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Requirements for promoting help-seeking behaviors in family caregivers of cancer patients: A qualitative study

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Abstract:

BACKGROUND: Caring for a family member with cancer is a challenging issue for families. Family caregivers often need the help of supportive resources to solve problems in their care role. A deep understanding of the requirements of caregivers to seek help is an effective step toward their ability to use supportive resources. This study aimed to identify and describe the requirements for promoting help-seeking behaviors in Iranian family caregivers of cancer patients.

MATERIALS AND METHODS: This qualitative study was conducted through in-depth semi-structured interviews with 28 participants selected using purposeful sampling method from 2019 to 2021. An interview guide with general questions about seeking help was used to maintain coherence in data collection. The interviews continued until data saturation. All interviews were recorded, transcribed and analyzed through qualitative content analysis.

RESULTS: The requirements of promoting help-seeking behaviors in family caregivers were grouped into four main categories: (1) improving social paths toward seeking help, (2) spiritual-psychological-cognitive empowerment toward seeking help, (3) strengthening the motivations behind seeking help, and (4) modifying the perception of cultural barriers to seeking help.

CONCLUSION: According to the results of this study, it is expected that by identifying the requirements of caregivers for seeking help and by health stakeholders designing comprehensive programs to address these needs, caregivers will be empowered to use supportive resources and provide a better care role.

Keywords:

Family caregiver, help-seeking behavior, neoplasm, qualitative research

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Introduction

Cancer is one of the leading causes of death worldwide, with nearly 10 million deaths in 2020.^[1] In 2020, the global cancer observatory reported the number of cancer cases in Iran to be approximately 131,000.^[2] The diagnosis of cancer is often sudden, involves complex treatments^[3] and causes significant changes in the life of patients and family members.^[4] These changes have increased today by promoting outpatient care and patient care at home by family

members.^[5] The role of care is often imposed on family caregivers (FCs) without prior experience and preparation, making them a potentially vulnerable population.^[6,7] Imposing the role of the caregiver without preparation and asking for help by FCs interferes with their effective care of the patient and their needs,^[8,9] so, the support of caregivers should be considered by health professionals.^[10] The results of a study showed that only one-third of caregivers are assessed by a health team for readiness for a caring role,^[11] while FCs need support in terms of the type of care, when to seek

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professional help and how to provide care.^[3] Frambes *et al.*^[6] pointed out that FCs need psycho-educational interventions, coping skills, and communication techniques to support cancer patients.

Due to limited resources for support and the priority of providing services to patients and caregivers who seek help,^[12] help-seeking behaviors are an essential factor in achieving better support and quality of life for patients and their caregivers.^[13,14] Help-seeking behavior refers to planned behavior aimed at getting help from health care providers for health changes, the management of which goes beyond individual resources and is affected by various factors.^[15] Despite the serious challenges of caregivers in meeting the needs of cancer patients and the lack of available support, most of them are hesitant to seek and receive help even if it is available,^[16-18] and do not get much help for problems.^[3] Some of the barriers to seeking help mentioned in studies include social stigma,^[19,20] the value of caring for the patient without the help of others^[19] and feeling weak and inefficient if asking for help.^[21] The aim of this study was to provide a clear and accurate understanding of a caregiver's requirements for ability to seek help, as well as to help health care providers plan a way to improve these requirements.

Materials and Methods

This qualitative study was conducted from October 2019 to January 2021 in one of the university hospitals of Isfahan province, which is a major referral center for cancer patients in central and southern Iran. The qualitative method is appropriate for this study as it helped researchers collect rich, simple and first-hand descriptions^[22] of such a context-specific and complex topic as help-seeking and its respective challenges in informal caregivers of cancer patients.^[21,23]

Study participants and sampling

A purposive sample consisting of 15 FCs and 13 health care staff (HCS) with maximum variation in terms of demographic characteristics and experience of the caring role were included in the study. Inclusion criteria for the HCS were having at least one year of work experience and a willingness to share experiences. Inclusion criteria for FCs included involvement in patient care in the hospital and at home, and had no cognitive problems. The number of participants was determined using data saturation principles until any new concepts and data were obtained by data analysis.^[24] Initially, the research team identified health care staff and stakeholders who played a key role in providing services to patients, as well as caregivers who provided services directly to patients. Participants were then formally invited to voluntarily participate in the study.

