

Caregivers needing care: the unmet needs of the family caregivers of end-of-life cancer patients

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Abstract

Purpose Family caregivers play a significant role in the care of cancer patients, especially in their end of life. Identifying and meeting the needs of these caregivers is essential to improving their quality of patient care. This study was conducted to identify the unmet needs of the caregivers of end-of-life cancer patients. **Methods** A total of 18 semi-structured interviews were held with the family caregivers of end-of-life cancer patients using purposive sampling. The interviews were recorded, transcribed, and analyzed using qualitative content analysis. **Results** The analysis of the data led to the formation of three main categories, including social needs, cognitive needs, and psychological needs. The social needs category comprised of the subcategories of support for care, effective communication and financial support. The cognitive needs category comprised of educational support and support in decision-making. The psychological needs category comprised of support for psychological trauma, preparation to confront the reality of the death of a loved one, and support for mourning.

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Conclusions The family caregivers of end-of-life cancer patients take on the responsibility of many aspects of care for their patient, but many of their own needs remain unmet. The findings of this study can be used for healthcare policy planning and the development of palliative interventions, particularly for the family caregivers of end-of-life cancer patients.

Keywords End of life · Cancer · Needs · Family caregivers · Descriptive qualitative method

Introduction

Families are the first to provide support for a cancer patient [1, 2]. They are the backbone of healthcare and social services [2, 3] and are permanent informal caregivers [4, 5] and an important part of the unit offering palliative care to patients with cancer [6, 7]. Families experience severe distress when confronted with the inevitable cancer diagnosis of a loved one and the pressures of examinations and treatment [8, 9]. The most difficult family experience with regard to cancer is to have to provide care to a patient at the end of their life [10–13].

The end-of-life cancer patient has problems and needs that require specialized care and family caregivers assume the responsibility to attend to these needs without any formal training or adequate resources [2, 13, 14]. This responsibility involves helping with the patient's daily activities, symptom management, therapeutic drug monitoring, coordination for examinations and treatment and providing emotional support [9, 15]. They assume this responsibility in addition to their other duties such as cooking and housekeeping, caring for other family members, and other social responsibilities [15]. The difficult and challenging experience of caregiving is associated with a reduced quality of life [8, 13], impaired daily

activities and physical, emotional, financial and job pressure [3, 4, 7, 16, 17], fatigue [8, 18], insomnia and sleep problems [15, 19, 20], anxiety and depression [14, 15, 21–23], moderate to severe stress [5, 22], fear [21, 24, 25] guilt and regret [24], changes in family roles [17, 26], and a general lack of time for family and friends [15].

Despite their own multiple needs, family caregivers often give priority to their patient's needs and deny or ignore their own [8, 16, 27, 28]. These unmet needs have a negative impact on their quality of life and also on the care they provide to the patient [16, 29]. The needs of caregivers are influenced by cultural values, beliefs, family systems, policies, available resources, and the public economy [24, 26, 30–32]. In Iran, cultural and religious norms create strong family bonds and support systems among families [33]; as the most important source of support for patient care [34], families willingly accept the patient [33, 35], and assume the responsibility of providing the highest quality of care to them [21, 30]. The problem is that these strong emotions and bonds in Iranian families tend to prevent them from expressing their problems and needs [35]. Moreover, the lack of palliative care centers and social organizations to support cancer patients and their families makes the families' care responsibilities even more difficult [30]. Studies on the problems and needs of the family caregivers of cancer patients in Iran reveal a significant level of anxiety and depression, considerable financial pressure and a moderate quality of life in this group [21, 26, 35].

The assessment of the needs of family caregivers is a prerequisite for developing care programs for cancer patients [36]. This qualitative study, which is part of a larger study, was conducted to identify the unmet needs of family caregivers of end-of-life cancer patients. The results can be viewed as a guidance for the development of strategies for meeting family caregivers' needs and the design of interventions for improving quality of life and health in family caregivers.

Materials and methods

This study was conducted using the descriptive qualitative method. Qualitative research can make important contributions to understanding this subject and help explain the complexity and the context-dependent nature of the experience of family caregiving and also assist in the development of empirical, conceptual, and theoretical frameworks for research and practice [6].

