day he\she gets worse; it is as if he\she is not gonna being better. Now, what can I do with someone who cannot speak and has many problems? Please, imagine the situation for some moment. I feel very painful."(P9)

Satisfaction with care

Almost most family caregivers pointed out their satisfaction with expressing their experiences of care assessment. Caregivers have argued that care is worth all this stress, and these moments are sweet, especially when you look at your dear's smile, and you feel relaxed with it. Subclasses achieved such as self-satisfaction, satisfaction with the patient's condition, and satisfaction from the patient's appreciation of interviewing caregivers.

In expressing his\her own sense of satisfaction, he\she said, *"I feel pleased with the sense of satisfaction. When a person is satisfied with his\her performance, she feels great satisfaction because I feel that I'm doing a positive thing. I'm doing the right thing, I got the right decision. My activity is with love and sincerity."*

In describing the sense of satisfaction for the condition of the patient (P6) said, *"Nothing makes me relief as much as I see my mother calm and her good condition. I'm glad that I am beside her and I can help her."*

In expressing satisfaction of the patient's gratitude (P7) said, *"Sometimes, I look at her for and she looks me then very kindly because she liked me very much. I feel like she loves me pleased with me. I feel satisfied with myself here."*

Personal growth

One of the most prominent positive effects of care for dementia patients was the personal growth for family caregivers. Individual growth classes were found in sub-class caregivers such as maturation feelings, highlighting positive personality traits, and spiritual growth.

In the description of the sense of maturation, participants stated that care increased their awareness and the surrounding environment and increased their understanding.

"Now I became more knowledgeable. I became more aware of my mother's love and understood it. I realized that now that I am here because of my mother's sacrifice. This makes me mature. This understanding brings awareness that I think I got it. I reached all this, I realized the love of my mother to myself, I realized that my mother was a gift of God, maybe I did not understand it before. This disease made me understand that."(P6)

Being under difficult conditions for caregivers has resulted in positive personality characteristics such as being patient, strong and resistant to hardships, calming down, enhancing the sense of altruism and helping people in need.

"Well, I got stronger, I became more patient, I became calmer. I can handle the hard conditions more easily" (P5)

Caregivers described their spiritual growth by expressing things such as changing attitudes to life and re-evaluating what is, trusting and hoping for God's blessing, finding the life path, thanking God and his blessings, knowing the magnitude of life, feeling close to God, which was formed during this period.

"Now a lot of things have changed, I appreciate more of life, I appreciate what God has given me and I appreciate my health much more than before, perhaps I a little neglected, thank God for all of this." (P3)

Caregiving gains

Caregivers expressed various experiences in the context of the gains of their roles as a caregiver. These gains included issues such as social affirmation by others and mastery in their role as caregivers.

She described social acceptance (P3) as *"We live in a small area and everyone knows each other. They all see that we keep our mother and they recall us with goodness. When a stranger sees me, encourages me. Everyone in our area has a good idea about us."*

In expressing the feeling of mastery in care, caregivers' experience was combined with things such as increasing the self-esteem, gaining a sense of ability and self-control in providing care, taking care with the whole power, doing the best in caregiving, considering this work at the first grade.

"Now, I feel that I became a master in my work because I am doing it for 6 years lonely. Now I can hold a class for others to guide them." (P9)

"I usually manage my mother's work, I'm happy because I can do it. I can do my mother's works. I feel I can accept more responsibility than this." (P3)

The philosophy of care

The Iranian family caregivers participating in this study referred to the acceptance of the role of care in expressing their own experiences of caring for their ideology; this ideology was categorized into three subcategories of being a pattern for others (spouses and children), reciprocal compensation, and the preservation and continuity of religious and family traditions. Caregivers often mentioned a combination of these reasons derived from the beliefs and value system in which they were educated and developed. The description of being a pattern for others, especially their children, (P7), stated *"My children see this and learn. My husband pays attention to parents and I think I have a good effect on my child's upbringing."*

From the viewpoint of Iranian caregivers, care provided a chance for reciprocal compensation of the person who is receiving the care always emphasizing that his/her previous effort should be compensated in some way.

"I'm doing my best for my mother. She is my mother, my dear, she raised us. She accompanied my father. I saw how she tried hard for her life. Now, I think I must do it because she accompanied my father very much, she was a good woman, sacrificed herself in her life." (P4)

In addition, Iranian caregivers considered it a godly thing to take care of the family with the family traditions and the obligations that people in the family had with each other, and with this kind of care, they were somehow committed to religious and family traditions.

