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Coping With Breast Cancer

A Phenomenological Study

KEY WORDS

Breast cancer
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Background: Breast cancer is the most common malignancy affecting women worldwide. In Lebanon, a country of 4 million people, breast cancer is also the most prevalent type of cancer among Lebanese women. Objective: The purpose of this study was to gain a more in-depth understanding of the coping strategies espoused by Lebanese women with breast cancer. **Methods:** The study followed purposeful sampling and saturation principles in which 10 female participants diagnosed as having breast cancer were interviewed. Data were analyzed following a hermeneutical process as described by Diekelmann and Ironside (Encyclopedia of Nursing Research. 1998:50-68). **Results:** Seven main themes and 1 constitutive pattern emerged from the study describing the Lebanese women's coping strategies with breast cancer. The negative stigma of cancer in the Lebanese culture, the role of women in the Lebanese families, and the embedded role of religion in Lebanese society are bases of the differences in the coping strategies of Lebanese women with breast cancer as compared to women with breast cancer from other cultures. Conclusion: These findings cannot be directly generalized, but they could act as a basis for further research on which to base a development of a framework for an approach to care that promotes coping processes in Lebanese women living with breast cancer. Implications for Practice: Nursing and medical staff need to have a better understanding of the individual coping strategies of each woman and its impact on the woman's well being; the creation of informal support group is indispensable in helping these women cope with their conditions.

Breast cancer is the most frequent malignancy affecting women worldwide. In Lebanon, a country of 4 million people, breast cancer is also the most prevalent type of

cancer among Lebanese women. It corresponds to 42% of all female cancers (Lebanese Ministry of Public Health, World Health Organization, and National Non-communicable Diseases

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Programme).¹ It is noted that at least half of the women with breast cancer will survive 5 years, as has been found for those living in developing countries.² Therefore, as the survival rates of breast cancer increase, the number of women living with long-term consequences of breast cancer treatment will also augment. Women's responses to and coping with the diagnosis of breast cancer have become an area of growing concern to many researchers.^{3–5} However, most research on women's coping with breast cancer has been conducted in western countries. So far, no documented research study is found on the experience of coping in Lebanese women with breast cancer. Consequently, the intention of this study was to gain more in-depth insights into how Lebanese women cope with breast cancer so that culturally sensitive care can be provided.

■ Background

Breast cancer diagnosis, and its subsequent treatment, is a traumatic experience with intense impact on all facets of human life. 4,6 Several studies have investigated coping strategies and their effect on cancer. According to Taleghani et al,⁷ Iranian women used a religious approach for coping. They used positive suggestions, hope, and intentional forgetfulness as coping mechanisms. Coping strategies as described by African American women included relying on prayer, avoiding negative people, developing a positive attitude, having a will to live, and receiving support from family, friends, and support groups.⁸ In a study on 100 newly diagnosed women with breast cancer in China, Li and Lambert9 reported that planning, positive reframing, and self-distraction were the most commonly used coping strategies. Manual et al, 10 in a study on coping in young women diagnosed as having breast cancer, reported that the most frequently used coping strategies were positive cognitive restructuring, wishful thinking, making changes, social support engaging in physical activity, using medications, and resting. This study also highlighted that different coping strategies were considered best in response to different stressful aspects of dealing with cancer. Comparable results were also highlighted by Stanton et al.¹¹ In a study on coping following breast cancer and psychological adjustments, Hack and Degner¹² reported that women who respond to their breast cancer diagnosis with passive acceptance and resignation are at a significant risk for poor long-term psychological adjustment. Butow et al¹³ reported that women with metastatic breast cancer who minimized the effect of cancer as a disease on their lives survived longer. Those who used minimization as a coping strategy revealed that the cancer did not influence social, work, or family life, nor was it an important cause of anxiety or depression. These women, who accepted their illness and its life-threatening potential, showed a better social adjustment, an ability to shift between appropriate mourning for their loss of health and approaching death, and a tendency to concentrate on ongoing positive aspects of their lives. These results imply that adequate support, active coping, and finding positive meaning in life can lead to a diminution of cancer's effect.

