

## Post-Diagnosis Experience of Iraqi Women with Breast Cancer: A Phenomenological Study

Tiran Jamil Piro\*

Department of Maternity Nursing, Hawler Medical University, Iraq

\*Corresponding author: Tiran Jamil Piro, Department of Maternity Nursing, Hawler Medical University, Iraq, E-mail: [tiran.jamil@nur.hmu.edu.krd](mailto:tiran.jamil@nur.hmu.edu.krd)

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### Abstract

**Aim:** The researcher in the present study aimed to investigate the patients' experiences who suffered from breast cancer. Since few studies have been conducted in Kurdistan in Iraq, and the experiences of patients have not been studied, by gaining insight into and awareness of these hurtful people, the world can be seen from their point of view.

**Material and Methods:** This qualitative study was carried out using a phenomenological approach. In this regard, a purposive sampling method was used in to select 12 women who suffered from breast cancer, a semi-structured interview was used to data gathering.

**Results:** The experiences of patients with breast cancer and understanding those involved in the disease are reflected in four main meanings or themes such as "looking for hope but promising", "Grief over Inability", "to do tasks", "fear of rejection", and "wounded but not scarred".

**Conclusion:** It can be said that breast cancer affects all aspects of the spiritual and social health of women and leads to a sense of frustration and disappointment. Therefore, they make an attempt to find hope which reduces the length of treatment. Therefore, this study can increase the caregivers' knowledge about the impact of the disease on the lives of the patients and whoever involved with the treatment system.

**Keywords:** Breast cancer; Experience; Phenomenology

### Background

Among various types of cancer, breast cancer is the most common cancer in women. It is known as the second leading cause of death in women aging 35 to 55 years old. In the United States, cancer accounts for 20% of all deaths [1-3]. Moreover, cancer is the second cause of death after cardiovascular disease. However, the prevalence of breast cancer is increasing in Asian countries including the Middle East and Arab countries such as Iraq [4]. The patients are usually diagnosed at advanced stages of the disease [1,5]. Breast cancer results in severe psychological consequences. The issue of death and mastectomy causes fear and anxiety in the patients [6]. The studies have shown that the disease increases dependence and vulnerability and decreases self-esteem. This disease usually leads to dizziness, pain, signs of physical and emotional disturbances, and improper daily functions. It also negatively affects social activities and intellectual relaxation. Additionally, these patients cannot participate in routine social activities, and the new roles make the patients more dependent and less able to support others [7-9].

In addition to prolonged hospitalization, other problems including frequent visits to the doctor, various treatments, and costly treatment reduce the quality of a patient's life in various dimensions. Usually, nurses and physicians treat patients with cancer in the same way as other patients, while cancer patients are in more need for psychosocial support. They expect everyone to support them [10].

A number of studies in this area have shown that patients describe their disease as hidden suffering. A qualitative study of 10 women who have recently been diagnosed with breast cancer has analyzed their experiences. This study aimed to investigate the experiences of women with breast cancer in order to enhance the insights of nurses into the experiences of patients with cancer, particularly breast cancer. This study revealed some aspects of the life of these patients, including emotional reactions, body changes, mental image changes, women's identity, main activities, and social networking [11].

It is very important for health care providers especially the nurses who support patients during treatment and recovery to understand these experiences. Nurses must learn this knowledge and be able to help women with breast cancer and their families to provide them with access to adaptive methods.

In their study, some researchers interviewed ten women with breast cancer and concluded that culture is an important criterion in women's experience regarding health and disease [11]. Another study at a cancer center in New York found that around 17% of cancer women who suffered from severe depression wished to have an early death. Given the profound effects of this phenomenon on patients and their families, and in order to provide appropriate care and support to such patients and their families, it is very important to gain knowledge about the experiences of people involved in this phenomenon because successful administration of patients and caregivers requires a comprehensive understanding of their experiences [12].