Participants

The study participants were selected through the purposive sampling of the caregivers of end-of-life cancer patients presenting to two teaching hospitals in Isfahan and Fars provinces

of Iran that are considered referral centers for cancer treatment in central and southern Iran. The study inclusion criteria were (1) currently or having cared for an adult, (2) being aware that the patient has advanced-stage cancer, (3) non-formal and active involvement in patient care without monetary compensation, and (4) submitting an informed consent to participate in the study. MH (the researcher) studied the participants. The first inclusion criterion was established through consultation with an oncologist or reviewing the care recipient's medical records. The other three criteria were established by consulting the care recipient's family members. A total of 18 participants were selected for the study from a list of current and bereaved family caregivers.

Data collection

Data were collected using semi-structured interviews held from November 2015 to August 2016. All the interviews were held in a private room by MH at the time and place chosen by the participants. The interviews lasted 20 to 60 min and were recorded with the consent of the participants. Sampling continued until data saturation occurred. Data saturation refers to the repetition of already-gathered information and the mere confirmation of previously collected data [36].

Before starting the interviews, the participants were briefed on the study objectives, were ensured of their right to withdraw from the study at any stage, and gave their oral and written informed consents. The interviews began with general questions aiming to create an atmosphere of comfort and closeness between the participant and the researcher, including "Please describe the onset of your patient's disease" and "What is your role in caring for the patient?" The interviews continued with more specific questions based on the participant's unique answers and the study objectives, such as "What problems and needs do you have with regard to patient care?" and "Which of your problems and needs go unnoticed and unfulfilled?"

Qualitative data analysis

Qualitative content analysis was used to analyze the interviews and preset categories were entirely avoided [37, 38]. The encoding and the initial development of the categories were mainly performed by the first and second researchers (AI and MH). All the interviews were transcribed verbatim. The transcribed interviews were first separately reviewed by both MH and AI to gain an understanding of their content, and MH offered AI explanations on them if necessary (since MH had held all the interviews). MH and AI then separately determined the meaning units and condensed meaning units of three select interviews. In the next step, the researchers

discussed the agreed-upon meaning units and the condensed meaning units. The condensation of the meaning units of the remaining transcribed interviews was performed by MH and discussed with AI. Codes were assigned to the condensed meaning units by AI and MH. Finally, eight subcategories and three categories emerged after MH compared the codes in terms of their similarities and differences. The categories and subcategories were discussed again with AI. In the case of disagreement, FT's opinion was sought as the third researcher. It is worth noting that the codes determined by AI and MH did not differ significantly from each other.

Data rigor

The four criteria of credibility, confirmability, dependability, and transferability proposed by Guba and Lincoln were used to ensure the accuracy and reliability of the data [36].

The researchers attempted to increase the credibility of the study through different steps, including a nine-month-long engagement in the study, spending sufficient time for collecting the data, effective interaction with the participants, conducting in-depth, semi-structured interviews to obtain rich data and presenting a summary of the obtained codes and results to the participants for verification.

In order to achieve dependability, the researchers documented and recorded a full description of all the research stages, including data collection and analysis, and also gave a clear and accurate description of the characteristics of the study population for other researchers to be able to audit the study.

To attain confirmability, the researchers avoided research bias by fully clarifying their perspectives on the study subject. Also, some of their colleagues and other faculty members who were experts in qualitative research examined the transcribed text and the codes of some of the interviews and confirmed the accuracy of the data analysis.

To enhance transferability, the participants were selected through purposive sampling with maximum variation in terms of gender, age, marital status, relation to the patient and education. In addition, the stages of the research were described in a precise and clear manner with direct quotes from the participants so as to allow others to judge the transferability of the results.

Results

A total of 18 participants, including 12 current family caregivers, and 6 bereaved family caregivers, were invited to participate in the study. Table 1 presents participants' characteristics. Qualitative and constant comparative analyses were used to analyze the data. After data reduction, three categories

of unmet needs emerged, including social, cognitive, and psychological needs. The categories, subcategories, and some sample participant quotations appear in Table 2.

Social needs

Support for care, effective communication, and financial support were the subcategories that shaped the social needs category.

Support for care

The participants stated that the care of loved ones at the end of their life is a difficult experience that is further complicated by families' inability to provide certain types of care, fatigue from continuous long-term care and impaired quality of family life.

The palliative care system in Iran is an underdeveloped system that, despite the recent efforts made by some charity organizations and NGOs to offer limited care services to patients at their own home, restricts most families to managing their patients non-professionally. Access to social support systems such as palliative care and home care and access to adequate care equipment were some of the unmet needs of the participants in this study.

