Support Care Cancer (2016) 24:1269–1276
DOI 10.1007/s00520-015-2906-3

ORIGINAL ARTICLE

Transition to the new role of caregiving for families of patients with breast cancer: a qualitative descriptive exploratory study

Masoumeh Hashemi-Ghasemabadi[1,4] · **Fariba Taleghani**[2] · **Alireza Yousefy**[3] · **Shahnaz Kohan**[2]

Received: 6 March 2015 / Accepted: 16 August 2015 / Published online: 26 August 2015

Abstract

Background Families, especially in Eastern and Muslim countries, routinely accept the responsibility of caring for cancer patients. This study describes the transition to the new role of caregiving from the perspective of family caregivers in Iran as part of the current trend of recognizing the experiences of family members of breast cancer patients from different cultural perspectives.

Materials and methods A descriptive exploratory qualitative research approach was used to investigate the experiences of family caregivers of patients with breast cancer in the transition to caregiving. The subjects were 23 family caregivers of breast cancer patients referred to cancer centers at Isfahan University hospitals who were selected by purposive sampling. Data was gathered through in-depth interviews. Interview transcripts were analyzed using conventional content analysis with an inductive approach.

Results Data analysis identified the following categories: grasping a new situation without preparation, perceived inefficiency, infinite absence, and abandoned in the role. Caregivers believed that they were not prepared for their new circumstances and did not have the necessary competence and capabilities to meet the challenges of caregiving. They experienced negative consequences resulting from the difficult responsibility of caregiving. Moreover, they believed that they received limited support from relatives, health-care providers, and the community.

Conclusion The transition to the new role of caregiving is affected by experiences specific to the conditions of the caretakers. When these conditions can be understood and identified, it is possible to provide detailed information for policymaking and planning for family-centered care.

Keywords Cancer · Role · Transition · Family caregiver

Background

Every country implements a different model for providing care to a cancer patient; however, informal care is provided in all countries. Informal care is that provided by family members, relatives, or friends to a patient free-of-charge. Family caregivers have a central role in providing care for cancer patients. Changes in the treatment systems mean the form of caregiving has changed from hospitalization to outpatient treatment. The role of the family has increased, and more than half of patient's needs are provided by family caregivers.

Breast cancer remains the most common cancer among women and ranks first among the five most common cancers afflicting Iranian women. Family members face new roles and responsibilities [1] when suddenly confronted with a cancer diagnosis. Being a caregiver itself is challenging [2–4]; the transition is associated with lack of stability and confidence that increases susceptibility of individuals to health risks. Healthcare and ultimately the quality of life of the patient are affected [4, 5]. Several studies emphasize the lack of support for and attention to caregivers and the importance of

---

✉ Fariba Taleghani
Taleghani@nm.mui.ac.ir

[1] Student Research Center, Faculty of Nursing and Midwifery, Isfahan University of Medical Sciences, Isfahan, Iran

[2] Nursing and Midwifery Care Research Center, Faculty of Nursing and Midwifery, Isfahan University of Medical Sciences, Isfahan, Iran

[3] Medical Education Research Center, Department of Medical Education, Isfahan University of Medical Sciences, Isfahan, Iran

[4] Department of Midwifery, Arak Branch, Islamic Azad University, Arak, Iran

studying the effects of their race, ethnicity, and socio-economic level [6–8]. Although caregiver perspectives regarding their role are influenced by family structure and cultural and religious beliefs, evaluation of their cultures in the context of caregiving has been limited to developed countries [4, 9]. Despite the high incidence of cancer in low- and middle-income countries, the lack of care facilities and treatment personnel and the central role of the family in caregiving mean research on the transition to the role of caregiving in these countries is limited [4]. Most studies have been carried out in Western countries, which differ in culture and perspective from Eastern, especially Muslim, countries [4, 10]. The results of these studies are not generalizable because of the structural, socio-economic, and cultural conditions of their settings; thus, the interpretation of the findings in non-Western countries is problematic and lacks the necessary efficiency [11].

Despite the high incidence of breast cancer and the important role of Iranian families in providing care, there is little information on this topic in Iran [4, 12–14]. Many Iranian women are afflicted with breast cancer at an early age; this higher incidence and survival rates mean that younger women are fighting this disease. The prolonged contribution of the family and the researcher's own experience in managing the problems of caregivers were the motivation behind this study.

