The Familial Experiences of Women with Breast Cancer Referring to Chemotherapy Clinic: A Qualitative Study

Abstract

Background: Breast cancer and its treatment affect both the patient and her family, where the entire family and their functioning undergo disturbance. Therefore, this study has been conducted with the aim of interpreting the experiences of women with breast cancer with regard to their family. Materials and Methods: The present study has been done through the qualitative method with conventional content analysis approach. The sampling has been done through the purposeful method with the participation of 12 patients with breast cancer referring to Chemotherapy Clinic in Zabol in 2016. The data collection method was semi-structured interview. Data analysis has been done using the proposed stages by Grenham and Landman. The accuracy and robustness of the data were investigated, and ethical considerations were also taken into account. Results: Based on the results, three main classes including mutual supports, mutual sufferings, and ambivalent feelings as well as six subclasses were extracted. "Mutual involvement of the patient and family with the disease" was also identified as the theme of this research. Conclusion: The findings of the research suggested that the experiences of these patients with regard to their family can be described as mutual involvement of the patient and family. The reason is that women and their family, due to experiencing the suffering from the disease, tried to support each other and these conditions had set the ground for the development of ambivalent feelings, such that some of them felt a sense of emptiness (deficiency) due to lack of familial support, while others had experienced a sense of competence thanks to motivation and encouragement. Investigation of the relevant papers suggested that through presenting educational and supportive interventions for the families of these patients, one can help them to indirectly gain better experiences about their family.

Keywords: Breast neoplasm, familial experiences, qualitative study

Introduction

Breast cancer is the most common type of cancer among women worldwide.[1] The age of its incidence in Iran is at least one decade younger than that of developed countries.[2-4] The last cancer statistics showed the level of advanced breast cancer among Iranian women is 24 cases per every 100,000 individuals.^[5] This disease causes sense of imperfection in the body and altered bodily image, which not only results in loss of self-confidence and quality of life but also defects of feminine attractiveness, followed by depression, despair, anxiety, shame. fear of cancer relapse, and death.[4,6] However, in addition to psychological problems and disorders, the patients also suffer from problems associated with the family, and their relationship with their

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children is weakened.[7-10] A woman with breast cancer is a mother, sister, girl, and even a friend; all these roles affect each other and the patient. Furthermore, the patient and their disease influence other individuals in their lives, and others in turn affect the patient.[11] Thus, it can be stated that when a woman as a mother develops cancer, the entire family and its function experience disturbance.[12] Indeed, following the diagnosis of cancer and initiation of the treatment course, a sense of responsibility develops in the family members of the patient to provide care.[13] Thus, this disease creates new familial roles; since the mother's focus is mostly on treatment and due to the effects of treatment, there are times when she cannot play her beneficial role as the director of the house. Therefore, the family members should adapt to new roles and should accept more responsibilities. In addition, the patients understand that

How to cite this article: Noorisanchooli H, Rahnam M, Haghighi MJ, Hashemi SA, Younesbarani Z. The familial experiences of women with breast cancer referring to chemotherapy clinic: A qualitative study. Clin Cancer Investig J 2018;7:210-6.

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Access this article online Website: www.ccij-online.org DOI: 10.4103/ccij_ccij_92_18 Quick Response Code:

their children pay more attention to them and take care of them due to concern about their situation and fear of losing them. Their increased sense of sympathy and support toward the mother causes a greater intimacy between the children and their mother.[11] Adams and Dell found that the women who chose mastectomy were concerned about their children as a mother. They sacrifice part of their body (breast) for this concern in order to maximize their chance of survival and to be with their children for a longer time. [14] Kim et al. found that the main concern of these mothers is related to taking care of their children, their health situation, and supporting them. These mothers fight to take care of both themselves and their children. Therefore, it can be stated that this disease interferes with the role and function of the mother, relationship with children, and function of children.[15] In general, mothers with breast cancer try to establish a balance between their personal needs and familial needs on the one hand and cope with keeping their identity of motherhood on the other.[11] Therefore, it can be stated that cancer is a real threat for the stability of the parental role of the mother. In addition to weakening her ability to take care of her children, cancer also weakens family stability.[16] Due to their mother's disease, children experience anxiety where this reaction of children to cancer diagnosis in their mother leads to psychological disturbance in the patient with cancer.[17] The emotional pressure resulting from the life-threatening diagnosis, unreliability of the progressive path of medical treatments, and hospitalization cause weakened relationship of the mother and children and thus impaired familial life.[18] The children of these patients suffer from psychological problems such as anxiety, depressed mood, low self-confidence, physical complaints, and behavioral problems. The problems mostly manifest themselves as diminished success rate in the school and reduced participation in social activities.[19] Understanding these experiences for nurses who are supporters of the patient during the course of treatment and improvement is crucial. The reason is that nurses should learn this knowledge and enhance their ability to help women with cancer and their families to gain access to adaptive methods. Due to the successful management of patients and their family, care providers need a comprehensive understanding of the experiences of people involved in this phenomenon.^[20] On the other hand, moreover, as quantitative research methods do not have the necessary capacity and ability for dealing with such problems, conducting a deeper study using a qualitative approach which results in describing the phenomenon through experiences of participants in the form of their talks and emotions seems to be essential. Accordingly, the researcher decided to perform the above study with the aim of interpreting the familial experience of women with breast cancer through content analysis method. It is hoped that the study can be helpful by presenting a clear

