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Running Title: Social Support Challenges in Patients with Cancer

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Social Support Needs in Patients with Cancer: A Qualitative Study

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Abstract

Background: Cancer is believed to be one of the most important health problems worldwide today. In Iran, the burden of cancer is also on the rise and social support is an important aspect of modern cancer care. Therefore, we conducted the current study to determine the social needs of patients with cancer employing a qualitative content analysis.

Methods: This conventional qualitative content analysis was performed based on a descriptive explorative approach. Data saturation was achieved after interviewing 10 patients with cancer with in-depth semi-structured interviews. Data was gathered from autumn 2017 to spring 2018, from all the cancer patients who referred to three hospitals in Kerman. We utilized MAXQDA10 software for data analysis.

Results: On average, the participants had 9 months to 4 years' experience of cancer. The mean age of the participants was 45.7 years old. The present study revealed that the most important needs expressed by the participants were related to "organizational-therapeutic support". This main category consisted of three sub-categories, including the need for financial support, inadequate environmental conditions in health care facilities, and not having the opportunity to choose.

Conclusion: The financial needs of cancer patients include the need for financial support from the spouse and the need for financial support from public and nongovernmental organizations. Their financial needs lead into not pursuing their treatment. Therefore, paying attention to the culture and values of patients is one of the important issues in providing care to these patients. Researchers have suggested focusing on further organizational support and ways to mitigate the needs of this group.

Keywords: Social support needs, Cancer, Qualitative study, Iran

Introduction

Cancer is one of the most important health problems worldwide nowadays.¹ Recently, Arbyn, M et al. (2020) reported that cancer causes 0.6 million cases and 0.3 million deaths per year.² Cancer now accounts for 12% of deaths worldwide.³ The incidence of cancers has increased from 3.5 million men and 7.4 million women in 2003 to 14.1 million people in 2014.⁴

In Iran, as a developing country, the number of people suffering from cancer is 92,000 each year.⁵ The financial burden of cancer in this country is about 85 million US \$ annually.⁶ In Kerman, the incidence of cancer has increased, with 483 cases reported in women and 287 in men per 100,000 people.⁷

Cancer is a chronic, lethal, and severe illness in the community, whose diagnosis can lead to negative physical, emotional, and social effects, creating needs for the patients.⁸ Patients encounter psychological and physical problems and face difficulties in performing daily activities of life.^{9,10} During the disease, many of them are worried about losing their jobs and financial problems, which put patients under physical and mental constraints.¹¹

Social support helps people deal with harsh conditions.¹² By reviewing the studies, social support could be related to the health-associated quality of life,¹³ the level of hope in individuals,¹⁴ and the improvement of the behaviors of cancer patients.¹⁵ In addition, studies have shown that social support significantly improves the performance of the patient's immune system,¹⁶ as well as psychological adjustment,¹⁷ positive coping strategies, psychological symptoms, and patients' longevity.¹⁸ Studies in Iran have also shown that investigation of psychosocial, nutritional, educational, and counseling needs in cancer patients is at the top of the country's research priorities.¹⁹

Supportive care could reduce disease progression²⁰ and increase patients' trust in professionals.²¹ The amount of time a nurse spends alongside the patient is considerable and is related to the feelings, concerns, pains, and problems and would help them identify the needs of the patient.^{22,23} In this regard, a qualitative study done by a nurse could help healthcare providers to understand the patients' needs.²⁴

Qualitative research is one of the ways to study a phenomenon in a culture for focusing on personal experience, understanding and knowledge of the participants. According to the patients, their satisfaction from health care system in Iran is lower than 50%.²⁵ Additionally, based on researchers' experiences in Iran clinical centers, the first practice for cancer patients is therapeutic interventions, and supportive care are in the second or third degree of care. Therefore, this study aimed to determine the social needs of patients suffering from cancer.