Aim

Modern research trends place an emphasis on the importance of the experiences of family members of breast cancer patients and the study of caregivers of different cultural groups [6, 15]. The present study examined the transition to the new role as a caregiver in the context of Iranian culture to gain a deep understanding of the roles of culture, race, and socio-economic background using qualitative methods.

Materials and methods

Qualitative research methods provide the best opportunity for better understanding of phenomena and exploration of life experiences in the area of social and cultural events [16]. The present qualitative descriptive and exploratory study examined the experiences of family caregivers of patients with breast cancer during the transition to the new caregiving role. To achieve maximum diversity and enhance transferability of the research findings, the participants were purposefully chosen with maximum variation from family caregivers of patients referred to cancer centers at Isfahan University hospitals. The inclusion criteria consisted of family caregivers of patients with breast cancer aged 18 years and older with the ability to read, write, and express experiences who are willing to participate in the study.

The data collection method applied was open-ended, unstructured, and in-depth interviews. Such interviews are best for conducting qualitative studies [16]. The personal interviews were conducted in a calm environment. The interviewer began by asking the general question: "Please talk about your experience regarding your new role." This was followed by semi-structured and exploratory questions (see Appendix). The interviews lasted 30 to 90 min and were recorded with the permission of the participants. The interviews were audiotaped and transcribed verbatim.

Sample size is not estimated in qualitative studies, and process of sampling continues to the point no new categories obtained, this is called data saturation [17, 18]; therefore, data collection in this study was continued until data saturation was achieved through interviews with 23 caregivers. Qualitative content analysis will suffice for many studies in the area of health, especially if they are exploratory or their aim is to describe an important topic in a particular group of people [19]. The present study used a conventional content analysis method with an inductive approach.

After the implementation of each interview and repeated readouts and reviews, the meaning units were identified as sentences or paragraphs of statements or interview texts. The initial codes were extracted, and each of the codes was matched with the participants' statements. Next, centrality and semantic similarities were employed to extract the subcategories and categories. Subsequently, the initial texts and the initial and final categories were reread several times. Every time changes were made to the number, content, and the names of the categories until the subcategories, categories, and the main themes were identified. Following an inductive processing, related subcategories were placed together in one category. Four main categories were obtained using the conceptual titles resulting from the categories.

Guba criteria were used to insure the rigor of the data [20]. For credibility, time integration was employed in the form of in-depth interviews conducted at numerous meetings and at various times and locations and feedback was obtained from the participants. To increase transferability, the participants were selected for maximum diversity of gender, age, marital status, kinship, education, and socio-economic status. Dependability and conformability were assured by having the participants and research partners review the findings, the continuous involvement of the researcher in the data, and constant comparative analysis to achieve detailed and in-depth information.

Procedures and ethical considerations of this study were confirmed by the Ethical Committee of Isfahan University of Medical Sciences, Isfahan, Iran. Before conducting the study, explanations were provided for the participants regarding the objectives of the study and the participants' rights. Written and verbal consent were obtained from the participants for recording their interviews.

Results

The participants were 23 caregivers aged 20 to 69 years with a mean age of 37.5. Most were women (69.6 %), were married (65.2 %), and had university education (56.5 %), and the largest percentage was their children (34.8 %). Caregivers varied in occupation, but were mostly housewives (34.8 %). The majority (43.5 %) earned an income of between 5,000,000 and 7,000,000 Rials per month. The mean time of patient care was 7.1 h per day (1.5 to 12 h) (Table 1). The main categories and subcategories produced by data analysis are shown in Table 2.

Grasping a new situation without preparation

This category contained the subcategories of unexpected realization of a catastrophic illness, confusion about the role of the caregiver, and control of the situation and mastering new responsibilities. Most caregivers were not prepared to deal with the new situation. The tangible aspects for caregivers were that they felt the need to be prepared for the transition to their new role. They experienced a change in identity upon embracing the new role, felt they were participants in care without having obtained adequate information, and struggled with the need to control the situation and master their new responsibilities.

The sudden exposure and the caregivers' initial perspective towards cancer as an incurable disease formed a frightening mental image of the disease that provoked reactions when hearing the diagnosis. A 38-year-old caregiver spouse stated: "As soon as they said it was cancer, I was scared. Cancer is like a terrible monster and I was devastated." Part of the reaction to the sudden confrontation with the illness was caused by the lack of skills of the treatment team in disclosure of the diagnosis. A 28-year-old caregiver sister stated: "The doctor gave us the news suddenly; they should know how to prepare the family and respect them."