image of human experiences to implement health-care strategies by the treatment team.

Materials and Methods

In this study, conventional content analysis method was utilized as one of the qualitative research methods. This method is suitable to understand the emotions and the hidden meanings in the experiences of human lives.^[21] Thus, in this study, to discover the experiences of women with breast cancer concerning family members, conventional content analysis method was used. The participants of this study were Iranian women with breast cancer who did not have previous background of having cancer. The exclusion criteria included speech and hearing problems as well as migration and death of the patient. Family members in this study refer to those who have first-degree relationship with the patient (father, mother, sisters, and brothers). In the present study, the sampling method was purposeful, and the data collection instrument included deep and semi-structured interview through open-ended questions. For example, the patient was asked "please talk about your experience when you were told you have breast cancer." Then, more specific questions such as the experiences and relationship with father, mother, sisters, and brothers were examined. Furthermore, if required, in the rest of the interview, exploratory questions such as "could you explain more please," etc., were used. The sample size was determined based on the collected data and their analysis. Therefore, 12 patients with breast cancer who qualified for the inclusion criteria were interviewed. The participants in this research were chosen from patients referring to chemotherapy clinic of the Imam Khomeini Hospital, Zabol, Iran. The sampling continued until data saturation was reached. The saturation involved replication and confirmation of the previously collected data. In other words, replication of previous information or repetition of themes suggested adequacy of the sample size.

In this research, the interviewer first invited female patients for the research. The aim of the research was then explained to them, and then, the interviews were performed in a peaceful and quiet environment as chosen by the patients in the chemotherapy clinic. The duration of the interviews was 45-60 min and was different given the conditions and patience of the participants. All interviews were recorded by the researcher, typed word by word, reviewed, coded, and immediately analyzed. Indeed, data analysis was conducted concurrently and constantly with data collection. The data analysis process was done according to the proposed stages of Graneheim and Lundman including (1) writing down the interview immediately after it; (2) reading the entire text of the interview to achieve a general understanding of its content; (3) determining the meaning units and preliminary codes; (4) classifying similar preliminary codes in more comprehensive classes; and (5) determining the hidden content in the data.[22]

To interpret the direction and robustness of data, four criteria including validity, reliability, conformability, and transferability were used.[23] To ensure the validity, after analyzing each interview, the researcher referred again to the participants, where the accuracy of the points was confirmed, and the necessary modifications were done. To interpret the conformability, the researcher has tried not to introduce his presumptions into the data collection and analysis as much as possible. To achieve reliability, the researcher has benefited from the guidance and supervision of expert professors. Finally, to interpret the transferability, the experiences of the participants were corresponded against the experiences of other women with breast cancer who had not taken part in this study. The ethical considerations of this research included acquiring informed consent from the participants to take part in the research and recording their interview, not writing the name of the interviewees on the tapes and implemented transcripts, adhering to the principle of confidentiality of information, and reserving the right of quitting the research at any stage of the research.

Results

The personal characteristics of the participants are presented in Table 1. Analyzing the data collected from the participants culminated in extracting three main classes and six secondary classes [Table 2] including: mutual support (the patient support from the family and the family support from the patient), mutual emotions (sense of emptiness (deficiency) and sense of competence), and mutual suffering (the patient suffering from the disease and the family suffering from the disease). These three classes were accounted for by a general class or main theme called mutual involvement of the patient and their family with the disease.

