

# Iranian caregivers, silent mediums in caring for relatives suffering from cancer

Masoumeh Hashemi<sup>1</sup>, Fariba Taleghani<sup>2</sup>, Shahnaz Kohan<sup>3</sup>, Alireza Yousefi<sup>4</sup>

## ABSTRACT

**Background:** Poor interaction of treatment personnel with patients' families leads to informational contrast in families, which may ultimately increase the tension and pressure in these conditions. Considering the necessity of caregivers' contribution for an optimized treatment, continuation of care, and supporting patients, and with regard to caregivers' important role, and also considering the emphasis placed by previous studies on the significance of the caregivers' experiences and as there are a limited number of studies on eastern countries, the present study attempts to justify caregivers' understanding of their own needs for interaction with the treatment team.

**Materials and Methods:** This study is a qualitative research conducted through a content analysis method with an inductive approach. 23 familial caregivers of breast cancer patients from Seyed-Al-Shohada and ayat-ollah khan sari Hospital of Isfahan and Arak were selected through purposive sampling. Data were gathered through in-depth interviews and field notes. The content was read for several iterations and units of meaning and primary codes were extracted, and then categories were extracted based on the centrality and similarity of meanings.

**Results:** Four categories were extracted: a) caregivers' contribution and acknowledging them in the treatment system, b) training in efficient caregiving, c) efficient interaction of the medical team with caregivers, and d) easy and dynamic access to the medical services.

**Conclusions:** The results of the study showed that family caregivers should cooperate and interact with the medical team. They also need training from the medical team on caregiving to cancer patients. An understanding of caregivers' experiences and needs in their interaction with the medical team and identifying their needs as an important aspect in cancer care system assists in designing evidence-based healthcare interventions and a comprehensive family-centered care program.

**Key words:** Cancer, Iranian family caregiver, need

## INTRODUCTION

Cancer is a bitter truth that affects the life of millions of people and has turned into one of the greatest tensions in their life.<sup>[1]</sup> One-fourth of mortalities in the USA is caused by cancer.<sup>[2]</sup> It is also one of the main causes of mortality in Iran.<sup>[3]</sup> Among all types of cancer, breast cancer is one of the main causes of death and disease

all over the world whose incidence is increasing day by day, especially in developing countries.<sup>[4]</sup> According to statistics, in the USA, the new cases of breast cancer number 235,030 among which 4430 cases end in patients' death.<sup>[2]</sup> Breast cancer is considered as the most common type of cancer and the fifth major reason for death among Iranians.<sup>[5]</sup> It is also worth noting that the mean age of contracting cancer by Iranian women is 47.1–48.8 years. Although Iranian women contract cancer 10 years earlier than women from developed countries, progress in treatment and care services has led to Iranian patients' improved survival and more successful outpatient treatments.<sup>[3,6-8]</sup> Thus, due to increased use of outpatient services for cancer patients and due to the decrease in referral to hospitals and patients' improved survival and caregivers' willingness for taking care of patients at home, the first step of care giving to cancer patients has moved from hospitals to houses. Family members and close friends have taken up the responsibility for taking care of these patients.<sup>[9,10]</sup> Informal caregivers are family members, spouses, or friends who provide support to the cancer patient.<sup>[11]</sup> According to statistics, two-thirds of cancer patients never use the facilities and services provided by the community for fulfilling their

<sup>1</sup>Student's Research Center, Faculty of Nursing and Midwifery, Isfahan University of Medical Sciences, Isfahan, Iran, and Department of Midwifery, Arak Medical Sciences Branch, Islamic Azad University, Arak, Iran, <sup>2</sup>Nursing and Midwifery Care Research Center, Faculty of Nursing and Midwifery, Isfahan University of Medical Sciences, Isfahan, Iran, <sup>3</sup>Nursing and Midwifery Care Research Center, School of Nursing and Midwifery, Isfahan University of Medical Sciences, Isfahan, Iran, <sup>4</sup>Department of Medical Education, Medical Education Research Center, Isfahan University of Medical Sciences, Isfahan, Iran

**Address for correspondence:** Dr. Fariba Taleghani, Nursing and Midwifery Care Research Center, Faculty of Nursing and Midwifery, Isfahan University of Medical Sciences, Isfahan, Iran. E-mail: Taleghani@nm.mui.ac.ir