Since few studies have been conducted in Kurdistan in Iraq, and the experiences of patients have not been studied, the researcher in the

present study aimed to investigate the patients' experiences who suffered from this disease. By gaining insight into and awareness of these hurtful people, the world can be seen from their point of view. It can help healthcare providers figure out their role in this process and realize what kind of services they should offer to the patients and how they can serve them as human beings. Therefore, this study aimed to describe and explain the structure and nature of the experiences of women with breast cancer.

## Material and Methods

### Data collection and participants characteristics

This qualitative study was carried out using a phenomenological approach. The present study investigated the experiences of people who were in post-diagnosis stages. In this regard, a purposive sampling method was used in this study. Accordingly, 12 women (43 to 63 years old) with breast cancer participated in this study. Two participants were single and the rest were married and had 3 to 4 children. The researcher interviewed the women in a deep and intimate manner. The interviews lasted 40-70 minutes and were recorded and transcribed. The participants were asked if they had any problems with voice recording. The interviewer read the following criteria and consulted the participants to obtain their consent. The criteria were as follows: confidentiality of interview sessions and concealment and removal of the interviewees' names after transcription. After each interview, the transcribed texts were all compared with the originally recorded audios. After interview No. 12, the researcher concluded that the data were saturated. After the participants' goals (in accordance with inclusion criteria) were taken into account and they were provided with sufficient explanation, the interviews were conducted. In inappropriate conditions or following the participants' request, other interview sessions were held. The interviews were conducted in a place which provided the participants with comfort, privacy, and silence. In this research, open questions were used. The interviews began with a broad and general question and requests such as "Explain this disease (breast cancer) from your own perspective", and then additional questions and queries were asked to encourage and obtain further explanations. It should be noted that few patients were pleased to participate in the interviews because of low tolerance and inability. Interviews are usually subject to such limitations which are directly associated with experiences of patients, particularly those with cancer. Therefore, it made the study a bit problematic.

**Data analysis:** Diekelmann and Allen's process of analyzing narrative text was followed in the present study. The analysis is usually conducted by the researcher that follows seven stages: 1) Reading the text to obtain an overall understanding, 2) Writing interpretive categories and supporting them with excerpts of the texts, 3) Comparing interpretations to find similarities and differences and to clarify discrepancies, 4) Identifying relational themes that cut across multiple texts, 5) Seeking constitutive patterns, 6) Validating the analysis by persons out of the researcher and the final step is Preparing the final report using sufficient excerpts from the texts to allow for validation of the findings by the readers.

**Trustworthiness:** This study provided four constructs, i.e. credibility, transferability, dependability, and confirmability, in establishing the rigor of qualitative research. Since an interpretative phenomenological approach was adopted in the current research, confirmation of the research findings (which were obtained by the integration of the researcher and participants' viewpoints) was not entailed. However, in

order to ensure the transferability of the findings, the research process and excerpts of the interviews were comprehensively explained. The dependability of the findings was also guaranteed by long-term contact of the researcher with the subjects and frequent assessment of their statements.

**Ethical considerations:** The research protocol was ethically approved by the Research Committee of Hawler Medical University/College of Nursing.

## Findings

As mentioned earlier, 9 women participated in this study. Given the ethical considerations, the details of the participants' specifications cannot be revealed. The data were analyzed by methods proposed by Diekelmann and Allen as follows. The experiences of patients with breast cancer and understanding those involved in the disease are reflected in four main meanings or themes such as "looking for hope but promising", "Grief over Inability" to do tasks", "fear of rejection", and "wounded but not scarred".

### Looking for hope but promising

According to the interpretations provided for the participants' experiences by the researchers of the present study, understanding the main theme "looking for hope but promising" can be extracted from the women' stories. It should be noted that this concept consists of two sub-themes known as "acceptance of truth" and "self-exhortation". From the perspective of the participants of this study, the world has come to an end and it seems that they can no longer see the next day with delight. They are no longer hopeful of the future, but at the same time, they are looking for a flicker of hope in the distance. They are also talking about hope for a while so that they can relieve their disappointed heart. This flicker of hope may bring them joy and delight. To emphasize this finding further, it is necessary to consider what the participant No. 3 stated: Although many people try to give me hope, saying that I am going to be alright. My husband says that I do not trust anyone and I will get back to my normal life again. Sometimes I reply to them that everything is going to be alright. People do not lie to me. Then, I smile and do my routine tasks.

