



Sudanese Women's Psychological Reactions to Breast Cancer Diagnosis and the Impact on Their Maternal-Child Relationship

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Abstract

Diagnosis of breast cancer leads to psychological problems for women, and affects their relationship with children. **Aim:** This study aims to identify the psychological problems, women with breast cancer face and examine how they affect their relationships with their children. **Method:** A qualitative method was used; data were collected through semi-structured interviews with eight women who were diagnosed with breast cancer and underwent treatment at the Radiation and Isotopes Center of Khartoum (RICK), Sudan. Depression and anxiety were assessed via the Hospital Anxiety and Depression Scale (HADS). The data were analyzed using cross-case interview analysis. **Results:** The study findings indicated that many Sudanese women with breast cancer suffered from depression after diagnosis; they were also pressured to hide their feelings from their children, became overprotective, and feared passing on the disease to their daughters. **Conclusion:** In addition to being aware and concerned about having breast cancer, breast cancer patients experience several psychological side effects. Having the fear of transmitting the disease to their daughters, being terrified of dying, and being pressured to tell their children about their conditions are all issues they face.

Subject Areas

Psychology

Keywords

Breast Cancer, Maternal Relation, Sudanese Women, Psychological

1. Introduction

The most common cancer among women around the world is breast cancer, and

it is second only to lung cancer as the leading cause of cancer deaths [1]. According to the American Cancer Society (ACS), there were 182,460 cases of breast cancer in the United States in 2008 [2]. Although breast cancer is rare in Sub-Saharan Africa, especially in Sudan, the picture of cancer in Sub-Saharan Africa is changing. There has been an increase in breast cancer incidence and mortality [1]. It is estimated that by 2025, over 19.3 million women, mostly from SSA, will be affected by breast cancer [3]. As of 2016, the incidence and mortality ratio range from 0.55 in Central Africa to 0.16 in the US, due to ignorance of breast cancer manifestations and other related challenges. Many challenges remain in identifying affected women in SSA [3].

It accounted for about 18% of the most common cancer deaths in Sudan in the years 2004-2006. Sudanese BrCa (Breast Cancer) women are more likely to suffer from anxiety and depression as they are in the last stages of disease progression. Nearly 700 new cases are estimated to occur every year [4]. Cancer is a life-changing experience that affects not just the person with the disease, but also their spouses and children [5]. In the case of screening for BRCA 1 and BRCA 2, patients are informed of the risk for their blood relatives and encouraged to inform them of this [6]. One of the most stressful aspects of the process is deciding how and when to tell their children about their diagnosis [7]. Previous studies using self-report screening measures have reported distress, anxiety, and depression in, on average, one quarter to one-third of breast cancer patients with levels up to 50% following diagnosis and treatment [8]. 1 in 12 women in the UK is diagnosed with breast cancer, and 30 percent of those diagnosed have children at home who are of school age [9].

In cancer care, distress is endorsed as a sixth vital sign by the International Psycho-Oncology Society [1]. It is a well-known fact that cancer-related distress has been observed at pivotal points in a patient's life trajectory (including the diagnostic, treatment, treatment recovery, and recurrence phases), and that the distress ranges from normal, acute reactions, which post-diagnosis may include initial fear, to more severe and more chronic stress reactions that adversely affect the function and well-being [10].

A growing body of literature recognizes the importance of breast cancer diagnosis, which is often a traumatic experience for a woman, creating an array of emotions such as fear, anger, and depression [11]. Patients can experience psychological and physical distress at any point along the cancer treatment continuum [12].

National Comprehensive Cancer Network (NCCN) defines distress as "...a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social, and/or spiritual nature that interferes with an individual's ability to cope effectively with cancer, its physical symptoms, and its treatment" [13]. In large-scale outpatient studies, findings indicate that people with cancer experience varying levels of worry, stress, and depression. In some cases, these feelings can be clinically significant [12]. It has previously been re-

ported that 9% of women with breast cancer experience major depression during their early stage of the disease and 27% experience minor depression. The incidence of anxiety disorders has been estimated at 48% in patients with a variety of cancer diagnoses. Women with breast cancer are 8.6% more likely to suffer from anxiety disorders, according to other reports [14].

