



THE ROLE OF PATIENT, THE PHYSICIAN AND HEALTH CARE SYSTEM IN EXPERIENCES OF CANCER PATIENTS UNDER OUTPATIENT ONCOLOGY TREATMENTS

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Summary

Background: Today, cancer is one of the most important medical problems. Successful management of cancer patients requires an understanding of their experiences.

The study aimed to explore cancer patients' experiences under outpatient oncology treatments.

Methods: The phenomenological approach was used to access the depths of experiences felt by patients. The study was done in specialized cancer hospitals and private hospitals. Data was gathered through in-depth and unstructured interviews with participants with previous arrangements. Data precision and robustness were determined based on Guba and Lincoln criteria. Data analysis was carried out based on Colaizzi's seven-step method.

Results: A total of 9 people participated in this study. The experiences of cancer patients were categorized into five main concepts, including 1) Individual problems, 2) Expectations from the physician and health care system, 3) the quality of the health care system, 4) Coping with cancer, and 5) Support in the fight against cancer.

Conclusions: These patients have a wide range of medical, psychological, support, and emotional needs, which are only known to themselves. Cancer itself is not the source of all these problems; instead, they have various sources, including family, society, policy-making, and treatment teams, many of which can be solved with proper education. Therefore, it is necessary to offer comprehensive planning, starting with medical teams, and create the required infrastructures in society.

KEYWORDS: *experiences, outpatients, qualitative research, cancer, oncology*

BACKGROUND

Today, cancer is one of the most important medical problems in the world. It is the second most common cause of death after cardiovascular conditions. In Iran, annually, there are reports of 51000 newly diagnosed cases of cancer and 35000 resulting deaths(1). There are four main methods: surgery, radiotherapy, chemotherapy, and hormone therapy used to treat cancer, and one or a combination of more than one of these methods can be used based on physician's guidelines. More than half of the patients are treated by surgery,

40% are treated using radiotherapy, and 10% are treated using chemotherapy or other methods(2). Given the advantages of outpatient treatments and the limitations of hospitalization, cancer treatment has shifted toward outpatient procedures requiring higher responsibility from caretakers and patients' families(3). Patient experience is essential in defining and improving the quality of cancer care and services worldwide(4,5). Many

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studies showed a positive association between the patient experience and health outcomes(6). The patient experiences allow for a better understanding of how well the health system delivers high-quality care. It is necessary to remember that these experiences are related to patients' culture and can change in different cultural situations.

Furthermore, care and treatment are also influenced by the culture(7), which in turn changes patients' experiences regarding care and treatment. However, it is necessary to know patients' experiences to improve the treatment process and provide better care(2). The current study aimed to answer the question regarding cancer patients' experiences under outpatient oncology treatments.

MATERIALS AND METHODS

The phenomenon investigated in this study is human experience. Therefore, the phenomenological method was used to assess the depth of experiences felt by various individuals(8). The study was done at Seyed-Al-Shohada Specialized Cancer Hospital and Milad Private Hospital. Purposive sampling was used in selecting patients. A minimum of a two-month lapse since the start of the treatment, lack of known psychological disorders, willingness to participate in the study, and patient's ability to explain their experiences were inclusion criteria for this study. Sampling was carried out to gain the best information and continued until information saturation was reached.

Data was gathered through in-depth and unstructured interviews with the patients based on general, open, and key questions without any guidance and direction. Discussion with additional questions helped participants to explain their experiences.

All interviews were done by the researcher, who was trained for interviewing. All nonverbal movements were also written down. Each interview was recorded by audio tape, and verbatim transcription of interview data was done at the earliest opportunity. Data precision and robustness were determined based on Guba and Lincoln criteria (1994), including credibility, dependability, confirmation, and transferability(9,10). Measures were taken to increase credibility and confidence in data and the likelihood of reporting acceptable data(11). To this end, participants were

allowed to guide the interviews, and enough time was spent during the data gathering and analysis process.

Furthermore, a member check process was also carried out. To this end, coded parts of the interviews were returned to the participants. Their opinions were sought regarding the similarity between extracted codes and their own experiences. Data was analyzed separately by two different people. The extracted results were compared to investigate the dependability of the results, which is similar to reliability or data stability over time and under similar conditions in qualitative studies.

Furthermore, an outside supervisor's analysis of findings and supporting evidence helped improve these criteria. A clear path of study steps was provided so that any reader could investigate the conditions using the same method and achieve the same results for confirmability. To achieve transferability and acceptance of the study's findings by people in situations similar to that of participants, we provided detailed, sufficient, and comprehensive information regarding the exact activities that were carried out to allow readers to transfer these findings to other structures(9).

