

A Qualitative Study on Cancer Care Burden: Experiences of Iranian Family Caregivers

ABSTRACT

The aim of this study was to explore the experiences of Iranian family caregivers with regard to the burden of caregiving. This is in the context of illuminating and identifying the experiences of family members from different contextual perspectives.

In this qualitative study, purposive sampling was conducted in 2016. Data were collected using semi-structured interviews and were analyzed using content analysis.

Data analysis identified four categories and eight subcategories: 1. Burn out (physical problems and psycho-emotional stress), 2. Role conflict (balancing caring roles and family responsibilities; failure in professional or educational roles), 3. Health system tensions (inadequate support from health professionals; ignorance of family members in health structure), and 4. Social challenges of cancer (economic burden; taboo of cancer).

In conclusion, nurses need to provide individualized support and counseling that addresses the sources of burden. This highlights the benefit of training healthcare professionals to provide culturally sensitive support based on family caregivers' needs and circumstances.

Keywords: Family Caregiver, Burden, Cancer care, Qualitative Study

Background

Cancer is considered to be one of the most common health problems in the world¹ that negatively impacts family members as well as patients.² In Western countries, family members play an important role in caring for patients with cancer.^{3,4} In Eastern countries, the role of family

members in patient care is amplified due to social structures, including family bonds.^{5,6} A review study fully assessed 234 articles and highlights cross-cultural differences related to cancer care. Cultural differences relate to beliefs about a patient's death and the ethical and cultural challenges related to how oncology staff discuss the cancer diagnosis with patients.⁷ In the Middle East, a cancer diagnosis is accompanied by social stigma; misunderstandings about incurability⁸ and in Iran, as the subject of this study, cancer is a taboo subject.⁹ In Middle Eastern countries, including Iran, the majority of populations are Muslim and social structures are based on family cohesion.⁸ Cultural rules, religious beliefs, and strong family ties mean that family members contribute high levels of care; however, this is not without issues.¹⁰ Research conducted in Eastern countries demonstrates that caring for a family member with cancer has financial, social and psychological impacts.^{11,12} Insights into the impacts of care on family members can help nurses to support the caring role and to provide service and interventions in line with the needs of family caregivers.¹³ Experience is subjective and cannot be objectively measured by others; therefore, no measures can be used to examine an individual's experience.¹⁴ Quantitative research tools on care burden might ignore the underlying causes of experiences and have also received some criticism for being "context-stripping". Consequently, the qualitative approach is suggested alongside quantitative studies.¹⁵

The literature highlights the need to examine the experiences of family caregivers in different cultures, ethnicities and socio-economic backgrounds.^{2,16} Iran is the seventeenth largest country in the world and the second-largest in the Middle East¹⁷; therefore understanding the experiences of family caregivers in Iran will support the development of mechanisms to better support Iranian family caregivers in both their social and caregiving roles¹⁸. It will also inform intervention development and the prioritization of resources to address key deficiencies in health services in Iran and similar cultural settings.¹⁹

Aim

The purpose of this study was to use qualitative methodology to explore the experiences of family members who were taking care of cancer patients.

Methods

Study design and setting: A qualitative method with a conventional content analysis approach was utilized.²⁰ This method is a subjective interpretation of textual data and content by the systematic process of coding and identifying themes or categories.²¹

The study was conducted at the main oncology center in East Azerbaijan Province, Iran. The selected hospital for this study is a main center for cancer treatment in the province and is a referral site for cancer patients in northwestern Iran.

Data collection: Data were collected through in-depth semi-structured and face-to-face interviews from January to December 2016. 25 interviews were conducted in total; in four cases follow-up interviews were conducted for more clarification. Interviews were held in the participants' preferred locations (either in hospital or outside the hospital). Data collection continued until saturation was reached. Data saturation is reached where no new category emerged from participants' responses.

Interview schedule: Interviews were guided by general questions such as: "please describe one day of your experience regarding caring for your patient". The discussion was continued with semi-structured questions including:

what are some of the good and negative experiences of providing care?

What are the difficulties you face whilst providing care?

How does caring for the patient affect your life?

Please give examples.

The interview duration was 30–80 minutes and the mean duration of interviews was 48 minutes. The researcher conducted all of the interviews and transcribed audio recorded interviews for analysis.

