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Experiences of cancer patients about seeking health information: a qualitative study

Seyedeh Leila Mousavi¹ · Mandana Saki² · Fatemeh Mohammadipour² · Mohammad Gholami² ·
Mohammad Almasian³ · Fatemeh Jafari Pour⁴

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Abstract

Objective Searching for health information is an important strategy in dealing with cancer that contributed to the improved management of cancer. This qualitative study aimed to explore the experiences of cancer patients seeking health information using the conventional content analysis approach.

Methods The 18 participants were selected by purposive sampling and data were collected through semi-structured in-depth interviews. Data were analyzed by software MaxQDA 10 based on conventional content analysis.

Results Data analysis led to the emergence of three central categories, including “optimal cancer management,” “poor information dissemination system,” and “perceived health literacy.”

Conclusion Knowing how cancer patients obtain health information can form the basis to promote patients’ health literacy and design a health information dissemination system tailored to the patients’ needs.

Keywords Seeking health information · Cancer · Information requirements · Qualitative study

Introduction

Despite advances in technology and diagnostic and therapeutic methods, cancer patients are recognized as a vulnerable population as they face many psychosocial and physical problems [1]. Many patients tend to seek more information about their disease after becoming aware of the diagnosis [2]. Numerous studies have reported that cancer patients need to have information about disease progression, treatment options and side effects, impact on family members and their risk of developing cancer, impact on work, daily activities and social life, self-care issues, and sexual issues [3]. Understanding patients’ needs in dealing with cancer helps healthcare staff, especially nurses, to provide appropriate counseling services to patients and their families [4]. Receiving reliable and understandable information reduces fear, increases self-confidence, and patients’ adaptation and participation in care for themselves [5, 6].

Searching for health information can help with controlling the disease trajectory, reducing the huge costs of treatment, and decreasing the psychological and mental stresses created by it [7]. The literature documented the use of the internet as a vast source of health information. However, there are challenges to information literacy and searchers’

✉ Mandana Saki
mandana_saki@yahoo.com

Seyedeh Leila Mousavi
leilamousavi414@yahoo.com

Fatemeh Mohammadipour
mohammadipourf@yahoo.com

Mohammad Gholami
mohammad13565@yahoo.com

Mohammad Almasian
almasian@yahoo.com

Fatemeh Jafari Pour
fatemehjafaripour69@gmail.com

¹ Student Research Committee, Lorestan University of Medical Sciences, Khorramabad, Iran

² Social Determinants of Health Research Center, Lorestan University of Medical Sciences, Khorramabad, Iran

³ School of Medicine, Lorestan University of Medical Sciences, Khorramabad, Iran

⁴ Department of Nursing, Behbahan Faculty of Medical Sciences, Behbahan, Iran

trust in the health information available on the Internet, and patients often prefer healthcare professionals as a reliable source of information [8]. In a study in Iran, radio and television, the Internet, and health care providers were listed as the most common sources of health information, respectively [9]. Due to the unfamiliarity of the majority of the Iranian people with English [10], poor information literacy and health literacy [11], lack of high-speed Internet access [12] and lack of authoritative Persian language sites, poor communication between health professionals and patients, and the specific cultural-religious context, patients follow a different pattern of seeking health information [13].

Cancer patients' beliefs and their strategies for coping with the disease [14], and insufficient knowledge and the risk of emotional reactions [15] can limit their willingness to seek information. Patients' involvement in the search for health information can help them discover the true meaning of the disease and the treatment [16].

Searching for health information is a key factor in facilitating the participation of cancer patients in treatment decisions, problem solving, health promotion, adaptation, and prevention of risk factors related to chronic conditions. Considering health promotion challenges of cancer patients in Iranian context as well as little knowledge of how to seek health information in this group of patients across the country and the world, it seemed necessary to address this issue and obtain direct information from patients themselves. To reach this goal, we conducted a qualitative study to explore the experiences of cancer patients seeking health information based on the Iranian culture. In this qualitative study, we used conventional content analysis approach whose aim is to describe phenomena and identify the goals, values, and aspirations of the target text, the author, or the interviewee.

Methods

Study design

This qualitative study was carried out according to the conventional content analysis approach.