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are, in fact, mediums for transferring information from the patients to the medical team and vice versa to make sure patients' treatment plans are performed perfectly. They are also considered as vital members of the support team for coordinating appointments with the specialists and labs.<sup>[12]</sup> As cancer is considered as a family issue and not only an individual and personal condition, it changes patients' family identity, as well as family members' roles and daily performance. Taking care of cancer patients is usually coupled with many challenges, a wide range of problems, and issues for the caregivers.<sup>[9,13]</sup> So, maintaining the relation with the medical team is necessary for providing care to patients. By providing training and knowledge on caregiving skills, and interacting with family members, the medical team plays a significant role in enabling the family members to maintain and improve the care provided to patients.<sup>[14]</sup> However, working with caregivers is a new and difficult role for the medical team as the physicians may know the significance of training the caregivers but they may overlook the significance of caregivers' need for the training.<sup>[15]</sup> Poor interaction of treatment personnel with patients' families and inadequate support to the patients lead to informational contrast in families and patients as well as incorrect application of resources that may ultimately increase the tension and pressure in these conditions.<sup>[8]</sup> Although caregivers are part of the patient support network, they are, as a frail population, deprived of the attention they need and are overlooked by the healthcare system. Thus, thorough identification and assessment of their needs and experiences is of great importance. Interventions made for helping caregivers are even considered as the standard component of patients' treatment.<sup>[16-20]</sup> Caregivers' problems have been studied in some researches, but inadequate attention has been given to caregivers of cancer patients.<sup>[20,21]</sup> On the other hand, most of the studies conducted on caregivers are related to western countries that are much different from eastern, especially Muslim, countries.<sup>[21-24]</sup> Thus, the findings of western countries would prove inapplicable and inefficient in eastern countries.<sup>[25]</sup> Caregiving is a multifaceted experience that is connected to race, nationality, cultural values, beliefs, and family systems.<sup>[11]</sup> Considering the cultural and religious values as well as the strong familial relations, Iranian families provide much care to the cancer patients and are considered as the strongest support system to patients; they actually are willing to take care of the patients.<sup>[26-29]</sup>

Considering the emphasis placed by international cancer organizations on the significance of the spouses' and family members' experiences and a necessity for studies on familial caregivers and the network of friends in different cultural groups,<sup>[30,31]</sup> the authors decided to study caregivers' understanding of their own needs with regard to the treatment team in a varied range of caregivers selected

from family members of breast cancer patients. The main focus of the study is on caregivers of breast cancer patients, as breast cancer is the most common type of cancer in Iran and patients have a greater chance of survival in the initial stages of diagnosis. On the other hand, Iranian women's contraction age of breast cancer is 10 years earlier than that of women in other countries. This implies that younger Iranian women are struggling with this condition. These two factors, i.e. higher survival rate and contraction by younger women, have made the caregivers and families to be more involved and make a greater and longer contribution. Despite the widespread incidence of this type of cancer and the important role of Iranian families as the best source of care for patients, insufficient information is available on this subject in Iran. This research has been motivated by researcher's experience with caregivers' issues, as well as the significance of the subject and was conducted due to the lack of domestic studies on the subject.

## MATERIALS AND METHODS

This study was a part of a PhD dissertation in reproductive health. A qualitative design, based on a conventional content analysis approach, was adopted to attain the objective of the study in 2013. The participants were selected through purposeful sampling from family members taking care of cancer patients who had referred to specialized cancer centers and support societies. The participants were over 18 and were able to read, write, and state their experiences. They were also willing to take part in the study. The researcher introduced herself and stated the main objectives of the study to gain participants' trust in the confidentiality of the interviews. The authors followed the ethical observations, and ensured the participants their freedom to discontinue their cooperation with the study at any moment they desired. Their oral and written informed consent for recording the interviews was then obtained. The interviews were then conducted in a calm environment. Interviews contained open-ended unstructured question and started with the general request, "please speak about your experiences about your interactions with the treatment team;" this was followed by semi-structured explorative questions. Each recorded interview was then listened to carefully and transcribed verbatim for analysis. Further interviews were conducted based on the analysis of previous interviews and the obtained data. The interviews took 30 to 60 minutes and were conducted with prior arrangement with participants and in their favourite venues. The criterion for stopping sampling was repetition of data and data saturation that yielded no new data. The conventional content analysis method with an inductive approach was employed for data analysis. To this end, after transcription of interviews and several iterations of review, meaning units were identified in

