



Lived Experiences of Iranian Cancer Patients After Survival: A Phenomenological Research

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Abstract

Background: There are significant issues in the treatment of cancer patients. Despite these issues, there is still room to explore unique lived experiences after survival. **Aim:** This study aimed to explore the experiences of cancer survivors after chemotherapy. **Method:** A descriptive phenomenological study was conducted in Zabol, Iran. A purposeful sample of 15 cancer survivors was selected to gather data using semistructured interviews. Colaizzi's method was used for data analysis. **Results:** Four themes were extracted from the interviews. These were altered body image, mood swings, uncertain and dark future, and choosing a solitary lifestyle. **Conclusion:** Cancer patients experience various physical, psychological, and social changes including stress, anger, nervousness, despair, worthlessness, depression, social isolation, and even the wish to die after chemotherapy.

Keywords

chemotherapy, patients, descriptive phenomenology, survivors, Colaizzi's approach

Introduction

Despite advances in medical diagnoses and treatments, cancer still involves pain, restrictions, deformity, and death. It is the second leading cause of death in the United States (1) and the third in Iran (2). Unpredictable outcomes and the possibility of death create continuous physical and mental problems in cancer patients (3). Cancer changes social roles and can lead to loss of independence and self-confidence; it causes depression, anxiety, fear, violence, difficulty in communication, and lack of willingness to participate in self-care programs (4). Cancer patients undergo different treatments. Chemotherapy is one of the most common methods of treatment, and it has many side effects (5). These side effects of chemotherapy are the worst aspect of cancer treatments (6). Chemotherapy accounts for emotional and social problems (7), exhaustion, sleep disturbance, and impairment in the quality of life of patients (8). Although the survival rate of cancer patients has increased by at least 5 years in developing countries, the side effects of chemotherapy result in a relatively constant alteration in the body functions of survivors (9,10).

Chemotherapy improves health-related quality of life, which has more relevance than survival for many patients and is a key outcome of treatment (11). Identifying the lived experiences of cancer patients after completing chemotherapy with qualitative research methods leads to a deep

understanding of clients' issues and helps care providers to plan comprehensive and effective support for them (12). Reaction to cancer diagnosis may vary in different cultures. Medical providers play a key role in the follow-up of cancer patients at various stages of their illness; yet, they have little knowledge on how to address the issue of conveying the diagnosis to clients (11). Iranians, particularly health-care providers, are unwilling to inform patients about their cancer diagnosis. They believe patients cannot bear to know the diagnosis (13). There is also a lack of experience in breaking bad news to clients. Physicians prefer to inform family members rather than the patients; hence, there is a strained relationship between patients and doctors (14). Therefore, patients usually receive indirect information from the nonverbal behavior of family members and health-care providers. However, most patients are willing to understand their diagnosis. Being

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Table 1. Characteristics of Participants (N = 5 Women and 10 Men).

Gender	Age (years)	Type of Cancer	Survival Time (years)	Gender	Age (years)	Type of Cancer	Survival Time (years)
Female	59	Breast	8	Male	42	Lymphoma	13
Female	44	Brain	9	Male	70	Prostate	3
Female	53	Breast	3	Male	67	Prostate	4
Female	42	Breast	2	Male	74	Colon	2
Female	51	Breast	4	Male	15	Blood	5
Male	62	Prostate	8	Male	13	Bone marrow	3
Male	42	Colon	6	Male	60	Prostate	7
Male	57	Brain	1				

reluctant to divulge the diagnosis can result in a pessimistic view of cancer prognosis (13,14). This study was performed to explore the experiences of cancer survivors after chemotherapy due to the importance of follow-up after cancer treatments and the lack of previous studies in this area.

Method

Design and Participants

This study aimed to explore the experiences of cancer survivors after chemotherapy. A descriptive phenomenological approach was used to portray the life experiences of survivors. Descriptive phenomenological studies focus on understanding the essence and nature of phenomena and human responses to events (12). In this particular descriptive phenomenological study, researchers “bracketed” their preexisting knowledge about the topic in order to position themselves to look at the phenomenon through the eyes of participants. A purposive sampling method was used to recruit the participants.

The aim of the purposive sampling was to recruit participants representing a range of perspectives on the period after chemotherapy. The diversity of experiences was based on various types of cancers, gender, and duration of survival after chemotherapy. The participants gave their consent to contribute to the study. The inclusion criteria consisted of the willingness to participate freely and voluntarily, being literate, and a gap of at least 6 months from chemotherapy courses. Participants were free to leave the study at any time. Overall, 15 cancer survivors participated in the study (5 women and 10 men) with a mean age of 59.1 years having histories of breast, brain, colon, prostate, and lymphoma cancer (Table 1).