Although research has indicated that coping strategies have a great impact on women's adaptation and response to breast

cancer, nothing is known about how Lebanese breast cancer women cope with breast cancer. Therefore, the intent of the present study was to gain a more in-depth understanding of the coping strategies followed by breast cancer Lebanese women so that culturally sensitive healthcare and culturally relevant coping strategies could be encouraged by healthcare providers.

■ Methods

Design

Our reflections on the concept of coping with breast cancer emerged while conducting a qualitative study about the lived experience of Lebanese women with breast cancer¹⁴ following a phenomenological approach as described by Barritt et al.¹⁵ This approach was chosen because it allows descriptions of phenomena as experienced in life and aims to offer an understanding of the internal meaning of a person's experience in the world.¹⁶ Thus, a comprehensive, culturally competent understanding of the phenomenon was obtained.

The idea of coping with breast cancer emerged from the participants' interviews as an important feature for living with the diagnosis of breast cancer. A second analysis of textual data (narratives) from the initial study was done following a 7-stage hermeneutical process as described by Diekelmann and Ironside. The previous interviews became the narratives that constituted the text for the present analysis. The second analysis was conducted immediately at the end of data collection when the researchers realized that coping was an important element of the women's lived experience. The focus of the second analysis was the coping process. To maintain scientific rigor in the second analysis, researchers' biases were reduced by careful attention to the text, use of team approach for analysis, and verification of the findings with the participants. In addition, findings were supported in the text by participants' excerpts.

Participants

Ten participants were chosen based on purposive sampling, saturation principles, and according to the following inclusion criteria: (1) Lebanese Arabic speaking; (2) living in Lebanon; (3) age of 25 years or older; (4) diagnosed as having breast cancer, stages (I-III); (5) without distant metastases, previous history of mental disorders, or the existence of other forms of cancer or other chronic diseases; and (6) agreed to be interviewed without the presence of a third person to ensure liberty for the participant to express her feelings.

Recruitment Strategies and Techniques

After securing the approval of the institutional review board of the American University of Beirut, the primary researcher talked about the study with community intermediaries (nurses, housewives, friends) and oncologists. After the community intermediaries identified the participant, the primary researcher phoned each potential participant and presented a request to join the study. Then, the researcher arranged for an interview date, time, and place with each participant according to her preferences. All participants read and signed a consent form.

Setting

All interviews were conducted at the participants' homes in rural and urban areas of Lebanon.

Data Collection

Data were collected between December 2007 and May 2008. Interviews were conducted in Arabic by the researcher. Each interview was translated to English by a translator and back translated to Arabic by a research assistant to check for accuracy of translation. In each interview, the participant was the main speaker, and the researcher was mostly a listener and a facilitator. The participants were reminded that their participation is voluntary and that at any time they could decline or withdraw from the study without any obligation. At the end of the second interview, each woman received a "mug" as a token of appreciation for her participation in the study.

The interviews were audio taped, and field notes were recorded. Each interview was coded so that only the researcher has a knowledge of the persons who participated. Participants were guaranteed confidentiality, and pseudonyms were used. The code list and the original tapes were placed in a locked file cabinet in the researcher's office for a period of 3 years, at which time the notes will be destroyed and the tapes erased.

The interval between the first and second interviews was 2 weeks. The first interview took 50 to 60 minutes, and the second interview took 30 to 40 minutes. The objective of the second interview was to validate the preliminary analysis with the participant. It is worth noting that the consensus between the researcher's interpretation and the participants was almost more than 95% in all interviews.

The first set of interviews was based on the following broad or grand tour question: "What has it been like for you since you were diagnosed with breast cancer?" Moreover, during the second interview, each participant was asked to validate if the statements, ideas, and words reported by the researcher illustrate her experience of coping with breast cancer.

