



Challenges of Help-Seeking in Iranian Family Caregivers of Patients with Cancer: A Qualitative Study

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Abstract

Background: The nature of cancer is such that it causes several problems for patients and caregivers. As a vital source of support for patients with cancer, family caregivers must seek assistance and make use of available resources to overcome these issues and offer better care for the patient.

Objectives: This study aimed at exploring the challenges of seeking help in Iranian family caregivers of patients with cancer from supportive sources.

Methods: This qualitative study was conducted from 2019 to 2021 on 15 family caregivers with a wide variety of caring experiences and 13 health professionals (i.e. nurse, physician, social worker, clergyman, and family counselor who were engaged with services for the patient and caregiver) via purposive sampling and semi-structured in-depth interviews in a central cancer care hospital in Isfahan. Graneheim and Lundman's conventional qualitative content analysis approach was used to analyze the data. To assess data trustworthiness, Lincoln and Guba's criteria were used. Data management was performed using MAXQDA (v. 10) software.

Results: Four main categories were identified consisted of (1) being strained by social desirability; (2) stigmatizing attitudes toward help-seeking; (3) reactive self-forgetfulness; and (4) resistance to change.

Conclusions: The need to develop and implement interventions geared to enhance family caregivers' preferred attitudes and personal skills in order to overcome socio-cultural obstacles to help-seeking behaviors was underlined in this research. Both health care professionals and the community should be prepared to make support services more accessible and usable for family caregivers.

Keywords: Challenges, Cancer, Help-Seeking, Family Caregivers

1. Background

Cancer is one of the four major non-communicable diseases and was the cause of nearly one in six death in 2020 (1). Today, cancer care has shifted more to outpatient and home care, and family caregivers (FCs) have become the leading provider of support for patients with cancer (2). Family caregivers often take various actions such as caring for the patient, managing symptoms, assisting with daily activities, and providing emotional support at home (3). They are often entrusted with the role of patient care without proper preparation and support, to the point where they do not even seek help for their own needs (4); leading them to undergo a significant burden of caring for the patient (5).

Care burden causes significant challenges in physical, emotional, and mental health for FCs (6). Some studies

have emphasized the importance of supporting FCs to reduce the burden of care and empower them to do better care for their patients (7, 8). Help-seeking skills have been identified as key factor that may enable obtaining support due to the restricted resources available (9, 10). Seeking help, according to Rickwood et al. (11) is a process of enlisting the assistance of others in the face of a difficult situation or event in order to get counseling, information, therapy, and public support.

Despite many challenges which caregivers face, some evidence showed that they, especially caregivers in Asian countries, are hesitant to seek and get help for their problems (12, 13) which some have attributed to Asian people's socio-cultural values such as their strong commitment to their own families that causes them to care for a sick person in the family without asking for help (14). Iran is an

Asian country where families give extraordinary care to patients with cancer due to their cultural and religious traditions. However, based on some evidence, individuals may prefer to perform this role without seeking assistance or support, which is why they experience a lot of burdens of care (15). According to Nemati et al. (9) the lack of awareness about support services is the cause for Iranian caregivers not seeking assistance. Moreover, Hashemi-Ghasemabadi et al. (13) highlighted that despite the major role of FCs in health care, little attention is paid to their education in the Iranian context leading them to receive limited support from the community. Other challenges to caregivers' access to support resources include the social stigma associated with asking for help (15, 16), societal negative attitudes and beliefs about cancer (17), the desirability of a commitment to care for the patient without the assistance of others (14, 15), and a sense of weakness associated with asking for help (7).

Pointed out that FCs should provide dynamic access to health and supportive services during their caring roles (15). Moreover, as the socio-cultural context uniquely affects the structure of services as well as people's health-related behaviors such as their willingness and attempt to seek help (18), it should be explored and considered to be able to design effective initiatives tailored to address the particular context-specific challenges. People from Asian and Asian-American cultures, for example, are less likely than those from European and European-American cultures to seek professional help (19). Asians' passive attitude toward asking for aid, according to Kim (20), is a product of their upbringing with cultural heritage values.

Shedding insight into the factors related to seeking help and support by FCs' and the challenges they face in the socio-cultural context of Iran may pave the way for effective interventions to promote health-related behaviors and caregivers' access to support resources.