"The commitment of my husband and wife is not just when they are healthy. No one can see the end. I can't ignore my wife because of the moral and family commitment I have to my wife." (P2)

Discussion

According to the results of this study, the Iranian caregivers' experiences of the elderly with dementia are by the cultural, social and value system governing the Iranian society in shaping the final assessment of their care. This appraisal has many negative and positive aspects, which ultimately include the concept of caring self-appraisal in Iranian caregivers, which includes six main categories, including "perceived burden of care," "losses and threats," "satisfaction with care," "personal growth," "caregiving gains," and "care philosophy."

In describing the explanations related to the care burden, It can be said that recent changes in the family structure in the Iranian society have had a great impact on the care of the vulnerable elderly at home, changes in the form of the family and the transformation into families, far from each other, and reducing the aspects of the family and, moreover, the increasing inclination of women to work outdoors and diminishing their care role with the absence of supportive mechanisms adapted to these social changes has made home-care care more difficult than before. As can be seen from the experiences of caregivers participating in this study, Caregivers suffer from very physical, emotional, occupational and financial pressures, despite the ever-increasing number of people suffering from dementia and the need to care for them at home. However, in Iran, there is still a severe shortage of supportive laws for family support and laws for caregivers working in the private and public sectors. On the one hand, due to the high costs of taking care of the elderly with dementia at home, it is necessary to have a job abroad for these expenses. On the other hand, the difficult conditions of care and the lack of short-term and secondary accommodation centers made interference in their official work and sometimes, with all the financial needs they have, they have no choice but to leave their jobs or to be fired.

Participating caregivers in this study considered the family care of the elderly with dementia as a loss and threat that was associated with the caregiver and person who need caring and surrounding environment, including the following subclasses "family conflicts," "lack of opportunity for self "and" gradual loss of the patient."

Caring leads to disrupting relationships between family members and creating disagreements among members about caring for elderly people with dementia at home. In this study, there were more differences in cases such as role division and disorder in another role of the caregiver. By changing the structure of society and, consequently, the family system and the tendency of individuals, especially the younger generation towards individualism, which is especially seen in large cities such as Tehran, such conflicts are expected between family members over roles and care elderly people are more likely to be seen in the future. Because, probably,

there is no adequate and acceptable growth in the services provided to the elderly needing care like those with dementia with the development and modernization of urban communities. Such inconsistencies between the roles and welfare facilities that originate from the conflict in the family and the interference with other social roles of the individual are monitored. Social commitment and family traditions continue to emphasize the care of the elderly at home, but along with these community requirements is facing changes such as increasing the employment of women outside the home, the nucleation of families, the increase of individualism in the community, the immigration of children to other cities and countries, and reducing the number of children who have faced with modernity. These changes are getting faster every day, which is a danger to all those who are in need of home care in policymaking and service provision for the elderly.

Other studies also included “shattered families” [18], “criticisms from other family members”, “family disputes” [19], “lack of family support”, “family trouble” and “family conflicts” [19–21] have been used to express differences and conflicts between family members and the collapse of relationships between them, which is in line with the present study.

The subcategories of “lack of opportunity for self” refers to the loss of opportunities and times that a person can dedicate to her\himself, but because of the role of care, it is necessary to spend those times in order to play the role. In other words, the caregiver prefers the needs of the caregiver to his\her needs and sacrifices him\herself. Other qualitative researchers examined the experiences of family caregivers such as “neglecting oneself” [22], “less freedom” [23], “loss of self” [24], “lack of opportunity for themselves” [25], “being destroyed”, which includes “the feeling of losing oneself” [26].

In stating the “gradual loss of the patient” that refers to the progressive evolution of elderly disability, other studies have shown that feeling of mourning occurs when a person is threatened with the security and confidence they feel in their relationships. Whenever the caregiver’s illness intensifies, the mourning rate of the caregiver will also increase [27]. This kind of mourning fluctuates over time [28]. In fact, the deficiencies that occur during the progression of the disease lead to the experience of a condition called dual dying. This means that the caregiver experience the caregiver’s death before the real and physiological death [27]. This is more observed in caregivers caring for older people with dementia [28, 29].

Along with this study, others themes such as “contradictory thoughts and feelings” [26], “changes in the relationship between patient and caregiver” [30], “anticipation of death”, “mourning before death” were also reported in other studies [31–33].