Data collection

Data were collected using in-depth, semi-structured interviews at times and places comfortable for the participants (such as patient room, staff room, etc.). An interview guide with general query questions was used to maintain coherence in data collection. During the interview, probing questions were asked to gain a deeper understanding of the requirements of seeking help. Table 1 shows examples of the interview questions. The interviews lasted between 20 and 100 minutes. In the present study, data saturation was obtained after 28 interviews.

Data analysis

Data management was performed using MAXQDA (version 10) software. Graneheim and Lundman's^[25] qualitative content analysis methods were used to analyze the data. The researcher who conducted the interviews maintained a receptive attitude, asking participants to elaborate on their unique experiences and statements. In this method, data is labeled and classified. First, B.H transcribed each interview after it was done; then, by reviewing several times, key sentences were selected as semantic units and coded with appropriate labels. After that, in several sessions, codes with conceptual similarity were categorized by B.H and M.A into sub-categories. Then, sub-categories with conceptual similarity were categorized into main categories. In the research process, codes, sub-categories and main categories were examined and discussed several times by the research team and a consensus was reached.

Rigor

Lincoln and Guba's^[26] criteria were used to ensure the rigor of the study. To increase the credibility of the findings, transcripts of several interviews and codes were provided to participants and they were asked to confirm the consistency between the codes and their experiences. Increased data credibility was achieved with the presence and long-term involvement of B.H with the research environment. To determine confirmability, some interviews were independently analyzed by four study authors. To ensure dependability, the work

Table 1: Example of interview questions

Participant	Questions
FCs	What is one day in your life like when you take care of a patient?
	Describe changes in your family's lifestyle after being diagnosed with cancer?
	Describe a day when you sought help and the challenges you faced?
HCS	What are your experiences dealing with caregiver problems?
	What is your suggestion for promoting help-seeking behaviors by caregivers?

process and findings were presented to three external peers to check the accuracy of the data analysis. To facilitate transferability, interviews, observations, field notes and selecting participants with maximum variation of caring and help-seeking experience were used.

Ethical approval

Before starting the study, the objectives of the study, the voluntary participation in the study and the confidentiality of information were explained. Informed written consent was obtained from all participants. This study has been approved with ethical code IR.MUI.RESEARCH.REC.1398.414 by the Ethics Committee of Isfahan University of Medical Sciences.

Results

The profiles of the participants are shown in Tables 2 and 3. Requirements for FCs to seek help were categorized under four main categories and eleven sub-categories [Table 4], which are described below.

Improving social paths toward seeking help

Promoting inter-professional communication and strong communication between health care providers and family caregivers lead to caregivers' access to supportive resources.

Structure of the communication chain in the health team

Expanding communication between professional staff through communication skills training and teamwork leads to identifying and meeting the needs of caregivers. Participants mentioned that inter-professional cooperation leads to a holistic view of the problems and ensures that the necessary services are received by the caregiver, and encourages them to seek help from support sources. One participant stated: "When the decisions are not teamwork, and the doctor does not know the teamwork and decides for his patient alone, the problems will not be resolved entirely" (HCS5). The hospital cleric believed, "[W]e do not have a holistic view. We should not look at problems