Effective communication

The participants said that one of their greatest needs was effective, adequate, and comforting communication with friends and acquaintances as well as with the healthcare personnel, which was mostly denied of them. According to them, the elements of such communication with friends included a good understanding of the conditions of patients and their caregivers, avoiding too many questions about the patient's condition, refraining from discussions of the future and the outcome of the disease, avoiding blame, and not having irrational expectations or those contrary to the caregivers' wishes.

From the perspective of the participants, communication needs unmet by healthcare personnel included understanding and empathy, attention to the needs of the patient's family and companions, and the devotion of sufficient time to responding to their questions, clarifying their uncertainties, and assuring them of the continuity of care and comforting their patients even at the very end of their life. When a patient is at the end of his/her life, the family's desire to take advantage of every remaining minute and spend more time with him/her increases. The participants argued that issues such as strict visiting hours, limiting the number of companions allowed in the room or isolating the patient and banning visits are caused by

Table 1 Sociodemographic characteristics of family caregivers

Gender	Male	5 (27.7%)
	Female	13 (72.2%)
Relationship with patient	Spouse	4 (22.2%)
	Son or daughter	3 (16.6%)
	Parent	8 (44.4%)
	Brother or sister	3 (16.6%)
Age	18–28	3 (16.6%)
	29–38	4 (22.2%)
	48–39	3 (16.6%)
	49–58	4 (22.2%)
	> 58	4 (22.2%)
	Work status	Part-time
Full-time		8 (44.4%)
Retired		2 (11.1%)
Housewife		4 (22.2%)
Educational background	Primary school	3 (16.6%)
	Secondary school and high school	6 (33.3%)
	College	9 (50%)
Location of residency	City/town	15 (83.3%)
	village	3 (16.6%)

the healthcare personnel's lack of understanding and empathy toward patients' families.

Financial support

The participants stated that the heavy costs of treatment, the lack of insurance coverage for services such as home care, the caregivers' reduced income because of their ongoing involvement in patient care and the patients' lack of financial independence and income impose severe financial stress on families. Financial support by the government and the healthcare system was one of their unmet needs.

Cognitive needs

The category of cognitive needs consisted of educational support and support indecision-making.

Educational support

The majority of the participants stated that educational support is an unmet need for them in the context of end-of-life care. They discussed end-of-life cancer patients' wide range of needs and problems and the multiple tasks demanded of their caregivers. They found the training received in this area inadequate and merely general without taking into account the unique conditions of each patient and family. The most important areas in

which they required training included symptom management, especially for pain relief, feeding, and bathing in the final days of life due to increased disability and the patient's reduced level of consciousness. They also required adequate information about palliative care centers and the services they offered and the course of death and its signs in their patients. Some of the participants believed that it is a duty of healthcare personnel to provide a clear explanation of the course of death to the patients' family so that they can prepare for it realistically.

Support in decision-making

Decision-making was one of the most difficult caregiving experiences discussed by the participants. In the context of end of life, especially when the patient is himself/herself incapable of making decisions, the family has to make the decisions for him/her. Fear of making decisions due to the lack of adequate information about the course of the disease and the care options available, the family's disagreement over the available care options, doubts about the decisions being right, and regret about the decisions after the patient's death are some of the issues for which the participants required support.

Psychological needs

Support for psychological trauma, preparation to confront the reality of the death of a loved one, and support for mourning were the subcategories of the psychological needs category.

Support for psychological trauma

The participants stated that confronting the reality of the incurable nature of the patient's disease, witnessing the patient's pain and suffering, and long-term involvement in caregiving and its consequences, such as fatigue and sleep deprivation, unwanted changes in everyday life, and the inability to manage the present condition imposed severe psychological and emotional pressure on them and caused anxiety, depression, guilt, anger, hopelessness, and a feeling of inefficiency. According to participants' views, in addition to friends, the presence of a psychologist or spiritual caregiver can also help deal with the psychological pressure of having an end-of-life patient.

Preparation to confront the reality of the death of a loved one

The participants confessed although death is an inevitable reality; just thinking about the death of a loved one is painful and unbearable. Given their religious beliefs, Iranians believe