Analysis

The second data analysis started at the end of the first study. Narratives (texts) were interpreted following a 7-stage hermeneutical process as described by Diekelmann and Ironside. The objective of this process is to portray shared practices and common meanings. The analysis team included the principal investigator and an experienced graduate assistant in qualitative analysis. Each text was examined as a whole to gain an overall understanding. Possible common meanings were identified from the texts with excerpts to support the interpretation. The researchers compared their interpretations for similarities and differences at biweekly meetings, reaching further clarification and consensus by returning to the original text. All texts were

reread to uncover themes that linked them. Researchers described a constitutive pattern that showed the relationship across themes among all texts. According to Diekelmann and Ironside, ¹⁷ the discovery of a constitutive pattern forms the highest level of hermeneutical analysis. A situation is constitutive when it gives actual content to a person's self-understanding or to a person's way of being in the world. Furthermore, themes were validated by the participants of the study. At the end, the principal investigator produced the final summary, including verbatim quotes that allow for validation by the reader. This multistage process permitted clarification and validation, which helped in eliminating unconfirmed meanings. The hermeneutic circle involves constant checking of the whole and the parts of the text. It is worth noting that the continuous reference to the text guaranteed that interpretations were grounded and focused. ¹⁷

■ Results

Sample Description

The sample consisted of 10 women; their ages ranged between 36 and 63 years, with a mean age of 51.3 years. Participants' experience with breast cancer ranged between 4 months and 9 years. Three women underwent total mastectomy of 1 breast, 1 participant endured partial mastectomy of 1 breast, and 6 participants had lumpectomy also on 1 side. Eight participants were still married at the time of the interview, and 2 were widowed. Three participants were living in rural areas and 7 in urban areas. All participants had children. The participants' educational background varied between intermediate (n = 3), secondary (n = 2), and university (n = 5).

Findings

All participants described their journey with the disease process as a nonstop fight against cancer. They also described cancer as a cut in their lives that they had to deal with. Despite the differences in the time since diagnosis, most participants spoke about similar facilitating and hindering factors for coping. Seven main themes and 1 constitutive pattern emerged from the study. Four themes described the participants' facilitating coping factors with the diagnosis of breast cancer, and 3 themes were considered as hindering factors to coping.

Facilitating Coping Factors

CANCER IS SOMETHING FROM GOD

All participants regardless of their religious background dealt with cancer as something coming from God that they had to accept because they had no power to change the situation.

Sirine, a 63-year-old lady, said:

Nothing happens to us except what God wishes for us. I had it so I have to accept it but I wish it had not happened. I am relying on God...

Sonia, a 55-year-old lady, talked about the issue and said:

I told them (my friend), let it be God's will. I did not feel anything, it did not affect me. I felt let it be God's will; it is ok. I felt that faith, true faith penetrated me; truly. Just yesterday I was telling my friends thank God that so far until now I have not felt that something has happened to me, I feel normal. Normal like if I have a simple flu. Thank God, this is God's will. I do not know. I told him my God let it be your will. If God wants this, what can you do? You have to tolerate it.

CANCER IS SIMILAR TO ANY OTHER DISEASE, MAINLY DIABETES

All participants, while describing their experience with cancer, repeated that cancer is not different or more dangerous than other diseases, and they specifically named diabetes. They all compared cancer to diabetes in terms of chronicity and complications.

Hala, a 36-year-old mother, said:

The cancer patient is much better than the diabetic patient. At least you do not have to worry about your food and medication every day. And the consequences of diabetes sometimes are much worse than cancer...

Kathy, a 44-year-old mother, also had similar ideas about cancer; she stated:

I consider cancer like any other disease. It does not mean death to me, it does not scare me, I consider it like diabetes...

POSITIVE SUPPORT FROM WORK, FAMILY, AND HUSBAND

Positive support from work environment, family, and husband helped the women diagnosed as having breast cancer to cope with their diagnosis and disease. By positive support, the women meant no differentiation in the conduct of others toward them.