the form of sentences or paragraphs in transcribed dialogs, and primary codes or open codes were extracted. Each extracted code was linked to participants' statements. Then, based on centrality and conceptual similarity, the main categories and subcategories were extracted. Next, the first transcriptions as well as primary and final categories were reread several times. Changes in the number, content, and name of categories were made in each review iteration up to the point in which primary categories, main categories, and subcategories were finalized. Guba and Lincoln criteria including credibility, conformability, dependability, and transferability were used to ensure data accuracy.<sup>[32]</sup> Enough time was allocated to data gathering; in-depth interviews were conducted in multiple sessions and at different times and places; the findings were reviewed by participants and supervisors; the data were analyzed by colleagues; and a variety of participants with regard to their gender, age, marital status, degree of closeness to the patient, educational level, and socio-economic condition were selected.

## RESULTS

Twenty-three caregivers participated in the study. The age of participants ranged from 20 to 69 with a mean age of 37.5 years. Most of the participants were women (69.6%), married (65.2%), and patients' children (34.8%) with academic education (56.5%). Participants were from a wide range of occupations. Most of them were housewives (34.8%). Most of them (43.5%) earned between 5,000,000 and 7,000,000 Rials of Iran as their monthly salary. The mean of care time was 7.1 h/day (with a range of 1.5–12 h) [Table 1]. Caregivers were providing support to patients at different stages of the treatment. Four categories were extracted from the analysis results of data gathered from the participants: a) caregivers' contribution and acknowledging them in the treatment system, b) training in efficient caregiving, c) efficient interaction of the medical team with caregivers, and d) easy and dynamic access to the medical services [Table 2].

### Caregivers' contribution and acknowledging them in the treatment system

Most of the participants were willing to contribute to be considered and acknowledged in the treatment system. However, in most of the cases, the treatment team did not allow them to contribute and help, and thus, the participants were marginalized. Consultation with patient and caregiver and explaining to them about the treatment plan and the prescribed medicine were among the points the caregivers mentioned for several times as contributions they liked to have with regard to patients' issues. Nevertheless, they did not receive any information on these issues and were not consulted.

**Table 1: Characteristics of family caregivers of breast cancer patients**

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

Contd...

**Table 1: Contd...**

Characteristics	Number (%) of participants
5,000,000-6,999,000 Rials (≅US\$ 151-212)	10 (43.5)
7,000,000-8,999,000 Rials (≅US\$ 212-272)	3 (13)
>9,000,000 (≅US\$>272)	2 (8.7)

*“They did not provide any information to us either on the prescribed drugs or the things they were doing. They did not even ask for patient’s advice. They did what they liked as they wished. They never mention these to the patient and caregiver and never ask for their opinion. We only followed them.”* (A 24-year-old caregiver, a patient’s daughter)

The caregivers emphasized that they liked to feel they were valuable and wanted to be seen by the treatment team. Caregiving to cancer patients is with much stress and concern. The caregiver feels obligated to be with the patient during the treatment process to decrease his/her stress. The treatment team is expected to pay attention to the caregiver and recognize his/her role.

*“The fact we (the caregivers) are not seen at all is much annoying. The doctors pay attention only to the patient. But my questions and concerns are different. We are like invisible entities coming and going. They do not see this.”* (A 20-year-old caregiver, a patient’s daughter)

### Training in efficient caregiving

The findings of the study confirm that caregiving by family caregivers is on an uncertain and misty path. They felt like travelers who were not prepared and trained adequately, even though they were with the patient on this uncertain path.

*“In my opinion, it is very important that one is prepared and knows what to do and how to care. I think caring is a skill and one needs to be trained so one can support the patient and be of any benefit to the patient. That is why all caregivers should be trained.”* (A 38-year-old patient – a patient’s husband)

Unpreparedness and lack of training and information were mentioned as one of the stressors of caregiving.

*“It happens suddenly, like an uninvited guest. One is not prepared for that at all. Then one is stressed, as one knows nothing about it.”* (A 38-year-old caregiver, a patient’s husband)

Many of them were confused about their role and had to refer to external resources for information and guidance.