Some participants described entering the caregiving world as entering the world of the unknown. They became caregivers unintentionally, without preparation, knowledge, or familiarity with the tasks. Despite accepting the various new duties, they could not explain their new identities as

Table 1 Characteristics of family caregiver of breast cancer patients

Characteristics	Number (%) of participants	Characteristics	Number (%) of participants
Age (years)		Occupational status	
18–28	8 (34.8 %)	Housewife	8 (34.8 %)
29–38	5 (21.7 %)	Employed	5 (21.7 %)
39–48	6 (26.1 %)	Self-employment	2 (8.7 %)
49–58	3 (13 %)	Student	6 (26.1 %)
≥58	1 (4.3 %)	Retired	2 (8.7 %)
Gender		Marital status	
Male	7 (30.4 %)	Single	8 (34.8 %)
Female	16 (69.6 %)	Married	15 (65.2 %)
Education level		Location of residency	
Primary	–	City/town	21 (91.3 %)
High school	10 (43.5 %)	Village	2 (8.7 %)
University	13 (56.5 %)		
Relationship with patient		Patient's treatment	
Husband	4 (17.4 %)	Chemotherapy	10 (43.5 %)
Patient's daughter	8 (34.8 %)	Radiation therapy	5 (21.7 %)
Patient's son	3 (13 %)	Surgery	5 (21.7 %)
Parent	2 (8.7 %)	Complete of treatment	3 (13 %)
Other relative and friends	6 (26.1 %)		
Hours of care (in 24 h)		Family income (per month)	
1–3	2 (8.7 %)	<5,000,000 Rials (≅US $ <151)	8 (34.8 %)
3–6	3 (13 %)	5,000,000–6,999,000(≅US $151–212)	10 (43.5 %)
6–9	13 (56.5 %)	7,000,000–8,999,000(≅US $212–272)	3 (13 %)
9–12	5 (21.7 %)	>9,000,000(≅US $ >272)	2 (8.7 %)

Table 2 Results obtained from data analysis

Theme shared between categories	Category	Subcategory
Transition to the new role of caregiving	- Grasping a new situation without preparation	- Unexpected realization of a catastrophic illness
		- Confusion about the role of the caregiver
		- Control of the situation and mastering new responsibilities
	- Perceived inefficiency	- Being trapped with negative thoughts
		- Facing the extreme commitment of caregiving
		- Feeling desperate in critical situations
		- Being inadequate to manage the challenges of communicating with patients
	- Infinite absence (loss)	- Self-sacrifice
		- Loss of normal life
		- Loss of former identity in the relationship with the patient
		- Loss of positive emotions and health
	- Abandoned in the role	- Lack of official support from specialized community support centers and health workers
		- Lack of informal support from family members, friends, and relatives

caregivers and were confused about it. A 20-year-old caregiver daughter stated: “Cancer is like an unwanted guest that comes unexpectedly. I have gained new responsibilities and I do not know whether I am really a caregiver or not. I assume that these are the duties of every child, but caregiving is probably something else.”

Taking care of a cancer patient is associated with unexpected and difficult duties which the caregiver is required to recognize and adapt to. A 34-year-old caregiver son stated: “At first it was hard; I was faced with new problems. Finally, I forced myself to believe that I have to live with this situation. I tried to define a new plan for my new life.”

Perceived inefficiency

The category of perceived inefficiency has subcategories of being trapped with negative thoughts, facing the extreme commitment of caregiving, feeling desperate in critical situations, and being inadequate to manage the challenges of communicating with patients. Most participants considered the current situation to be critical and, in most cases, they did not have the ability to cope with the challenges. They believed that they were inadequate to deal with the problems and achieve the goal of care. Their sense of responsibility and excessive commitment to care, distress at some circumstances, inability to meet the challenges of communication, and the influx of negative thoughts provoked feelings of inadequacy and helplessness in them.

One participant discussed the frustrating situation and the negative and vexing thoughts that formed upon acceptance of the role of caregiver. A 35-year-old caregiver sister stated: “Thoughts about the good old days and comfort and peace do not mean anything now; thinking about what kind of problems might occur in the future upsets me.” Some individuals bear the entire burden of this responsibility alone and do not leave the patient for even a short time. A 25-year-old caregiver daughter stated: “There were times when I could not continue and really needed rest, but I couldn’t give up.” Critical conditions complicate the care process and produced feeling of desperation and helplessness. A 45-year-old caregiver spouse stated: “Chemotherapy caused fatigue and mood changes and the fact that I did not know how to manage mood changes, vomiting, or pain grieved me.”