Even though diagnosing and treating breast cancer creates multiple stressors for women of all ages, younger women are especially at risk for adverse psychosocial effects [15]. Several researchers have recently examined the effects of a cancer diagnosis on families, finding that a diagnosis of advanced cancer affects the whole family; 32% of families newly referred to palliative care demonstrate severe or overwhelming anxiety [16]. Anxiety, depression, and other emotional difficulties affect parents facing life-threatening illnesses and chronic health conditions [17]. Leaving children vulnerable to problems and compromising parenting. Children, like their parents, are susceptible to these types of feelings as well. In accordance with the American Psychological Association, “A cancer diagnosis affects the entire family.” Psychologists consider family members to be the patient’s “secondary” [11] sources of support. As a result of the cancer diagnosis, family members often experience similar levels of distress and lack the skills or confidence to speak about and support their loved ones [18].

There is evidence that family functioning, the physical characteristics of the patient’s illness, and the level of distress are associated with depression, anxiety, and distress [19]. In the study of children of mothers with breast cancer, different domains of concern about their mother’s disease were distinguished, but only concern about their family’s well-being was significantly affected by depressed maternal mood [20]. Following a breast cancer diagnosis, a woman’s level of distress and emotional well-being is related to her interpersonal relationships [21].

Due to the recent increase in breast cancer cases, it is difficult to ignore the psychological effects of breast cancer diagnosis. Women experience worries and misery when they are told about their diagnosis; concerns about leaving their children alone, and fear that they might pass the disease on to their daughters are all factors contributing to their depression. In addition to developing depression traits, they also develop protective behaviors and a desire for closeness with their children as a result of having a sense they will soon leave them behind. Throughout the paper, we attempt to examine the psychological effects of a breast cancer diagnosis on a mother, especially those related to her relationship with her children. In addition, their perception of passing the disease on to their daughters is examined.

2. Method

To investigate how breast cancer affects the psychological well-being of women and their children, this study uses a qualitative case study approach. Studying the effects of breast cancer on the spouse or other family members is beyond the

scope of this study. The research data were collected from two main sources: in-depth interviews and the Hospital Anxiety and Depression Scale (HADS). Eight women with breast cancer at the Radiation and Isotopic Center of Khartoum (RICK) were enrolled in the study. To obtain comprehensive data for the paper, outpatients and inpatients, as well as patients under follow-up, were selected purposively based on the following criteria: married women diagnosed with breast cancer between 6 months and 4 years ago, with a diagnosis in stage 2 or 3, over 30 years old, with different educational levels, with no cognitive impairment, physically able to be interviewed, and have more than one child of different ages. The demographic data are shown in **Table 1**.

Procedure

To protect the participants' privacy, the data were collected in an isolated room at the Radiation and Isotopes Center in Khartoum (RICK) between February and July 2018. Interviews with the target group were conducted using purposive sampling. The interviews lasted between 30 and 45 minutes. All the participants signed the consent form after being informed of the study's purpose and methods in simple, clear language by the researcher. The institute also verbally consented to participate in the study. The study did not use names or identifiers, to protect the privacy of the interviewees. A semi-structured face-to-face interview was conducted by the researcher. In this method, the researcher and a participant engaged in a dialogue guided by a flexible interview protocol and supplemented with follow-up questions, probes, and comments. Using this method, the researcher "can collect open-ended data, investigate participant thoughts and feelings, and explore sensitive and sometimes personal issues" [22]. All participants were asked the same simple initial questions, which provided a safe and comfortable environment for spontaneous questions to be raised. The interviews were tailored to the interviewees and their narratives, allowing for prompts and exploring topics that were raised spontaneously during the process. The interviewees were encouraged to express themselves freely and openly, by asking them questions like:

- "How is your feeling?"
- "Tell me about your relationship with your children after the diagnosis?"
- "How did your children know about your diagnosis?"
- "What do you know about breast cancer?"
- "Tell me about your feeling when you first knew about the disease?"

Table 1. Demographic data of the study participants.

age	No. of participants	Educational level	No. of children
31- 35	3	Illiterate 2	2 - 6 children 5 participants
36 - 40	2	Primary level 2	7 - 11 children 3 participants
41 - 45	2	Secondary school 3	
46 - 50	1	Postgraduate 1	

All of the interviews were tape-recorded and some were written and transcribed verbatim (by the researcher). Interviews continued until saturation was reached. A saturation threshold is a criterion used in qualitative research to restrict data collection or analysis. It can be traced back to grounded theory [23]. Transcripts were cross-checked with the original recordings more than once. Cross-case interview analysis involves grouping answers from different people to the same questions or examining different perspectives on central issues [24]. The collected information was treated with the utmost confidentiality and was used exclusively for the purpose of the present study.