According to the results of this study, satisfaction with care was obtained as one of the positive experiences of caregivers. This concept is one of the most commonly used concepts in the positive evaluation of care [34]. This concept was originally defined as rewards from care, but then a group of researchers called it the perceived mental benefits of care, which is one of the positive aspects of care given to caregivers [35]. The caregivers’ understanding of how much he\she could meet his\her expectations on caregiving role determines his\her satisfaction level of care. They also bring satisfaction with words such as adequacy and efficiency. The value of the role of care in the view of the caregiver is introduced as another element in determining the level of satisfaction. The value is the meaning and purpose that the caregiver linked to his\her role. Studies have shown that the quality of this satisfaction varies among caregivers so that some caregivers will be satisfied with non-emotional ways such as doing the best in care, and some other with deepening care and gaining pride

in their role [36]. The quality of the relationship between caregiver and elderly is important in gaining positive experiences such as satisfaction. Satisfaction in care can reduce the stress of care and improve the emotional outcomes of care. The level of satisfaction with caring under different titles has been gained in the experiences of family caregivers and their assessment [37–40].

Items such as “understanding the sense of appreciation by the caregiver”, “feeling more close to the elderly”, and “feeling happy and satisfied with caring” [41], “feeling pleasure from being with the elderly”, “satisfaction with oneself and the care who provides” [38]. Self-affirmation, which includes “feelings of being appreciated,” “feeling good to oneself”, “feeling of being useful” and “feeling of being important”. Satisfaction of caregiver includes “self-satisfaction” and “friendship and companionship with the elderly” [42]. The theme of “rewards of care” was the “feeling of pleasure from being with the patient” [23] and the “maternal care” which included the experience of “feeling pleasure from being patient” and “satisfaction from the patient’s condition and peace” [26].

The “personal Growth” category has been obtained in several studies as one of the positive aspects of individual assessment of their care [34, 39, 42–45]. Studies have shown that 55–90% of family caregivers experience individual growth during the care process [44, 46]. Lee et al. introduced the aspect of “maturation” followed by caregivers’ growth, life expectancy, better relationships with caregivers, a good sense of caregiving and helping and better relationships with other members of the family [15]. These results are in line with the results of this study. In stating the description for spiritual growth, studies regarding family caregivers of Alzheimer’s patients have shown that these caregivers feel a higher level of relationship with superior power during the spiritual solutions such as praying, talking about spiritual affairs with friends and relatives, and reading spiritual books [47]. Islamic religion and the book of the Qur’an stated that rewards are given in the face of hardship, which has repeatedly expressed the contributors to the spiritual growth of caregivers against the difficulty of care.

Based on the results of this study, “social affirmation by others” was referred to as another positive aspect of caring. This kind of social affirmation can be seen in societies such as Iran that care for a person needs assistance especially for the elderly and family members is a worthy and worthwhile practice and has always been repeated in different historical periods and considered as a positive cultural point in different generations. This subclass is less common in other studies [23, 37, 39, 41, 42, 45]. Navab et al. described social confirmation as a way of reaching the cognitive maturity of caregivers in Iran [26]. Comparing the experiences of family caregivers between countries in the United States and Japan showed that American caregivers lacked this appreciation and social approval for their care role [48]. Leipold et al. also show this lack of social acceptance in their study [49]. So with this result, the dependence of this type of experience is endorsed by the culture and values that govern the community in which care is being taken.

The sense of mastery in caring is defined as a dynamic and multi-dimensional conception. When a caregiver feels that he\she can help the person who loves him\her, his\her self-esteem rises. When a caregiver has a sense of mastery in caring feels less stress in daily works and can continue to play a more vigilant role later; in some cases, proficiency in care also plays the role of a bumper [50]. “The sense of mastery in caring”, has been reported in other studies with phrases such as: “assuring the role”, “feeling of success in care” “sense of

competency", "mastery of work", "personal development", "self-belief", "feeling of pride" and "ability to be proud", "Self-esteem" and "Self-efficacy in care" [21, 34, 37–39].

The caregivers in this study considered their care philosophy to be a good model for other people, especially their children, and this motivation facilitated the continued role of care for them. As perceived, these caregivers were inspired by others as a model for the role of caring for their dear, which somehow played a role in creating this type of ideology. Other studies also mention the past stories and experiences of care in their lives and their ideology for care [43]. In other studies, caregivers mentioned less reason for their care motivation. This can be attributed to the great influence of existing social and family values and the role of successful patterns in the continuation of these values among Iranians. It has attracted caregivers, who, like themselves, who have had successful patterns in the past, have put this template at the forefront, especially for members of their families and those around them.