2. Objectives

This study aimed at exploring the challenges of seeking help from supportive sources in Iranian family caregivers of patients with cancer.

3. Methods

3.1. Design and Setting

This qualitative study was conducted from 2019 to 2021. This method of study is appropriate for uncovering and exploring socio-cultural complex issues (7, 21) such as the challenges of seeking help in Iranian family caregivers of patients with cancer in the Iranian context.

3.2. Participants

Participants consisted of 15 family caregivers with a wide variety of caring experiences and 13 health professionals (i.e. nurse, physician, social worker, clergyman, and family counselor) who were engaged with services for the patient and caregiver. Purposeful sampling was used to provide the maximum variation. Inclusion criteria for the health care staff (HCS) were at least one year of service to caregivers and patients. Inclusion criteria for FCs were being involved for at least 3 months in patient care at the hospital and home, not having effective cognitive problems to participate in interviews. The exclusion criterion was an unwillingness to continue participating. The first author (B.H) conducted the interviews. He has participated in the workshop of qualitative studies and analysis on qualitative data and has been a clinical instructor at the cancer hospital for 5 years.

3.3. Data Collection

From October 2019 to January 2021, data was gathered via in-depth and semi-structured interviews at one of Isfahan's university hospitals. Field notes were also taken during the interviews. The leading question for FCs consisted of "would you please describe the day you sought help from outside resources and the challenges you faced during your caring role?"; and for the HCS it consisted of "would you please describe the challenges for family caregivers seeking help from support resources as you perceived?". These questions were adjusted as needed to further elicit participants' experiences and understandings, and interviews were followed by more questions. Interviews lasted between 30 to 90 minutes and were performed at times and locations that were convenient for participants. Data collection was continued until data saturation was achieved, until the content was duplicated and no new data were added to the previous information (22).

3.4. Data Analysis

Data were analyzed using Graneheim and Lundman's (23) approach in 5 steps consisting of (1) B.H transcribing the interviews verbatim then he read them several times for a general impression; (2) the text was divided into meaning units by B.H. (for example: my mother said do not ask anything from anyone, we will fix it ourselves, my mother sold her gold to pay for the hospital); (3) key sentences were selected by B.H and M.A as semantic units and coded with appropriate labels (for the above example: solving disease problems only by a family member); (4) separation of codes according to their similarities and differences into sub-categories with the cooperation of all

authors (“seeing illness as a family problem” in the mentioned example); (5) the subcategories with the same conceptual meaning were placed next to each other, and the main categories were extracted (i.e. “being strained by social desirability” in this sample). Data management was performed using MAXQDA (v. 10) software.

3.5. Rigor

Lincoln and Guba’s criteria were used to ensure rigor and trustworthiness of data and the inferences (24), which include credibility (i.e. a, long-term presence in the study setting; and b, using member check to ensure consistency of inferences), dependability (i.e. analysis of some interviews independently by research team members), confirmability (i.e. checking and approving the text of interviews, and respective emerged codes by three independent experts in qualitative studies), and transferability (i.e. selection participants with maximum variation in terms of demographics and contextual properties, and detailed description of participants’ characteristics).

3.6. Ethical Considerations

The present study is a part of the doctoral dissertation in nursing which has been approved by the Ethics Committee of Isfahan University of Medical Sciences with the code IR.MUI.RESEARCH.REC.1398.414. Before starting the research, the study objectives, voluntary participation in the study, and confidentiality of information were explained to the participants. Written informed consent was obtained from all participants.

4. Results

This study was conducted with 28 participants (Table 1). The mean age was 37.93 years for the FCs, and 41.53 years for the HCS. The HCS had a mean work experience of 13.53 years. The FCs had a mean caregiving role experience of 2.36 years. Four main categories emerged from the data analysis process: being strained by social desirability, stigmatizing attitudes toward help-seeking, reactive self-forgetfulness, and resistance to change. These four categories include 10 sub-categories, which are listed in Table 2 and addressed in sequence.

