

Women with breast cancer, listening to the unheard voices: A qualitative study

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ABSTRACT

Objective: This is a descriptive qualitative study with the aim of examining experiences of women diagnosed with breast cancer.

Methods: The semi-structured interviews were conducted in the oncology clinic in Al Basheer Hospital in Jordan and included 15 women.

Results: Several themes were identified such as knowledge before and after diagnosis, side effects of treatment, social and economic problems, lockdown and financial challenges in corona pandemic, coping strategies, and disclosure issues. Appropriate knowledge concerning causes of breast cancer, and side effects of administered drugs were lacking. Additionally, women were not comfortable telling others about their breast cancer diagnosis and considered it a private issue. During the COVID-19 pandemic, they faced many difficulties reaching hospitals, financial struggles, and inability to meet with their loved ones during lockdown.

Conclusion: This study revealed the diversity of personalities and unique disposition of women regarding all the topics covered in the interviews. These differences should be considered in the support provided to these patients.

Keywords: breast cancer, knowledge, concerns, women, qualitative, Jordan

INTRODUCTION

In 2020, 2.3 million women were diagnosed with breast cancer globally, and 685,000 women died from breast cancer. Breast cancer was the most prevalent cancer in the world with 7.8 million survivors [1]. In Jordan, occurrences of breast cancer in women have increased from 674 in 2005 to 1,138 in 2015, a total increase of 69%. The highest incidence was in the age group 60 to 64 years [2].

Numerous studies were conducted in the previous years to explore the profound repercussions of breast cancer on the lives of the women. Psychologic effects such as depression was associated with living alone and using measures that lower estrogen [3], depression and anxiety was reflected on low quality of life [4]. Distress caused by the fear of stigma was significant in women with lower education level and those who underwent surgery [5], the type of surgery had an impact on health-related quality of life [6]. Coping mechanisms were evaluated, religion and spirituality were important factors that helped women cope with their condition [7-9]. The impact of the COVID-19 pandemic was also investigated, fear from the severe complications of infection in the COVID-19 pandemic was identified [10] and was apparently mitigated by family resilience [11].

Concerns of breast cancer survivors are affected by age; young women are troubled by issues that differ from those that face older women [12]. These worries are related to fertility, family planning and pregnancy [13], body image, and emotional well-being [14]. Women also must endure worries about the reaction of society towards breast cancer, concerns regarding embarrassment and stigmatization [15]. Studies showed that embarrassment and stigma were major barriers to screening, early diagnosis of cancer, and early treatment [16, 17]. Additionally, disclosure of their diagnosis to work colleagues and family members produced difficulties at work and affected close relationships [18].

Many studies were conducted to evaluate women's knowledge of breast cancer [19, 20]. Adequate knowledge is essential to make informed decisions and be actively involved in therapeutic care plans, which might lead to a better treatment satisfaction [21].

This study explores knowledge, concerns, and coping strategies of women diagnosed with breast cancer. These issues are influenced by cultural and religious aspects, which makes findings unique to a conservative, middle eastern community like Jordan.

Table 1. General characteristics of the participants (n=15)

N	Age	Occupation	SS	DD	Treatment	MI	Education	Stage	Type	Receptors
1	42	Nurse	Single	3 years	Mastectomy/radiation/chemotherapy/hormonal	400-800	College	4	IDC	PR+/ER+/HER2+
2	46	Farmer	Married	3 years	Lumpectomy/mastectomy/radiation/chemotherapy/hormonal	400-800	Elementary	2	IDC	PR+/ER+/HER2+
3	49	Teacher	Married	8 years	Lumpectomy/radiation/Chemotherapy/hormonal	400-800	University	3	IDC	PR+/ER+/HER2+
4	42	Cleaner	Widower	4 years	Lumpectomy/radiation/Chemotherapy/hormonal	<400	High school	4+M		PR+/ER+/HER2-
5	46	None	Married	6 years	Mastectomy/radiation/chemotherapy/hormonal	>800	High school	3	IDC	PR+/ER+/HER2+
6	49	Teacher	Married	5 years	Mastectomy/radiation/chemotherapy/hormonal	<400	College	4+M	IDC	PR+/ER+/HER2+
7	53	Farmer	Married	4 years	Mastectomy/radiation/chemotherapy	<400	No school	4+M	IDC	PR-/ER-/HER2+
8	63	None	Married	2.5 years	Chemotherapy	<400	High school	3	IDC/TNBC	PR-/ER-/HER2-
9	57	None	Divorced	7 years	Mastectomy/chemotherapy/hormonal	400-800	College	4+M	IDC	PR+/ER+/HER2+
10	61	Hand crafts	Married	4 years	Single mastectomy/chemotherapy/hormonal therapy	<400	University	3	IDC	PR-/ER+/HER2+
11	60	None	Married	3 years	Single mastectomy/radiation/chemotherapy	>800	High school	4+M	IDC	PR-/ER-/HER2+
12	51	None	Married	4 years	Lumpectomy/radiation/chemotherapy/hormonal therapy	400-800	High school	3	IDC	PR+/ER+/HER2-
13	42	None	Married	5 years	Single mastectomy/radiation/chemotherapy/hormonal therapy	400-800	High school	4+M	IDC	PR+/ER+/HER2-
14	50	None	Married	6 years	Single mastectomy/radiation/chemotherapy	<400	High school	2	IDC	PR-/ER-/HER2+
15	55	None	Married	7 years	Single mastectomy/chemotherapy	<400	High school	2	IDC/TNBC	PR-/ER-/HER2-

