

Cancer Patients' Perceptions of Family Psychological Support: A Qualitative Study

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Abstract

Background and Aim: Family psychological support is a highly important concept concerning patients diagnosed with cancer. The purpose of this study was to investigate cancer patients' perceptions of family psychological support.

Methods: This study had a qualitative approach using inductive content analysis method. Through purposive sampling, 15 patients were selected who underwent semi-structured, face-to-face interviews. After data collection, all the interviews were transcribed and analyzed via content analysis.

Results: In general, 298 codes were extracted and categorized into two main themes: *seeking support from family* and *valuing the patient as a family member*. Seeking support from family composed of two subcategories, i.e., *emotional support seeking* and *spiritual support seeking*. Also, valuing the patient as a family member had two sub-categories consisting of *unconditional acceptance* and *respect*.

Conclusion: From the point of view of the participants, emotional and spiritual support seeking as well as unconditional acceptance and respect play a significant role in the psychological support of the families for these patients.

Keywords: Neoplasms, Patients, Family, Suicide, Assisted.

Introduction

Cancer is among the main causes of mortality across the world. Predictions go that by 2030, 12 million deaths would occur each year as a result of cancers out of which the share of developing and under-developed countries might be 9 million (1). This disease is also the third largest cause of death in Iran. As indicated by accessible estimations, the incidence of cancer is 98 to 100 cases in every one hundred thousand people (2).

Cancer patients experience a highly changeable condition during the process of illness and treatment. Such a condition diminishes the quality of their lives and reveals the need for psychological support to them (3). The results of a research on cancer patients in the United Kingdom revealed that 40% of them suffered from severe kinds of mental tensions and needed to receive psychological support (4). In fact, psychological support allows the patients to prevent the occurrence of stressful situations, or if such a situation already prevails, to control it in order to reduce further threatening effects (5). In other words, supporting cancer patients psychologically leads to their

compatibility with stressful events (4).

The findings of a study in Thailand showed that cancer patients experience more anxiety compared to those without cancer. That study proposed giving psychological support to cancer patients (5). The diagnosis of cancer in a family member affects the other members deeply and induces family support to the patient (3). In fact, help and support provided by family members can play an important role in patient's well-being and improved quality of life. In other words, such a support by the family reduces the patient's sense of isolation and in turn improves the process of self-care in him/her (6). A study in Greece showed that meanwhile between cancer diagnosis and chemotherapy, the patients fall in a fear of the unknown. These researchers emphasized the importance of families' psychological support for patients after diagnosis and during treatment (3). A similar study in Sweden found that family support of cancer patients ensures better treatment processes, e.g., chemotherapy for patients, and leads to their increased self-efficacy (6).

Therefore, as family is the primary supporter of cancer

patients, the concept of psychological support is crucially important to these patients. Despite the importance of family in the psychosocial support of such patients, there is no comprehensive qualitative study on this matter presenting a broader view of the concept under study. There is also no qualitative study on family psychological support of cancer patients with a focus on Iranian social and cultural context. Such a gap along with the necessity of family psychological support for the patients during cancer highlighted the need for a deeper scrutiny into this problem (7). This kind of support is affected by patients' cultural context and background as well as the existing differences between them. In addition, identifying and perceiving the visions, beliefs, emotions and feelings of the patients concerning family support using a qualitative approach will reveal the concerns of patients in this regard. Therefore, as for the lack of a qualitative study on this topic, especially in Iran, this study aimed to explore the perceptions of cancer patients of the psychological support of their families.

Methods

As a qualitative study, the present investigation was based on deductive content analysis approach (8). Participants of this study were selected using purposive sampling from two centers affiliated to Tehran University of Medical Sciences, i.e. Cancer Research Institute and Dr. Shariati Hospital. Having cancer was used as the main criteria for selecting patients. Sampling of cancer patients continued until there was data saturation. In this study, 15 patients underwent an in-depth, semi-structured and face-to-face interview which lasted between 35 to 45 minutes. All the patients were interviewed once and a total of 15 interviews were performed.