Some of the participants said that it is all up to God and emphasize that the disease is a divine test. As they put it: When God decides to make a person sick, He also gives patience and treatment to that person. For example, when you lose a beloved person, you say that you cannot live without him/her, but after three days, you eat, go out, and laugh; it is God's work and God is so great.

Participant No. 2 likened the disease to jail and said that one has no choice but tolerating it, confirming that the concept of "acceptance of truth". As she said: "I was always a healthy person. I have never been sick at all. Of course, this is the initial stage of my disease. Maybe this is the reason why I have lost my hope, but I will get well soon. I know that I will get well soon. A man who goes to jail for the first time finds it quite difficult and weird. Then, he gets used to it.

Referring to her hard life in the past and loss of her beloved ones, one of the participants added: I lost my parents and two brothers who were 21 and 22 years old. Can't I overcome this disease now? I sure can. Maybe this grief has led to the disease. No, the doctor said that the disease had nothing to do with the grief. Anyway, I'm going to endure. This is my fate. I have to endure. Maybe it is good for me. It all depends on God. He is great.

These expressions indicate the initial disappointment of these patients and the fact that they have lost hope for recovery, but they finally cope with the situation and accept the truth.

### **Grief over Inability**

Inability to perform maternal duties and establish marital relationships and mourn for the past all have led to the emergence of inability as one of the main themes. It refers to the fact that the women's understanding of the meaning of their disease was also affected by their inability to do their tasks. To make this concept clearer, one of the participants shared her ideas by reviewing her memories and the happy life of the past: I lost my parents and two brothers who were 21 and 22 years old. Can't I overcome this disease now? I sure can. Maybe this grief has led to the disease. No, the doctor said that the disease had nothing to do with the grief. Anyway, I'm going to endure. This is my fate. I have to endure. Maybe it is good for me. It all depends on God. He is great.

Patient No. 7 continued, My son is in the high school. Well, he needs his mother. I get nervous soon. I'm not a good mother for him. Another participant pointed out that her only concern is her 14-year-old daughter who has not learned cooking and cannot do her tasks without her mother.

I'm only concerned about my 14-year-old daughter who is very dependent on me. I have not asked her to help me in housekeeping activities. She literally knows nothing about these things. However, she has to learn how to cook, clean, and wash. I cannot address their problems the way I did in the past. I always used to cook for my children. My husband does not have an intimate relationship with our children, and he cannot be like me. I was closer to my children. I wish I were delighted and strong like before.

**Fear of rejection:** A number of the patients expressed their fear of being dismayed by their family, especially their spouse; so they decided to cover their chest (after surgery and removing it). For this reason, they tried to hide the changes. For instance, one of the participants said: My husband is 12 years older than me. He does not treat me warmly. He has always been inflexible in manners. There has never been an intimate relationship between us. I have not allowed him to see my hair. I have not let him. I have not even let him get closer to me.

**In this regard, another participant said:** My sisters treat me well, but I do not like to tell anyone. If they know about my disease, they will say, 'Oh, poor woman, she is ill.' It feels bad when people pity me. I do not want people to sympathize with me. As was deduced from the participants' stories their fear of loneliness make them conceal the truth also hatred of the subsequent compassions of others towards them, all of which imply that those patients are afraid of being rejected by their family and community. Because of changes and defects in their organs and their appearance, they believed that others will disregard them.