Table 2: Profile of FCs

Identifier	Age (years)	Gender	Employment status	Educational level	Relationship to patient	Duration of caregiving role
FC1	56	Female	Housewife	Illiterate	Cousin	18 y
FC2	48	Male	Working	Diploma	Brother	1.5 y
FC3	32	Female	Housewife	Diploma	Spouse	1 y
FC4	37	Female	Employed	Master's	Daughter	5 m
FC5	45	Female	Housewife	Elementary	Sister	1 y
FC6	32	Female	Housewife	Diploma	Daughter	6 m
FC7	30	Female	Housewife	Master's	Daughter	5 y
FC8	30	Male	Self-employed	Elementary	Son	1.5 y
FC9	44	Male	Manager	PhD	Groom	1 y
FC10	23	Male	Unemployed	Bachelor's	Son	1.5 y
FC11	34	Male	Employed	Bachelor's	Son	4 m
FC12	43	Male	Self-employed	Elementary	Father	8 m
FC13	50	Male	Self-employed	Diploma	Spouse	4 m
FC14	30	Male	Military	Associate degree	Son	3 y
FC15	35	Male	Self-employed	Bachelor's	Son	5 y

Table 3: Profile of HCS

Identifier	Age (years)	Gender	Occupational status	Work experience with FCs
HCS1	30	Female	Psychiatric nurse	2 y
HCS2	28	Female	Family counselor	2 y
HCS3	38	Female	Social worker	15 y
HCS4	35	Female	Doctor	6 y
HCS5	45	Female	Educational supervisor	20 y
HCS6	61	Male	Manager	10 y
HCS7	43	Female	Head nurse	20 y
HCS8	55	Female	Head nurse	30 y
HCS9	35	Female	Head nurse	10 y
HCS10	45	Male	Oncologist	11 y
HCS11	42	Male	Nurse	18 y
HCS12	48	Male	Nurse	23 y
HCS13	35	Male	Religious consultant	10 y

Table 4: Emerged categories and sub-categories

Categories	Sub-categories
Improving social paths toward seeking help	Structure the communication chain in the health team Rebuild relationships and social skills of family caregivers Resolve ruptures in the follow-up and referral of caregivers
Spiritual-psychological -cognitive empowerment toward seeking help	Establish a correct understanding of the impact of beliefs on treatment processes Managing emotional-cognitive changes Information management in cancer
Strengthening the motivations behind seeking help	Resolve doubts about the treatment process Control the role of the patient as a barrier to seeking help
Modifying the perception of cultural barriers to seeking help	Excessive commitment in a caring role Correct the stigma around seeking help Cancer as a family problem

one-dimensionally so that the caregivers would follow us to ask for help” (HCS13).

Rebuilding the relationships and social skills of FCs

The findings showed that the wrong knowledge of FCs about the cause of cancer and attributing it to each other’s moral error disrupts relationships with each other. On the other hand, due to the lack of social skills in caregivers, their interaction and asking for help from others should be reduced. A family counselor stated: “I had a female client who had a sick daughter. This lady was rejected by her husband. I told her why you do not want help from your husband! She said that we do not have a good relationship because my husband blames me for my daughter’s illness” (HCS2).

Resolving ruptures in the follow-up and referral of caregivers

Participants stated that caregivers were confused by the lack of an integrated system for following up and referring to their needs at the time of admission and also the disconnection from the hospital after discharge: “When the patient left the hospital, we didn’t know what was going on with the patient and his family. We don’t have a follow-up” (HCS7).

Spiritual–psychological–cognitive empowerment toward seeking help

FCs will not benefit from supportive resources, especially information, if they experience various distress.

Establishing a correct understanding of beliefs impact

Another theme in the occurrence of help-seeking behaviors in caregivers were their beliefs. The findings showed that sometimes caregivers did not consider

medical treatment sufficient for cancer treatment and turned to spiritual resources such as gods: “Sometimes beliefs cause them to underestimate medical treatment and focus more on beliefs and not take the patient to the doctor” (HCS11).