Although it is important for caregivers to provide emotional support for the patients, they faced challenges in providing such support. A 38-year-old caregiver spouse stated: “A cancer patient needs to receive love from others, but sometimes this caused problems.” Some could not cope with their personal relationship with the patient and felt weak and unsure. A 24-year-old caregiver son stated: “Sometimes when I am busy she has expectations and demands that frustrate me and I mistreat her. Later I am saddened and distraught because I am not a good caregiver.”

Infinite absence (loss)

Transition to the new role of a caregiver was associated with a sense of loss. Feeling the infinite absence as a category includes the subcategories of self-sacrifice, loss of normal life, loss of former identity in the relationship with the patient, and loss of positive emotions and health. Transition to the role of a caregiver, in addition to the negative physical, psychological, social, and economic effects and the disruption of the normal rhythm of life, also affected the caregivers’ current and previous roles. Focus on the patient, ignorance, and self-neglect highlighted the emerging sense of loss.

Full commitment to providing care and support to the patient submerged the caregivers into providing care and caused them to neglect issues and matters related to themselves. Caregiving caused limitations that made them ignore personal activities, especially in the initial days of transition. A 30-year-old caregiver sister stated: “When I look back, I see that I have lost many opportunities. I did not live my life; I just took care of my sister and thought about her.” Some mentioned that a sense of duty and obligation was the reason for the self-neglect and refusal to deal with personal needs. A 20-year-old caregiver daughter stated: “Anyone in my situation would do the same; I cancelled all my programs and dedicated my life to taking care of my mother.”

Changes in the normal rhythm of life and relationships with others were evident in their comments. A 25-year-old caregiver daughter stated: “Cancer and caring for my mother changed my whole life. I relocated to be closer to my mother; I cannot take care of my husband and children the way that I should.” Some caregivers were faced with financial hardship and employment problems and caregiving interfered with their other responsibilities and social life. A 45-year-old caregiver spouse stated: “Because of my spouse’s condition, I had to work part time and this increased our financial problems.”

Accepting the role of a caregiver changed the relationship between the caregiver and the patient so that the former identities of some caregivers had weakened. The patient-caregiver relationship had overtaken their other relationships and roles. A 45-year-old caregiver spouse stated: “I sometimes forget that I’m her husband, I provide care for her like a mother, a completely emotional and feminine role.” When a child was the caregiver, accepting dual roles and experiencing changes in the parent-child relationship was difficult. A 20-year-old caregiver daughter stated: “I felt like I was my mother’s mother; I had to care for her and my little sister. It was difficult because sometimes I had to act like a mother and sometimes it was like she was my own age.”

Transition to the new role of caregiving was associated with negative health consequences for the caregiver. A 45-year-old caregiver mother stated: “During this period, I have developed high blood pressure, headaches, and insomnia, and I am always anxious and fearful.” Some caregivers, by refusing to talk with the patient and by hiding their negative emotions, try to create a calm environment to avoid and decrease anxiety in the patient and other family members. A 54-year-old caregiver mother stated: “I cry when I am alone. How can I cry in front of her when I am trying to give her hope? I pretend that everything is ok, but inside I am devastated.”

Abandoned in the role

Caregivers face challenges in their transitions to the new role; however, what was most striking in their statements was that they provided care with no support. They saw themselves as isolated and abandoned in the role and complained of not receiving adequate support. The category of abandoned in the role included subcategories of lack of official support from specialized community support centers and health workers and lack of informal support from family members, friends, and relatives. A 25-year-old caregiver daughter stated: “What was most upsetting was that my relatives abandoned us in this situation.” Their need for support from health personnel was clear in their statements. A 28-year-old caregiver son stated; “It would be really useful if a nurse would advise us or train us on how to care for a cancer patient, but unfortunately they disregard this.”

Lack of insurance coverage and the high cost of treatment were the greatest concerns of the participants. A 45-year-old caregiver spouse stated: “For the cost of treatment, I had to get a loan with high interest. The insurance did not cover it.” The disregard for the needs of caregivers and lack of support programs tailored to their needs was also expressed by the participants. A 34-year-old caregiver son stated: “At the hospital, only the patient receives attention; there was no training provided for us.” To fill this emotional void and provide for their needs, some caregivers form informal support groupings. A 38-year-old caregiver sister stated: “I met a woman at the hospital who was also a caregiver. We call each other and she helps me. It is calming to see people who are in circumstances similar to mine.”