Tina, a 48-year-old woman, mentioned:

It means a lot to be treated like a normal person. The normal treatment that I received from the school where I teach helped me a lot. The director refused to decrease my teaching hours saying that I could make it, and in fact, his trust in me made me feel strong inside. At home we did not change our way of living. My husband insisted that we go out as usual; he did not allow me to stay in bed. I think all this helped me to move ahead from after a "cut" (cancer considered as a cut in her life), a cut that passed in my life. When my children and friend were present, I used to forget that I was sick. I used to stop thinking of my disease. You know I used to think that I have people that I love and that they love me too; this idea used to relieve me. My husband had a big role in all this...

Irene, a 59-year-old lady, added:

The support that my relatives and friends gave me boosted my morale; it helped me a lot. My daughter played a big role. At school, the director refused to change the class that I teach because I am teaching a graduating class, and I felt that it was not fair for them (students), but to tell you the truth, the director's decision made me feel stronger and it helped me to fight...

SHARING THE EXPERIENCE WITH PEOPLE WHO KNOW

Sharing information with other people who lived the same experience was considered as a helping factor. Benefiting from others' experiences and also sharing one's own experience were considered as important factors for coping with breast cancer.

Luma, a 62-year-old lady, stated:

If we were living in a normal country, there should have been a center where you could meet with people who had had the same experience. It helps a lot to ask them how they behaved. What did they do? I like to speak with a person who has lived the experience because people who have lived the experience understand you better and can help you.... I do not like to speak to people whom I know, like friends and family...

Sabine, a 48-year-old lady, revealed in this regard:

My sister's friend had gone through the same experience, and she helped me a lot when I talked to her. I felt more relaxed because I stopped feeling that I was going to the unknown. After my talks with her, I started to accept the issue better, and I felt as if I was preparing myself psychologically for what I was going to go through. There is a big difference between expecting things or to be suddenly shocked by things... later, I was called by a lady who was newly diagnosed with breast cancer and she started asking me questions. I felt very happy to be able to provide her with answers; this action gave me satisfaction...

Hindering Factors for Coping

CHANGED BODY IMAGE

The hair loss was the main aspect that disturbed the participants of this study. They all reported that the hair loss was very detrimental to their coping and self-esteem.

Lamis, a 50-year-old lady, said:

I cried because I was losing my hair, losing my hair. When my hair started to fall, I was prepared for it; however, one day I was doing sports, and suddenly under the shower, I lost all my hair. I started crying, I called my husband and I felt crashed from inside...

FEAR OF REOCCURRENCE

The idea that cancer might hit again was always present in the participants' mind. This idea was preventing them from coping with their current situation. It was disturbing them from inside.

Sirine, the 62-year-old lady, said:

I am always afraid to have it in another place. They say it can hit again, it can hit in different places. This is why I am always afraid. This idea is bothering me a lot, it is disturbing me, and it is preventing me from continuing my life normally.... This idea that cancer might hit again is haunting me day and night....

BEING PITIED BY OTHERS

Being pitied by others was reported as very disturbing. Participants reported that they were obliged to hide their disease and their suffering for others not to pity them. This idea of being pitied by others prevented them from coping with their condition; on the contrary, it pushed them to hide their proper feelings and physical sufferings.

Sandra, a 48-year-old lady, said in this regard:

I do not like others to pity me to say "YA HARAM" [meaning more or less "what" in English]. The person with diabetes suffers more than I do, and they do not pity him.

Constitutive Pattern

CANCER IS A CUT IN OUR LIVES THAT WE HAVE TO FIGHT

The constitutive pattern linked the related themes across text. Overall, the participants of this study described their journey with breast cancer as a continuous battle. Participants were trying to gain this battle by using positive coping strategies; however, through their journey, they were faced by hindering factors that at times prevented them from coping with breast cancer. The pattern, "Cancer is a cut in our lives that we have to fight," was present across all interviews and across all themes. This fight against breast cancer made the participants more aware of their needs and rights as patients. This pattern runs across all interviews and across all identified themes.