*“I didn’t know how to take care. I felt lost. Sometimes I read some articles or searched on the web.”* (A 32-year-old caregiver, a patient’s son)

Another concerning issue for caregivers is the patients’ spiritual and mental mood. A need for guidance and training on how to treat patients and support them mentally and spiritually was emphasized repeatedly by participants.

*“They don’t explain clearly how one should treat cancer patients. Even on their mental and spiritual mood. The patients have the same stress and fear of death and that is enough for them. One should know how to treat them.”* (A 24-year-old caregiver, a patient’s daughter)

### Efficient interaction of medical team with caregivers

Caregivers are mediums between the treatment team and the patient during the treatment process to make sure the treatment procedure is conducted fully and patients receive adequate and efficient support. For the realization of this, it is necessary for the treatment team and caregivers to have a mutual and efficient interaction and relationship with one another. It was mentioned by the participants that their role and status was not respected by the treatment team and they did not have a good inter-personal relationship with each other. They were sensitive about the inappropriate behavior of the treatment team toward the caregivers. A statement made by a participant in this regard is as follows:

*“When I talk to her doctor, the doctor does not answer my questions. When I talk to the ward personnel, they do not answer my questions. I feel like being rejected. I feel like being left alone with my problems.”* (A 38-year-old caregiver, a patient’s husband)

Some participants mentioned short visits made by the doctor and the presence of other people or patients at the doctor’s room during their visit.

*“I had made a list of questions to ask when we wanted to go to doctor’s office. But when we went in, there were other patients and their companions and I didn’t find the time to ask any questions at all.”* (A 38-year-old caregiver, a patient’s husband)

Receiving information in a simple and comprehensible language and without any medical jargons was important.

*“When they explain something to me, I like it to be comprehensible to me. I don’t like them talking to me with their technical jargons.”* (A 20-year-old caregiver, a patient’s daughter)



**Table 2: Results obtained from data analysis**

Theme shared between categories	Category	Subcategory
Need for caregiver-centered health system	Caregivers' contribution and acknowledging them in the treatment system	Explain about the treatment plan and the prescribed medicine
		Complete description of patient's condition
		A sense of being valued and seen by the treatment team
	Training in efficient caregiving	Training for psychological and spiritual support to the patient
		Training on development symptoms of the cancer
		Training for special care
		Respect the caregivers' role and their human dignity
	Efficient interaction of the medical team with caregivers	Allocating adequate time and a sense of responsibility toward caregivers' questions
		Presenting information in a simple and comprehensible language
	Easy and dynamic access to the medical services	Necessity of skill for disclosing the bad news and cancer in medical team
		Interaction with the treatment team at any time of the night or day
		To prioritize cancer patients in the treatment center
Introducing more advanced medical centers		

Perceiving cancer as an untreatable disease in many cultures and as a taboo in Iran causes much stress in patients and their families. Many caregivers considered the diagnosis and disclosure moment as a critical and extremely difficult moment.

*"The moment the doctor said it was cancer, I said, 'Oh, Cancer!' The name of cancer kills one. I was devastated by the news."* (A 38-year-old caregiver, a patient's husband)

Another significant and noticeable issue in the caregivers' experience was how the news of cancer diagnosis was disclosed by the treatment team. To understand the caregivers' condition and sympathize with them at the moment of diagnosis were emphasized in caregivers' statements.

*"The doctor told us quite frankly and without standing on any circumstances that the cancer had spread to her lungs and bones. I didn't expect the doctor to tell us this way, without any introduction and preparation. The doctor shattered us that way."* (A 28-year-old caregiver, a patient's sister)

### **Easy and dynamic access to the medical services**

Easy and dynamic interaction with the treatment team, and access to the team members even through phone and at any time of the night or day to obtain their advice on the correct and necessary measures at emergency conditions were participants' other concerns.

*"It would have been really great if they gave us a nurse's contact number so we could contact her in emergencies or to ask our questions. Exactly like that in other countries."* (A 24-year-old caregiver, a patient's daughter)

Some participants mentioned long waiting time for visits to doctors in government hospitals and access to other health services such as the appointments diagnostic, therapeutic and drug approval.