4.1. Being Strained by Social Desirability

This category points out that family caregivers are compelled to operate according to social standards and norms in order not to be judged by society and feel safe in their social life. This view leads to the isolation of family caregivers because they prefer to be self-reliant rather than asking others for help with problems. This category included: (1) “Seeing illness as a family problem”; (2) “pretending all is well”; and (3) “feeling self-made”.

4.1.1. Seeing Illness as a Family Problem

Caregiver participants believed that when they have a disease in the family, it should remain confidential and that problem should be solved by the family members rather than anyone else. Patient care was seen as a duty. Some caregivers perceived people around them as outsiders who could not understand or solve their problems. As a consequence, they assumed that asking them for help would be futile: “If anyone is going to solve my problem, it is me and my family. Others do not know many things about me” (HCS3-social worker).

4.1.2. Pretending All is Well

Caregivers thought that cancer diagnosis elicited sympathy in the form of compassion from everyone around them, which made the caregiver uncomfortable, so she pretended to be nice to avoid others’ pity and keep the patient’s spirits up. A participant stated: “We have many, many problems, but we never wanted to express it, we always wanted to keep our appearance so that no one would feel sorry for us” (FCs3-patient’s spouse).

4.1.3. Feeling Self-made

As a consequence of cultural taboos, individuals, especially men, avoid seeking assistance in resolving their difficulties in order to maintain their place within the family structure and to demonstrate that they could care for the patient entirely on their own. Health team members also view gender taboo as a barrier to seeking help. In this regard, men ignore help-seeking because of their support role in the family structure. A male participant stated: “I prefer to be independent. My father often helps me. I feel kind of ashamed” (FCs15-patient’s son).

4.2. Stigmatizing Attitudes Toward Help-Seeking

Caregivers see the perceived stigma towards seeking help in society as an obstacle to seeking help from supportive sources. Participants noted their fear of society’s negative view of seeking help. This category included: (1) “fear of being judged”; (2) “help-seeking as a symbol of disability”; and (3) “viewing help as a burden to others”.

4.2.1. Fear of Being Judged

Participants said that by asking for help from others, they felt that they are exposing themselves to negative feedback from others, and hence prefer not to ask others for help. Sometimes caregivers hesitated to ask others for help to preserve their reputation. One participant indicated that they either avoid seeking assistance or prefer to seek assistance covertly to avoid being criticized by others: “My family is sensitive and does not like to be helped in the

Table 1. Participants' Characteristics

Participant	Age	Gender	Education	Marital Status	Job Status/Specialty	Duration of Caregiving Role (y)	Status of the Support System
Family caregivers	20 - 30: 1; 30 - 40: 8; 40 - 50: 5; > 50: 1	Female: 6; Male: 9	Illiterate: 1; Primary school: 2; Diploma: 4; University: 8	Married: 13; Single: 2	Housewife: 5; Employed: 9; Unemployed: 1	< 1: 5; > 1: 10	Relatives: 1; non-governmental organization: 1; Institution: 3; None: 10
Health care staff	20 - 30: 2; 30 - 40: 4; 40 - 50: 5; > 50: 2	Female: 8; Male: 5	Specialist: 1; Bachelor: 7; Master: 4; PhD: 1		Oncologist: 1; Psychiatrist: 1; Nurse: 5; Socialworker: 1; Others: 5	1 - 9.9: 3; 10 - 19.9: 6; > 20: 4	

Table 2. Emerged Categories and Sub-categories

Categories	Sub-categories
Being strained by social desirability	Seeing illness as a family problem; Pretending all is well; Feeling self-made
Stigmatizing attitudes toward help-seeking	Fear of being judged; Help-seeking as a symbol of disability; Viewing help as a burden to others
Reactive self-forgetfulness	Overestimating caring responsibilities; Self-neglect as a sign of commitment
Resistance to change	Traditional communication patterns; Fear of self-disclosure

way of being questioned about their help-seeking status” (FCs6-patient’s daughter).

4.2.2. Help-Seeking as a Symbol of Disability

Caregivers’ experience showed that accepting help from others in caring for a patient is interpreted as weakness, so they try to deal with problems alone. It was difficult for them to ask for help because asking for help was seen by others as judging their abilities. Certain caregivers said that they were not yet incapable enough to need assistance and hence did not use available resources to serve more vulnerable caregivers: “I am not weak to seek help from anyone, after all, there is someone more incapable than me. They have a greater right to use the resources and services” (FCs8- patient’s son).