Participants and setting

Participants were selected using the purposive sampling method from two hospitals affiliated to Lorestan University of Medical Sciences in Iran. Participants were first interviewed from among the patients. The interviews were performed, analyzed, and coded one by one which means that the next interview was done to fill the gap obtained from the previous one. According to the extraction of basic concepts and patients' interviews and their emphasis on the role of health workers as a source of information and also their

emphasis on family support for seeking health information, in consultation with the research team, other participants from the health staff and the patients' family caregivers were also enrolled into the study. To collect and provide rich data, 18 participants were interviewed during 12 months (from August 2018 to August 2019), including 12 patients, three nurses, and three family members. Inclusion criteria for patients were being older than 18, a definitive diagnosis of cancer during at least the last 3 months, knowledge of the diagnosis, willingness to participate in the study, physical and mental ability to participate in interviews. For health professionals, the inclusion criterion consisted of having at least 1 year of experience with the treatment and care of cancer patients. For family caregivers, Inclusion criteria were being older than 18, the main caregiver of the patient, having experience in providing care to cancer patients.

Data collection

The current study was conducted after obtaining permission from the ethics committee and the research deputy of Lorestan University of Medical Sciences. The researcher who conducted the interviews was the first author in this study and not involved in providing nursing care to patients. To collect the data, semi-structured interviews were conducted in Persian using an interview guide. Based on the main research question, interviews began with the open-ended question "What did you do when you became ill?" As needed, the interview continued with exploratory questions such as "What do you mean" or "Please explain more?" First, twelve interviews were conducted with patients, then a total of 18 interviews were conducted to achieve data saturation in the qualitative research. The interviews lasted between 30 and 45 min. The interviews were conducted in coordination with the participants in their leisure time and a secluded environment next to the patient's bed or the break-room in the oncology ward. If the participants agreed, the interview would be recorded in mp3 format.

Analysis

All authors were asked to analyze the data. The initial analysis, including reading the interviews and extracting, comparing, and merging initial codes was conducted by the first and corresponding authors. Then, other authors participated in correcting, entitling, and finalizing categories and subcategories. Within 24 h, interviews were transcribed verbatim and typed in the Microsoft Word software. To immerse the researcher in the data, the interviews were listened to several times, and the transcriptions were reviewed, coded, and analyzed several times. Data analysis was performed simultaneously and continuously with data collection.

Data analysis was performed based on the Lundman and Graneheim approach and using qualitative data analysis software MaxQDA 10. There were three stages, including preparing, organizing, and reporting. Data preparation was performed by determining semantic units, coding the text and comparing the codes with each other in terms of similarities and differences and classification, developing the categories based on similarities and differences and summarizing, identifying the themes and comparing categories with each other, and finally reporting them [17]. Criteria of credibility, dependability, transferability, and confirmability proposed by Guba and Lincoln were used to evaluate and ensure the accuracy of the findings [18]. In this study, to increase the credibility of the data, the researcher was presented in the research environment for a long time during the study and was also continuously involved with the data for a year. Additionally, all interviews and the list of categories were reviewed by other colleagues experienced in the field of qualitative research in regular meetings. The confirmability of the data was confirmed by providing different sections of the categories to two faculty members familiar with qualitative research and comparing their opinions and interpretations, which showed a great deal of agreement. For transferability, the researcher accurately recorded and reported the stages and process of the research and provided quotations from the participants, and participant selection was conducted to achieve maximum diversity.

Ethical consideration

The present study was approved by the Ethics Committee of Lorestan University of Medical Sciences, with the code LUMS.REC.1397.098. Written informed consent was obtained from all participants and they were reassured about the principle of anonymity, confidentiality, the voluntary entry into the study and freedom to withdraw from the study

at any time. All methods were carried out in accordance with relevant guidelines and regulations.

Results

Twelve patients with cancer, including 7 (58%) females and 5 (42%) males participated in the study. Their mean age was 47 years and most of them were married. The three participating family caregivers included two women and a man with a mean age of 40 years. Participating healthcare providers included three nurses, two women and one man, with a mean age of 45.

By analyzing the data obtained from the 18 interviews, 898 initial codes were extracted and after analyzing and comparing the data, twelve subcategories emerged and finally after merging the categories, three central categories emerged, including “optimal cancer management,” “poor information dissemination system,” and “promoting perceived health literacy” described below (Table 1).

Optimal cancer management

Patients’ experiences have shown that optimal cancer management occurs as a process, beginning with information deficits and continuing with motivations including hope for cure, striving to overcome complications and illness, staying calm, and striving for survival.

Information needs

At the time of diagnosis, participants were faced with a dearth of information about their disease.

