

Dignity of Iranian Women with Breast Cancer: A Qualitative Study

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Abstract

Background: Respecting the human dignity of patients is one of the most important ethical requirements of the medical and nursing profession. Respect for dignity in all patients, especially in patients with breast cancer, is important because of the profound and lasting effects of this disease on patients. This study aimed to understand the perspective of patients with breast cancer on the concept of patient dignity from June 2020 to December 2020 in Iran Mehr Hospital (Radiotherapy and Oncology Center) in Birjand.

Methods: This study was conducted using a qualitative approach. The data were collected through semi-structured individual interviews and analyzed using qualitative content analysis. The data were saturated after interviewing 16 patients with breast cancer who were selected using purposive sampling from June 2020 to December 2020. The main interview question was, "What does 'dignity' mean to you based on your experiences during your time with cancer?" The data elicited from the interviews were analyzed using content analysis via MAXQDA 2012 software.

Results: Analysis of the patients' statements and experiences of maintaining dignity revealed three main themes. The first main theme was respect for human values, which included the subthemes of personal privacy, avoiding curiosity, confidentiality of information, and use of same-sex caregivers. The second main theme was psychological support, which included the subthemes of spousal and family empathy and support, understanding the patient's concerns and preoccupations, resentment of pity, and disclosing cancer diagnosis. The third main theme was socioeconomic support, which included the subthemes of spousal and family financial support, financial aid by support organizations, and community awareness.

Conclusion: Receiving care by respecting dignity is the right of every patient. Since patients with cancer are more vulnerable, it can be argued that maintaining the dignity of these patients is more important than other patients due to the nature of the disease and the long-term involvement of patients with the disease.

Keywords: Breast cancer, Nursing, Ethics, Respect, Iran

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Introduction

Cancer is a leading health problem worldwide (1) and the second leading cause of death in the world (2,3). Compared to other cancers, breast cancer is the most common cancer in women (4-6). According to the Disease Management Center, breast cancer has been the most common cancer and the second leading cause of cancer death among Iranian women (7). In Iran, the number of breast cancer patients was 12 802 in 2015, and the age-standardized incidence rate was 32.63/100 000. It is estimated that about 10 000 women are diagnosed

with and receive treatment for breast cancer each year (8). An estimated 1 in 8 women in the United States will develop breast cancer. The rate is very high in Eastern (93.1 per 100 000) and Western (89.7 per 100 000) Europe according to the GLOBOCAN report (9).

Iranian women get the disease at least a decade earlier than other women in developed countries, demonstrating the severity of this disease (10). Furthermore, the survival rate of cancer patients is longer and as a result, they are involved with this disease and its complications and problems for an extensive period (11). Patients with



breast cancer undergo a stressful experience that affects all aspects of their life (12). The most important issues inducing stress in these women are disease status, their role in the family, lack of information, changes in body structure and image, issues related to femininity, decreased self-efficacy and self-esteem, and non-compliance with the current situation and treatment methods, especially chemotherapy (13).

In fact, emotions such as inferiority and worthlessness following the special conditions of these patients such as dependence on others, awkwardness, changes in self-image, changes in appearance, and frequent hospitalizations can affect their human dignity (14). Dignity is a primary concern for hospitalized patients (15,16).

Human dignity, as a moral value, is a key concept in medical ethics (17). Respect for dignity is at the heart of ethical relationships and treatment (18). Preserving human dignity has been emphasized as a moral duty of healthcare providers around the world (19). Preserving and promoting the human dignity of patients and facilitating death with dignity are the essence and core of nursing care. In other words, the deepest moral motivator of care is the protection of human dignity (20). Patients who are in the final stages of life are in a situation where their human dignity is likely to be violated and they are expected to confront many spiritual and existential challenges. A decreased sense of dignity for people with cancer is associated with high levels of psychological distress and loss of desire to continue living (14).