The subclass of "reciprocal compensation" was also one of the components of the "philosophy of care" which family caregivers in this study explained it as the reason for accepting and continuing the role of care in the form of this subcategory, explained the reasons for the acceptance of subclass. Iranian caregivers, like caregivers in other cultures, assumed care as a way to compensate for the efforts and good things of the caregivers' past. Regarding the sense of the kindness that has been observed in the educational culture of Iran, and in addition to the emotional attachment that exists in Iranian families, care for the individual needs help with family relationship is very important and the love and affection between the caregivers and the caregiver always facilitate the start of the role of care and its continuity. Reciprocal compensation unlike the sense of duty derived from the cultural and social values and traditions of societies plays an active role in the acceptance of the role of care. The source of those past relationships is between caregivers and caregivers so that whatever the previous relationship was better reveals a better feeling and overcomes the "sense of duty" to accept and maintain the role of care [43]. Wassman stated that caregivers referred to the word "my turn," in which the caregiver considered it an opportunity to compensate for the good of the caregiver in the past and enjoyed the opportunity [23].

Other ideologies of care were "the preservation and continuity of religious and family traditions" so that family caregiver feels committed to providing care to their family member who needs this care. This sense is rooted in Iran's cultural, social, and religious beliefs as unwritten rules that they had come up with in an obvious and inevitable commitment [22]. Such beliefs are more common in Asian countries than in Western countries. Zarit et al. have argued that the core family system in Asian families is different from Western countries, which is important very much. The commitment of children to parents plays an important role in accepting and providing care [51]. This subclass is similar to the results of other studies entitled "normative action," "commitment to what should be done," "sense of duty," "moral obligation," "social expectations," and "social aspects of care." [43, 45].

Strengths and limitations of the study

Some of the strengths of this study were the collection of data through a profound interview conducted by the researcher and his ongoing involvement with the concept. In this study, caregivers with the highest diversity were used for this purpose, which helped to enhance the quality of the data and to obtain a clear picture of the concept of care assessment from the viewpoint of family caregivers.

This study had limitations, including that the data were selected based on qualitative methodology with a small sample size through purposive sampling. Therefore, the generalizability of the results to other communities is affected like other qualitative studies, although some of the results were in line with other studies.

Conclusion

According to the results of this study, the family caregivers’ appraisal of their care not only does not have negative aspects but also covers a large number of positive aspects, in which the cultural and social conditions prevailing in the Iranian society play a significant role in the formation of these positive aspects.

Declarations

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Authors’ contributions

AF designed the study, conducted the interviews and performed the data analysis. MF, LSM and SH N assisted in the study design and the data analysis. MF, SS M and FM interpreted the data and drafted the manuscript. All authors read and approved the final manuscript prior to submission.

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Ethics approval and consent to participate

The study was approved by the Ethics Committee of the University of Social Welfare and Rehabilitation Sciences in Tehran, Iran. All participants were informed about the study and only those providing a written informed consent were enrolled in the study.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

Tables

Table 1. Characteristics of the family caregivers of older adults with dementia

Living together with the person with dementia	Income	Number of family of caregiver	Marital status	Duration of care (year)	Family caregiver's role	Education	sex	Age (year)	Participants
Yes	Poor	3	Married	3	Wife	Illiterate	Female	56	P1
Yes	Appropriate	2	Married	1.5	Husband	Primary	Male	65	P2
No	Fairly appropriate	4	Married	3	Daughter	High-School Diplomas	Female	47	P3
No	Appropriate	3	Divorced	3	Daughter	Academic	Female	69	P4
No	Appropriate	4	Married	2	Daughter	Academic	Female	54	P5
Yes	Appropriate	2	single	3	Son	Academic	Male	55	P6
Yes	Poor	5	Married	5	Daughter-in-law	High-School Diplomas	Female	48	P7
Yes	Fairly appropriate	2	single	7	Daughter	Academic	Female	65	P8
Yes	Fairly appropriate	4	Married	6	Husband	Academic	Male	63	P9
Yes	Fairly appropriate	2	Married	3	Husband	High-School Diplomas	Male	74	P10
Yes	Appropriate	2	Married	2	Wife	High-School Diplomas	Female	65	P11
Yes	Fairly appropriate	2	Married	3	Wife	Academic	Female	72	P12

Table 2. Categories and subcategories extracted from the qualitative content analysis of Iranian`s family caregivers' experiences

Theme	Categories	Subcategories
Self appraisal of caregiving	Caregiving burden	Physical burden
		Emotional burden
		Occupational burden
		Financial burden
	Satisfaction with care	Self-satisfaction
		Satisfaction with the patient's condition
		Satisfaction from the patient's appreciation of interviewing caregivers
	Personal growth	Maturation feelings
		Highlighting positive personality traits
		Spiritual growth
	Caregiving gains	Social affirmation by others
		Mastery in their role as caregivers
	Philosophy of care	Being a pattern for others (spouses and children),
		Reciprocal compensation
		Preservation and continuity of religious and family traditions
	Loss and threat	Familial affairs
		Lack of opportunity
		Gradual loss of the patient

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