Materials and Methods

Study design and setting

This conventional qualitative content analysis was performed using a descriptive explorative approach. Herein, we aimed to attain a condensed and broad description of the phenomenon.²² Content analysis can be performed with various degrees of interpretation. In each text, there are manifest messages versus latent messages although both messages require interpretations which may vary in terms of depth and level of abstraction.^{22,23}

Sample size and sampling

Since there are no absolute rules for estimating the number of participants needed, sampling continued to achieve data saturation. In the present study, data saturation was achieved after interviewing 10 patients with cancer. To capture rich and diverse information, the participants with

different characteristics, such as age, role, and work experience, were chosen by the second researcher. On average, the participants had 9 months to 4 years' experience of cancer. Their mean age was 45.7 years old (Table 1). From autumn 2017 to spring 2018, all the cancer patients who referred to three hospitals affiliated with Kerman University of Medical Sciences were included for the current investigation. The inclusion criterion comprised all the patients with leukemia, Non-Hodgkin's Lymphoma, and colon, pancreas, and breast cancers. A key informant recommended one person who in turn, recommended another.²⁶

Data collection

In-depth, semi-structured interviews were conducted to collect data. The time and place of interviews were determined based upon the patient's agreement. The participants were asked to narrate their experiences of social support needs associated with their disease. Probing and encouraging questions were used during the interviews such as:

'What were your essential supportive needs after being diagnosed with cancer?

Can you give an example?

The interviews were tape recorded, transcribed verbatim, and analyzed by the first author. The interviews lasted for 40 to 110 minutes.

Data analysis

To perform conventional qualitative content analysis, the following concepts were considered to be important: unit of analysis, meaning unit, condensation, code, sub-category, category, and main category.²⁶ The qualitative content analysis was based on the unit of analysis according to Graneheim and Lundman.²⁶ Unit of analysis refers to those interviews that are large enough to be considered as a whole and small enough to keep in mind as a context for the meaning unit during the analysis process. In our study, each interview was considered a unit

of analysis. After determining unit of analysis, the text was divided into meaning units. Each meaning unit consisted of words, sentences, or paragraphs containing aspects related to each other in terms of their content and context. In the next step, we condensed the meaning units while still preserving the core. Afterwards, we labeled the condensed meaning units with a code and created the sub-categories. The next step was to create categories that are the core feature of qualitative content analysis. A category is a group of codes that are similar in a manifest level. A main category is a recurrent thread of underlying meaning running through codes and categories; it can be seen as an expression of the latent meaning of a text.²⁶ Even though the analysis process was systematic, it was a back-and-forth movement between the whole and parts of the text. Table 2 gives an overview of the analysis process executed on each text.

Ethical consideration

This paper was extracted from a nursing PhD thesis. The thesis was approved by the Ethical Committee center of Kerman University of Medical Sciences (Ethical Code: ir.kmu.rec.1395.580). The procedure of this work was explained to the participants and they were informed that they could withdraw from the study at any time. The participants were assured about the confidentiality of their information as no names or facts were stated in our data. Speaking about the needs during the treatment and experiencing some relevant problems has an emotionally charged nature and may lead to a painful reminder of various situations. This risk was handled by the researchers by being attentive and sensitive to the interviewees' emotional reactions.

Trustworthiness

Four issues are normally used to describe various aspects of trustworthiness: credibility, confirmability, dependability,

and transferability.²⁷ Several techniques were used to enhance trustworthiness in the present study. Peer checking was done by the second researcher's supervisors (the first and third researchers). The research team tried to collect data from the participants with different experiences and socio-demographic characteristics. Through holding frequent sessions, the study's progress and process were reported and discussed between the second researcher and the supervisors. Member checking was completed with some of the participants in order to validate the interpreted findings (codes and categories). Some of the faculty members checked the encoding process and access to categories (external checks). In addition, a clear and detailed description of culture, context, selection, and characteristics of the participants, data collection, and process of analysis were provided.

Results

The present study revealed that the most important needs expressed by the participants was related to "organizational therapeutic support". This main category consisted of three sub-categories, including the need for financial support, inadequate environmental conditions in health care facilities, and not having the opportunity to choose, represented in table 2.

Based on the experiences of our participants, once patients are admitted and treated in a health center, receiving the optimal health care is their most important right. In addition, they need to receive information on their disease in the most comprehensive and sufficient manner. They also expressed that they need the freedom to choose and decide freely for the provided health service. The environment in which the service was received had a desirable quality and appropriate setting. The most important

expressed needs within the organizational and social context of the participants were the needs for financial support, adequate welfare facilities of the treatment environment, and independent decision making.