If the patients' dignity is maintained, they will feel comfortable, confident, and valuable, and will be able to make decisions about their treatment process. Conversely, if their human dignity is disrespected, in addition to experiencing feelings of insecurity, humiliation, and shame, their treatment outcomes will be affected and their hospital stay will be longer (16,21). The disregard for the dignity of patients can affect their body, soul, mood, and spirituality and expose them to stress (22). Patients who receive dignity-based care show more compatibility with relevant treatments and are more satisfied with the care (23). Besides, respect for the dignity of the cancer patients leads to the restoration and maintenance of their psychosocial and economic balance, increasing the patients' efficiency and ability to cope with the disease (24).

Previous studies have shown that meddling in personal affairs (25), disrespect for the patient's values and beliefs (24), not giving information to the patient (26), and asking unnecessary questions (25) can violate the patient's dignity. Patients surveyed in most studies highlighted issues such as confidentiality (27,28), psychological support (15), respecting individual identity (29), respectful atmosphere (30), understanding of illness-related concerns (31), treating the patient as a valued

person not an object (32), communication behaviors (20), and inclusive support (33). Various studies have addressed maintaining dignity by surveying nurses (34), nursing students (35), physicians (19), caregivers (19), and different groups of patients including the elderly (18, 36,37), autistic (33), cardiovascular disease (38,39), adult (22,40), and cancer patients (16,21,41,42) as well as the patients admitted to general wards (30).

Given the consequences of not maintaining dignity in patients, especially cancer patients who have been struggling with this disease for a long time, it is important to provide care while maintaining dignity in patients with cancer (43). Moreover, since the number of women with breast cancer in young age groups in Iran is increasing and also the probability of survival of patients with this disease is higher than other cancers, the study of the dignity of these patients and its related factors is very important. Although many attempts have been made to define the concept of dignity and its related factors, this concept has not been well studied in patients with cancer, especially women with breast cancer. Thus, it seems that further studies in different societies and cultures may help to show the different aspects of this concept and the factors associated with maintaining patient dignity and providing care services based on it. Therefore, the present study aimed to investigate the concept of dignity from the perspective of breast cancer patients.

Methods

This study employed a qualitative research design. To address the research question, the qualitative content analysis approach was used. Content analysis as a research method is a systematic and purposeful way to describe a phenomenon and is used to summarize, describe, and interpret data (44). This approach has been chosen to collect rich and new data (45).

The present study was conducted from June 2020 to December 2020 in Iran Mehr Hospital (Radiotherapy and Oncology Center) in Birjand. A total of 16 women with breast cancer with the age range of 28 to 72 years participated in the study. The cancer patients were selected with maximum variation in terms of age, socioeconomic status, education, and duration of disease. The inclusion criteria were having a medical record with a diagnosis of cancer, at least 18 years of age, knowledge of the disease, interest in participating in the study, auditory and physical ability to participate in the study, the ability to provide rich information about the concept in question, and having mental and physical ability to attend the interviews.

The data in this study were collected via semi-structured interviews. To this end, the researcher attended the research setting, talked to the participants, and explained the purpose of the study to them. After obtaining the participants' consent, each interview was conducted in a

quiet place to provide the most comfort and satisfaction for the participants. The time of the interviews was also determined upon the participants' agreement. Each interview began with several general questions about the subject matter. The questions were developed following a review of the literature and surveying subject-matter experts. The interview questions focused on the patients' experiences of maintaining their dignity during the time of cancer. Examples of the questions asked are:

- What does 'dignity' mean to you based on your experiences during your time with cancer?
- What experiences do you have about maintaining or disrespecting human dignity during your time with cancer?
- In your view, what factors have contributed to maintaining and promoting your dignity based on your experiences during your time with cancer?
- What factors have threatened your dignity based on your experiences during your time with cancer?

Following qualitative studies, the participants in this study were selected using purposive sampling and the sample size was estimated based on data (46). Accordingly, the patients who met the inclusion criteria were selected for the interviews. The data collection process continued until no new information was found with additional interviews (47) and the data reached saturation after interviewing 16 patients. In the last two interviews, no new theme emerged from the data analysis and the members of the research team concluded that the data were saturated. Each interview lasted 35 to 65 minutes and varied for each participant.