Data analysis was carried out based on Colaizzi's seven-step method. First, the researcher read all the important descriptions and findings of the participants and sympathized with them. Then, important sentences, words, and those related to the studied phenomenon were extracted. A specific concept was assigned to each of these important extracted sentences. The researchers and other peers reviewed descriptions offered by participants, and similar concepts were categorized in different groups. All extracted opinions were transformed into a general and comprehensive description, and a complete description of the phenomenon was offered as a summarized description using this method. In the final step, the credibility of the findings was confirmed by a number of participants.

ETHICAL CONSIDERATIONS

Before the study, necessary introductory letters were obtained from Isfahan University of Medical Sciences. In case of acceptance, participants filled out a written informed consent form. After making arrangements with each participant,

the time and location of the interview were determined, and interviews were conducted.

RESULTS

A total of 9 people participated in this study, including seven women and two men. The average age of the participants was 48.33 years (with an age range of 19–64). Six participants had breast cancer, one from Leukemia, one from tongue cancer, and one from spinal cord cancer. The patients were undergoing treatment with chemotherapy or radiotherapy. The experiences of cancer patients were categorized into five main concepts, including 1) Individual problems, 2) Expectations from the physician and health care system, 3) the quality of the health care system, 4) Coping with cancer, and 5) Support in the fight against cancer.

Individual problems

Individual problems of cancer patients were divided into five subthemes: a) Complications of treatments, b) psychological problems, c) Financial concerns, d) Family challenges with cancer, and e) Lack of understanding by the community.

Severe complications of chemotherapy and radiotherapy were part of the complications of treatment. One of the participants described the complications of chemotherapy: *Chemotherapy is horrible! I also had problems after the surgery, but nothing is worse than chemotherapy (a 50-year-old with breast cancer). Another participant stated: Chemotherapy was really hard; I mean, radiotherapy was nothing against chemo. Radiotherapy had no symptoms, but chemotherapy was too hard. There are times one thinks his life is over. I suffered a lot.*

Cancer as an emotional shock, out-of-control feelings, and disappointment were three subcategories of psychological problems.

One of the participants stated: *I had lost myself. When they tell you that you have cancer, there is this initial shock where you just remain there, not knowing if you are still on Earth or not. You think about every single person you will lose, all of your family members. You feel a strange fear.*

Feelings of disappointment were another feeling experienced by the participants: *There were nights when I cried until morning. I was disappointed; hopeless. I felt I can't be cured. I couldn't leave everything around me behind and die.*

Catastrophic medical costs and inability to pay were subcategories of financial concerns. One of the participants said: *Treatment costs are too high. I have just paid 5 million [50 Million Rial] for a PET scan, and insurance only covers a third, 1.5 million, back to me. Even if you want to use the medicines, their cost is too high. Like, once, the cost of just one prescription was 2 million. There is a lot of stuff on TV and state media, and maybe people even believe them, where they call happily saying medicines are now free, they are now cheaper, and the like. It's not true at all.*

The subcategories of family challenges with cancer included the effects on family and family's reactions: *I had a little girl. I feared for her; I thought it could affect her. I was worried what she would do if she saw me like this with no hair. The intensifying of cancer's psychological effects due to the spouse's young age was among the problems: My husband was young just like me. It affected us badly.*

Society's inappropriate response to patients and misconceptions about cancer were subcategories of lack of understanding by the community. One participant said: *People think cancer is contagious or you are about to die. They either sympathize too much or run away from you.*

Expectations from the physician and healthcare system

Patients' Expectations from physicians and healthcare systems could be divided into three subthemes: a) Awareness, b) Patient-based/centered interaction, and c) Consultation.