Interviews were conducted at the bedside by the main researcher (the corresponding author) who had the experience of doing qualitative studies. The interviews were carried out the patient's consent and at his/her convenience. During the interviews, the patients were asked questions such as "How can your family give psychological support to you?" and "What makes your family offer a good support for you?" In addition, to get more information, interviews were followed by questions such as "What do you mean by...?" or "Can you explain more about it?" These interviews were recorded after obtaining the written consent from the patients. The patients were assured that the information will remain confidential and their audio files would be destroyed after transcription, or if they liked, they could have them.

Data analysis was performed based on text content analysis (8). To this end, the researcher went through the following stages: transcribing the audios, preparing data (typing the interview texts), determining the units of meaning, coding the transcripts, re-examining the codes against the transcript (reviewing and comparing the codes in terms of similarities and differences with each other and combining similar codes), classifying and developing the categories based on similarities and conformities,

reviewing the categories and re-comparing them with the data to ensure the strength of codes, identifying the categories and comparing them with each other and lastly, reporting the findings.

To ensure accuracy of data, use was made of criteria as credibility, dependability, confirmability and transmissibility (8). In the same way, to enhance credibility, all the interview transcripts and the list of categories were reviewed by two colleagues of the researcher who had an extensive experience in conducting qualitative research. The initial coding of each interview was also returned to the interviewee in the early stages of analysis to confirm its accuracy. Mixed method was used partly for data collection as well (interviews and field notes). However, the field notes mostly entailed the non-verbal behaviors of the participants (including their facial expressions and excitements during speaking which revealed states as sadness and anger). Confirmability of the results was promoted by presenting them to two of the faculty members familiar with qualitative research and comparing their opinions and interpretations with each other. The researcher also registered all the steps and processes of the research project to allow other researchers to be familiarized with the stages taken. To allow transferability of the results, the statements of the participants were presented in their intact form. Moreover, the findings were shared with 2 external participants with similar conditions who confirmed the results.

Results

Participants included 9 men and 6 women with a range of 34 to 50 years of age (11 married and 4 single). All of the participants were Muslims. The educational level of the patients ranged from elementary to university graduates. The majority of them were high school graduates ($n=8$). As regards the type of cancer, 6 patients had breast cancer, 4 of them suffered from gastrointestinal cancer, another 4 had leukemia and one of them suffered from lung cancer. The shortest time interval from the primary diagnosis was 2 months and the longest was 4 years. After analyzing the data, 298 codes were extracted which were categorized into two categories, i.e., "seeking support from family" and "valuing the patient as a family member" (The full text of the interview was adopted as the unit of analysis. Then, the units of meaning were allocated which consisted of the selected segments of statements of the participants on the concept under study. Next, the act of coding was performed. Finally, the codes were categorized and summarized and based on similarities and differences, the categories and subcategories were formed.).

Seeking Support From Family

One of the categories drawn from the participants' statements was "seeking support from family". This category included the subcategories "emotional support seeking" and "spiritual support seeking". According to the perceptions of patients, families can play a significant role in providing psychological support to them by providing

emotional and spiritual support. This might be why patients always sought support of their family.

Emotional Support Seeking

Support seeking participants who looked for support by family members perceived this kind of support in the form of offering comfort to them, listening to their talks, and joking to them:

"My family is and has been with me through all the stages of the treatment; they help me a lot, console me, listen to me and, kid with me" (Patient No. 2).

To reduce mental tensions, patients sought support from their father, mother, son and wife. They liked to be with their family members and to be understood by them in the difficult circumstances.

"When I understood that I suffer from such a disease, I wanted my parents to be next to me more than any other time and talk to me to reduce my stress" (Patient No. 7).

"Just from the beginning of the disease, my son didn't let me be alone by any means. He said if there's any problem, he'd solve it himself... His presence here is very important for me" (Patient No. 10).

"More than anything, I needed the support of my wife. I felt the only person who can understand me was her" (Patient No. 9).

Spiritual Support Seeking

As regards the spiritual support subcategory, according to the participants, families are allowed to implement their supporting policies on patients by building on this type of support:

"It might be considered hypocrisy to say it, but every time that I come for chemotherapy, my father prays for me and asks Allah to protect me. I say to myself that you must trust in God to heal you. Every time that I'm here for chemotherapy, my mother passes me under the Noble Qur'an and asks the Sender of the Quran to cure me ... I think that families can psychologically support the patients by such beliefs and deeds. I have felt such a need" (Patient No. 12).