Table 2 Categories, subcategories, and sample quotations from the participants

Category	Subcategory	Sample quotation from the participants
Social needs	Support for care	A current (wife) family caregiver described the fatigue caused by her caregiving role: "I get backaches because I have to constantly move him around the house by myself and care for him. Someone must help us with the care. It is impossible to complete the tasks alone."
	Effective communication	A current (daughter) family caregiver described the inconvenience of ineffective communication with relatives: "They seem to come to express their empathy, but only ask questions. They see the patient's condition and know that she is at the end of her life, but always ask the same questions, 'Now what?' 'What did the doctors say?' 'Did the doctors give up on her?' They see that their questions hurt you, but keep asking them." A current (mother) family caregiver said: "If you say hello to them, they don't respond, let alone answer your questions. They have no sympathy with the patient's companion, let alone taking them into account. The doctors who come here with their nursing team hate that I ask questions; they don't answer you. The doctors really devote no time to us."
	Financial support	A current (father) family caregiver stated: "My son is only 21 years old. He was a student. It takes us six hours of driving to get here. We sold everything we had for his treatment. I had to sell the car within several months of the diagnosis. It's very difficult to bring him here without a car over such a long distance. And in the meantime, no one supports us, not even a penny."
Cognitive needs	Educational support	A bereaved (sister) family caregiver said: "We didn't know what to do in that last week. Nor did we know how much pain she was under, or what to do for feeding her. She hadn't eaten for a week; she couldn't even drink water. I didn't know what she needed or how to meet her needs." A bereaved (mother) family caregiver said: "They never told us what would become of my daughter, what she would look like in the last month and last week or what she would lack. They should've told us about these symptoms so I could've made the right decisions."
	Support in decision-making	A bereaved (daughter) family caregiver spoke of her regret regarding not giving her father chemotherapy: "We decided not to give him chemotherapy because he hated hospitals and needles so much. We wanted for him to have lived a good life as long as he was alive. After his death, I wished that we had done the chemotherapy; perhaps he would have lived longer. I will always believe I was wrong."
Psychological needs	Support for psychological trauma	A current (son) family caregiver said: "When I see how much pain he is going through and I can't do anything but look on as he withers away, believe me, we all become depressed at home. I don't really feel like doing anything." A current family caregiver (daughter) said: "I feel guilty for saying this, but I wish this would end soon. Our life is a mess. My mother looks 100 years older. She is depressed and cries all the time. She doesn't sleep at all. Her blood pressure has gone up. She doesn't even eat. She says, 'When my loved one can't eat, I can't either.' We don't laugh at all in this house anymore."
	Preparation to confront the reality of the death of a loved one	A bereaved (mother) family caregiver said: "We were not at all prepared psychologically to face his death. They just told us this is the last stage and we didn't know what that meant. We didn't think about death at all. It's so hard when you suddenly face the death of your loved one. If I'd known from the very beginning, I could've at least prepared my family and made them a little more aware so that they could have coped with the issue better."
	Support for mourning	A bereaved (sister) family caregiver said: "My niece is only ten years old. She retired into her shell after her mother died. She never utters her mother's name. For example, if there is a program about cancer on TV, she will turn it off. She's become a very aggressive, opinionated and stubborn child. And her grades have fallen sharply since her mother died."

in an afterlife and thus, perceive the presence of a spiritual or religious caregiver for helping them prepare for loss and mourning very helpful.

Support for mourning

Psychological support for mourning was another need discussed by the participants in this study. The bereaved

participants discussed a wide range of problems and experiences they were faced with during their mourning. Feeling lonely, sad, depressed and angry, denying the death of their loved one, and ultimately accepting their death were among the experiences discussed by these participants. Although the presence of friends gave them relative comfort, they said that some of their family members needed more specialized support services from healthcare personnel.

Discussion

This study was conducted to provide information about the unmet needs of the family caregivers of end-of-life cancer patients. An extensive review of literature revealed this study to be one of the first to address this subject among the family caregivers of end-of-life cancer patients in Iran.

The problems and unmet needs of family caregivers affect their health and well-being as well as the quality of care they provide to their patients [40]. An accurate identification of these needs and planning to meet them are therefore the main responsibilities of healthcare systems.

Contextual factors and supporting systems have always been conceptualized as an important element in comprehensive models of cancer family caregiving. In fact, caregivers' needs are multidimensional and are affected by their access to supporting systems and the health care system such as levels of financial, psychological and practical support, and access to information, relationship with medical team members, and adaptation to their caregiving role [39, 40]. Thus, affected by the level of access to these factors, caregivers in developed and developing countries can have different needs from each other. Understanding the needs of caregivers in different contexts by listening to their experiences can thus give valuable insight into their demands that can help inform the planning of cancer care services in different contexts [32].

In this study, participants' unmet needs were divided into three main categories, including social needs, cognitive needs, and psychological needs. In our interviews, social needs were found to be a consistent theme across all of the participants. The reason for this is probably the faint role of social support systems in Iran.