Hospital Anxiety and Depression Scales (HADS) were used to assess depression and anxiety in patients. A total of 14 items comprised the HADS, seven of which dealt with anxiety and seven dealt with depression. The anxiety and depression items are coded based on a 0 to 3 system (Table 2), so the scores can vary from 0 to 21, as a function of the severity of symptoms [25]. HAD scales are simple to administer, well accepted by patients, and sensitive to mood changes that may occur during the disease [26].

Table 2. HADs score.

For both scales, scores of less than 7 indicate non-cases	
8 - 10	Mild
11 - 14	Moderate
15 - 21	Severe

According to the HADs assessment, depressed mood was the most common symptom among respondents (5 counts), while anxiety was less intense in this sample (1 count).

3. Result

Four themes were revealed from data analysis for this study, namely:

Demographic characteristics: the study showed that the respondents were aged between 31 and 50. One of them held a postgraduate certificate, and the majority of the respondents were well educated. Most of the interviewees had children ranging in age from 4 to 6 years old.

1) Breast cancer knowledge: Most respondents (five) had misunderstood or had incorrect information about breast cancer.

“The only thing I know is that breast cancer is a killer disease and there is no treatment’, one of the respondents said. Another one stated, “I don’t know what it is, I just know it’s a killer disease, and we shouldn’t go to the doctor because it’s incurable...”

“When someone smokes a cigarette, infection occurs; it is contagious.”

On the other hand, one had full understanding of it, as she said:

“I know a lot about breast cancer and I know it can be inherited.”

2) Disclosing the diagnosis to children; a few chose to hold back the diagnosis from their children because they were still young (2/8), while the majority disclosed it to their children at their partner's request (2/6) or because they believe their children will know one day, and it is better to know it directly from her. According to one interviewee:

“At the beginning, I didn't want to tell them because I didn't know how this would affect them and I wanted to protect them from the bad news distress, but then I did it since I knew they would eventually hear about it from someone else.”

According to another woman:

“My husband insisted that I had to tell my children since a lot of changes had taken place in the house, so they will have to adjust as a result.”

One of them told her daughter because she was with her when she knew; her daughter broke down, as she states:

“When my daughter received the news, she cried and refused to accept it, which made me feel even worse.”

3) Sense of need for closeness: Nearly all of the interviewed women were anxious about their children (6/8), as they will die and leave them behind (2/6); however, anxiety and overprotection were indicated as a result of the diagnosis (4/6), as one interviewee stated:

“Absolutely, my children and I developed different relationships after the diagnosis, and I'm trying to get closer to them because I'm afraid of dying and leaving them behind.”

Another one reported that: “I just want them by my side all the time, I thought I would die any time...” Before I was diagnosed, I used to let my children sleep in their bedrooms, but after I was diagnosed, I wanted them with me”...“They were absolutely not allowed to play with neighbors”.

4) Concerns about passing on the disease to their daughters: Result showed that less than half of the interviewees were worried about passing on the disease to their daughters. One of the participants expressed this concern by saying:

“Sometimes I think about what if my daughter inherits it?”

The same number (3) of respondents had strong faith; one of them even mentioned that:

“It was according to the will of God.”

4. Discussion

The present study hypothesized that: 1) Women with breast cancer rarely tell their children about the diagnosis; 2) Women with breast cancer are prone to

depression and anxiety during the treatment process; 3) Overprotective maternal behaviors result from the fear of passing on the disease to their daughters.

The study found that mothers don't disclose the diagnosis to their children because they are concerned about its psychological impact on the children. They want to protect them, and they believe the disease will cause distress and pain to the child. This result corroborates some relevant studies which found "a considerable amount of consistency in the reasons given for not disclosing information to children about the disease" [27]. Parents, most often, avoided children's questions, as they hoped to reduce the distress of their children and themselves, particularly avoiding the topic of death" [7]. According to the result of another relevant study [28], several women mentioned their attempts to remain positive and to "protect" or "distance" their families as well as their children from their diagnosis; this attitude was typical to avoid the death atmosphere related to cancer diagnosis.

This finding was somewhat surprising; because there are several commentators who suggest that disclosing one's experiences with cancer can help reorganize one's thoughts and feelings, as well as help the person make sense of it all [29] [30].