Managing emotional–cognitive changes

The findings showed that at the time of cancer diagnosis, because caregivers considered it a life-threatening disease, they experienced aggression, frustration and stress, which prevented them from seeking help. One participant stated that in the beginning, because they thought it was a serious illness, they were always looking for information: “I feel obsessed. I think it would have been better if I hadn’t researched my father’s illness anymore and just talked to the doctor” (FC4). The head nurse stated: “[C] aregivers, especially if it is their first time entering the hospital, find cancer frightening and aggressive” (HCS9).

Information management in cancer

According to the participants, obtaining correct and sufficient knowledge from a reputable source by the caregiver prevents them from being confused. A caregiver said the following about educating caregivers: “Tell us that your patient is a cancer patient who may not be able to get oxygen to his brain at any moment and die; it makes you feel relaxed so not that you do not know where the treatment is going” (FC11). Another participant stated that, “Caregivers search the Internet for the disease and its prognosis, when it realizes all that it does not need to know, they are completely confused” (HCS9).

Strengthening the motivations behind seeking help

Sometimes caregivers are hesitant about treatment and seeking help because of the length of treatment and the patient’s over-dependence on them.

Resolving doubts about the treatment process

Participants believe that the formation of a relationship based on trust and support for caregivers by the health team in decision-making reduces their doubts about the impact of treatment and increases their motivation to pursue treatment: “If a relationship is established based on trust with the caregiver and you can help, they will raise their problems” (HCS9). A hospital social worker said, “The caregivers see that the patient in the bed next to them died, even though the caregivers took care of so much, and they have the mentality that whatever they do is useless” (HCS3).

Controlling the role of the patient as a barrier to seeking help

Sometimes, because of the difficulty of treatment and the feeling of death, the patient becomes too dependent

on the caregiver and takes the opportunity to seek help from the caregiver: “I don’t go anywhere and leave him alone when I’m with my father. I’m not going into the hallway, just in the room with my father” (FC6).

Modifying the perception of cultural barriers to seeking help

The experiences of caregivers have shown that caring for a cancer patient is a family responsibility and getting help from others indicates that they are weak.

Excessive commitment in a caring role

According to the participants, excessive commitment to patient care is a socially desirable behavior, and asking for help from others is as weak as they are. A nurse stated: “Most caregivers, especially in caring for a patient’s spouse, do everything on their own so that no one can say they are weak or incapable in caring for the patient” (HCS12). Excessive commitment to the role of caregiver forced them to sacrifice their personal lives: “I am so involved in caring for my father that my own life is forgotten, and I even think that I do not want to have children at all” (FC6).

Correcting the stigma of seeking help

Most participants pointed out that they don’t ask for help because of negative judgments about seeking help and maintaining self-esteem. A nurse stated: Caregivers usually don’t ask for help because they feel they are questioning their dignity and self-esteem in front of others by asking for help. “[T]heir self-esteem doesn’t others to speak behind their backs; they say that we somehow get over this disease and they do not get help for fear of losing their reputation” (HCS11).

On the other hand, excessive caring responsibilities caused many psychological problems in caregivers, and since the views on referring to a psychologist in the community were negative, caregivers did not ask for any kind of help for these problems: “[P]eople’s vision of the psychologist is bad; they say I go to the psychologist people think I’m mental.” (HCS3).

Cancer as a family problem

From the perspective of caregivers, cancer is an issue within the family. Because those around them did not have the ability to understand their problems, they couldn’t help solve their problems, and this thinking was a barrier to caregivers asking for help: “[W]e try to solve problems at home. We don’t tell anyone we’re trying not to move it out” (FC10). The hospital worker said, “Caregivers see others as strangers who just interfere with their work and don’t help much, caregivers say if someone is going to solve my problem, I’m myself, the stranger may not be able to help, because it’s a problem only my family and I can understand.” (HCS3).