Note. PR: Progesterone receptor; ER: Estrogen receptor; HER2: Human epidermal growth factor receptor 2; JOD: Jordanian Dinars; M: Metastasis; IDC: Invasive ductal carcinoma; TNBC: Triple negative breast cancer; N: Patient number; SS: Social status; DD: Disease duration; & MI: Monthly income

METHODS

This is a descriptive qualitative study to examine experiences of women diagnosed with breast cancer. It was conducted in the oncology clinic in Al Basheer Hospital, the biggest governmental hospital in Jordan. Patients were enrolled if they fulfilled the inclusion criteria; older than 18 years, diagnosed for at least two years, and were administered some sort of treatment. Women who were recently diagnosed or severely ill were excluded from the study. Face-to-face, semi-structured, 30-45-minute-long interviews were guided by questions to provide uniform approach and keep the interviewer focused on the main issues. The questions were developed after extensive literature review, the moderator conducted three interviews that were not included in the study but allowed tuning of the questions to achieve the study objectives.

A registered nurse at the oncology department at Al Basheer Hospital conducted the interviews in June and July 2021. Patients who visited the oncology department during that period and fulfilled the inclusion criteria were approached for recruitment in the study. The aims, nature of the study, and how it would be conducted was fully explained to the patients. Patients signed an informed consent form which stated that they agreed on publication of their patient information anonymously. Patients were informed that the interview would be audiotaped. When saturation was reached and no new information was added, three extra interviews were conducted to confirm data saturation.

The audios were transcribed verbatim in Arabic, and transcribed interviews were translated into English language. The transcription and translation processes were revised by

the researchers to ensure that what the participants revealed was accurately and thoroughly captured.

Thematic analysis involved the following steps: reading the transcripts several times to identify interesting information, identifying a connection between emerging ideas to form themes, expanding themes into different dimensions in form of subthemes using similar codes, and finally linking subthemes with their related quotations from participants' interviews.

RESULTS

15 women diagnosed with breast cancer were interviewed. Participants were between ages 42 and 62 years. General characteristics of the participants are shown in **Table 1**.

Knowledge

Two themes of knowledge emerged: knowledge of cancer before and after diagnosis with four subthemes; causes of the disease, survival, types of treatment and their side effects, and sources of information (**Table 2**).

Perceived causes of cancer

Patients mentioned many possible causes of breast cancer, but the narrative of women was indecisive and involved repetition of the phrase "I do not know". One patient was convinced that taking hormones during IVF procedures was the cause:

"For my cancer, I think that the hormone injections that I used to take were the cause, because all my body was different ... I had extra activity in my hormones" (Patient 3).