Mutual supports

The experiences of women with breast cancer with regard to the family indicated that in addition to being supported by the family, these women tried to support their family as much as possible even in such difficult conditions.

The patient supporting their family

Many of the women with breast cancer stated that to prevent discomfort and concern of the family members (father, mother, sister, brother, and children), they consented to bearing the heavy burden resulting from the disease. Thus, they tried to hide the disease from their parents and children to prevent their sorrow and sadness due to the unsuitable psychological conditions of the family.

A 35-year-old woman who has undergone mastectomy described supporting her children as follows: "Whenever I come back home from a chemotherapy session, with considerably difficulty I try to make food for my children, tidy the house, and even hide many of my pains from them.

Table 1: Demographic characteristics of women with breast cancer

| Variables | n (%) | |
|-----------------------------------|----------|--|
| Age | | |
| >40 | 9 (75) | |
| 40-50 | 3 (25) | |
| Range | 28-47 | |
| Mean±SD | 36±6 | |
| Marital status | | |
| Married | 10 (83) | |
| Divorced | 2 (16) | |
| Education | | |
| Primary school | 7 (58) | |
| Diploma | 3 (25) | |
| Academic | 2 (16) | |
| Occupation | | |
| Housewife | 12 (100) | |
| Treatment type | | |
| Surgery-Chemotherapy | 8 (66) | |
| Surgery-radiotherapy chemotherapy | 4 (33) | |

SD: Standard deviation

Table 2: The main classes and subclasses extracted from data analysis

| Main theme | Theme | Sub theme |
|--|---------------------|---|
| involvement of patient and family with the disease support of patient and family with the disease support of the d | Mutual supports | The patient supporting the family The family supporting the patient |
| | Ambivalent feelings | Sense of emptiness (deficiency) |
| | Mutual | Sense of competence The patient suffering from the disease |
| | sufferings | The family suffering from the patient's disease |

Throughout this time, I had temperature for several days in the house, but I did not say anything to my children because I didn't to make them sad."

The family support from the patient

Further, many of these patients had been supported by their family members, each of whom had supported them in some way.

A 30-year-old woman who had undergone mastectomy stated her brother's financial support in the course of treatment as follows: "I owe my life to my brother, if it not for him I would have definitely died. Every time I want to go to a chemotherapy session, my brother takes a leave from his job, picks me up and takes me to the chemotherapy session. Whenever he cannot take leave, he sends his spouse with me and finances all my commuting and treatment costs."

Ambivalent feelings

The experiences of women with breast cancer indicated that given the reactions of family members when facing their disease, these women had experienced ambivalent feelings about them. These ambivalent feelings ranged from a sense of emptiness (deficiency) to a sense of competence.

Sense of emptiness (deficiency)

Some patients with breast cancer felt a sense of emptiness or deficiency as their family members were negligent and did not follow the course of treatment. In this regard, a 37-year-old woman undergoing chemotherapy stated noncooperation of her brothers in the course of treatment and being reprimanded by her spouse due to this lack of cooperation as follows: "My brothers do not care for me very much, though they may have their own particular problems. However, I expected more from them, because sometimes due to my husband's expectations of my brothers, if they don't care about me, my husband resents and abandons me for some days."

Sense of competence

Some patients with breast cancer stated that through gaining motivation and assurance by their family, they feel that they have the necessary competence to cope with the disease. Some patients believed that the family members' affection has been an important factor for accepting and continuing their treatment. Furthermore, their own affection and love of their family members including their children was a strong factor to cope with the disease and overcome it.

In this regard, a 37-year-old married woman expressed her love to her children as follows: "Thank goodness that I have three children, because thanks to my love for my children I was able to fight the disease, and I owe my improvement to them." Some patients also admitted that the family members helped them laugh and boost their spirit by developing a joyful and happy atmosphere, which contributed to preventing isolation and withdrawal of these patients, and further encouraged them.

A 28-year-old housewife stated that "the people around me treat me very well, especially my own family. For example, my sister and even my mother when they come to our home, have a good laugh and sense of humor. There has not been even one single time they cried around me or became sad. They always laugh. All these are really valuable and helpful, and encourage me further."