One of the participants said about the disease: “*I understood from the hospital staff that I had pulmonary lymphoma. At that time, I did not know what lymphoma meant*

Table 1 Summary of study findings

Subcategories	Categories
Optimal cancer management	Information needs
	Struggle for survival
	Obtaining information from different sources
Poor information dissemination system	Ambiguity in the information
	Deficiencies in receiving information from the health system
	Deficiencies in information received from social media
Promoting perceived health literacy	Creating a forum
	Dialogue
	Introducing a reputable site to patients
	Improving the education of nurses
	Using a new educational method
	Improving the level of education in society

at all. I searched on Google with my cell phone and found that it is a lump inside the lung.” (p4).

Some participants did not know how to take care of themselves and the proper diet they had to follow and were confused. One participant said, “Now we are just confused. Some say he should eat meat. Some say he should not. I do not know.” (p. 14).

In the face of the disease and its diagnosis and treatment, asking and seeking information about the nature of the disease, its causes, prognosis, treatment, and stages were very important for patients. They seemed to want to have more and better control over the disease and its complications by asking questions about it. One health caregiver said, “Most patients like to know what the future holds, where the disease is taking them. Whether their disease responds to treatment or not. They need to get information about these issues.” (p. 13).

Struggle for survival

With the motivations of hoping for treatment, practicing to stay calm, trying to cope with the side effects of drugs, patients obtained information for survival. They also said that one of the reasons for treatment success was timely follow-up and attention to the symptoms of the disease, for example, participants said, “When I noticed the mass in my breast, I immediately told my daughter, who was a nurse, and fortunately the cancer was diagnosed quickly and I started treatment, soon. My daughter says that because I noticed it early and started the treatment, I will get well.” (p. 7).

During diagnosis, patients tried to maintain a positive mood and control negative emotions by obtaining information about the disease. Persistence in maintaining peace of mind was rooted in religious beliefs and acceptance of destiny. For example, one participant said, “When I learned about the disease and its treatment, I realized that the disease is no longer fatal and if you treat it in time, you will get better. Now I rely on God, and whatever God wills will be done.” (p1).

Obtaining information from different sources of information

Patients referred to different sources of information to obtain the information they needed. For some people, it was very important to receive information from a reputable and authoritative source, and they referred to the sources of information in order of trustability. Healthcare workers were the professional and most trusted sources of information for individuals. Some people only trusted their doctors. For example, one participant said, “I asked

most of my questions from my doctor. For example, when blood samples were taken from me, I asked him what they were for.” (p2).

Another participant said about his source of information: “When I have a question, I ask the nurses. Mr. ... is a nurse, but he has lots of information. When I have a problem, I call and ask him, and he answers. His information is very good. He is very well informed.” (p. 7).

The Internet was another source of information used by some patients and their families. For example, one participant said, “Now my husband is constantly searching on the Internet for information about this disease, even for my medications and what they do.” (p. 1).

Peers and other patients were the sources of information from which patients obtained information. They thought their peers had gone through the stages of the disease and shared the best information based on their successful experiences. For example, one participant said, “When I went to the hospital, I talked to other people who had the same problem as me, asking what they did to get better, what foods to eat or not to eat. I asked them whether they had gotten better with chemotherapy or not.” (p9).

Other sources of information were magazines or journals, articles, and educational pamphlets distributed by hospitals. Patients’ level of education had a great impact on obtaining information from these sources, such that people with higher levels of education were more inclined to obtain specialized information from reputable scientific articles and journals. One participant said, “I had access to books and doctors myself. I either asked questions or found the answers in books. I got most of the information I needed from books and articles and by asking doctors questions.” (p 9).

Applying the information

Having information was so important to patients that it was considered a determining factor in informed decision-making and the treatment process. For example, one contributor said, “I think some information may be considered trivial by some people, but the same trivial information is very important for our treatment decision. Information has played an important role in my treatment decision from the very beginning, when I wanted to decide whether to under operation or not up to now that I am taking medications.” (p. 7).

Poor information dissemination system

Patients’ experiences showed that they seek information to meet their needs and manage their illness in the context of a weak information system.

Ambiguity in the information

Patients were confronted with conflicting information when seeking information, in which case they would refer to a source they trusted for accurate information, for example, one participant said, *“Sometimes you have a question about something, the nurses say one thing, the doctors say another thing. For example, some say don’t drink milk. Dairy products make you sicker. They make the chemotherapy ineffective. Some say it’s OK to have dairy products. I finally ask my doctor and whatever he says I’ll do it.”* (p. 8).