■ Discussion

This is the first qualitative study that has portrayed how Lebanese women cope with breast cancer. This study sheds light on an important aspect of this group of women's coping strategies. According to the results of this study, Lebanese women viewed cancer as a major cut in their lives (which might be expressed as an intrusion), and they described their journey with cancer as a continuous battle. The major positive coping strategy noticed was their reliance on God. It is worth noting that Lebanon is known for its religious diversity. The 2 main prevailing religions in the Lebanese culture are Christianity and Islam.¹⁷ However, there are as many as 18 diverse sects. The term God is recurrently used in the Lebanese language. Most Lebanese, regardless of religion, consider God as powerful, capable, and the source of miracles. This positive relationship with God and full reliance on Him gave all participants hope that God is in control. Participants coped with disease, having in mind that it is something from Him. It is worth noting that God was perceived as powerful, compassionate, and fair. Results suggested that this belief in God helped participants to accept their diagnosis, cope with their disease, and to bear willingly the consequences. This belief in relating to God evoked in the participants the feeling of hope and the need to cope. Studies conducted in different parts of the world reported that religion offers hope to those with cancer; it plays a big role in facilitating the disease acceptance process, and it has been found to have a positive effect on the quality of life of cancer patients. However, as noted by Hack and Degner, women who respond to their breast cancer diagnosis with passive acceptance and resignation are at a significant risk for poor long-term psychological adjustment. The use of belief and relationship with God to foster hope and strength to cope with the disease is the positive coping aspect that must be contrasted with the passive acceptance leading to resignation and a sense of helplessness, which was not expressed by the participants of this study.

The second emerging theme related to comparing cancer to an acceptable chronic disease in the Lebanese culture, diabetes, which was not highlighted in any of the reviewed research articles. All participants defended their need to communicate and speak about their breast cancer by comparing cancer to diabetes. It is worth noting that diabetes as a disease is better accepted than cancer within the Lebanese culture, especially when it comes to matters of stigma and marriage. Breast cancer is known for its familial inheritance. So mothers with breast cancer were living with guilt feelings, thinking that their daughters may not be chosen for marriage if it is known that their mothers have breast cancer. This issue does not exist for diabetes. Assessing the perception of people toward cancer and comparing it to other chronic diseases within the Lebanese culture needs further investigation.

The third theme is related to the impact of positive support from work, family, and husband on the coping process. Participants of this study stressed the important and pivotal role that family members, and especially husbands if available, can play on the morale and coping strategies of the women diagnosed as having breast cancer. The positive support received from the family and husbands of the participants helped them to accept their conditions and gave them the support needed to engage in their fight against cancer. These findings coincide with those of other studies^{8,21} that highlighted the important role that the family plays in terms of support and coping. All the participants of the study wanted to survive for the sake of their children; for the sake of seeing them growing and enjoying life with them. This attitude is well explained within the Lebanese culture, where the mother plays an important and central role in the family. These results are in line with other studies conducted by Henderson et al⁸ and Ashing et al,²² in which the primary concern of women was to survive and combat the disease for the sake of their children. In addition to the previous 2 factors, work environment also had an influence but in a different way. Working women reported that they maintained their work and work pace as before because they were afraid from being labeled as "cancer patients," which means being pitied by others, a condition that they do not like. They forced themselves to cope with their disease and succeed in their battle. The success was translated by keeping their jobs without any change in the job description and by hiding their diagnosis from colleagues. Participants described this situation as successful, but nevertheless, it was achieved through" selfcoercion." They all reported an obligation to do that in order not to be pitied by others. This condition led all participants to complain about the negative cancer stigma within the Lebanese culture. This attachment to work, as experienced by Lebanese women, contradicts the results of studies^{23–25} that reported a voluntary stop or reduction in working hours after breast cancer, along with a changing attitude among cancer survivors, who began attaching less importance to work than prior to their diagnosis and valuing a more balanced approach to life. On the other hand, Steiner et al²⁶ and Nachreiner et al²⁷ reported that returning to work enhances the patients' quality of life and could be perceived as a sign of recovery.