*"Our waiting time for MRI is 3 months. Our waiting times for tests are 4 weeks. Why? May be recurrence in these times."* (A 28-year-old caregiver, a patient's sister)

Others known cancer as a particular disease and they were willing to attention to these patients and putting them in priority to access services.

*"Cancer is as a particular disease and it is different from other diseases. So, patients should take priority for treatment, medication, tests and other things."* (A 54-year-old caregiver, a patient's mother)

Another issue of concern for the caregivers is the presence of equipped medical centers, with other services.

*"We went somewhere else previously that wasn't equipped. Here (Seyed-Al-Shohada Hospital) it is admirable. We were introduced to nutrition consultant."*

*We had classes. My mum had lymphedema. We were introduced to the physician.”* (A 20-year-old caregiver, a patient’s daughter)

## DISCUSSION

The results of the study showed that the most significant needs of caregivers are contribution, being acknowledged in the treatment system, training on efficient caregiving, medical teams’ interaction with them, and easy and dynamic access to the medical services. At the beginning of the treatment, decisions need to be made with regard to treatment options. Thus, providing information to and efficient contribution from the patients and caregivers are vital in making decisions.<sup>[28]</sup> Our results confirm the results of other Iranian studies indicating lack of awareness of the disease, diagnosis, treatment process, and plan of patients and their families.<sup>[33-35]</sup> Despite Iranian doctors’ belief that family members need to be aware of treatment decisions and contribute to the treatment from the initial stages of diagnosis, this has been overlooked in Iran’s treatment and healthcare system.<sup>[33]</sup> Other western studies also show that caregivers are marginalized in the decisions made by the treatment team and patients, and they are not informed on the nature of the disease, treatment program, and patient’s condition, while they need to contribute actively and the treatment team should view them as part of the caring team and share their knowledge and information with the caregivers.<sup>[36]</sup> Training for caregivers was their other need.<sup>[8,37]</sup> Despite the major role of caregivers in caring, this has not been addressed in Iran’s treatment and healthcare system adequately and there is no comprehensive treatment program in this regard.<sup>[38]</sup> Our results confirm the results of other studies indicating non-provision of training and information by oncologist personnel to caregivers with regard to caring for cancer patients, disease development symptoms, mental–spiritual support to patients, and interaction with them.<sup>[8,12,39,40]</sup> Access to services and interaction with healthcare professionals was also mentioned as another important issue.<sup>[41]</sup> Other studies also have emphasized caregivers’ familiarity with medical literature and having a honest, clear conversation with them.<sup>[12,18,27]</sup> Our results confirm the results of other studies indicating the importance of support to caregiver by treatment teams and access and relationship with the treatment personnel.<sup>[11,12,42-46]</sup> Another aspect deemed as important by the participants was treatment teams’ skill for disclosing the cancer diagnosis news. However, studies have emphasized caregivers’ emotional feedback to the diagnosis and prognosis of cancer and the necessity for providing emotional support to caregivers individually.<sup>[10]</sup> Unfortunately, Iran lacks supportive caring, such as consultation, even for patients themselves. Due to

specialists’ poor skills of disclosing bad news and their poor management of the emotions of patients who are aware of the diagnosis, the patients also suffer from mental distress which affects their life quality negatively.<sup>[47]</sup>

## CONCLUSION

As caregivers are valuable members of treatment team and assist the healthcare system to achieve its treatment goals for patients, they need to interact with the treatment team so that they receive necessary services, equipment, and information. On the other hand, it has been proved that recognizing caregivers as separate people with their own special needs will have beneficial effects on both the patients and caregivers. Thus, understanding their experiences, preferences, and needs in their interaction with the treatment team is of prime importance in the care system for cancer patients. This will help to make effective interventions to this end by correct use of limited resources.

The findings of this study, which were obtained from caregivers’ viewpoints, provide a better understanding of their needs in their interaction with the treatment team. These findings can also assist with providing a framework for effective, culture-sensitive, and appropriate medical interventions in cancer healthcare system planning. Thus, caregivers need to be viewed as a standard part of cancer care programs, and a comprehensive family-centered care program needs to be designed so that the needs of familial caregivers, as the first responders to cancer patients’ problems, are addressed in healthcare policies. These policies need to be designed based on the obtained results and evidences.

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