Despite a six-decade history of hospice and palliative medicine [41] and the obligation imposed on all countries by the World Health Organization to prioritize relief programs [42], palliative care is a missing link in the Iranian healthcare system. In Iran, limited palliative care services are provided in a few select hospitals and treatment centers, and there are no programs for providing support to the family caregivers of patients with advanced diseases. Nevertheless, motivated by religious teachings and the Iranian culture, family caregivers value caregiving and provide it under even the harshest conditions and refuse to express the problems they are faced with in this role [43]. In the absence of social organizations and services in Iran, kinship relation and family functioning as important contextual factors have become stronger and more developed. Families seek the help of friends and acquaintances who often cooperate in caregiving and supporting the families of those with diseases. It is worth noting that in Iran, visiting and offering a helping hand to those with diseases is considered a religious duty.

The need for psychological support for family caregivers during their patient's treatment and after his/her death is an

important dimension of palliative care [15, 29]. The psychological distress resulting from the caregiving role causes health problems such as anxiety, depression [4, 9], fear [9], and stress [15]. Anxiety, depression, and worries about death and reduced quality of life have been reported by more than half of the family caregivers of cancer patients in Iran. While psychological support or bereavement services are not provided for family caregivers in this country [44], the psychological and spiritual support provided by friends and family is an important factor helping to cope with difficult situations. Nonetheless, the friends and family of patients/caregivers should seek to respect a few behavioral guidelines in showing their support; for example, respecting the patient's/caregiver's privacy, understanding the patient's condition, choosing an appropriate time to visit, and being sensitive about asking questions about the severity of the patient's pain and their treatment costs and symptoms, expressing doubt about the patient's physician or prescribed medications, and blaming the patient or their family for the disease.

Although financial needs are a common problem faced by families and family caregivers of cancer patients [4, 15, 21, 29, 43], patients have fewer financial concerns in developed countries compared to in developing countries. In most developed countries, palliative care is available and financed by the government and charity organizations [32]. In Iran, organizations such as the State Welfare Organization and Imam Khomeini Relief Foundation provide financial support to these families. Yet, this level of support cannot meet the families' needs, and the inadequacy of insurance coverage for many healthcare-related services and medications [30] imposes a heavy financial burden on families. Moreover, treatment centers for cancer patients are usually located in large cities, and patients incur the heavy costs of transportation to these centers as well. A proper social support system, health insurance, and healthcare system should also provide financial assistance to cancer patients and their families.

In light of this information, the healthcare system in place in Iran should plan for providing support services to families and family caregivers during their patient's treatment and also after the patient's death and for mourning.

Areas for further research

Overall, this research study encourages the finding that support is an important element of the cancer care, and suggests that social, cognitive, and psychological unmet needs of family caregivers play an important role in adverse outcomes for family caregivers and directly influence patients. This study also highlights several directions for future research. According to our finding, we suggest the potential importance of targeting interventions that enhance quality of life and well-being at caregivers who are high risk. Also specific attention should be paid

to how family caregivers experience the role of “caregiver” and what sources of support they find most helpful.

Educational and training approaches should be designed for health professionals in cancer communication and multidisciplinary team effectiveness.

Development of evidence based clinical guidelines by using a multidisciplinary approach is another essential part in promoting cancer care. These guidelines should be adapted to Iranian family caregivers needs, be easily accessible and provide benchmarks for auditing the safety and quality of service provision.

Study limitations

Findings of this study should be interpreted in the light of its limitations. As is the case with all qualitative studies, the transferability of the findings to other settings and populations is limited. Our study was restricted to family caregivers of end-of-life cancer patients, the results cannot be generalized across all treatment phases. We did not gather data related to cancer diagnosis, and therefore, we are unable to distinguish whether the results varied by cancer type. The majority of family caregivers interviewed were women from urban areas, and a female viewpoint on the caregiving experience may have therefore dominated the data.

Conclusion

Family caregivers are an invaluable part of healthcare teams whose needs remain unmet in many communities despite their active role in patient care. The present study provides a valuable insight into the unmet needs of the family caregivers of end-of-life cancer patients. It addresses the unique experiences of the participants and can be used for planning and decision-making about family-centered health and palliative interventions.

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Compliance with ethical standards

Ethical considerations This study was approved by the Ethics Committee of Isfahan University of Medical Sciences. Before each interview, the participants were orally briefed on the objectives of the study and gave their informed written and verbal consent for participation. They were also told that they could freely withdraw from the study at any stage they desired.

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

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