Sharing the experience with people who know, with people who went through similar experiences, was a request and a need. All participants who shared their experiences with survivors of breast cancer reported better coping mechanisms because they knew what to expect. Also, discussing their own experience with other patients who were newly diagnosed as having breast cancer boosted the participants' morale and gave them the feeling that they were still useful and strong. This feeling helped them to develop positive coping strategies. This sort of interaction and mutual communication were reported to be very beneficial and useful by the participants. These findings advocate the necessity to create patient support groups. Actually, participants themselves raised the need for such a group. These results match the results of a study conducted by Landmark et al,²¹ in which women stressed the importance of fellowship with others who are in the same situation. Recognizing that one is not alone and that others share comparable thoughts and feelings seems to offer support. For the participants of this study, information sharing was viewed as a resource that enhanced coping.

The change in the physical appearance, specifically hair loss, was conceived by the participants of this study as a hindering factor for coping. The hair loss could be linked to the concept of loss of control. It is worth noting that control is a principal concept in the psychological theories of emotional well-being, adjustment, and coping.²⁸ Similar results were found by Frith et al²⁹ and Perreault and Bourbonnais,⁴ in which losses impacted not only the physical dimension but also the psychological, social, and spiritual dimensions of the individual. In Lebanon, a woman's hair loss has perhaps even deeper meaning for her sense of being a woman. The major cultural roles of Lebanese women are still to gain a husband, have his sons, and keep him interested in her. Even though many Lebanese women now have a higher education and work in professions, the cultural norms of the male-dominated society are intact. This sense of losing her feminine attractiveness would be expected to have a greatly negative effect on her coping. The participants in this study did not reveal negative coping elements based on the loss of attractiveness, which would have been expected. Participants were afraid that, despite wearing a wig, people might know that they have cancer, and they might start pitying them.

The fear of being pitied by others was another factor that was perceived as a hindering feature for coping by the participants of this study. This factor of being pitied was not found in any of the reviewed articles, and it needs further clarification within the Lebanese culture. In speculation, we could say that this fear might be due to the nature of the reciprocal relationship within

the Lebanese culture. If a person cannot reciprocate, he/she is perceived as weak or vulnerable. According to Lam and Fielding, ³⁰ people want to keep away from being perceived as different and stigmatized in the society. This sense of being pitied also reduces perceived status relative to the others who are doing the pitying. Status is an important and pervasive aspect of Lebanese and Middle Eastern culture in general. Loss of perceived status increases the sense of vulnerability and would be perceived as hindering the ability to cope.

The fear of the recurrence of breast cancer was perceived as a threat by the participants. They all reported that this idea haunted them day and night and prevented them from coping. Similar results were reported by Bottorf et al³¹ and Browall et al.³²

■ Conclusion

Our findings provide increased in-depth understanding of Lebanese women's coping strategies for dealing with breast cancer. The constitutive pattern, "Cancer is a cut in our lives that we have to fight," represents the tie between all themes. This pattern, in addition to all emerging themes, reverberated in all interviews regardless of the time since diagnoses and the age of the woman interviewed. All participants reported a precipitous change in their lives and difficulties at times in coping with those sudden changes accompanying breast cancer. Different coping strategies were found to have different impacts on the participants' lives and morale. Healthcare workers need to be conscious of a multitude of factors including the motivational and hindering factors for coping with breast cancer. The findings of this study highlight the importance of identifying the motivational factors for coping in women living with breast cancer. Therefore, a specific assessment of coping strategies as an initial approach to patient care is highly suggested, and the creation of informal support group is needed to help these women cope with their conditions. Moreover, the results of this study can serve as a framework for further studies leading to the development of an approach to care that promotes coping processes in Lebanese women living with breast cancer. Furthermore, nursing and medical curricula need to sensitize students to the concept of coping in relation to breast cancer and its impact on the women's well-being.

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