Deficiencies in receiving information from the health system

Most participants reported the failure of healthcare staff to provide accurate information and the negligence of health staff regarding this issue. Patients stated that the information provided by the pamphlets handed out in hospitals was insufficient and incomplete. This information did not meet their educational needs and was not understandable and useful for patients in cases where the patient was not educated.

Another point mentioned by the participants was the lack of specialized knowledge of ward nurses that did not meet the information needs of patients. For example, one participant said, *“Unfortunately, the nurses’ level of specialized information was very low, ... In the last three sessions of chemotherapy, I asked them about one of my medicines and they did not know much.”* (p. 9).

Deficiencies in information received from social media

Patients’ experiences showed that television networks do not provide adequate and sufficient information to people and do not pay much attention to this issue or the time of broadcasting of educational programs is not appropriate and they cannot use them. One participant said, *“Our system does not care about patient education at all, even on radio and television, there are no useful educational programs.”* (p. 9).

Deficiencies in information obtained from cyberspace

Lack of access to specialized sites was one of the cases mentioned, and most people, especially those with low education, obtained their information from a general search on Google. *“I get my information from general searches,”* said one participant about Internet search (p. 4).

Promoting perceived health literacy

This concept indicated that patients needed to obtain information and use the information to better control the disease, and is suggestive of their proposals regarding improving the information system and health literacy.

One of the suggestions of participants was to set up a forum consisting of experienced and skilled people so that patients can easily get their information from trusted sources and do not have to worry about the uncertainty of information. For example, one participant said, *“Virtual information groups should be formed, patients should become members, and doctors and nurses should be in the group to answer patients, especially those who are younger. Patients need a lot of psychological support and information.”* (p. 9).

In this regard, recommending reputable sites to patients is one of the basic solutions proposed by participants. One participant said, *“In my opinion, if someone wants to get information from the Internet, to be sure what is right and what is wrong, it is the duty of the hospital to at least recommend authoritative sites to patients.”* (p. 6).

Forming virtual groups consisting of patients was cited as one of the ways to increase learning and information. For example, a participant said, *“It is important that hospitals start programs for individuals who have overcome cancer to talk to patients who have just started their treatments about their hopes for the future, about how to overcome their problems and their treatment experiences.”* (p. 6).

Discussion

The findings suggest that seeking health information in patients leads to knowledge, increased awareness of the disease, and self-care, and ultimately all of this leads to better control and management of the disease.

One of the focal points of the study was “optimal cancer management.” Due to their information deficiencies and needs, patients obtained their information from various sources to be able to manage the existing conditions, diseases, and the effects they have on themselves and their lives in the best possible way. These results are similar to the findings of a study by Blödt et al. [19], which referred to the role of information in controlling acute conditions and also the four categories of “increasing self-confidence and participation in treatment decisions,” “adapting to one’s condition,” “understanding the consequences of the disease and its treatment,” and “coping with the fear of illness” extracted in this study indicated patients’ information deficits when facing the disease and their lack of knowledge about the

disease and its symptoms, treatment, and self-care as mentioned in the study.

Information needs of cancer patients included the need to know about the nature of the disease, the management and different treatments of cancer, side effects of drugs, and prognosis. A study by Chua et al. [20] also showed that the most important information needs of cancer patients were to obtain information about the nature of the disease and its prognosis, as well as information about a healthy lifestyle and daily living activities, which is similar to the present study. In the study by Okuhara et al. [21], most patients expressed the need for information to achieve a healthier life and control and manage the disease better. Disease management and control to increase the quality of life is an important issue expressed in both studies. The results of this study and existing studies have shown that understanding the needs of cancer patients and their interests helps professional staff, especially nurses, provide appropriate counseling services for patients and their families.

Decreased appetite and nausea were among the side effects of the treatment that most participants expressed concern about and sought information about appropriate strategies to overcome these side effects. The results of other studies have shown that the side effects of treatment and the use of different treatment methods affect appetite and the treatment regimen [22].

Patients' experiences have shown that one of the most important sources of information for them is healthcare staff, which includes physicians, nurses, and other health professionals. A study by Ghazimirsaeed et al. [23] showed that the most common source of information is "the nurse" and patients are most willing to obtain information from their treating physicians. By creating a suitable setting, the treating physician can encourage the patient to be able to easily express his/her need for information related to cancer and to experience less stress due to search and distrust of other sources.

Most participants stated that they gained their information from experienced peers and other patients. Dri et al. [24] also showed that peers are considered as an important source of information for cancer patients. Patients' experiences have shown that one of the most reliable sources for information is magazines, books, articles, newspapers, and hospital pamphlets that can provide them with reliable information.