Discussion

The aim of this study was to describe the transition to the new role of care giving from the perspective of family caregivers in Iran. Four main categories were extracted: grasping a new situation without preparation, perceived inefficiency, infinite absence, and abandoned in the role.

The participants of this study lacked readiness to confront the reality of cancer, of providing care, rising to crises, and proficiency in performing their new duties. Stress and terrible mental images of cancer resulted from the shock of diagnosis to the caregivers. Other studies have reported that cancer is a trauma to the family that creates tension in caregivers [21]. There is no unit for cancer patient care in the structure of Iran’s health-care system and providing care for them is fraught with challenges [22, 23].

In Iran, no formal training is provided for physicians to enhance their skills of communication and disclosure of bad news; they often lack the ability to communicate appropriately with patients and their families [24]. Studies have emphasized the need for separate emotional support for caregivers of cancer patients [3]; nevertheless, supportive care is not available in Iran, even for the cancer patients. When doctors lack the skill to appropriately disclose bad news, it means that patients also suffer psychological distress [25].

Caregivers were plunged into caregiving without preparation and having many questions and uncertainties; caregivers reported being always in doubt and worried. Studies have also shown that caregivers usually begin their roles suddenly and they are not prepared to deal with the crisis [3, 26–28]. In Iran, despite the major role of caregivers in healthcare, little attention is given to them and there is no comprehensive plan for caregiving [22, 23]. The family that must provide comprehensive care needs support as much as the patient does [29, 30]. The lack of training for caregivers has been a topic of previous study [26, 27].

Self-efficacy affects the responses of individuals to stressful situations. People who were inefficient in caregiving tended to focus on the difficulty of caregiving, their poor self-care skills, and the negative aspects of their position. Their negative understanding of their status decreased their motivation to perform their duties [31]. Although most caregivers possessed a strong commitment to provide care, they did not always have the ability to control the situation and suffered an influx of negative thoughts. One reason for a feeling of inadequacy in caregivers was the pressure of care and their strong commitment to providing care. This resulted in an inverse relationship between high efficacy and pressure of care [32]. Previous studies have reported that self-efficacy is an important factor in moderating negative and upsetting thoughts [33]. Carbone et al. [34] observed that there is a strong relationship between self-efficacy of caregivers and the relationship between caregiver and patient [34].

Their strong commitment to and prioritization of the patients resulted in self-neglect, negative care outcomes, and changes in the lives of the caregivers. The cultural rules, religious doctrine, and strong family ties of Iranian families mean they tend to provide high levels of care [12, 13]. Studies indicate that 70 % of caregivers have experienced problems related to care and to adjusting to the responsibility of caregiving [35].

Caregiving is time-consuming and competes with other responsibilities. The results of the present study were consistent with those of the previous studies for effect of care on individual priorities, normal pattern of life, positive feelings, and the health of the caregiver [36–39]. The close relationship with the patient caused changes in the relationship of the caregiver with the patient, shifted focus to the role of caregiver, who experienced duality of roles, and changes in or loss of previous identity. In this regard, the results of the present study were consistent with results of previous studies [28, 36].

The caregivers interviewed had expected to receive comprehensive support from relatives and the medical team. The nature of the Iranian caregiving was one reason for the lack of extended support. In Iranian culture, the patient and the family receive high levels of support during the initial days after diagnosis of a chronic illness, but this support decreases over time [40]. The results of this study were consistent with the results of previous studies for rejection by and lack of support from relatives, society, and the treatment team [27, 28, 36]. Forming relationships with individuals in similar circumstances with whom they could share their experiences and feelings as a source of support was mentioned by participants; this finding is consistent with the results of other studies [27].

Conclusions

This research provides a better understanding of cancer caregivers' transition to the new role. Our results showed that the breast cancer family caregivers experienced lacked of readiness to confront the reality of cancer, of providing care. They were inadequate to deal with the problems and achieve the goal of care and experienced infinite absence. Also, they experienced lack of support. So quality of care is reduced in the situations.