Data Collection

Data were collected between January and June 2017, using semistructured interviews and observational field notes. Interviews were conducted according to the convenience of participants at prearranged times and places. The majority of participants wished to be interviewed at their respective homes. The duration of interviews ranged from 45 minutes to 1 hour. Open-ended questions were included in the in-depth interviews to gain more information. The questions focused on lived experiences starting from the time of cancer diagnosis. Initially, the participants were asked questions such as “What

have you experienced during and after chemotherapy?” Follow-up questions were also asked to clarify thoughts, feelings, and ideas and to gain deeper understanding on various aspects of experiences. Reflective questions such as “How do you feel about life after chemotherapy?” were asked. However, suggestive questions were avoided. Additionally, researchers took notes to record observed cases, interactions, communication, environmental factors, and nonverbal gestures.

The data were saturated after 12 interviews, but 3 additional interviews were conducted for certainty. Data collection and analysis were performed concurrently. Interviews were recorded using a digital voice recorder with the consent of participants. Each recorded interview was listened to multiple times after verbatim transcription.

Data Analysis

Colaizzi’s method (15) was used for data analysis as follows: (1) Researchers read the transcription of each participant’s interview and also listened to the audio-taped interview multiple times to acquire a feeling for the participants and their responses. (2) Researchers underlined and extracted significant statements from the transcripts that directly pertained to the phenomenon under investigation—the experiences of cancer survivors after chemotherapy. (3) Researchers formulated and wrote the meanings of each significant statement. These formulated meanings faithfully reflected the intent of the participant’s statements while becoming increasingly abstract. This required constant comparison of each participant’s original transcript, statements, and formulated meanings. (4) Researchers organized the formulated meanings into 4 clusters according to themes. To validate clusters or themes, researchers compared them with the original interviews and refined them in order to reflect the intent of the participants. This took several iterative cycles. (5) Researchers integrated the results of data analysis into an exhaustive description of the phenomenon under study—the experiences of cancer survivors after chemotherapy. (6) Researchers asked available participants to read the exhaustive description to ensure that it represented their experiences (as a measure of credibility and validity of research findings). In this study, only 3 participants were available to read the exhaustive description after the completion of data analysis.

Rigor

The rigor of the study was assessed through credibility, dependability, confirmability, and transferability strategies (16). Credibility ensures that the phenomenon was accurately identified and described, which was done through triangulation, audit trail, repetitive comparison of statements, formulated meanings, and the exhaustive description, as well as a review of statements and formulated meanings by 3 participants and 3 researchers (M. A., A.A., and M.N.). Dependability indicates consistency in findings, which was achieved by clarifying vague information or data during interviews using the code–recode procedure for analyzing interviews and through examination of data by an external reviewer. Confirmability indicates confirmation of results by others, which was achieved through explication of study methods, double checking of results by researchers, and bracketing of ideas, thoughts, and preassumptions on the research topic. Transferability refers to the generalization of findings to other settings or contexts; in this case, researchers attempted to include participants with different types of cancer though the transferability of data was questionable due to a limited context.

Ethical Consideration

This study was approved by the research ethics committee of the Zabol University of Medical Sciences, Zabol, Iran (ethical code: Zbmu.1.REC.1396.216). The participants filled in the consent form and had the right to refuse to participate in the study. The researchers assigned a code for the participants to keep confidentiality.

Findings

Four major themes emerged from the interviews: altered body image, mood swings, uncertain and dark future, and choosing a solitary lifestyle.

Altered body image. The cancer survivors had experienced a variety of physical changes such as premature aging, weight loss, and hair loss that resulted in alterations in body image.

I'm not well. I lost my hair, and I don't like putting on a hat and meeting my old friends. (Participant 1)

... I'm getting thinner and thinner. My cheekbones can be seen and people's attention is drawn to me because I can't eat much and have no appetite. (Participant 8)

... I feel I can't do anything like even drinking a glass of water. I feel I'm like an 80-old man, much older than my real age. (Participant 12)

Mood swings. Mood swings comprise a range of feelings from being at a higher level of wellness or happiness to feelings of severe sickness, sadness, worthlessness, and/or social isolation. The participants reported irregular or inconsistent patterns of feelings after survival.

Sometimes I'm feeling powerful and active, and sometimes very depressed and apathetic. I only struggle to survive. (Participant 1)

... Sometimes I feel good and sometimes I wish I were dead. (Participant 4)

Changes in my daily life are extreme; sometimes I'm happy and sometimes sad. So, I'm unsatisfied. (Participant 5)

Uncertain and dark future. The patients experienced many side effects during the disease and treatments, which weakened and predisposed them to other diseases. These side effects led to unstable physical conditions. Also, survivors feared the risk of cancer recurrence that resulted in uncertainty, despair, and expectation of early death.