Table 2. Dimensions, themes, subthemes, & codes

Dimension	Themes	Subthemes	Codes	
Knowledge	Before diagnosis	Causes of disease	No knowledge/exposure to radiation/food contaminated with hormones/fate/environmental contamination/IFV procedure/sugar/smoking/genetic predisposition/microwave radiation/tension & psychological issues/using deodorants/wearing tight underwear (bra)/marriage at an old age/envy	
		Survival & curability	Low survival rate/early discovery is important/survival in breast cancer is higher than other types	
		Treatment & side effects	No knowledge/chemotherapy/radiation/surgery/chemotherapy changes facial features/chemotherapy is lethal/reading Holly Quran	
	After diagnosis	Source of information	Facebook/common people/television/educational lectures	
		Cause	Exposure to radiation/contaminated food/genetic/tension/fate	
		Survival & curability	Patients can be cured/early discovery is important	
		Treatment & side effects	Chemotherapy/radiation/hormonal/surgery/HER 2 antagonists/immunotherapy/supplements & vitamins/side effects managed with drugs	
		Source of information	Patient's experience/doctors/nurses/other patients/the Internet/leaflets & lectures	
		Side effects of treatment	Chemotherapy	Hair loss/fatigue
			Radiation	Entering big machines/burns body & skin/painful
Surgery	Wounds-prolonged healing & infection/removing breasts & physical appearance/pain/losing femininity/cannot take off clothes in front of husband/fear from plastic surgery/loosing balance after mastectomy			
Hormonal therapy	Reducing libido/gaining weight			
Burden & concerns	Social & emotional problems	Relationships	Financial & emotional support/neglect/death & leaving kids	
		Relationships (other than relatives)	Feeling of pity was upsetting/loss of privacy/welcomed extra attention/seclusion	
	Economic & logistic problems	Relationships with the physician	Perfect relationship	
		No effect	Medical insurance available	
		Buying medicine	Problem if no insurance	
		Workplace	Too tired to continue working/taking leave of absence is a problem/kept job despite difficulties	
Challenges during COVID-19	Curfew-lockdown	Transportation	Using a wheelchair/no one can take me to hospital/civil defense helps	
		Psychologic	Happy to spend time with family/emotionally depressed from lack of jobs for family members/depression from not being able to get out & see family members/lots of house chores/afraid from getting corona	
		Hospital visits	Difficulty in transportation to hospitals/fear from having corona in hospitals/did not go to hospital for long time/long time to reach hospitals using civil defense vehicles	
	Financial challenges	Access to medication	Treatment was delivered to home by COVID-19 governmental platform services	
		Daily expenses	Staying at home increased expenses/took loans during pandemic/received financial support from family members	
	Having the corona	Losing jobs	My husband & sons lost their jobs/reduced income from private businesses	
		Burden of disease	I got corona & was terrified/after infection with corona suffered from loss of smell & taste/household chores	
Disclosure	Comfortable telling others	Who did you tell	Family members/close friends/neighbors	
	Not comfortable telling others	Why did you tell people	I needed to talk to someone/I needed their support	
		Causes of not telling others	Did not want the feeling of pity/private matter/parents & friends will be worried about me	
Coping with breast cancer	How did you cope with breast cancer?	Coping	Isolation/exercise/offering support to other patients/participation in cancer department activities/visiting friends & family/relaxation/social media groups for cancer patients/travelling	
		Religion	Reading Quran/attending religious lessons/praying	
	Support	Attitude towards accepting help	Accepts help from people/does not accept help	
		Type of support	Financial or spiritual/physical help-getting dressed, cooking	

Treatment and side effects

Patients heard many rumors concerning side effects of treatment; some were correct like hair loss and others were exaggerated:

“My aunt had cancer, they say that after chemotherapy her body was inflated and filled with water. Cancer cells spread and ate her body and her breast started to disappear” (Patient 9).

The importance of willpower was emphasized by many patients in addition to commitment to pharmacologic treatment, this was explained in the following narrative:

“Cancer is a very tiring disease, but someone with strong willpower can fight it. One can take control and manage the disease ... the most important thing is power and strong will ... chemotherapy and other types of treatment and medicine also have an important role” (Patient 4).

Some perceptions on the different methods used for treatment of cancer changed after patients received them. Many admitted that side effects were difficult, but patients were able to tolerate them.

Survival and curability

Many patients changed their views on fatality and curability of breast cancer after they were diagnosed. Before diagnosis, most of the women thought that if you had cancer you would die:

“People are afraid of the word cancer, whenever you heard that a woman had breast cancer you knew that she would die” (Patient 13).

Source of information

Before diagnosis, patients had several sources of information: social platforms, relatives, and television:

“I got the information from television, they do not explain a lot on television, so I got this information from myself. On the TV, they say that people with blood cancer do not live, but those with breast cancer can be cured” (Patient 7).

After diagnosis, patients obtained information from the medical team, their own experience, and other patients:

“I took information from doctors, nurses and patients that I talked to” (Patient 8).