"When my wife went to Mecca, I asked her to bring me Zamzam water. I believe in its miraculous calming effect; I firmly believe it to be a remedy" (Patient No. 4).

Valuing the Patient as a Family Member

Another category that was derived from the patients' narratives was "valuing the patient as a family member." This class had the two subcategories "unconditional acceptance" and "respect". Participants believed that by respecting and accepting them unconditionally, families provide a kind of psychological support for them besides valuing them.

Unconditional Acceptance

As the patients suggested, the immediate acceptance of them by family was necessary to provide a great deal of psychological support to them:

"Our families should somehow accept us along with all our concerns; they should view us as a member of the family who is sick the way we are, with all the problems we have, or we might possibly have. The families must not, God forbid, set out any conditions for doing things related to us ... If our family provide us with this kind of support, they'd guarantee our long-term support" (Patient No. 14).

"When I had a surgery and a part of my colon was removed, I was too worried; I felt bad, but my children said, 'Don't bother yourself; you're our father; we accept you as you are'" (Patient No. 11).

Respect

As illustrated by the perceptions of patients regarding the subcategory of respect, being honored by family displays the reverence of family towards the patients until the last moment of life:

"When my wife respects me, I feel that I'm valuable for her. The reverence shown in her behavior makes me understand that I have a good supporter that will help me till I'm alive, one who can be with me until the last moment of life and support me, a permanent supporter ..." (Patient No. 5).

Moreover, during healthcare services, patients' family members, besides companionship, showed great respect for them, providing psychological support to them:

"Every time that I wanted to go to the hospital for chemotherapy, my only sister and brother accompanied me with dignity and respect; they were beside me and gave me strength and courage" (Patient No. 13).

Discussion

In this study, the concept of family psychological support for cancer patients was raised in terms of patients' perception of support seeking from family. *Seeking support from family* was divided into *emotional and spiritual support seeking*, while *valuing the patient as a family member* was subcategorized into *unconditional acceptance and respect* for them. Results of the present study showed that the concept of psychological support was considered highly important by patients. In line with our findings, the results of a descriptive study of cancer patients in Hungary showed that 61.6% of them believed in usefulness and effectiveness of psychological support (9).

One of the main categories of this investigation was "seeking support from family." To achieve this, patients emphasized the importance of emotional and spiritual support. As regards psychological support, participants suggested that family can reduce the patients' fear of the disease by talking to them. Family is thus able to reduce the patient's stress. Consistent with this finding is the results of a study in Norway which indicated that while treating cancer patients, talking to them can be effective in reducing tensions. The researchers in the given study reported that cancer patients suffer from intense levels of tension and this tension is affected by the type of their disease (10). Similarly, researchers in China during a psychological

intervention for cancer patients under chemotherapy found that the intervention as psychological support for patients can reduce the negative psychological effects of the disease such as depression and anxiety. This study also highlighted the importance of psychological support for cancer patients by effective individuals on them such as family members (11). Researchers in Australia also performed a psychological program on cancer patients. Further follow-ups that were performed 6 months after the intervention indicated a decrease in patients' tension levels. According to these researchers, psychological support of patients led to promoted mental health in them (12).

In the current study, patients looked for a range of supports from their family members. The patients' support seeking needs was obviated in the form of comforting to and joking with them. Moreover, participants sought support of the family members including their wives. According to a few studies in the United Kingdom and Australia, cancer patients need to receive support from their spouses (13-15). In addition, patients expected this kind of support from family members such as father, mother, wife and children in order to decrease the types of stress experienced. Findings of an investigation in France also demonstrated that supporting the cancer patients reduces their experiences of anxiety and depression (16). The notion of family psychological support for cancer patients has recently been subsumed under family centered comprehensive care which necessitates enhanced attention to this type of healthcare issue.

As indicated by the participants of this study, to support cancer patients psychologically, families can pay attention to their spiritual needs. As the patients asserted, by encouraging them to seek help from God and appeal to the holy Imams, families can implement their spiritual supporting strategies on patients. Apparently, it is necessary for cancer patients' families to consider various aspects of spirituality while addressing them and to identify these dimensions correctly. If appropriate spiritual care is provided to the patient by the family, s/he would achieve a valuable resource to cope with traumatic events in his/her life. Consistent with this finding, the results of another study revealed that spiritual care leads to a positive change in patient's attitude towards his/her disease. This finding unveils how spirituality exerts its supportive effects on the patient (17). An investigation in Italy also showed that spiritual support, in addition to promoting the spiritual well-being of cancer patients and their religious faith, improves their quality of life (18).