**Wounded but not scarred:** As participants' stories conveyed this meaning showed patients' pain resulting from prolonged and recurrent treatment courses. The participants described these treatment courses as unbearable and unending after they were diagnosed with the disease and underwent chemotherapy. The researcher discovered a very important theme known as "wounded but not scarred". The stories the participants narrated led to the emergence of subjective meaning such as "endless suffering" and "intolerance of treatment". For example, one of the patients explained her own experience of treatment courses and said: Surgery ended after 3-4 months, and it did not hurt anymore.

However, chemotherapy did not come to an end and lasted up to a few months. You may lose your temper at some point and decide not to go on with this treatment. You may not want to keep going again. You cannot even walk. When you work, you get tired soon. Suddenly, your heart starts beating fast. You do not have any other options, and you have to end it.

**Another patient also expressed her feelings as follows:** Another patient said: "After treatment, I was not feeling well at all. Particularly, I felt that I was getting paralyzed. I got a fever, and my headache did not go away. Additionally, my heart rate sometimes reached 107. My blood pressure was high. The doctor said that this was all because of my treatment course. It's very hard. When you go to the clinic, you feel like they are going to torture you. A participant, who had three children, described the treatment long and inexhaustible and said Doctor says I must start another treatment after chemotherapy. He says I need a laser-based treatment. Why is this? Why is this treatment taking so long? What is all this trouble for?" Although few patients agreed to talk about their experience, they seemed to feel good to share their feelings with the researcher. They described their feeling and understanding as a sense of rejection and grief.

### **Discussion**

According to the results of this study and the basic themes such as "looking for hope but promising", these patients need hope since they repeatedly emphasized this. They stated that they lost their hope at the beginning of the disease many times and were trapped in grief for an obscure future. However, sometimes they looked for hope or asked others for it. This study and other studies reflect the physical, psychological, and social crisis. Perhaps the reason why the participants react in this way is in part due to their fear of death which leads to a loss of hope. The study showed that support is a critical and multidimensional need and should be provided continuously to the clients. Usually, nurses and physicians prioritize physical support, while patients prioritize psychological support especially when they feel disappointed [13-15]. Besides, fear of failure to perform maternal responsibilities puts the relationship between family members at risk. This is perhaps the reason for their greater disappointment. A number of researchers have reported in their studies that breast cancer is a frightening and catastrophic event for many women. The feelings of grief, anxiety, confusion, and anger are obvious in women with breast cancer. Concerns about the future and their children have led to frustration and mourning for the past. A study showed that women with cancer wish to get back to their normal life as before. It should be pointed out that their feelings have also affected their family [3]. Another study showed that losing breasts means losing the identity of femininity. Moreover, long-term treatment and chemotherapy negatively affect the life and physical and mental well-being of patients with cancer. These results are in good agreement with those of the present study which found that the participants suffering from long-term treatment described their treatment as intolerable. They sometimes mourn for the past and think of their ambiguous future and their children. Moreover, changes in the mental image of women due to hair loss or surgery leads to concealment of truth. For example, in a study, the suffering during the treatment was described as a fundamental issue that reflected the women's emotional reactions to the treatment. It was also seen as a crisis [16]. Kocan and Gursoy in their study stated that women with breast cancer and undergone mastectomy experienced the negative effect of this life crisis on their sex lives [17]. In contrast, the study showed breast cancer women

wanted to present stronger for their family, so they try to hide their disease from their children or husband [18,19]. According to various studies, the disease can affect other family members, and all members of the family are somehow looking for ways to help the patient get rid of the crisis [20-22]. In summary, it can be said that breast cancer affects all aspects of the spiritual and social health of women and leads to a sense of frustration and disappointment. Therefore, they make an attempt to find hope which reduces the length of treatment. They also struggle to regain their past abilities and heal their hidden scars. Accordingly, long-term treatment has diminished their patience and tolerance. Therefore, this study can increase the caregivers' knowledge about the impact of the disease on the lives of the patients and whoever involved with the treatment system. The present study aimed to inform the patients, their families, and the community. Further research is recommended in this area.

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