By understanding their experiences in the transition to the new role, it is possible to provide detailed information for designing evidence-based health-care interventions and comprehensive family-centered care program. Also, interventions can be tailored to the objectives and resource limitations, for the support and resolution of the challenges of caregivers to decrease the negative consequences of caregiving. Breast cancer family caregivers experience of transition into and within the caregiving role is a complex issue and needs further research.

Acknowledgments This paper was extracted from a Ph.D. thesis and was funded by the research department of Isfahan University of Medical Sciences. The authors would like to thank Isfahan University of Medical Sciences for supporting this research and the cancer patient caregivers who took part in the interviews for their time, patience, and friendly contributions to the study.

Conflict of interest The authors declare that they have no competing of interest.

Appendix

The interview guide

1. Describe your experience through a day of caring for the patient?
2. What are some of the good experiences of providing care?
3. What are some of the negative experiences you have faced?
4. What are the difficulties you face whilst providing care?
5. Describe your care giving role.
6. What does the care giving role mean to you and why is it important to you?
7. What motivates you to provide care?
8. How does this role affect your life?

9. How has this role affected your physical and mental health?
10. How do you take care of your own needs while taking care of the patient?
11. How do you deal with your own emotional issues?
12. What social support do you receive?
13. What other support do you think would be beneficial to you?
14. Is there anything else you feel is important to mention?