One of the important points mentioned by the participants was the necessity of increasing society's awareness regarding screening and early diagnosis of cancer. *They have to make people aware if they are too young, have previous history or not. They have to do checkups since they turn 20. Women around my age should be under careful supervision. They shouldn't take any pain lightly.*

The patient-based/centered interaction subcategory was part of a better relationship with patients, while the subcategory of consultation was part of the attention to patients' side problems. The presence of physicians with patients during radiotherapy was one of the needs of participants: *Another thing is that I don't know the doctors who come to you here are interns or anything else. The physician himself should come for radiotherapy. If the physician himself is doing the radiotherapy, it will be a bet-*

ter job with better results. Even if they come here to learn, at least a radiotherapy physician should check me personally once a week. No one checks on us here. The importance of consultation and guidance was also high, and one of the participants stated: *They should give you consultation if there are any problems. They say there was an earthquake; why do you expect no cracks on the walls? It's true that we are sick but we don't have to suffer. No matter who we asked, they couldn't give you a good answer.*

The quality of the healthcare system

The lack of quality in the healthcare system can be divided into five subthemes: a) Dissatisfaction with the doctor, b) Dissatisfaction with staff, c) Dissatisfaction with equipment, d) dissatisfaction with facilities, and e) Differences in services at different centers.

Dissatisfaction with doctors had subcategories of Inability to make early diagnosis and treatment, suppression of patients' Morals, and Ignoring patients' rights of physicians. A patient said: *You know, first of all, I didn't go to a specific physician because they couldn't diagnose my problem since the start. They finally managed using MRI. Before that, no one could diagnose my condition.* (19-year-old participant with spinal cord cancer). Complications as a result of late or incorrect diagnosis were one of the problems mentioned by the participants: *Two years ago, no matter how much I told the doctors my spinal cord aches, they say it's cold, or you are having spasms; they paid no attention. Then, around one year ago, we say it had become more severe. Then I did a bone scan, and they gave me Aromasin pills, but they had no effects. Then, I did radiotherapy on my spinal cord, and the pain remained. They said there is nothing else you can do. Then I went to Tehran myself, did a PET scan, and then came back here with the results.*

Service problems included subcategories such as dissatisfaction with staff and hospital office workers. Inappropriate behavior and lack of understanding regarding patients' conditions were also reasons for dissatisfaction. One of the participants said: *Maybe it would be better if they had more interactions with patients. They have no interactions. The staff members are too mechanical.*

Dissatisfaction regarding equipment and facilities had two subcategories: Lack and defects of diagnostic and treatment equipment and lack of hospital welfare equipment. Lack of trust among

patients toward diagnostic laboratories was one of the codes related to lack of diagnosis and defects of diagnosis and treatment equipment. One of the participants stated: *This lab, they had lost the result of my test. I had paid in advance, and when I demanded answers, they said a file of I don't know what has been lost, the computer is damaged, our information is gone; all other excuses. But all of those were lies.* Regarding the lack of hospital welfare equipment, and one participant said: *I see a lot of neglect in the hospital, and it's also very busy ... they never ever pay attention to these things in the hospital.*

Differences in services at different centers included three subcategories: Diversity in the service type, Diversity in the costs, and Diversity in the quality of service. Participants believed that services provided in different centers are different. Some centers offer consultation with a group of specialists, and some centers have a better and more accurate laboratory. Participants also believed that the private sector offered better quality of services: *"I saw that there is a lot of neglect in public hospitals, and they are also very crowded. Here (a certain private hospital) is much better. I asked the doctor to transfer me here. I wanted to come here"*.

Coping with cancer

The concept of coping with cancer included three subthemes: The patient coping with cancer with subcategories of a) Spirituality, vivacity, coping with the conditions, b) Strengthening the body, and c) Continued treatment. Participants believed spirituality to be about prayer and trust: *You have to improve your trust in god and have a high motivation.* Another participant stated: *I trusted in god and never felt afraid. I never thought to ask why things are like this or not like that. We follow god's will, and god willing, we'll be cured.*

The doctors in the fight against cancer had the subcategory of Efficient doctors. The participants mentioned trust in the physician, the physician's presence in treatment sessions, and timely diagnosis and correct treatment. As a strong support pillar, the family was also mentioned in the subtheme of *the family in the fight against cancer*. Regarding the role of family, one participant said: *Well, my daughter, my spouse, and my mother helped me a lot. For example, when I had to do chemotherapy every 21 days, my mother helped me a lot. When someone gets sick, several families get involved. But it's*

good because they can give moral support; it was the only thing they could do. My daughter, husband, and mother didn't let me do any work. It was really helpful.

Support in the fight against cancer

Supporting the patient in the fight against cancer had three subthemes, including a) Emotional support, b) Financial support, and c) Information support. Fulfillment of patients' emotional needs and sympathy were the subcategories of emotional support. Regarding financial and emotional support, one participant said: *I only say, in places where people go to do chemotherapy, they have to take care of patients' emotional conditions. Financial and emotional support are the best help you can offer a cancer patient. These two are the best possible ones. Even now, some people don't have insurance.*

Information support also included two subcategories of general and specific information. Acquisition of information through the internet and other people, participation in educational workshops, and knowledge gained from physicians were the sources of information mentioned by the participants.