Discussion

This study explores the caregivers’ requirements for seeking help from supportive resources. The findings of this study highlighted the importance of caregivers’ communication skills in their help-seeking behaviors. Participants noted that due to inter-professional ruptures and a lack of strong communication between health care workers and FCs, the needs of caregivers were not being identified and followed up. We found that following the diagnose of cancer, the roles and communication patterns of family members changed, including reduced interactions and excessive involvement in caring for the patient, so they had little time left to take care of themselves and even seek help to address their own needs. Similarly, Hashemi-Ghasemabadi *et al.*^[18] pointed out that FCs do not have the necessary competence to meet the challenges of caring, leading them to receive inadequate support from relatives, health care providers and the community. Results of Moghaddasi *et al.*^[27] have highlighted the communication problems of FCs of cancer patients and they have emphasized on preparing these people, which may help them improve patient care through improving their social interactions and having better access to potential support.^[28,29] The study also highlighted that establishing a correct and trusting relationship between caregivers and the health team is essential to reducing the caregivers’ skepticism about treatment and persuasion to seek help. Studies have also emphasized the importance of effective communication between the health team and caregivers to increase their ability in the caring role.^[30,31]

Based on the findings of the present study, at the time of diagnosis of the disease, FCs need to be empowered in the spiritual–psychological–cognitive dimensions to benefit from all of the potential and opportunities in the community for patient care. Spiritual knowledge and beliefs have been perceived as being influential in the caregivers’ hopefulness and motivation to carrying out self-care activities.^[32] Believing and trusting in god has been identified as a reliable power that can cure even incurable diseases.^[27] Participants’ experiences showed that sudden diagnosis of cancer, incomplete preparation for the role of care and uncertainty about the future cause cognitive and emotional problems in caregivers. Hashemi-Ghasemabadi *et al.*^[18] stated that due to insufficient readiness, caregivers are not always able to control the situation, which may lead to their cognitive and emotional imbalance. Other studies have found that caregivers’ confusion and stress are due to their unpreparedness and unwillingness to seek help from supportive sources.^[33,34] This kind of findings emphasized on the value of providing knowledge and necessary skills to caregivers which may be helpful in changing

the patients' and families' perceptions of illness,^[35] and receive more support from the respective patients.^[36]

The value of ties between family members in Asian countries has made it the duty of family members to take care of the sick person in the family.^[37,38] In line with the findings of our study, previous research has highlighted that FCs, due to their social values, consider accepting help from others in patient care as a sign of their inefficiency, which is why they perform the role of care alone and without seeking help from others;^[22] they even make important treatment decisions themselves to prevent patient harm.^[39] On the other hand, due to the value of excessive patient care without seeking help, caregivers have had to sacrifice their personal lives to perform a caring role.^[18,21] The findings suggest that a family's adaptation to a chronic illness is a difficult process that requires comprehensive support and training programs to empower family caregivers to do their caring role.^[40]

This study shed more insight into requirements for promoting help-seeking behaviors of Iranian family caregivers of cancer patients. However, some limitations to the study should be considered. The findings of this study only include data from FCs who have referred to the central hospital for cancer patients. Thus, caution should be exercised in the transferability of results. This is the first study on the requirements of seeking help for FCs with cancer patients. With the recognition and fulfillment of these requirements, FCs will be empowered to receive social support and improve on their role as a caregiver.

Conclusion

This study provides a comprehensive understanding of the requirements for seeking help for family caregivers of cancer patients. Based on the study's findings, caregivers do not have a tendency and readiness to seek supportive resources due to cultural challenges, poor communication structures, and limited resources, and therefore, they face many problems in their caregiving roles. By identifying and meeting the requirements for seeking help, the opportunity of caregivers to benefit from the available supportive resources in the community can be increased and the negative consequences of the role of caregiver can be reduced. These findings can also be considered as a framework for stakeholders to plan effective and culturally sensitive interventions in areas such as modifying attitudes toward and the stigma around seeking help and improving communication structures in cancer health care systems.

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