Data Analysis: Data collection and data analysis were conducted concurrently. Data were analyzed using Graneheim and Lundman's techniques.²⁰ We used the following steps to generate codes through direct and inductive evaluation of data:

1. Transcribing data: repeated reading of the files to understand the initial idea,;
2. Creating basic codes: coded word-by-word and line-by-line;
3. Searching themes: putting codes in potential themes;
4. Reviewing themes: relating themes with each other and with the extracted codes and the entire data set;
5. Defining and naming themes: continuous analysis, extracting the core meaning and creating clear definitions and names for each theme; and
6. Reporting: final analysis, moving between interviews and themes, selecting stories representing each theme and reporting.

In this study 1569 initial codes were obtained according to the six steps previously mentioned. Similar codes were classified into four main categories and eight subcategories within the theme

'Cancer care burden' of family caregivers. MAXQDA software was used to manage the data analysis.

Rigor: To strengthen the qualitative research rigor, Guba's criteria (credibility, dependability, confirmability and transferability) were applied.²² The credibility of the data increased using the prolonged involvement with the data (15 months). To increase dependability of the data, a limited literature review was conducted at the beginning of the study to avoid bias in the data collection and analysis process. Confirmability of data was obtained by registering and reporting various steps of the study. To increase transferability, people who were invited to participate in the study had the maximum variation in care experiences, demographic characteristics, and type of relationship with the patient.

Ethical considerations: The Regional Ethics Committee at Tabriz University of Medical Sciences approved the present study (TBZMED.REC.1394.6.14). All participants were informed of the objectives of the study and gave written consent.

Results

A purposive sample of 21 participants were enrolled in the study. Participants included 16 family caregivers and five health professionals. The inclusion criteria for family caregivers were that they had to be aged over 18, with the mental and physical ability to participate in the study; and they were caring for a family member with cancer. A small sample of five health professionals were also recruited to confirm the opinions of family caregivers and further enrich the study. However, it should be noted that these were not the main target group of the investigation. Inclusion criteria for health professionals included having at least two years of work experience in the field of oncology. The mean age of health professionals was 49 ± 22 . The mean age of family caregivers

was 39.3±13 years. Most caregivers (66.7%) were female; married (71.4%), with a college education (52.4%), and most family caregivers (38.1%) were the child of the patients. We selected different types of cancer and duration of caregiving to reach the maximum variation in care experiences. Key informants characteristics are presented in more detail in **Table1**.

Data analysis identified the following four categories: burn out; role conflict; health system tensions; and social challenges of cancer. The subcategories appear in **Table 2**

1. Burn out

Care of patients with cancer is lengthy, time-consuming and multidimensional. The role of caregiver to a family member with cancer physically and psycho-emotionally affects the health of caregivers over time. Some caregivers referred to physical problems such as stomach pain and sleep disturbances being the result of the psycho-emotional stress of providing constant care. This category is composed of two subcategories, including physical problems and psycho-emotional stress.

Physical problems

Many family caregivers (FC) reported a variety of health problems resulting from their role as long-term caregivers. Physical problems cited included: pain in specific areas such as knees, wrists and stomach; overall body pain; sleep disturbances; weight and appetite loss; gradual decline in physical abilities; and weakness of the immune system and fatigue. One family caregiver commented:

“My physical abilities have declined over time [...] I acquired frequent infections .I developed a peptic ulcer that I did not have before.” **FC: 40-year-old daughter**

Similarly, health professionals (HP) also recognize the physical impacts of caregiving. As one nurse commented:

“Family members get physically sick because of providing 24-hour care.” **HP: 42-year-old**

Psycho-emotional stress

When a family member develops cancer, family caregivers experience a wide range of psycho-emotional stress. Unpreparedness to deal with the diagnosis of cancer, lack of understanding of the disease and its consequences and the fear of death result in family caregivers experiencing symptoms such as shock after diagnosis, sadness, stress, anxiety, fear of the future for the patient, loss of morale, crying, losing hope, denial and nostalgia. Family caregivers reported more severe stresses during the post-diagnosis early stages of cancer. One family caregiver related:

“The name of this disease is hard; I did not expect my child to be diagnosed with cancer. I cried, away from my son.” **FC: 53-years-old mother**

2. Role conflict

Family caregivers enter the caring role without any preparation. Becoming a family caregiver leads to increased workload and hence decreased effectiveness in occupational and educational responsibilities and impacts on family caregivers’ social roles. This category consists of two subcategories.