Need for financial support

According to the participants' experiences, when patients faced with tremendous medical costs, they felt they needed further support from family, relatives, and supportive organizations. Given that the treatment process of cancer is long and consistent, it is highly stressful and painful. They also suffered greatly from financial problems along with the disease-induced complications and physical problems. These heavy health costs have adverse consequences, including the lack of timely treatment, the abandonment of treatment, and delayed treatment. Considering that patients who were breadwinners had no family supporter and had to pay for their living expenses and treatment, some of them left the treatment, and consequently, the disease was exacerbated and further complications appeared.

"10 days ago, I visited a doctor. An injection and a few pills cost me 320000 Tomans. It was a hormonal injection that I have to do every three months. In addition to these costs, my chemotherapy costs are too high, and I do not receive any support from anywhere." (Patient number 6)

"If I do chemotherapy, it would mean absolute rest and I would not have any energy. After exactly one week, I got some energy. Therefore, when I saw that I had a lot of problems and no financial supporter, I decided to give up." (Patient number 8)

The participants claimed that financial support from the health center and charity organizations was not enough since they paid a very small percentage of the cost of the treatment, and supplementary insurance was such that the person must first pay the

treatment costs, and after that, the insurance company would pay the cost by reducing the franchise, leading to a very painful and disturbing problem for these patients.

" The only help I received was for getting my teeth repaired in Yas charity center. However, in terms of medical expenses, they did not help with anything. For this reason, I feel anxious since we do not have much money. My father and mother want to sell their house to help pay for my treatment" (Patient number 5)

Inadequate environmental conditions in health care facilities

The bustle of the therapeutic environments, the weakness of the hospital nutrition program, inadequate facilities, inappropriate environment, and the unwillingness to be admitted in emergency departments were the most important issues that were addressed by the participants as the needs of the treatment environment. Those in emergency and physical inaccuracy waited for several hours in doctors 'offices to visit the doctor or for beds to become available in the oncology wards of hospitals. According to the participants, there were not even enough chairs in the physicians' offices to allow them to sit down, so they had to spend several hours standing up, which led to exacerbation of the patients' conditions.

"They just told me that I had to have a bone marrow test. I did the test and then they said that the name of the disease was lymphoma and I had to be hospitalized. I waited for a month to receive the treatment since the hospital was too crowded and the beds were full." (Participant number 1) Another problem in the setting of the hospitals expressed by the participants was related to inability of hospitals to provide a diet for such patients. The diet that is given to these participants is not specialized and is similar to that of other patients; most of them were not fully satisfied with this diet and thought that it had to be modified.

"I got anemia because of the bad diet and the side effects of medicine in the hospital and I did not have a good financial situation to order food from out of the hospital. Unfortunately, the food is the same for the patients who have surgery, receive chemotherapy, or have diabetes, although it must be taken into account that the needs of our body are different." (Participant number 6)

Many healthcare settings do not have a good health condition. These participants experienced severe immunosuppression due to numerous medications and treatment process, and this poor sanitary environment was a threat to their health and could lead to development of other diseases and infections in their bodies. Inadequate facilities, inappropriate temperature of radiation therapy setting, and inadequate sanitary facilities in the department were evidence of the lack of facilities for the participants and their caregivers.

"This department is so weak in comparison with other departments, which is the reason of many infections is the unhealthy environment. For example, there are patients who should not be with us at all." (Participant number 7)

Another challenge that the participants pointed out was the need for adequate green space in the hospital environment. Due to the fact that these patients had an inappropriate psychological condition, faced with a psychological crisis at the beginning of the disease, and underwent frequent hospitalizations, they required a favorable environment. Green space and walking around in fresh air for a few hours could make the environment more relaxing for the patients and the side effects would appear with less severity.