Data analysis was performed simultaneously with data collection using qualitative content analysis and continuous comparisons (48-50). Each interview was transcribed word-by-word within a maximum of 24 hours and their content was reviewed several times by the researchers to get a general idea of the interviewees' experiences. The key themes in the statements and paragraphs were identified and coded. The extracted codes were then compared based on their similarities and differences and those with similar meanings were placed into a theme. Finally, the collected data were analyzed using MAXQDA 2012 software.

To establish the rigor of the data, four criteria proposed by Guba and Lincoln were used (51). The credibility of the data was ensured by allocating sufficient time to collect data, using subject-matter experts' opinions in data analysis, and having the extracted themes reviewed and confirmed by the participants. The researcher also quoted some examples of the participants' statements when reporting the results of the study to make it possible for readers to assess the dependability of the findings. In general, the researchers tried to increase the credibility of the findings by long-term engagement with the data, the confirmation of the findings by the participants, and the

use of different methods of data collection (interviews, observations, and notes). Furthermore, the procedures taken to collect and analyze the data were recorded and reported in detail to make it possible for other people to assess the reliability of the research procedure and the results if necessary.

The researchers tried to gain the trust of the patients to participate in the study. The objectives of the study were explained to the participants. The reason for using a voice recorder during the interview was explained to them and the interviews were recorded with their permission. Furthermore, all participants were informed that they were free not to participate in the interview sessions if they wished. Moreover, a written consent form was signed by the participants.

Results

The mean age of the participants in this study was 45.26 ± 1.38 years (ranging from 28 to 72 years) (Table 1). Based on the analysis of the participants' statements, dignity in patients with breast cancer was conceptualized into three themes (respect for human values, psychological support, and socioeconomic support) and 11 subthemes as shown in Table 2.

Respect for human values

Respecting patient privacy was one of the important themes highlighted by the participants in this study. Non-use of dividers and curtains, unnecessary touching and examinations, nudity before the examination by a doctor, nudity in the presence of other patients, and naked parts of the patient's body that were not related to the medical examination were the main components of patient privacy:

"It's very embarrassing. There is no curtain or screen. I do not like everyone to look at me and stare at me when my dressing is changed. This is disrespect for the patient" (Participant 12).

Most of the participants felt dissatisfied with unreasonable snooping, meddling, and repetitive questions asked by healthcare staff especially the nurses and those around the patient about their private and family life and marital relations, which did not affect their treatment and care, and considered it against moral principles and dignity:

"The nurses used to ask me if my husband gave me a cold shoulder or whether he was going to marry another woman since the time I had had a mastectomy and lost my hair. These questions really ruined my self-confidence and I tried not to appear in public" (Participant 4).

Most of the patients stated that they were reluctant to disclose information related to their illness to even the closest family members, especially their spouse's family for a variety of reasons including fear of rejection, fear of being judged by others, and pity:

Table 1. The participants’ demographic data

Participant	Age (year)	Marital status	Education level	Occupation	Duration of diagnosis (month)
1	34	Married	MSc	Teacher	6
2	70	Married	Diploma	Housekeeper	36
3	47	Married	Diploma	Self-employed	12
4	28	Married	MSc	MSc student	14
5	32	Married	Diploma	Self-employed	6
6	56	Married	Diploma	Retired	60
7	37	Married	BSc	Employee	12
8	41	Married	BSc	Employee	18
9	33	Single	BSc	Employee	18
10	32	Married	BSc	Employee	14
11	45	Widow	BSc	Employee	36
12	56	Married	Diploma	Housekeeper	24
13	72	Married	Primary school	Housekeeper	28
14	58	Married	Diploma	Housekeeper	8
15	42	Divorced	BSc	Employee	7
16	56	Widow	High school	Housekeeper	14