Balancing caring roles and family responsibilities

Lack of information in the early stages of the disease was an important concern mentioned by participants who are family caregivers. Without adequate information and knowledge about caring

for people with cancer, family caregivers lack confidence in their ability to provide care. Similarly, increased responsibility for a family member with cancer, means that family caregivers are unable to fulfill their family roles and responsibilities and in some cases, they become confused and unable to balance caregiving duties and other everyday responsibilities:

“I was confused in the early stages of the disease [...]. I could not balance between care and other responsibilities. Due to lack of knowledge, I did not know what to do.”

FC: 30-year-old daughter

“I forgot myself and my family and had no control over my life. I lost the control of my life.” **FC: 33-year-old sister**

Failure in professional or educational roles

Providing long-term care and having increased responsibility affects family members' social roles, particularly in relation to their professional and educational roles. Caring for a patient requires the family caregiver to spend more time with their sick relative, which leads to less time and energy to dedicate to work and/or study and reduces the family caregiver's effectiveness in these areas. In some cases, family caregivers are forced to take time off work or temporarily withdraw from school or studies:

“Due to being the sole caregiver, I had to leave university. Increasing responsibilities at home has taken away my opportunity to study.” **FC: 40-year-old wife**

“Family members staying all night by the patient and going to work in the morning ... was difficult and decreases the work quality. We had a mother that retired early to take care of her child.” **HP: 25-years-old**

One of the family caregivers, who lives in the village, talks about the effects of caregiving on his job. He says:

“Our living place is located in a village far from the hospital. It is one month that I’m near my wife in the hospital. I can’t go to work because of giving care to her and the long distance to my work place. I’ve quit my job.” **FC: 38-year-old husband**

3. Health system tensions

Health systems and services are well placed to prepare family members to provide care in the home to people with cancer. However there are limited formal programs and measures to prepare and support family caregivers. This category consists of two subcategories.

Inadequate support from health professionals

Family caregivers need support from health systems to provide care to family members living with cancer. Family caregivers report that health professionals exclude them from involvement in patient care and do not consider their needs as caregivers, particularly when patients are not receiving care in hospital. Family caregivers reported instances where they have been sent out of the hospital room when the doctor visits the patient and after discharge to home, there are limited mechanisms in place for family caregivers to communicate with medical professionals and to receive support. As the following participants attested:

“There are communications and interactions between doctors and family members, but not at an acceptable level. This needs improvement [...] There is no formal consultation system in the hospital.” **HP: 55-year-old**

“During the visits, they [health professionals] would not allow us to enter the ward.”

FC: 43-year-old wife

“The psychological dimension of family caregivers was not considered. For example,

I was much more upset than the patient.” **FC: 42-year-old son**

Ignorance of family members in the health structure

The high workload of medical specialists and nurses can lead to family members being ignored. Family caregivers have stated that formal and comprehensive training is not provided to them. They commented that requests for assistance from health professionals often received responses; however this support is considered insufficient. Another issue is that, in the hospital structure no space has been considered for family members to take rest or to stay overnight. Patients’ family members, who come from neighboring cities or villages, have problems staying in the hospital or taking rest. Nothing has been devised by the health organization to handle this problem. This can be seen in the quotations from participants below:

“When patients enter the ward, we provide training to family, but with the large number of patients, we have no time to identify the specific needs of family members.”

HP: 41-year-old

“Considering the rising statistics of cancer, the number of care centers should increase.

The capacity of hospitals is limited and not responsive for patients and family members. Family members complain about lack of suitable places for taking rest and unfortunately hospitals lack spaces for family members to reside or relax in. This problem is more notable in families who are referred to the hospitals from other cities or villages and impose more pressure on them.” **HP: 25-year-old.**

One of rural family caregivers states that:

“Because of far distance between our village and the hospital, daily commuting is impossible for me and I have to stay with my mom during her hospitalization. In this period, I myself need rest but there’s not any separated room for it. ” **FC: 40-year-old daughter**

4. Social challenges of cancer

The study findings highlight the multiple impacts of cancer on families. Family caregivers referred to both the financial and social implications of a family member receiving a cancer diagnosis. Some family caregivers receive support from charities, although this is limited to financial support. Support which takes into consideration commonly held beliefs about cancer and the psychological and emotional impacts that a cancer diagnosis entails, are not given consideration. This final category also consists of two subcategories.

Economic burden

Cancer often leads to financial difficulties for families. In Iran, as in many other Middle Eastern countries, men are often solely responsible for earning the family income. A cancer diagnosis has an impact on families’ financial situation particularly when the person receiving a diagnosis is the primary income earner.