Burden of the Disease

Some patients were severely affected by the diagnosis:

“Of course I collapsed at first, because it was unlikely for me. I did not expect to get cancer. I was devastated and I started to cry. Then, nurses came and started talking to me and told me to look around, many patients are taking treatment and doing well, some were diagnosed 20 years ago” (Patient 3).

Radiation and surgery

“I did not know what radiation was, what will it do to me. I did not know, and I did not understand. They wanted to put me inside this big machine, what will it do to me when I enter it? This big machine that I will be put in, I was afraid of the electricity. Then, after my first dose it turned out to be a normal thing and I kind of relaxed” (Patient 1).

Surgeries, especially mastectomies, were a great concern to most patients:

“It is very difficult. I love my personality and femininity. How can I tell you this ... hmm ... the beauty of the woman is in her breasts” (Patient 4).

“Some patients said that if they open you up and the tumor is exposed to air it will spread. I do not know; you hear the world (meaning people) saying that” (Patient 5).

Social and emotional problems

Women confided in close family members, their sympathy and support made them happy. However, the patients' attitudes towards people outside their family members were diverse. Some did not welcome the curiosity:

“People wanted to know what happened with me, how far did the treatment go. I wanted to keep these things secret, these were my private issues. So, at one point, I stopped visits because I only wanted to see my sisters” (Patient 1).

Some considered the affection from people disturbing:

“I told people about my condition, but I do not like the look of pity, I am not weak, I am strong. I am strong with my willpower and God's power. When people look at you and say: poor thing, she is sick, you feel broken” (Patient 12).

Others welcomed attention:

“I felt that all the people who knew me or did not know me came to visit me. They felt sorry for me but that was fine. They brought me gifts and people who I did not know visited me in my house for the first time” (Patient 13).

Economic and logistic problems

Most patients were medically insured but transportation was a challenge:

“I was crippled at first, they used to carry me in a wheelchair, we had stairs, and it was difficult getting to the car and then getting out of the car” (Patient 4).

Some patients thought that despite hardships, keeping their job was important for them:

“I have been teaching for the last 21 years, students ask for me by name. This was motivation for me to be strong and finish my work. I have been in the same job for the last 21 years, thank God, my work did not change” (Patient 3).

Challenges During COVID-19

Patients had obstacles during the COVID-19 pandemic:

“One time we had to wait almost 3 hours for a taxi to get to the hospital, we were wearing gloves and masks, and we were afraid” (Patient 13).

Another patient did not believe that the COVID-19 pandemic was real:

“It is all a lie. It is just a simple cold. I am not convinced, and I am not afraid of it” (Patient 14).

The trip to the hospital was very difficult, civil defense vehicles would take several patients from distant areas, drop them off at different sites and pick them up at the end of the day:

“The bus picked up a lot of people and dropped them off, the same thing happened in the way back from the hospital, it was so difficult” (Patient 2).

Disclosure

Some women were comfortable telling people about their disease, but others did not want to share this information:

“I am not ashamed of my disease; one should not be ashamed of death or disease because they are from God, and it cannot be hidden” (Patient 5).

Others were not comfortable telling their friends, tried to hide their true feelings, and pretended they were fine so that they would not worry about them:

“I was tired on the inside and wanted to cry and scream, but I did not show it because I did not want anyone to be sad or worried. So, I make jokes and laugh” (Patient 4).

Coping With Breast Cancer

Strategies to cope

Women found that it was the hard to cope with their diagnosis at the beginning:

“In the beginning, I was not positive dealing with the disease, on the opposite, I was devastated. what will I do? How will I live? Before the disease you have dreams and ambitions, you have a future to think about. I wanted to travel, I wanted to buy a car, wanted to invest in something. All that was gone, it stopped, you cannot dream anymore. Now after three years, I receive treatment, why should I put pressure on myself, I go out, live normally, and see people” (Patient 1).

Women had different strategies to cope with their disease, many resorted to religion and spent time reading the Quran. Some lost the desire to embark on life and chose seclusion:

“I do my housework, and I sit in my house, there is nothing ... except for my neighbor when she comes from her work she comes over , just that” (Patient 12).

Women wanted to participate in life for the sake of their families:

“I wanted to live for my kids, my father, my mother, and my husband. There are lots of loved ones around me. You must be strong so they can be strong” (Patient 5).