"For example, there should be a center with a green space like a park for cancer patients. For 10 to 20 days, I was forced to just sleep on the bed and in stuffy and constant air. If

there was a place where we could sit in fresh air, it would be great. We really need to get fresh air.” (Participant number 4)

A number of participants tended not to be close to the emergency patients, because in this situation, they felt a sense of comparison, and as much as they tried to deal with it, they became disappointed. Being in a comparative position made them consider themselves as being close to death, and the other patients’ death was painful for them. On the other hand, due to the lack of adequate facilities in the department, they sometimes had to spend time in a room where a patient was dying, which was clearly difficult for them.

“One of the important issues was that the emergency patients and those who were better, were together in the same room. It really affected my mood. I became disappointed. When the patient next to me was dying, I felt I was going through the same experience.” (Participant number 2)

Not having the opportunity to choose

The patient's reluctance to refer to a male physician, limited number of oncologists, and not having the opportunity to choose the medical environment were some of their most important needs. The participants with breast cancer were reluctant to refer to a male physician for breast surgery and mastectomy. They were generally reluctant to refer to a male physician, and these issues were evident in their needs.

“We do not have a female surgeon. I said I would not go to a male doctor. Then I went to a gynecologist and she sent me to Mr. ... and I had to be operated with a male surgeon.” (Participant number 4)

Another issue encountered by the participants was the lack of opportunity for choosing a doctor and the health center. There were not enough specialists and doctors in the city where this study was conducted, and the patients did not have the opportunity to choose another doctor.

“There are only one or two doctors in Kerman who are specialized in this field and we just had to choose them for our treatment.” (Participant number 3)

According to the patients, there were no central hospitals offering a private service for cancer patients, and those who wanted to be hospitalized in a private section had to go to other provinces.

“Unfortunately, there are no private hospitals for special cases and those with financial ability who want to be hospitalized in a private environment.” (Participant number 10)

Discussion

The results of the present study indicated that the most important needs of the participants were organizational constraints, financial problems, inadequate palliative-therapeutic care, unwillingness to be close to the emergency patients, and inadequate opportunity to choose. The financial problems of the participants included the need for financial support from the family or public and nongovernmental organizations, and the cost of treatment, leading the patient to abandon the treatment. According to Brooks (2011), financial problems are directly related to individuals’ income status, socioeconomic status, insurance status, and severity of illness; meanwhile, individuals' stress is related to the cost of disease and home care as well as the lack of access to specialized cancer treatment facilities.²⁸

According to the results of the studies conducted by Gordon (2007), Bradley (2007), and Zaidi (2012), government-recruited patients are less worried about the cost of disease than those who are not employed. In addition to the cost of treatment, patients encounter issues such as care of children, meeting the needs of the family, providing the necessary medical equipment, and cost of providing special

diet and supplementation.²⁸⁻³¹ These concerns are more pronounced in lower income families, affecting the quality of life of these people to a greater extent.³²⁻³⁴ In other studies, this has been mentioned that the unmet needs reported by these individuals, caused financial concerns, psychological complications, and psychiatric disorders, including depression and a decrease in quality of life in cancer patients.³³ This is important in particular once the patient is the breadwinner. According to the data obtained through our interviews, most patients, in this developing country, faced with economic difficulties. Accordingly, it seems that one of the solutions to reduce the burden of cancer and its consequences on sufferers is management of patients' economic problems. Fathollahzadeh et al. (2015) and Abdollahzadeh (2014) introduced economic problem-induced stresses as one of the most important concerns of Iranian cancer patients, appearing in different stages, from diagnosis to treatment and rehabilitation.^{35,36} However, on the contrary to the current study and studies conducted in Iran, Fenn (2014) reported that 8.6% of patients faced financial problems, 11.7% had a moderate financial need, 10.3% had little financial need, and 69.6% did not face any financial problems.³³ The difference between the results of this study and the other studies shows that health policies are different between developing and developed countries. In developing countries, such as Indonesia,³⁷ India,³⁸ South Korea,³⁹ Southeast Asian Nations,⁴⁰ and Turkey,⁴¹ the high cost of diagnostic process, treatment, and hospitalization are known to be the most important concerns in cancer patients and the main part of family income is spent on the treatment process of these patients. These concerns and problems are related to the support received by the supportive organizations and charities. In the current