Table 2. Main themes and subthemes

Themes	Subthemes
Respect for human values	Personal privacy
	Avoiding curiosity
	Confidentiality of information
	Use of same-sex caregivers
Psychological support	Spousal and family empathy and support
	Understanding the patient’s concerns and preoccupations
	Resentment of pity
Socioeconomic support	disclosing cancer diagnosis
	Spousal and family financial support
	Financial aid by support organizations
	Community awareness

“A cancer patient does not like everyone knows about her illness even her relatives. But they have written the phrase ‘Breast cancer’ on my medical file and I have to carry it with me everywhere. I think this is really an offensive behavior toward the patient” (Participant 3).

The reluctance of the female patient to see a male physician, restrictions on the choice of physician, and having a choice for the treatment environment were among the most important issues that violated the patient’s dignity as was pointed out by the participants. They tended to be cared for by female staff so that their privacy was not compromised and they did not feel embarrassed:

“There was not a female surgeon in the hospital. I said I would not like to be visited by a male doctor. I went to a gynecologist and she sent me to the same doctor again and I had to have a mastectomy done by the male doctor” (Participant 5).

Psychological support

Psychological support covered four subthemes of *spousal and family support, resentment of pity, understanding the patient’s concerns and preoccupations, and disclosing cancer diagnosis.*

One of the issues highlighted by most participants as effective in maintaining and enhancing their dignity was the support from their spouse and family. The married participants stated that their spouses played the most important role in relieving their pain.

“My husband is my best supporter. I feel good when I talk to him. He comforts me and says he and the children are by my side until the end of my treatment. His words calm me down and I feel that I am so important to them that they are supporting me eagerly” (Participant 5).

The participants stated that cancer diagnosis and their exposure to it raised concerns and worries in them, which led to severe psychological changes in them and thus they became sensitive to the feeling of the loss of dignity. According to the participants, it was difficult for them to face a different appearance in front of their husbands and in public and to accept these changes.

“When I was going to do a mastectomy, I was all worried about how I would look after the breast was removed and I feared that my husband would not accept me anymore” (Participant 13).

The participants stated that they had experienced issues such as excessive love and attention, clumsy support and help, unwarranted compassion, excessive sacrifices, and a pathetic look or tone, etc., which were considered harsh and disrespectful to them and sometimes forced the patients to hide the disease from others:

“Unreasonable sympathy of those around me makes me more annoyed. I heard they said the poor guy has cancer.

Some people look at it with pity, so I believe that there is no need to tell everybody about the disease” (Participant 4).

The participants stated that the cancer diagnosis should be disclosed to the patient by a physician or nurse with some prearrangement, suitable words, and consideration of the patient’s mental state so that these patients suffer less from psychological harms associated with knowing about their disease:

“Breast cancer is a very serious disease for women. It’s a matter of a woman’s beauty. When the doctor once told me without any explanation that I have breast cancer, I was shocked and could not speak. The way they treated me was not humane at all” (Participant 4).

Socioeconomic support

Socioeconomic support was the last theme identified in this study and covered three subthemes including *spousal and family financial support, financial aid by government and support organizations, and community awareness.*

A survey of the participants’ experiences indicated that when patients face staggering medical expenses, they need to receive support from family members, relatives, and support organizations, and this financial dependence on those around them led to a loss of dignity and a sense of inefficiency in cancer patients:

“I have to inject a hormone ampule once every three months. I also have to pay expensive chemotherapy costs. Well, this is a great cost for a woman who is the head of the family. So, I need to be supported by several sources. I mean my main problem was that I did not receive financial support from my husband” (Participant 3).

According to the participants, the misconceptions and wrong beliefs of the community members about cancer, cancer stigma, cancer taboo, and lack of community awareness about cancer had caused discomfort and resentment in these patients. The patients also stated that there was a need for raising the awareness of people in the community and the patients themselves about cancer to help maintain cancer patients’ dignity:

“When I was undergoing chemotherapy and I was wearing a mask, a friend of mine later told me that at that time she was afraid to shake hands with me. I think even one percent of people do not know how to deal with a cancer patient” (Participant 10).