Support

Some women were willing to accept emotional help, but not financial, because they felt that financial help would disgrace them. Accepting help from people was not easy, even if it was offered by family members:

“It is very difficult to accept anything from people easily, I can hardly accept it from my brother. Yes, it is difficult” (Patient 8).

Another woman expressed her refusal to any help because she liked to depend on herself:

“I like to depend on myself, in everything and in every detail of my life I like to depend on myself. I do not depend on others; I like to offer help to others” (Patient 3).

Some found it hard only at the beginning:

“I used to be shy when people offered to help, now it is normal” (Patient 4).

DISCUSSION

Women’s knowledge on cancer was centered around causes of cancer, treatment side effects, and survival. It was clear that the women had many misconceptions related to breast cancer.

Many studies have shown that women’s poor understanding of the disease at early and advanced stages might affect their choices of treatment [22, 23]. Women who know more about treatment options were also less likely to be under treated, and consequently had a better chance of survival than those who were less knowledgeable [24]. Factors associated with poor knowledge include low educational level and low income [25]. Misconceptions of risks and benefits of medication influence adherence to anticancer treatment [26].

Belief in God was evident in the interviews, religious attribution and that it was fate from God was mentioned as a cause by many patients. Before diagnosis, women believed that it was unlikely for a woman with breast cancer to live long. After diagnosis, women were more optimistic about living longer after receiving more information from medical staff and breast cancer survivors. Strong believers emphasized the importance of inclusion of faith-based approach in the management of breast cancer. It was examined women’s perception of changes to body image in Jordan [9]. Religion was a major factor in helping women to cope with their condition [9]. Incorporating spiritual care into cancer management might contribute to coping with the illness and increase life satisfaction in highly spiritual women [7, 8].

During the COVID-19 pandemic, cancer patients faced many challenges, such as postponing appointments and enhanced risk of infection [10]. Patients had difficulties reaching hospitals for appointments. During lockdown, women did not experience problems with home confinement due to the presence of family members, family resilience was an important ameliorating factor that reduced negative consequences of the pandemic [11].

Cancer patients received support from family members, many were reluctant to accept help, especially financial support. Women found comfort in confiding in another female, sister, neighbor, or a friend. Social support is important in reducing cancer related stress [27] and decreased depression [4], which are common in women with breast cancer. In Jordan, it was revealed that half of breast cancer patients suffered from abnormal levels of anxiety and depression. The participants did not welcome inquiry regarding their medical condition because it was a private issue and were not interested in continuously reading about breast cancer because they did not want all their time to be centered around their disease. This type of behavior is related to a coping pattern called cognitive avoidance [28]. Breast cancer patients showed individual traits and preferences, breast cancer support groups should have

general strategies but must also consider different needs and personalities.

Similarities among women include the prevalence of misconceptions regarding survival rates in breast cancer and the dramatic effects of treatment. Additionally, most women resorted to religion to find comfort and ease distress and grief caused by breast cancer. During COVID-19 pandemic women faced similar difficulties, among which, transportation to and from the hospital, which was costly, time consuming, weary, and exhausting.

Women were different in revealing their disease to either family members or others. Some women found it acceptable to confide in family members or friends, but another group of women were reluctant to reveal their medical condition to family members of other for various reasons. Accepting help was also divergent, some welcomed the attention and assistance, while others were not comfortable receiving help because they may be judged as weak, vulnerable and did not want to face their looks of pity.

This study has several limitations, such as limited sample size, the qualitative nature of the study, the lack of control on cancer severity, and presence of confounding factors, such as educational level, family income, presence of children and marital status. Most patients received chemotherapy, radiation, and hormonal therapy and so comparison between those who received only one type was not possible.

Despite these limitations, the study offers the first deep insight into the knowledge, concerns, and coping strategies of patients with breast cancer in Jordan.

CONCLUSION

Lack of knowledge of correct facts concerning breast cancer was evident before and after diagnosis and treatment. Healthcare workers should focus on communicating accurate information regarding different treatments and their side effects. Participants in general were reluctant to disclose their medical condition even to family members, stressing the importance of privacy of patient's medical condition and diagnosis. Coping strategies were versatile, but belief in God and religious faith were common between women. This finding suggests that spiritual activities should be part of coping approaches in breast cancer programs in addition to medical and educational guidance.

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Data sharing statement: Data supporting the findings and conclusions are available upon request from the corresponding author.

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