The introduction of the Health Sector Evolution Program is one of the steps that the Iranian Government has taken to reduce costs and reduce the financial burden of disease on patients and their families. While family members welcome such measures they repeatedly spoke of the financial concerns that long-term cancer treatment and care entail. Some social charities provide

financial support to families in need; however, participants highlighted that support is often insufficient to cover costs.

“The first issue was the financial problem [...] although insurance supported us but the costs were high.” **FC: 28-year-old son**

“These families refer to us and have problems in providing the treatment costs, even after governmental support.” **HP: 80-year-old**

Taboo of cancer

In Iran, commonly held societal beliefs about cancer are that it is incurable and is a death sentence. These beliefs are associated with misconceptions about the disease and meanings that people associate with the disease. Due to misconceptions and fears about cancer, family members may not divulge a cancer diagnosis to others. In some cases, due to changes in a patient's appearance, families reduce their interaction with others. Due to a lack of knowledge about cancer among the general population people, including health professionals, associate the word cancer with a death sentence.

“We reduced our communication with others, so that they would not be aware of the disease, because cancer has an unpleasant meaning (equal to death and hopelessness); anyone who hears it becomes upset and just feels pity.” **FC: 53-year-old mother**

“Despite the high work experience in the field of oncology, by hearing the name of cancer, we still fear losing our beloved patient.” **HP: 41-year-old**

In a remote area or a village, there are incorrect ideas about diseases due to the lack of knowledge and this false perception is more common about cancer. One of the family caregivers, who lives in a village, talks about this issue:

“My dad had completely lost his hope ... Unfortunately in our village there’s a common belief that when a person gets a fatal disease such as cancer, he or she is being trialed by God. So, we didn’t want our relatives to know about his illness diagnosis and I tried to turn to spiritual matters such as praying to deal with this issue and giving good care to my dad. I also asked him to get help from religious beliefs to reform his own thoughts, since we believe that any hardship in life is from God and this idea makes the problem more bearable for us.” **FC: 34-year-old daughter**

Discussion

This qualitative study presents the current status of family members taking care of patients with cancer and discusses the personal, social and health system challenges and outlook of the caregiving burden in Iran. The results of this study indicate that physical and psycho-emotional stress impact the health of family caregivers. In studies relating to family caregivers conducted between 2000 and 2010, concepts and variables such as anxiety, emotional distress, mood disorders, feeling guilt, panic disorder, post-traumatic stress disorders, and unresolved sadness were reported.²³ Also studies conducted in Western countries and literature reviews found similar results to our research^{2,13,24} and highlight a lack of difference in varied environments. Multifaceted efforts are warranted in order to attend to the caregivers’ physiological needs, concerns and safeguarding. Through investigating the burdens imposed by caregiving to the family members, it is possible to identify and introduce the actions required to improve clinical care and health policy.

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Cultural and health beliefs appear to have an effect on the use of complementary and alternative medicine (CAM) and its use varies among different tribal, racial and ethnic groups.²⁶ This issue has been under investigation globally; however, in Iran only a few studies have addressed it.²⁷ A

common idea among Muslims is that spiritual beliefs and practices help them lessen their physical distress. Iranians, who suffer from cancer, and their families turn to prayers and spiritual / religious practices as a form of complementary medicine to heal the disease.²⁸ This has been considered as an important source of support for those living with cancer.²⁹ The ability of nurses to identify, recognize, and support these beliefs is important in the provision of holistic care.

An interesting finding in this study was role conflict between their existing responsibilities and the new ones created by the family caregiver role: impact of caregiving on the family caregiver's ability to effectively participate in employment and education. The complexity of caregiver roles is often variable and difficult to define.³⁰ Women in Iran are interested in studying at higher levels and having active roles in society³¹; however, tensions still exist between the traditional and modern roles of women. They experience more difficulties and face more obstacles in fulfilling social roles.³² When women adopt a caregiving role they are less likely to maintain participation in employment and education. Conflicting results are reported on the topic of the caregiving role. According to Kim et al³³ women, usually, adapt more easily than men to the role of caregiver. In China both female and male caregivers used maladaptive coping styles.³⁴ In general, it is unclear which gender performs better in care and social roles. Contradictory results of role conflict have been reported in both sexes and in different countries; thus more specific research is needed. Family caregivers, who are referred to general hospitals from villages or remote areas, experience various work problems due to the frequent travels and tiredness.³⁵ A systematic review showed that there were undesirable outcomes for the participants from villages, since they have limited access to resources. They sometimes have to live far from their home and family members and it causes them to experience a lot of concerns relating to their job and other responsibilities to their family members.³⁶ Multifaceted support is often needed to give care to patients with cancer. Such

support includes physical, psychological, spiritual and emotional domains.³⁰ Nurses are required to identify the burden imposed to the family caregivers and make an effort to employ helpful strategies in order to reduce it. This is an important role performed by the nurses.