DISCUSSION

Findings showed that treatment complications are among the patients' problems. Among outpatient treatments, chemotherapy had the most significant amount of side effects, which has also been reported in other studies investigating cancer patients' experiences(12-13). The complications resulting from chemotherapy not only have immediate and direct effects during treatment sessions but can also lead to damaging emotional problems.

Participants stated that being informed about their cancer had caused them physical and emotional stress. Other studies also reported that after being diagnosed with cancer, patients feel that they are in an uncontrollable and challenging situation(14). Patients with a cancer diagnosis and their families experience anxiety, fear, anger, and hopelessness, and it can be intensified over time if it remains unaddressed(15). They experience unexpected life-changing events. They might experience reactions such as shock, disbelief, confusion, sadness, anger, guilt, and resignation(16). While they suffer, the research stresses that healthcare

providers do not have sensitivity in delivering the cancer diagnosis(17).

Financial problems and the inability of the patients to cover diagnosis and treatment costs were other problems experienced by the patients. These costs alone can sometimes be a more significant threat to patients' lives(18). Suffering from cancer leads to high treatment costs and financial burdens for families, which can lead to psychological problems(12).

Patients stated that cancer affects all their family members. They were worried about the effects of their condition on their family members. Lack of understanding from society and concerns regarding negative social reactions can have negative effects on adaptation to cancer and make it difficult for patients to return to their everyday lives.

One of the participants' expectations in this study was increasing patients' awareness. Studies show that patients who had access to information from the healthcare system regarding their condition, early diagnosis, and treatment methods showed higher satisfaction with the healthcare system(19,20,21), and it reduced patients' anxiety(13).

Education and guidance about side problems such as nutrition were some of the expectations of patients from the healthcare system. Cancer increases the changes of nutritional disorders in patients, which can lead to increased complications. Therefore, it is necessary to carry out early dietary interventions in cancer patients. Nutrition is integral to clinical care and is often neglected in patients(22). One of the factors that can indirectly affect patient satisfaction is a suitable nutritional plan based on their condition(21).

Patient-centric interactions were among the expectations of the participants. In literature, patient-centric interaction is the type of interaction in which patients' needs, beliefs, values, and preferences are considered(23). The demands mentioned by the participants were better interaction, understanding of patients, and attention to patients' problems and questions.

Lack of competence in the healthcare system was another main theme of this study—the inability of different healthcare sectors to satisfy patients' needs. The current study identified several factors for patient satisfaction, including the performance of physicians, medical staff, equipment,

and facilities. These factors are also mentioned in other studies(21). Bridge et al., in their investigation of patient experiences, found out that patients had three main wait times relating to the clinic environment: Waiting for health care providers, Waiting for tests, and Waiting for treatment(17). Differences in services provided in different centers, not receiving suitable care, and having to transfer to treatment centers in larger cities were among the experiences that caused problems for patients.

Among the problems mentioned in dissatisfaction from physicians was ignoring privacy and methods of being informed about their condition. Although patient-physician relation is based on professional factors and physicians' attitudes, participants stated that physicians did not pay attention to information offered by patients during treatment and only concentrated on the condition instead of patients and their feelings. Patients interpret these interactions as a lack of support from physicians and medical staff, leading to untrusted relationships(24). Even though many studies report understanding of patients' conditions by medical teams, offering proper mental health care can lead to reduced stress and anxiety, especially before receiving chemotherapy(7). Such improvements might build additional support and trust between patients and healthcare providers(17).

Coping with cancer was another of the main themes extracted in this study. Patients move past the initial crisis stage, attempt to understand their situation and return to normal lives. There are various adaptive strategies in this stage, and several factors affect these strategies. Religious beliefs can be one of the most effective strategies based on the religious nature of Iranian society. Participants believed that spirituality is one of the effective factors in coping with cancer, which was also mentioned by the majority of participants in other studies(1,25,26). This concept is closely related to the idea of supporting patients in coping with cancer. In this regard, patients mentioned financial, emotional, and information support. Family members, the medical team, and society offer this support. Kinsinger also emphasized the need for support systems(27). The need for support was also one of the study's main findings by Vardy(28).