What distinguishes the spiritual care component of patients in the Iranian cultural context from other cultures, however, is that the local culture and religion here moves patients towards spirituality and further obedience to God when a patient's life is exposed to tremendous risk. This fact has led the patients under study to include the spiritual care in their perception of psychological support by family. Our findings highlight the need to consider spiritual support and the need to subsume spiritual

support together with its multiple dimensions into the set of healthcare services presented to cancer patients by care systems, caregivers as well as families.

As the present study found, based on the patients' perceptions, 'valuing patients as a family member' consisted of two subcategories i.e. 'unconditional acceptance' and 'respect'. As per the patients' statements, for families to value them, they should be acknowledged unconditionally along with the problems associated with them. In this regard, a qualitative study in Korea investigated the experiences of family care-givers concerning cancer patients who were in the terminal stages of their lives. According to that study, a major proportion of patients with terminal disease and their family care-givers favored exposure, and patients who were aware of their terminal state had a lower level of distress and a higher quality of well-being (19).

As regards patient acceptance, the findings of a study on women diagnosed with cancer in Canada showed that cancer has many short-term and long-term impacts on the lives of the patients. These researchers concluded that, as different aspects of these patients' lives have been affected by the disease, taking care of them entails recognition of these aspects and the related problems (20). Similarly, the findings of a qualitative study in our country showed that in relationships with cancer patients, the overall acceptance of them is a humanitarian approach towards them (21). Also, a research in China on cancer patients showed that an understanding of the problems of this group of patients in totality, along with a consideration of all aspects of their lives results in their improved well-being. Therefore, by considering the different problems of cancer patients, which overshadows the personal and social aspects of their lives, and accepting them, they can be assisted at any stage of the disease progress with their decisions concerning their disease or with other personal and social problems they have (22). A qualitative study in Italy demonstrated that cancer patients need a comprehensive and holistic care plan, which provides them with psychological support during long-term palliative cares (23). The results of the present study highlighted the importance of ethical concepts such as respect and unconditional acceptance in palliative care given to patients by family.

With reference to the respect subcategory, participants of our research emphasized honoring the patient and maintaining reverence towards him until the last moment of the life. Respect for patients has also been addressed in other studies. For example, the results of a qualitative study in the United States highlighted respect and dignity for the patient (23). In this context, researchers in Iran and Australia underlined the importance of respect for people with cancer as well (24,25). However, since the expectations of individuals regarding respect is shaped based on their attitudes, if the patient's dignity is preserved, a sense of empowerment and positive mental image would be reinforced in him/her which not only increases his/her self-esteem, but would also further his/her sense of self-worth. On the contrary, lack of respect for a patient as

a human and ignoring his right in this regard threatens his/her dignity (21). Although respect for the patient is important in other cultural contexts as well, in the present study, respect is limited to the social and cultural problems of the Iranian society. This is because Iranians observe the requirements of respect during encounters with each other highly courteously, and if they see a sick person, still they exhibit higher levels of respect and reverence towards him or her.

At the end, it should be acknowledged that, although studies in different cultural contexts have almost yielded the same results, supporting others in the Iranian culture, particularly providing psychological support, especially for a person that has a terminal disease such as cancer, is granted a high public social approval. Such a point distinguishes the findings of the present study from the studies conducted in other cultural contexts.

Conclusion

As regards the fact that this research is the first qualitative study on the psychological support of family for cancer patients, its results can disclose aspects of family psychological support for cancer patients which could be subsumed into the family-based psychological care for these patients. In other words, psychological support for cancer patients is an essential part of the comprehensive care which should be given to these patients. The findings of this study demonstrated the necessity to design and run support programs to alleviate the psychological sufferings of cancer patients. In view of this, nurses can play an active role in designing, presenting and implementing these programs. As a future research area, the researchers are recommended to do a content analysis of families' psychological support of cancer patients from the view point of family members.

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