The ignorance of family members in the health structure and inadequate support from medical personnel are other findings in this study. Due to the high workload of medical staff, the provision of training for family members is reported as insufficient. Caregivers were not allowed to attend during medical consultations with the patient and it was mentioned that the hospital system does not prioritize the support of family members.

In a study conducted with Western caregivers, the majority of caregivers reported the need to be visible for the health care providers to appreciate their expertise in caring for the patient and thus involve them during the consultation. They were interested in receiving transparent and accurate consultation and treatment information and expected emotional support from health professionals.³⁷ In a systematic review of informal caregivers' need, it has been reported that information and communication between family members and health staff is insufficient. It was also emphasized that time must be spent not only with the patient, but also with family members to discuss their needs and concerns, as this can directly or indirectly affect the patient. Caregivers should be introduced to the available support groups and social services by nurses and be prepared for the caring role.³⁸ In Anglo-Saxon countries, nurses were reported as being the best health professional to discuss the patients' feelings and concerns, but unfortunately in many non-western cultures, the education provided by the nurses and medical students was reported as insufficient.³⁹ Studies have mentioned problems in the interaction with health care providers.² Nurses believed that ignoring patients' rights by some health care providers and doctors causes patient dissatisfaction and alienation during their time in the hospital.⁴⁰ The present study highlighted that

families are unsatisfied with the health structure and perceived care. Caregivers feel that they have not received what they need.

Since nurses spend much more time with patients and their families, evaluating caregivers' burden and devising suitable interventions is more achievable for them. Nurses as professional caregivers are in a position to assist patients and their family to identify and lessen the health system tensions. Through reducing the burden of caregivers and improving health outcomes, nurses' professional vocation can be supported. There should be a great emphasis on communicating with families in order to understand their values, beliefs and preferences concerning health system tensions.³⁰

The social challenges of cancer care in this study were expressed as the economic burden and taboo of cancer. Studies have shown that the economic burden of cancer ranges from 14.8% to 78.8% average reduction in income in different parts of the world.⁴¹ Studies in the social structure of Iran have highlighted the high costs associated with diseases such as cancer. This causes some families to be forced below the poverty line or to need to borrow money from others due to financial distress.⁴² A comparison of hospital costs in cancer in seven developed countries showed that the Netherlands and England had the lowest costs.⁴³ In the United States, one-quarter of families experienced economic burden and reduced savings due to medical care.⁴⁴ It should be noted that low-income and high-income countries have very different social and economic structures. The governments have different plans to ease economic burden. In Iran, the Health Sector Evolution Program commenced in 2013 in the health system. One of the goals of this project is to reduce health care costs. However, because of the chronic nature of cancer and indirect costs, economic burden remains one of the challenges posed to Iranian caregivers. The results of a review study clarified that caregivers living in villages or other cities have to go on several trips; consequently, extra financial burden is imposed on them. This systematic review emphasizes that

the needs of rural families with a cancer patient are unknown and more investigations are required in this field.³⁶ Both nurses and caregivers should help raise the discussion about public support since families might not have enough knowledge about these resources within the health care system.⁴⁵