Along with the treatment concept, there is the belief that caregivers and medical teams must understand human pain to offer their services in

an emotional and empathic context. Support from close acquaintances is precious and can help patients to fight more seriously against their condition. A study on the experiences of women who have breast cancer shows that family support is the most crucial source of emotional support for patients(13,29).

Limitations: One of the limitations of this study was the need for more centers with the possibility of follow-up on patients' history because the patients change clinics or their physicians, and they don't select special centers from the beginning to the end. Therefore, it was impossible to choose patients who underwent various treatments. Still, only people under treatment for several sessions were selected and interviewed during the visit to the chosen center. Based on the results of this study, we suggest a quantitative investigation of factors mentioned in this study based on prevalence, importance, and accountability. This helps to determine the priorities of patients for further planning.

CONCLUSION

Cancer patients have a wide range of medical, psychological, support, and emotional needs, which are only known to patients. Patients are also faced with various problems in their treatment process. Cancer itself is not the source of all these problems; instead, they have multiple sources, including family, society, policy-making, and treatment teams, many of which can be solved with proper education. Therefore, it is necessary to offer comprehensive planning, starting with medical teams, and create the required infrastructures in society and related public and private health organizations to improve patients' conditions and the health situation of cancer patients.

DECLARATIONS

Ethical Approval

This study received ethical approval from the Institutional Review Board (IRB) of Isfahan University of Medical Sciences, Iran to which the researchers are affiliated [IUMS 295016]. All study protocols were performed in accordance with the Declaration of Helsinki. This study considered

ethical considerations such as the confidentiality of the interviewees' names and the written consent of interviewees and scholarships. Interviews were conducted in 2019. Informed consent from each participant was obtained after clearly explaining the objectives as well as the significance of the study for each study participant. We advised the study participants about the right to participate as well as refuse or discontinue participation at any time they want and the chance to ask anything about the study. The participants were also advised that all data collected would remain confidential.

Competing Interests

The authors declare that they have no competing interests.

Author's Contribution

M. Sh. conceived the study and was involved in the study design, reviewed the manuscript, analysis, report writing and drafted the manuscript. F. K., K. S. and M. H. were involved in the study design, analysis and drafted the manuscript. All authors read and approved the final manuscript.

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Availability of data and Materials

The datasets used and analyzed during the current study are not publically available due to ethical restriction and personal data protections but are available from the corresponding author on reasonable request.

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Sažetak

ULOGA PACIJENTA, LIJEČNIKA I ZDRAVSTVENOG SUSTAVA U ISKUSTVIMA OBOLJELIH OD RAKA TIJEKOM AMBULANTNOG ONKOLOŠKOG LIJEČENJA

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Dosadašnje spoznaje: Danas je rak jedan od najvažnijih medicinskih problema. Uspješna sveobuhvatna skrb o pacijentima s rakom zahtijeva razumijevanje njihovih iskustava.

Cilj studije bio je istražiti iskustva pacijenata s rakom tijekom ambulantnog onkološkog liječenja.

Metode: Fenomenološki pristup korišten je za pristup analizi iskustava koje proživljavaju pacijenti. Istraživanje je provedeno u specijaliziranim bolnicama za rak i privatnoj bolnici. Podaci su prikupljeni kroz dubinski i nestrukturirani razgovor sa sudionicima. Preciznost i robusnost podataka određeni su na temelju Gubinih i Lincolnovih kriterija. Analiza podataka provedena je na temelju Colaizzijeve metode u sedam koraka.

Rezultati: U istraživanju je sudjelovalo ukupno 9 osoba. Iskustva pacijenata s rakom kategorizirana su u pet glavnih koncepata, uključujući 1) Individualni problemi, 2) Očekivanja liječnika i zdravstvenog sustava, 3) kvaliteta zdravstvenog sustava, 4) Suočavanje s rakom i 5) Podrška u borbi protiv raka.

Zaključci: Ovi pacijenti imaju širok raspon medicinskih, psiholoških, potpornih i emocionalnih potreba, koje su poznate samo njima. Sam rak nije izvor svih tih problema; Umjesto toga, imaju različite izvore, uključujući obitelj, društvo, timove za donošenje politika i liječenje, od kojih se mnogi mogu riješiti odgovarajućim obrazovanjem. Stoga je potrebno ponuditi sveobuhvatno planiranje i edukaciju, počevši od medicinskih timova, i na taj način stvoriti potrebnu infrastrukturu u društvu.

KLJUČNE RIJEČI: *iskustva, ambulante, kvalitativna istraživanja, rak, onkologija*