Although it is important for the patients themselves as it helps in finding support and relief from distress, Sudanese women are not willing to share this information with their children or even their relatives because of stigma in addition to avoiding the feeling of sympathy shown by others around them. They don't like the feeling other people transfer that she is going to die, as culturally most families, when they know about the diagnosis for one of the relatives with such a fatal disease, they move and live with her, or be around her all the time, in addition to neighbors who visit her frequently. Although this practice offers some sort of support to the patient, at the same time may lead to deepening the feeling that "I'm going to die".

4.1. Transmitting the Disease to Daughters

Patients were almost universally concerned for their sisters, mothers, daughters, and nieces, especially their daughters [31] about inheriting breast cancer. Thus, it is very important for clinicians to provide their BrCa patients with all the information they need about breast cancer and its causes; information about the disease and its etiology is essential to survivors' attitudes and concerns about their daughters. Genetic risk is challenging to communicate because of the inherently uncertain nature of the information, as well as the difficulty of explaining complex concepts to non-experts [32], but generally, clinicians should offer information based on the patient's knowledge and educational level. In this study, respondents who knew about the disease were concerned about passing it on to their daughters, based on some studies which revealed that family history is one of the major risk factors for breast cancer [33] [34], which leads to anxiety and overprotective behavior. On the contrary, respondents who had a vague or erro-

neous understanding of the disease and its transmission were less anxious. Sudanese women, just like other women around the world, have a tendency to be protective of their children after diagnosing, according to their own beliefs about protection. As it is shown by the results of the present study, some mothers try to protect their children by sleeping in the same room with them, others by not letting them have a social relationship to keep them as close as possible. A person's conceptualization of something can differ from how they act in certain situations; they may know that this behavior will not protect them from having the disease but they still practice it.

4.2. Depression and Anxiety during Treatment

According to some studies, 48% of patients with a variety of cancer diagnoses experience anxiety disorders. Some other studies reveal that the incidence of anxiety disorders among breast cancer survivors is 8.6% [3]. An interesting point about this is that, in this study, the HADs assessment revealed no cases of anxiety among Sudanese women, and that could possibly be attributed to their strong faith in God. Denmark's population has been studied, and the researchers found that depression is not a risk factor for developing breast cancer.

According to them, breast cancer was associated with depression [8], which is comparable to our study that confirms many women became depressed after diagnosis and during treatment. Women of all ages face multiple stressors following diagnosis and treatment, but younger women are especially vulnerable to negative psychosocial sequelae [15]. Due to the changes in their life expectations concerning marriage, giving birth, and breastfeeding following a diagnosis, women experience multiple stressors due to the beginning of their new family life. Furthermore, hair loss, weight gain, and physical appearance may contribute to stress in the treatment stage. As children of mothers who have breast cancer, they distinguish between different domains of concern about their mother's disease, but only the child's concern about the family's well-being was significantly affected by their mother's depressed mood [20]. As a result, children of mothers with breast cancer will suffer psychologically and emotionally as a result of their mother's depression.

5. Conclusion

This paper tries to identify the effect of breast cancer on women's psychological well-being as well as the consequence of it on their children; in addition to finding out their perception about passing the disease to their daughters. Eight participants were selected from the Khartoum Radiation and Isotopes Center purposively and then interviewed face to face until saturation was reached. Moreover, HADs was used to assess the psychological effect of breast cancer. Collected data were analyzed through cross-case interview analysis and revealed that, women with breast cancer experience several psychological consequences due to their knowledge and awareness of their condition and their concern about their child-

ren. They worry about transmitting the disease to their daughters, fear death, and the feeling of being pressured to disclose their conditions to their children.

6. Recommendations

Further research on the best ways to provide psychological support to these mothers regarding their relationship with their children should be carried out, bearing in mind the social belief about breast cancer as a stigma. In addition to awareness campaigns about breast cancer should be held continuously to improve the acceptance and lessen the psychological distress for mothers as well as for their families. Moreover, utilizing social support systems as a strong means of helping families deal with breast cancer diagnosis stresses.

This study has some limitations, such as little access to previous studies and literature in the same area in Sudan. Due to the small sample size, this study may not be generalizable; however, it can be used as an introductory study for further research in this area.

Conflicts of Interest

The authors declare no conflicts of interest.

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