4.2.3. Viewing Help as a Burden to Others

The findings showed that caregivers spent all their time and energy caring for the patient and trying to cope with the problems. They believed that by asking for help, they would disturb the feelings, time, and plans of others, and cause them trouble: “We tried to do our job, no matter how difficult it is. We do not like to disturb anyone” (FCs9-patient’s relatives).

4.3. Reactive Self-forgetfulness

Participants indicated that, despite their urgent need for assistance to sustain themselves and the patient, they opted to offer care on their own to guarantee better patient care. In order to fulfill their feeling of responsibility

for the patient, family caregivers have typically prioritized patient care above their own and other family members’ health concerns. This relieved them of guilt about their patient later on. This category included: “overestimating caring responsibilities” and “self-neglect as a sign of commitment”.

4.3.1. Overestimating Caring Responsibilities

Excessive overestimation of care obligations has resulted in an overemphasis on care activities; by doing extreme caring activities, the patient has become too reliant on the caregiver, and caregivers have been unable to satisfy their requirements. One participant explained that she has become so immersed in the role of caregiver that her own life was forgotten so that she could not be separated from the patient: “When I am with my father, I do not go anywhere at all only staying in the room with my father I think that I do not want to have children at all” (FCs6- patient’s daughter).

4.3.2. Self-neglect as a Sign of Commitment

Participants believed that family members’ neglect of themselves was culturally acceptable when caring for a patient with cancer. This not only demonstrates the caregivers’ dedication to the patient and their willingness to make sacrifices, but it also demonstrates their devotion to the patient. One caregiver stated that he would not take care of himself as long as his family member was ill, and considered this to be his spiritual duty. “I have a lot of problems myself. I can’t do anything for myself right now; if I

have a chance later, I will take care of my problems” (FCs14-patient’s son).

4.4. Resistance to Change

Health professional participants believed that several families were not prepared to change their traditional beliefs about the role of the family as a caregiver. They are reluctant to disclose their problems, make new connections as well as express the need for help which are prerequisites for receiving help from others. This category included: (1) “traditional communication patterns”; and (2) “fear of self-disclosure”.

4.4.1. Traditional Communication Patterns

Participants pointed out that some families have a strong pattern of relationships that limits interaction, especially asking for help from people outside the family. A participant stated that because of the strong interpersonal relationships among family members, they do not like to use anyone other than the family members to solve problems and always they would prefer to rely on the family rather than strangers: “We want to be able to always stand on our own two feet and never depend on anyone. We do not want to ask for help from anyone other than our family” (FCs5- patient’s sister).

4.4.2. Fear of Self-disclosure

The findings indicated that the hesitation to disclose a need for assistance is motivated by both distrust and fear of the implications of sharing information that is sometimes considered a family secret. Family caregivers often suffer from a variety of psychological disorders associated with cancer, which hurts their function as a caregiver but do not disclose them due to lack of trust. A social worker said: “Although they need to seek professional help, because in Iranian culture having problems, especially psychological problems are perceived by the family as a weakness and even a stigma, they refuse to disclose the problems caused by cancer” (HCS3-social worker).

5. Discussion

The experiences of seeking help from support resources based on the perspectives of Iranian family caregivers of patients with cancer and health professionals were explored in this study.

The findings of the present study highlighted the role of social expectations for the family caregivers to accept the caregiving role and its related behaviors, such as deciding to ask for help. In the present study, we found that

some family caregivers tended to see the disease as a family problem that should only be managed by family members; which then may lead them to miss the potential support resources. Similarly, the findings of an Iranian study by Hashemi-Ghasemabadi et al. (13) showed that, due to the social desirability of caring for a sick person by family members, they feel an outstanding obligation to support the ill member which sometimes makes it difficult to get support from outside the family. Kusi et al. (25) pointed out that sociocultural structures often determine the state of acceptance of the caregiving role, and help-seeking behavior among family members.