Mutual suffering

The experiences of women with breast cancer showed that they had to shoulder mutual sufferings. The consequence of this disease was mutual sufferings incurred to both groups, which can be described as patients suffering from the disease and the family sufferings.

The patient suffering from the disease

Many of these patients experienced suffering and sadness by seeing the side effects of chemotherapy. On the other hand, since they were not able to take care of themselves, they were worried about their future, the destiny of their children, and how and by whom they will be raised, further intensifying their sadness.

In this regard, a 36-year-old woman with a bachelor's degree stated that "The first time I went through chemotherapy, when I took a shower, I passed my hand through my hair and felt a kind of pain. When I stroked my hair, it easily came off my head, I was choked with tears, cried out in solitude, and in this way, I released the heavy emotions from myself."

A 35-year-old housewife also stated that "I am not in a condition to take care of my children. This really bothers me. I am worried about whether I will get well or not. How will the future of my children be? I am always worried about my children, because I don't want them to be raised by another person and this really annoys me."

The family suffering from the patient's disease

Observation of chemotherapy side effects including loss of eyelashes, eyebrows, and scalp hair was painful to both the patient and their family members. In some cases, the children of these patients felt fearful by seeing their mother. On the other hand, since these patients were not able to perform their maternal duties, the physical and psychological pressure and suffering were intensified.

In this regard, a 36-year-old married patient said that "my children have become sick of my situation and they always say, when mom gets well. Since they have seen my eyebrows and eyelashes falling out, they have become fearful and begin to cry, why has mom become like this?. This really shatters me and I don't want them to feel sad."

Discussion

The experiences of women with breast cancer with regard to their family indicated that in addition to being supported by their family, these women tried to support their family as much as possible despite this difficult situation because the consequence of this disease was mutual sufferings imposed to both groups. Confronting these sufferings had different feelings in these patients, where some of them due to lack of family support had experienced a sense of emptiness, others, thanks to gaining motivation and encouragement from their families felt that they possessed the necessary ability to cope with their disease. In other words, it can be deduced that the experiences of these women concerning their families can be described as "mutual involvement of patient and family with the disease."

Mutual supports

The experiences of women with breast cancer indicated that they and their family did their best to support each other. In this regard, Baider writes that during the development of serious diseases, all family members become closer to each other. According to the investigated experiences, the

women themselves tried to reduce the pressures exerted to the family as much as possible and support them in some way. In this way, most of them had hidden their disease, physical problems, and the associated side effects from the family in order not to worry them. Further, in spite of severe physical weakness, they tried to perform their household duties as well as the responsibilities related to the children. Possibly, these women tried to normalize the disturbed course of life. As one of the results of the study by Stenberg et al. entitled the effects of cancer patient care, one of the obtained themes, was the effect on the daily life of family members. [25] The study by Taleghani et al. also indicated that women with breast cancer had patience and composure against this disease due to the love they had for their children. They believed that this will result in improved spirit and prevent disease aggravation, [26] which is in line with the results of the present study. In the present study, the women patients had experienced financial and spiritual support of the family in the course of diagnosis and treatment. Hydary regarding this states that in the course of breast cancer, one of the important groups that provide service to patients is family members. In Iran, due to solidity of the family base, most patients with cancer are taken care of at home and by their permanent family members.[27] Taghavi et al. also mentioned family members as the source of support for patients with breast cancer. [28] According to the patients, the psychological support of some family members was so great that to prevent a sense of sadness and loss in the patient, they tried to hide the disease from them and shoulder the burden resulting from disease diagnosis alone. Aghahosseini also mentions that the culture of the Eastern countries is known to be family oriented. In this culture, family members may try to hide the cancer diagnosis from the patient in order to protect their family member. This is considered a kind of sacrifice. in which the family members divide the stress resulting from the diagnosis among themselves, thereby protecting the patient.[29]

Mutual sufferings

According to the experiences stated by women with breast cancer, this disease had imposed considerable suffering to them and their families. Shojakazemi and Mehavar write that cancer and its resulting suffering are among the most bitter of human experiences, and with progression of the disease, patients undergo different types of sadness. [30] In the qualitative study by Khademi et al. in which the experiences of patients with breast cancer and the individuals involved in this disease were investigated, one of the identified central concepts was immersion in suffering due to confronting consequences of treatment, inefficient care, and impaired daily life of the family.[31] In the present study, for the patient, inability to perform maternal responsibilities and imposing its heaviness on children, confronting unfulfilled expectations of children and their sense of disappointment, observing the bad mood of their children and worry about their future, confronting the states of sorrow and sadness among the family members as well as anxiety about their fate and future were painful. Confirming these points, Shojakazemi and Mehavar write that if the family of a patient with cancer undergoes considerable pressure of duties and burdens, the patient themselves will also be bothered.^[30]