I was always thinking about death because no one can survive cancer and I feel that death is very close to me. (Participant 2)

I hope that the course of chemotherapy is effective and the problems that I've tolerated become positive for my life. (Participant 3)

Although I've undergone chemotherapy 5 years ago and there is no tumor in my brain now, I think that another organ of my body will get cancer. Just a few days ago when I was eating something, I felt that the food is stuck in my throat and I couldn't swallow it. I was afraid that it might be a tumor, so I immediately visited my doctor. (Participant 6)

Thinking about the future bothers me because the future is unclear. (Participant 7)

... I hope all my previous problems and attempts at treatments become successful. (Participant 9)

Choosing a solitary lifestyle. Changes in lifestyle were manifested in physical changes, sleep disturbance, fatigue, restrained relationships between couples, sexual dysfunction, and social isolation. Sleeplessness was related to anxiety and gastrointestinal problems including stomachache, lack of appetite, nausea, and vomiting.

My sexual desires have decreased very much and I do not have any desire; my husband is very reluctant too because he feels it annoys me and affects my mentality. (Participant 2)

I'm weak now. I get a cold easily and infections. It's forced me to stay at home. I'm afraid I have become too cautious. (Participant 10)

... Our lives have changed a lot. We used to enjoy our lives, and go out to eat and go to the cinema together before getting the disease. On holidays, we visited beautiful places with our family to have fun. But I don't like to go out now. My appetite has changed. I'm unwilling to eat. When I see them [family members or friends] not willing to go outdoors, it depresses me. (Participant 11)

I usually get sick a lot and catch a cold because of weather changes. Now my lungs are inflamed and this annoys me very much. I think these problems are related to the chemotherapy effects. My doctor said that I must be careful to avoid injuring myself and I should avoid anything that causes bleeding. For that, in fact, I have locked myself at home and I've been really isolated. (Participant 13)

I still cannot eat properly. My appetite and sleep habits have changed. I don't know when to sleep and when to get up. I don't even like watching TV and being with others. (Participant 14)

Discussion

This study aimed to explore the lived experiences of Iranian cancer survivors after chemotherapy. The results showed 4 themes: altered body image, mood swings, uncertain and dark future, and choosing a solitary lifestyle. These extracted themes were in agreement with previous studies (17–19).

Altered body image was one of the themes identified in cancer survivors. Chemotherapy complications led to physical and emotional changes in survivors that, in turn, resulted in loss of appetite and feeling like an elderly person. Chemotherapy has certain side effects that influence the body image of patients, reducing their self-esteem (20). This altered body image is a physico-psychosocial issue in cancer patients affecting their perceptions, thoughts, feelings, and general behavior (21).

The second theme was mood swings, which refer to emotional fluctuations in survivors. The life-threatening nature of cancer causes high levels of stress and mood changes. Patients face periods of depression, anger, and nervousness. The survivors experienced irregular patterns of emotional feelings varying from optimal levels of well-being to an increased sense of self-dissatisfaction, worthlessness, and even the wish to die. Mood disorders are one of the major side effects of chemotherapy that lead to life failure (22). In cancer patients, mood changes causing anger, nervousness, and depression are related to the stressful and life-threatening nature of the disease (23). Most of these mood changes result from the fear of death (24). Other studies have also confirmed that mood disorders are the major side effects of chemotherapy that affect the success of treatment (24–26). Mood swings could also result from a sense of loss.

The uncertain and dark future is another theme which arises out of negative thoughts regarding the outcome of treatment and fear of recurrence even after survival.

The survivors experienced physical weakness and predisposition to infectious diseases. Unstable physical conditions and the probability of cancer recurrence lead to uncertainty, despair, and expectation of death in survivors. Cancer patients experience ambiguity in their lives despite advances in treatment (1). The risk of cancer recurrence is reported even 5 to 25 years after treatment, which could be a late complication of cancer treatments (27,28). Besides, the life-threatening nature of cancer frightens people with regard to the future and possibility of death (29). Preoccupation with cancer recurrence and expectation of a painful death result in anxiety, depression, reduction in physical and social activities, and familial problems (30–32).

Choosing a solitary lifestyle is the other theme that survivors faced after chemotherapy. The survivors experienced anorexia, loss of libido, susceptibility to infections, changes in emotional relationships with family members, restrained

relationships, and social isolation. These changes affect the quality of life of cancer patients even after survival and result in social isolation and preference for a solitary lifestyle, which may have adverse effects in the process of recovery.

Patients experience many issues such as gastrointestinal problems, bowel problems like diarrhea and constipation, sexual dysfunction, and lack of support from family and society (33,34). One of the strong points of this study was to evaluate the experiences of patients with cancer after the completion of chemotherapy courses. The participants were of all ages, both male and female, having different types of cancer, and experiencing a new life after chemotherapy. One of the limitations of this study, however, was the lack of discussion on critical issues like death and dying, which some of the participants were unwilling to address. Additionally, the themes presented in this study cannot be generalized to all cancer survivors but are applicable only to those with similar experiences.

Conclusion

Cancer survivors expect to achieve recovery after the completion of chemotherapy but experience a lot of physical, emotional, and psychosocial issues including changes in body image, mood, lifestyle, and concerns about the future. These changes lead to other issues such as stress, anger, nervousness, despair, worthlessness, depression, social isolation, and even the wish to die.

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