According to the participants, when those around the patient and people in the community became aware of their illness, they began to judge the cause of their illness, and even some considered their cancer as atonement for their past sins:

“When someone especially a woman gets cancer, many people jump to a conclusion and say that she has done a great sin so God is punishing her with the illness. I have heard this lot. It really ruins the patient’s dignity” (Participant 4).

Discussion

Based on the analysis of the participants’ statements, dignity in patients with breast cancer was conceptualized into three themes (*respect for human values, psychological support, and socioeconomic support*) and 11 subthemes.

Human dignity is one of the most important therapeutic features and one of the most important ethical concerns in nursing care (15). This study explored the perspectives of patients with breast cancer on the concept of patient dignity.

The cancer patients in this study stated that the breach of cancer patients’ privacy damages their dignity, hence they demanded care in a private environment. Various studies have suggested that the patient’s dignity is closely related to privacy in such a way that the two issues are inseparable (24,26). Accordingly, Ebrahimi et al and Matiti & Trorey confirmed that non-observance of patient privacy threatens the patient’s dignity in medical settings (52,53). The participants in the present study considered curiosity in private life and issues related to their illness as something immoral and stated that healthcare staff’s interference with their personal and private issues, treatment, and care was damaging their dignity. Similarly, Khoshnood et al stated that disrespecting the privacy of human beings, curiosity about personal issues, and asking them unnecessary questions can lead to the violation of the patient’s human values (54).

Some of the participants in the present study reported that as most people in small towns know each other, they went to nearby cities for treatment because they feared other people get to know about their disease. Moreover, many participants stated that due to the fear of losing their chance of marriage, divorce, or rejection by their spouse, the social stigma of cancer, and the negative attitudes of people in the community towards cancer, they hid their disease from family members and friends and expected the medical staff not to divulge information about their disease. Human dignity is a culturally dependent concept. Thus, given the religious and cultural beliefs of Iranians, some participants stated that they felt embarrassed, anxious, and upset as they were forced to get naked and examined by an opposite-sex doctor or nurse and considered it immoral and a threat to their dignity. The participants in this study stated that their physical privacy was an important issue and they preferred to receive care from female medical staff. These perceptions seem to have their roots in some cultural, religious, and social norms of Iranian patients, which emphasize the need to cover the body of a Muslim woman in front of non-mahram men.

The present study showed that psychological support was another theme related to respecting patient dignity. According to the results of the present study, support from family members, especially the spouse, was an important factor in promoting a sense of self-worth. Furthermore, Khanjari et al highlighted that psychological

support can lead to more enjoyable experiences for breast cancer patients (55). In other studies, family and friends have been considered a source of support for breast cancer patients, and this support is widely effective in improving the psychological status and quality of life of patients (7,56). Given the culture of the Iranian people and the Iranian community as a collectivist society, and considering that Iranians attach great importance to communication with family members and support from spouse, family, and others, these interactions give cancer patients a sense of fulfillment of their dignity during their illness.

One of the issues that can contribute to maintaining dignity in cancer patients is understanding these patients' concerns and preoccupations. The results of other studies also suggested that one of the effective factors in maintaining and promoting the patients' dignity is paying attention to their worries and anxieties (57). Concerns about diminished attractiveness have a significant negative effect on the mental health and quality of life of breast cancer patients, leading to feelings of inability to play feminine roles and the emergence of emotions such as inefficacy, anxiety, depression, and awkwardness, thus decreasing self-esteem and a sense of worth in patients (58). It can be argued that in most societies and cultures, the breast is a symbol of gender, female identity, and maternal characteristics. Therefore, the removal of this organ, especially in younger women, means the loss of female identity and reduced sexual attractiveness (59).