study, the participants complained about poor service delivery by charities and well-being organizations, and they considered the lack of information and lack of response to patients' demands as one of their most important problems. Armes (2009) also argued that certain factors, such as relationship with the health and treatment system, the behavior of the staff of these organizations, and the social support that patients receive, were effective on determining the extent of the care needed.⁴² In addition, O'Brien et al. (2017) reported financial needs and the need to have a medical card as important concerns of cancer patients.⁴³ In a study conducted by Pourreza et al. (2017), the cost of cancer patient was divided into two types of direct and indirect costs associated with the treatment. The highest expenses for the patients referring to the diagnostic and therapeutic centers of Tehran University of Medical Sciences were related to chemotherapy costs (48%), surgery (25.8%), diagnostic tests (8.6%), nonofficial costs (2.4%), and interurban travel for access to health services (3.4%).⁴⁴ In the present study, the main concern for the residents of provinces was the availability of health services. Unfortunately, the lack of sufficient facilities in the cities has resulted into several interurban or even provincial trips and the accommodation of the patients in large cities to access health services, which is in line with Pourreza's et al., (2017) and Gordon (2009) findings.^{44,45} Another indirect cost-imposed issue on cancer patients is accessing and providing a diet appropriate to the treatment and disease. Pourreza et al. (2017) and Caccialanza et al. (2016) also stated that providing appropriate food was one of the factors imposing high cost on cancer patients.^{44,46} Other problems of the patients participating in the present study were the busyness of

medical environments, the lack of a medical care center, inadequate welfare facilities and inappropriate settings, and the admission of cancer patients in emergency department, indicating no palliative- therapeutic services for patients. According to WHO, palliative care includes all active and complete measures to reduce suffering and improve the quality of life in the patient. In general, palliative care approach is particularly designed for patients with a specific condition that do not respond to treatment, and the direct result of the disease is death; this kind of care only relieves the patient and reduces the symptoms of the disease.⁴⁷ Moore et al. (2015) conducted qualitative in-depth interviews with 8 cancer patients and concluded that the management of the disease in a person depended on the appropriate health environment and the amount of support that the individual received after the treatment.⁴⁸

Based on the results of this study, the most important problems expressed by the participants in social and organizational fields were financial needs. Other researches have also shown that satisfactions of patients from health care system and financial support is lower than 50%. Inadequate palliative care environments the need for financial support from public and nongovernmental organizations, and the high cost of treatment that causes abandoning treatment were found to be the most important needs in patients with cancer in this study. On the other hand, having the opportunity to choose a physician with the same sex or a health center is a very essential need for patients, particularly in woman. It could be attributed to culture and religion of Iranian people whose religion prevents them from choosing a male doctor. Therefore, attention to the culture and values of patients is one of the important needs in providing patients care. Therefore, we could suggest focusing on further organizational

support and ways to reduce the needs of patients.

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Conflict of Interest

None declared.

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Table 1. Characteristic of participants

Patient's code	Age	Gender	Cancer type	Marital status
1	34	Male	Leukemia	Single
2	47	Female	Breast	Married
3	29	Male	Leukemia	Single
4	55	Female	Breast	Married
5	44	Female	Breast	Married
6	40	Female	Breast	Divorced
7	70	Male	Colon	Married
8	56	Female	Breast	Married
9	37	Female	Pancreas	Married
10	45	Female	Non-Hodgkin's Lymphoma	Married

Table 2. Main category, categories, and sub-categories of the qualitative process in content analysis

Main category	Sub-categories	Sub-sub-categories
Organizational-therapeutic support	Need for financial support	<ul style="list-style-type: none"> • Need to sponsor spouse and family • Financial problems are a factor in exacerbating disease and giving up treatment • Inadequate support of supportive organizations
	Inadequate environmental conditions in health care facilities	<ul style="list-style-type: none"> • The crowded therapeutic environment • Insufficient hospital diet support • Inadequate facilities • Inappropriate environment • Unwillingness to be near sick patients
	Lack of opportunity to choose	<ul style="list-style-type: none"> • Female patient to refer to male physician • Limit on the choice of medical practitioner • Not having choices for the therapeutic environment