Today, the Internet is considered as one of the main sources of health information. A lot of the information on the Internet is inaccurate, incomplete, or outdated. However, using health information on the Internet without control and supervision can be harmful and misleading [25].

Another pivotal category of this study was the poor information dissemination system. A study by Shih and Chien [26], consistent with the present study, also showed that physicians do not spend enough time to provide information

and answer patients' questions. Another study showed that patients face insufficient support from healthcare providers in getting information when they need information, and physicians and nurses do not spend enough time to provide the education and information that are needed by patients [27]. Psychological and social support is a vital component of improving the quality of patient care and requires psychological counseling by a psychologist, which is unfortunately inadequate in developing countries due to the lack of skills of staff, including trained nurses [28]. In this study, participants reported not receiving proper information from the media, including radio and television, as well as the Internet. It seems that a lack of attention to media sources such as magazines, television, radio, newspapers, and the Internet may be due to a lack of close oversight of their content by a responsible organization.

Jünger et al. [29] showed that lack of easy access to information, lack of access to specialized and informative websites and educational channels are among the barriers to access to health information.

The central category of perceived health literacy in this study refers to health literacy and its promotion, and on the other hand, includes the participants' strategies for promoting health literacy. Health literacy involves a range of simple and complex skills that allow a person to participate in treatment decisions, thus encouraging the patient to receive more information and seek treatment. In other words, high health literacy has led to shorter stays of patients in the hospital, which in turn reduces costs and in other words, prevents the loss of part of the health sector budget [30]. On the other hand, due to the physical problems of these patients due to the complications of the disease itself, the side effects of chemotherapy drugs, frequent hospitalizations, and various infections that affect cancer patients, health literacy has a very important role in improving the general health of these patients. In this study, to promote health literacy, some solutions were suggested, such as creating online or offline forums, as well as forming virtual groups for patients to communicate with doctors and other patients and to obtain information and ask questions about the disease and its treatment and self-care. Saberi et al. [31] have also shown in their study that it is essential to hold training workshops to strengthen communication skills for obtaining health information, as well as to form virtual channels such as Telegram channels to inform cancer patients.

Limitations

Despite the researcher's efforts to gain an in-depth knowledge of the individuals' experiences and feelings, some participants may not have provided accurate and complete

information to the researcher due to their emotional conditions. For these limitations, the researcher tried to conduct interviews at appropriate times when patients were able to respond fully.

Conclusion

In the present study, the information needs of patients were identified. In addition to the treatment team, information services include the use of cyberspace and the formation of virtual groups, the recommendation of authoritative sites to patients, the use of counselors and forums in treatment centers to respond to patients' information needs were among the issues explored in this study. According to the research findings, nurses can provide supportive and informational care interventions to cancer patients. Hence, nurses can empower patients in self-care by considering educational programs on various aspects of the disease, drugs and their side effects, and diagnostic and therapeutic measures, and reduce their worries and concerns by providing them the correct information.

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Author contribution All authors contributed to manuscript writing, editing and final approval, including table design. Mousavi, Saki, Mohammadipour, Gholami, Almasian, and Jafari Pour conceived the study. Saki, Mohammadipour, Gholami, Almasian, and Jafari Pour facilitated recruitment.

Mousavi, Saki and Mohammadipour led the data collection. Data analysis was performed by Mousavi, Saki, Mohammadipour and Gholami with consensus discussions with all authors. All authors reviewed the draft manuscript and provided approval to the final manuscript.

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Data availability The datasets generated and/or analyzed during the current study are not publicly available due to regulations provided by the Ethics Committee of Lorestan University of Medical Sciences in order to protect data and maintain the privacy of participants. Besides, the nature of this study was qualitative which means that sharing full interview transcripts, written in Persian, and 898 initial codes before analyzing and emerging main sub-categories and categories was impossible because of ambiguity and not really easy to understand. However, data are available from the corresponding author on reasonable request.

Declarations

Ethical approval and consent to participate The present study was approved by the Ethics Committee of Lorestan University of Medical Sciences, with the code LUMS.REC.1397.098. Written informed consent was obtained from all participants and they were reassured about the principle of anonymity, confidentiality, the voluntary entry

into the study and freedom to withdraw from the study at any time. All methods were carried out in accordance with relevant guidelines and regulations.

Consent for publication Not applicable.

Competing interests The authors declare no competing interests.

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