One of the most interesting findings in this study revealed that cancer is a taboo subject in Iranian society. Cancer has an unpleasant meaning in Iran and usually equates to death in the minds of the majority of people. Cancer related mythology is different from one country to another. Cancer is stigmatized in Middle-Eastern countries. Interviews with people have identified the common opinion that nothing can be done and that cancer is a death sentence.⁴⁶ A qualitative study in Iran identified mutual concerns in family members and health professionals, as well as patients, about cancer being a taboo subject.⁹ Western countries encourage complete disclosure of the truth about cancer or prognosis of disease⁴⁷ but in Asian countries like Saudi Arabia, physicians tended to discuss issues with family members rather than the patient.⁴⁸ In Singapore, family members preferred to hide the diagnosis of cancer³⁹ while telling the truth about cancer is reported to be compatible with Turkey's cultural context.⁴⁹ In Iran, it is detected that concealment is preferred and physicians tend to disclose the truth to one of the family members rather than the patient. Also in most cases, this non-disclosure culture meant that the word “cancer” was not mentioned and discussions about cancer were shunned.⁵⁰ Even in countries with Latin cultural backgrounds like Spain, views were different from northern European countries and Anglo-Saxon countries. Spanish families were aware of the cancer more than the patient. It is clear that there are cultural differences about the meaning of cancer in the structure of different communities.³⁹ Most of the patients and families in Western countries wanted more accurate information¹⁶ but there are few studies in Muslim countries in these areas⁵. Muslims turn to spiritual sources for reducing the burden caused

by cancer. Spiritual healing is used frequently among Muslim cancer patients. Reviewing the studies about Iranians has shown that families employ a spiritual approach to lessen the tensions imposed by cancer since they consider it as a source of hope and peace. In Saudi Arabia, most cancer patients believe that their prognosis is in God's hands and the patients' destiny is out of the doctor's control.⁵¹ Similarly, Malaysian Muslims, who suffer from cancer, consider Islamic beliefs as a source of power to cope with the disease.⁵² Religion and spirituality are regularly used sources in adjusting to the problems caused by cancer.⁵¹ Finally, there is a need to do more specific studies about the impact of social structure on the perception and treatment of cancer patients and their family caregivers.

Implications for nursing practice: Once a caregiver is identified as having the burden of caring for a family member with cancer, applying culturally appropriate interventions should be emphasized in order to reduce the effects of caregiving. Family members acting as informal caregivers are often not recognized for their contribution in the burden of care of relatives with cancer. They are largely invisible to the health system and are seldom identified as care partners, despite health professionals' expectations that family caregivers provide complex care to people with a cancer diagnosis. Nurses need to view the patient-caregiver dyad as the unit of care and offer more information and support to caregivers to ensure that family members can provide high quality care to patients and to maintain their own health and quality of life.

Nurses are in the best position to reduce cancer misconceptions at the right time and improve the community's understanding of the concept of incurability and death in cancer. Since cancer is considered as a taboo disease amongst people in many cultures, nurses can alter this idea through communicating with them and discussing its treatments. This way the dominant culture of fears about cancer may be changed. If common beliefs about cancer are addressed and medical

discussions are determined mutually, sharing knowledge and information will be facilitated for both nurses and caregivers. Apart from the origin, language, religion and ethnicity, all families have a culture to which communicating information should be adapted and the norms of those cultures should be considered. In Middle Eastern countries, many individuals rely on their spirituality and faith when faced with illness⁴⁶; therefore nurses need to design culture based programs to support families who are from different cultures. Finally there is a need to do more research specifically on the oncology population in dissimilar contexts regarding socioeconomic factors.

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Table 1. Demographic characteristics of the study participants

Characteristics	Number (%)	Characteristics	Number (%)
Age in years		Caregiving duration	
21-38	9(42.8)	0-1(years)	6(28.6)
39-58	11(52.3)	2-4(years)	8(38.1)
≥58	1(4.8)	≥5(years)	7(33.3)
Marital status		Gender	
Single	6(28.6)	Male	7(33.3)
Married	15(71.4)	Female	14(66.7)
Education		Cancer site	
Uneducated	1(4.8)	Hematological	5(31.3)
Primary	4(19)	Digestive	5(31.3)
Diploma	5(23.8)	Breast & Gynecologic	3(18.8)
University degree	11(52.4)	Other	3(18.8)
Relationship with patient		Location of residency	
Parent	2(9.5)	City	12(57.1)
Son or daughter	8(38.1%)	Town	3(14.3)
Spouse	3(14.3%)	Village	6(28.6)
Sister or brother	3(14.3%)	Cultural background	
Health professionals		Azeri	14(66.7%)
Nurse	3(14.28)	Kurdish	4(19%)

Physician	2(9.52)	Persian	3(14.3)
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Table 2. Results obtained from data analysis

Theme	Categories	Subcategories
Caregiving burden	Burn out	Physical problems
		Psycho-emotional stress
	Role conflict	Balancing caring roles and family responsibilities
		Failure in professional or educational roles
	Health system tensions	Inadequate support from health professionals
		Ignorance of family members in the health structure
	Social challenges of cancer	Economic burden
		Taboo of cancer