The findings also showed that the family caregivers felt uncomfortable when they perceived peoples’ behaviors as signs of sympathy and compassion, leading them to be reluctant to seek help from others while pretending all is well. Similarly, Mohabbat-Bahar et al. (26) reported that patients and family caregivers withheld information about cancer due to their reluctance to the compassion and generosity of others. Some family caregivers perceived relying on their abilities to care of family member as being so valuable that caring for the patient without receiving support have made them feel more satisfied. This finding contradicts the results of some other studies which showed that receiving social support has led to greater caregivers’ satisfaction (7, 27).

Based on the findings of the present study, another potential barrier to seeking help was a stigma against cancer which was perceived as being associated with fear, judgment, disability, and coercion; which have forced them into social isolation and further missing the potential support. Occhipinti et al. (28) pointed out the role of stigma as a great problem that has often been experienced by the family caregivers of patients with cancer and patients’ other relatives. Some family caregiver participants in this study considered asking for help as a sign of their weakness, which might be caused them to feel stigmatized. However, it is recommended that future research investigate the mechanisms related to patients with cancer stigmatization. In addition, we discovered that this stigma was more prevalent among male caregivers. It may be because of cultural expectations of men to be strong and solve problems on their own without asking for help. This finding is consistent with Wendt and Shafer’s (29) study that concluded that men are less likely to display positive help-seeking attitudes. Our data revealed that some caregivers avoided requesting assistance because of a desire not to disrupt others’ everyday lives or to irritate them by exposing potentially distressing facts. Yamaguchi et al. (30) reported the same finding on Japanese family caregivers in their study. This may be due to the cultural framework of some Asian countries, in which caregivers refuse to

ask for help to avoid harassing others (14). Our data highlighted that caregivers had a strong commitment to care responsibilities that gave them the strength and motivation to continue caring, as a result, they devoted practically all of their time to the patient, neglecting their own needs and forgetting about themselves (13, 31). It is pointed out that this burden of care hurts the quality of life of caregivers and the quality of care provided by them (32, 33).

In our study, we found that some family caregivers refused to express the need for help because seeking help from external sources required them to change their communication patterns that it was not compatible with their cultural patterns. According to the research by van Rooij et al. (34), some patients with cancer and their caregivers avoided changes in their daily life and social contacts in an effort to conceal their status as cancer patients. The findings of this study, in addition to the need to develop help-seeking skills in family caregivers of patients with cancer, emphasized the need for the health system and society to be ready to accept and support the families of these patients.

5.1. Study Limitations

Despite the system's relative uniformity in delivering health care to patients with cancer, diverse socio-cultural circumstances exist in different areas of Iran that may be influential in forming and manifesting family caregivers' behaviors. Although attempts were made to include the maximum diversity of the participants to cover a wider range of experiences of caregivers and health professionals, it was not possible to cover all the diversity in the socio-cultural context of Iranian society. Besides, the COVID-19 pandemic and its impact on patients' access to health care services limited our access to patients' family caregivers.

5.2. Conclusions

This study highlighted the importance of developing and implementing interventions tailored to improve family caregivers' favorite attitudes and personal skills to overcome sociocultural barriers to help-seeking behaviors. Moreover, it is worthwhile to suggest that on the one hand, health care providers facilitate the family caregivers' access to supportive services and on the other hand, prepare the community to get acquainted with the needs of these people and offer their support to them.

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Footnotes

Authors' Contribution: BH and MA were involved in study design, data collection. BH, MA, FT MFM were involved in data analysis. BH writing of initial draft manuscript. BH, MA, MFM and FT reviewed and edited of draft and final manuscript. BH submitted the paper.

Conflict of Interests: Fariba Taleghani, as one of the authors of the article submitted to the journal, is also a member of the journal's editorial board. This author, as the editorial board, has no role in the review processes of this article. We also introduced this author with CoI during the submission as an opposed reviewer.

Ethical Approval: The study was approved by Vice-Chancellor in Research Affairs -Medical University of Isfahan (registry number: IR.MUI.RESEARCH.REC.1398.414) (link: ethics.research.ac.ir/ProposalCertificateEn.php?id=93691).

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Informed Consent: Written and oral consent for the interview and audio recording was obtained from all participants. They were assured that the information would be confidential and that they could withdraw from the investigation at any time. In order for the participants to remain anonymous, a code number was considered for each of them.

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