It seems that the mother's inability in playing the role she used to have has been painful. In this regard, Vaziri et al. write that living with cancer interferes with the role and function of mother, the relationship with children, and the children's function since the mother's focus is mostly on treatment and there are times when the mother is not able to perform her useful role as the house director.[11] Therefore, family members should accept more responsibilities.[11] Nevertheless, investigation of the experiences of patients in this study indicated that having breast cancer brought about sufferings to the family as well, where the patient had seen the sadness and tears of her family members. Even in some cases, this sadness had resulted in incidence of shock followed by the hospitalization of one of the family members in the hospital. Furthermore, some family members were constantly confronted with the reason why their family member had developed this disease. Sercekus et al., in the result of their qualitative study entitled the experiences of family members with cancer, stated that during the care process, family members experience different problems, whose effects can be identified in three groups of physical, psychological, and social problems.[32] The results of the review study by Stenberg et al. also confirmed the confrontation of family members of patients with cancer with social, physical, and psychological problems adversely affecting their quality of life.[25] Hydary L, also writes that family care providers, in response to taking care of the patient with cancer, may experience economic, social, psychological, physical, and spiritual problems, which are problematic if neglected.^[27]

Ambivalent feelings

Investigation of the experiences of women with cancer indicated that they had experienced different feelings ranging from a sense of emptiness (deficiency) to a sense of competence. In this regard, some complained about the absence of family members around them and a sense of loneliness in the course of the diagnosis and treatment, where the resentment of getting help from the family bothered them. Masmooi et al. also write that the process of disease and treatment among cancer patients brings about various complications including diminished satisfaction with life, adaptation and self-confidence, increased emotional tensions, anxiety, depression, and psychological disorders.[33] However, investigation of the psychological experiences of women with breast cancer in the qualitative study by Khansari et al. showed that although most patients had a sense of anger or sadness after the diagnosis and emphasized the necessity of psychological support on the part of the family members when hearing the risk of developing cancer, over time it had caused them to adapt to the disease and the complications. They concluded that the time can result in altered psychological experiences of these patients, [34] which is to some extent different from the results of the present study. Possibly, the difference can be attributed to the research context and cultural issues.

The experiences of some other patients indicated that thanks to the motivation and encouragement, they had acquired from their family, they felt that they possessed the necessary competence to cope with their disease. In this regard, Parsa et al. write that in patients with cancer, increased emotional needs of patients result in diminished sense of self-efficacy in them. Therefore, to reduce emotional needs and improve the level of self-efficacy, precise planning as well as educational required.[35] supportive interventions are Confirming these ambivalent feelings, Soroush et al. (2015) stated that some patients with breast cancer, after the treatment, manifest positive psychological characteristics such as extravasation, sociability, intimacy, altruism, flexibility, spirituality, and positive thinking along with some negative characteristics such as anxiety, loneliness, depression, sadness, anger, and despair.[36]

Conclusion

In this study, it was found that the experiences of these patients with regard to their family can be described as mutual involvement of the patient and the family. The reason is that women and their family, due to experiencing the suffering from the disease, tried to support each other. These conditions set the ground for the incidence of ambivalent feelings in these patients, where some patients felt a sense of emptiness (deficiency) due to lack of familial support, while others had experienced a sense of competence due to motivation and encouragement. Investigation of relevant papers suggested that through presenting educational and supportive interventions for the families of these patients, it is possible to help these patients indirectly gain better experiences from their families.

Acknowledgment

This paper is part of MSc thesis of nursing with the approved code of Zbmu. 1.REC.1396.57 at Zabol University of Medical Sciences. The researchers highly appreciate the cooperation of authorities and employees of Chemotherapy Clinic of Imam Khomeini Hospital, Zabol, as well as the patients without whose cooperation, conductance of this study would have never been possible.

Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent forms. In the form the patients have given their consent for their images and other clinical information to be reported in the journal. The patients understand that their names and initials will not be published and due efforts will be made to conceal their identity, but anonymity cannot be guaranteed.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

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