One of the bitter experiences of the participants that violated the human dignity of the patients in this study was the expression of unnecessary pity and compassion from healthcare staff and those around the patient. One of the topics that have recently been discussed with an emphasis on moral and human values and addressed in the American Nurses Association Code of Ethics is the provision of compassionate care (44). Iranian nurses do not fully understand the meaning of compassionate care and only convey their feelings of discomfort and regret to the patient. Previous studies have also confirmed that many patients with breast cancer tried to hide their disease from others and expressed dissatisfaction with the negative and sympathetic reaction of family members, friends, and community members (60,61). Some of the participants expressed their displeasure that the news of their illness was given suddenly and without any preparation and believed that was very unpleasant and contrary to moral principles and their dignity. One of the needs of health caregivers regarding how to disclose the disease and prognosis to patients is the awareness of instructions for how to inform the patient of the disease (62). Accordingly, cancer diagnosis should be disclosed by taking into account the patients' conditions and upon their request (16).

The present study showed that socioeconomic support

was another need highlighted by breast cancer patients. According to the experiences of the participants in the study, when patients are faced with staggering treatment costs, they feel the need for help from family, relatives, and support organizations, and considering that the treatment process in these people is long and consecutive, this process is considered very anxious and painful. In fact, in addition to the complications of the disease and the physical problems they experience during the treatment, they suffer a lot of stress from an economic point of view. Although cancer patients received financial support from their family and friends, at the same time, they demanded the government to cover the costs of drug treatment as well as living expenses, and they considered the non-fulfillment of this to be against their dignity.

The study by Khoshnood et al showed the most important needs expressed by cancer patients in the organizational field are financial needs. The financial needs of the participants included the need for financial support from the spouse, the need to obtain support from governmental and non-governmental support organizations, and also the concern about providing the expenses, which caused the person to abandon the treatment (54).

In a similar vein, Harandy et al confirmed that one of the main problems of breast cancer patients is the lack of psychosocial support, lack of or insufficient insurance coverage, expensive chemotherapy drugs, and other treatment costs (61). The participants in the present study considered the inappropriate treatment of people and the wrong beliefs and judgments of people in the community about cancer patients as one of the factors effective in maintaining their respect and dignity. Abadi Bavil and Dolatian (7) and Taei et al (63) stated that the lack of social support leads to a decreased sense of self-worth and consequently loneliness and frustration. The results of the present study showed that to maintain and promote the dignity of cancer patients in society, there is a need for raising the awareness of people in the community and patients themselves about cancer. Lopez-Class et al also reported that one of the most important problems for women treated with breast cancer is the feeling of isolation and shame and problems in communicating with people in the community following the disease, which have greatly developed stress in these people (26).

Based on the literature review, this study was the first qualitative study investigating the dignity of women with breast cancer. One of the limitations of the present study was its small sample size. In addition, the data were exclusively collected through individual interviews in Iran Mehr Hospital in Birjand. Accordingly, future studies are recommended to collect richer information and investigate the views and experiences of doctors, nurses, patient companions, and other health care professionals through focus group interviews. Moreover,

since the concept of dignity depends on culture, it seems that more studies in different societies and cultures can help to show different aspects of this concept and the factors related to maintaining the patient's dignity and providing care services based on it.

Conclusion

The present study showed that respect for human values, psychological support, and socioeconomic support were the three main factors affecting the dignity of patients with cancer. Receiving care by respecting dignity is the right of every patient. Since patients with cancer are more vulnerable, it can be argued that maintaining the dignity of these patients is more important than other patients due to the nature of the disease and the long-term involvement of patients with the disease.

Discovering the meanings of dignity in patients, especially patients with breast cancer, can be considered a new achievement for making correct decisions in care and treatment settings and improving the quality of life of patients and even their families in providing nursing care.

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Competing Interests

The authors declared no conflict of interest.

Ethical Approval

The present study was approved by the Ethics Committee of Birjand University of Medical Sciences with the code of ethics IR.BUMS.REC.1399.215.

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