References

1. Kim Y, Carver CS, Deci EL, Kasser T (2008) Adult attachment and psychological well-being in cancer caregivers: the mediational role of spouses' motives for caregiving. Health Psychol 27:S144
2. Given BA, Given CW, Sherwood P (2012) The challenge of quality cancer care for family caregivers. In: Editor (ed)^(eds) Book The challenge of quality cancer care for family caregivers. Elsevier, City, pp. 205–212
3. Glajchen M (2003) The emerging role and needs of family caregivers in cancer care. J Support Oncol 2:145–155
4. Walker A (2011) Perceptions of family cancer caregivers in Tanzania: a qualitative study. In: Editor (ed)^(eds) Book Perceptions of family cancer caregivers in Tanzania: a qualitative study. University of Pittsburgh, City
5. Ducharme F, Lévesque L, Lachance L, Kergoat M-J, Coulombe R (2011) Challenges associated with transition to caregiver role following diagnostic disclosure of Alzheimer disease: a descriptive study. Int J Nurs Stud 48:1109–1119
6. Adams E, Boulton M, Watson E (2009) The information needs of partners and family members of cancer patients: a systematic literature review. Patient Educ Couns 77:179–186
7. Gibson MJ, Kelly KA, Kaplan AK (2012) Family caregiving and transitional care: a critical review family care giver alliance, National Centre on Care Giving
8. Gorji MAH, Bouzar Z, Haghshenas M, Kasaeeyan AA, Sadeghi MR, Ardebil MD (2012) Quality of life and depression in caregivers of patients with breast cancer. BMC Res Notes 5:310
9. Jones BL (2012) The challenge of quality care for family caregivers in pediatric cancer care. In: Editor (ed)^(eds) Book The challenge of quality care for family caregivers in pediatric cancer care. Elsevier, City, pp. 213–220
10. Kochaki-nejad Z, Mohajjel Aghdam A, Hassankhani H, Sanaat Z (2013) A brief review on patient caregiver studies in Iran. Int Res J Appl Basic Sci 5:999–1001
11. Silbermann M, Arnaout M, Daher M, Nestoros S, Pitsillides B, Charalambous H, Gultekin M, Fahmi R, Mostafa K, Khleif A (2012) Palliative cancer care in middle eastern countries: accomplishments and challenges. Ann Oncol 23:15–28
12. Karimollahi M, Abedi H, Yousefi A (2008) Antecedents of spiritual distress experienced by Iranian Muslim patients. Res J Biol Sci 3: 491–499
13. Mobasher M, Nakhaee N, Tahmasebi M, Zahedi F, Larijani B (2013) Ethical issues in the end of life care for cancer patients in Iran. Iran J Public Health 42:188
14. Radmard AR (2010) Five common cancers in Iran. Arch Iran Med 13:143–146
15. Given BA, Sherwood P, Given CW (2011) Support for caregivers of cancer patients: transition after active treatment. Cancer Epidemiol Biomark Prev 20:2015–2021
16. Speziale HS, Streubert HJ, Carpenter DR (2011) Qualitative research in nursing: advancing the humanistic imperative. Lippincott Williams & Wilkins
17. Ploeg J (1999) Identifying the best research design to fit the question. Part 2: qualitative designs. Evid Based Nurs 2:36–37
18. Polit DF, Beck CT (2012) Nursing research: generating and assessing evidence for nursing practice. Lippincott Williams & Wilkins
19. Green J, Thorogood N (2013) Qualitative methods for health research. Sage
20. Guba EG (1981) Criteria for assessing the trustworthiness of naturalistic inquiries. ECTJ 29:75–91
21. Zhang Q, Yao D, Yang J, Zhou Y (2014) Factors influencing sleep disturbances among spouse caregivers of cancer patients in northeast China. PLoS One 9, e108614
22. Iranmanesh S, Hosseini H, Esmaili M (2011) Evaluating the "good death" concept from Iranian bereaved family members' perspective. J Support Oncol 9:59–63
23. Zamanzadeh V, Azimzadeh R, Rahmani A, Valizadeh L (2010) Oncology patients' and professional nurses' perceptions of important nurse caring behaviors. BMC Nurs 9:10
24. Beyraghi N, Mottaghipour Y, Mehraban A, Eslamian E, Esfahani F (2011) Disclosure of cancer information in Iran: a perspective of patients, family members, and health professionals. Iran J Cancer Prev 4:130–134
25. Valizadeh L, Zamanzadeh V, Rahmani A, Howard F, Nikanfar AR, Ferguson C (2012) Cancer disclosure: experiences of Iranian cancer patients. Nurs Health Sci 14:250–256
26. Given BA, Given CW, Sherwood PR (2012) Family and caregiver needs over the course of the cancer trajectory. J Support Oncol 10: 57–64
27. Harding R, Epiphaniou E, Hamilton D, Bridger S, Robinson V, George R, Beynon T, Higginson I (2012) What are the perceived needs and challenges of informal caregivers in home cancer palliative care? qualitative data to construct a feasible psycho-educational intervention. Support Care Cancer 20:1975–1982
28. Holm M, Henriksson A, Carlander I, Wengström Y, Öhlen J (2014) Preparing for family caregiving in specialized palliative home care: an ongoing process. Palliative and Supportive Care: 1–9
29. Jayani R, Hurria A (2012) Caregivers of older adults with cancer. In: Editor (ed)^(eds) Book Caregivers of older adults with cancer. Elsevier, City, pp. 221–225
30. Wagner CD, Das LT, Bigatti SM, Storniolo AM (2011) Characterizing burden, caregiving benefits, and psychological distress of husbands of breast cancer patients during treatment and beyond. Cancer Nurs 34:E21–E30
31. Steffen AM, McKibbin C, Zeiss AM, Gallagher-Thompson D, Bandura A (2002) The revised scale for caregiving self-efficacy reliability and validity studies. J Gerontol Ser B Psychol Sci Soc Sci 57:P74–P86
32. Durmaz H, Okanlı A (2014) Investigation of the effect of self-efficacy levels of caregiver family members of the individuals with schizophrenia on burden of care. Arch Psychiatr Nurs 28:290–294
33. Romero-Moreno R, Losada A, Mausbach B, Márquez-González M, Patterson T, Lopez J (2011) Analysis of the moderating effect of self-efficacy domains in different points of the dementia caregiving process. Aging Ment Health 15:221–231
34. Carbonneau H, Caron C, Desrosiers J (2010) Development of a conceptual framework of positive aspects of caregiving in dementia. Dementia 9:327–353
35. King CR, Hinds PS (2011) Quality of life: from nursing and patient perspectives. Jones & Bartlett Publishers
36. Årestedt L, Persson C, Benzein E (2014) Living as a family in the midst of chronic illness. Scand J Caring Sci 28:29–37

37. Carlander I, Sahlberg-Blom E, Hellström I, Ternestedt BM (2011) The modified self: family caregivers' experiences of caring for a dying family member at home. J Clin Nurs 20:1097–1105
38. Dalteg T, Benzein E, Fridlund B, Malm D (2011) Cardiac disease and its consequences on the partner relationship: a systematic review. Eur J Cardiovasc Nurs 10:140–149
39. Erlingsson CL, Magnusson L, Hanson E (2012) Family caregivers' health in connection with providing care. Qual Health Res 22:640–655
40. Kazemi M, Nasrabadi AN, Hasanpour M, Hassankhani H, Mills J (2011) Experience of Iranian persons receiving hemodialysis: a descriptive, exploratory study. Nurs Health Sci 13:88–93