Living with breast cancer: Iranian women’s lived experiences

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Background: Breast cancer is the most common form of cancer among women. Women with breast cancer encounter many psychosocial stresses as well as physical problems.

Aim: To capture the meaning of living with breast cancer from the unique perspective and through the lived experiences of Iranian women with breast cancer that were explained with their own words.

Methods: A phenomenological approach was used to explore the meaning of living with breast cancer for Iranian women. The patients’ feelings and lived experiences with breast cancer were investigated using semi-structured interviews with probing questions with 13 women between 34 and 67 years old.

Findings: The participants explained their experiences of living with breast cancer as losing something important, lack of confidence, living with fear, emotional dizziness and the need to be supported with the negative aspects of breast cancer and helped to explore new aspects of life as positive aspects of this event.

Conclusion and Implications: Understanding the phenomenon of ‘living with breast cancer’ seems to be crucial for nurses to help women with breast cancer to find themselves in confronting the consequences of the changes associated with the illness.

Keywords: Breast Cancer, Iranian Women, Lived Experience

Introduction
The cancer diagnosis is usually perceived as a crisis for both patients and their families. Among women, breast cancer is the most common form of cancer (Taleghani et al. 2006), particularly in the Western world in which the highest percentage of breast cancer is seen (Radice & Redaell 2003).

According to the World Health Organization estimations, more than 1.2 million people were diagnosed with breast cancer worldwide in 2001 (Günes et al. 2004). The risk of getting breast cancer increases significantly with age, and approximately 4700 women over 55 years developed the disease during 2002 (National Board of Health and Welfare 2002).

Even though the highest rate of breast cancer is seen in the USA, Australia, New Zealand, South America, Eastern and Western Europe (Radice & Redaell 2003), the incidence is also rising in many developing countries. For example, breast cancer is the second leading cause of cancer and the leading cause of death for 35- to 59-year-old Taiwanese women (Chen et al.
Although at one of the less incidence rates in Iran as other Asian countries, during the last four decades, increasing incidence rates have made breast cancer one of the most prevalent malignancies among Iranian women (Fakhariyan 2011), which constitutes 25% of all cancers among Iranian women, with the highest rate occurring in those aged between 35 and 44 years according to the latest report of Iranian Cancer Institute in 2003 (Mohagghaghi 2003).

Women with breast cancer encounter many psychosocial stresses as well as physical problems. They have to change their lifestyle following a long period of treatment, and this may well influence their quality of life. Their everyday life is full of stress and worry regarding their family/sexual roles in addition to the feeling of uncertainties about their future life in terms of their general functionality status.

In Iran, some cultural issues are added to these problems. The women’s life as a spouse is very important in the family, and all intimate relations with men are in this format. For this reason, when a woman feels that she is not sexually attractive to her spouse, this might be the end of her sexual life. The spouse’s reaction to the physical deficits caused by breast cancer may negatively affect women’s self-esteem and confidence. These psycho-emotional problems can subsequently increase the physical problems. In contrast, when a spouse is knowledgeable and understanding, the situation goes toward getting better for both the woman and the family.

A review by Rustoen & Begnum (2000) shows that the research regarding quality of life in breast cancer has been mainly descriptive, through the use of standardized questionnaires, and there have been difficulties in implementing the results in cancer care. One reason for this could be that these quantitative tools have difficulties in capturing what is unique in patients’ experiences and therefore risk omitting important issues that patients may have expressed in a study with a qualitative approach (Luoma & Hakamies-Blomqvist 2004).

Breasts are viewed mostly as the women’s unique sexual appearance and even in Muslim cultures such as Iran in which the women are expected to cover their body; changes in body image can result in some subsequent problems in relation to their spouse. Taleghani et al. (2006) in a qualitative study using a grounded theory approach interviewed 19 breast cancer women in Iran to explore how Muslim women cope with this unpleasant event. The main themes emerging in their study that could demonstrate the process of coping with the disease included coping a religious approach (accepting the disease as God’s will and spiritual fighting), thinking about the disease (positive thinking, positive suggestions, hope, international forgetfulness, negative thinking, hopelessness, fear and impaired body image), accepting the fact of the disease (active acceptance and passive acceptance), social and cultural factors and finally finding support from significant others.

Exploring the problems that breast cancer women encounter is a realistic cornerstone for planning and implementing medical and nursing interventions to help them live with their optimum level of functioning.

Breast cancer-related issues, both in the world and in Iran, have been mainly studied using quantitative approaches. These are not simply answering the complex questions regarding human nature, and exploring deep layers of human feelings needs a more holistic approach (Holloway & Wheeler 2009). Qualitative research allows researchers to get to the inner experience of the participants to determine how meanings are formed through and in culture and to discover rather than simply test variables (Corbin & Strauss 2008).

Taleghani et al. (2006) conducted a qualitative research in Iran to find how the women cope with breast cancer. That was a valuable piece of the work, but still the meaning of living with breast cancer for the women was ambiguous. The aim of the current qualitative study was to capture the meaning of living with breast cancer from the unique perspective and through the lived experiences of breast cancer women explained by their own words in a private clinic in Iran.

**Literature review**

There are some qualitative studies available on experiences (Richer & Ezer 2002; Ashing et al. 2003), quality of life (Luoma & Hakamies-Blomqvist 2004; Berteró 2002; Overcash 2004), daily living (Davies & Sque 2002), social support and coping in cancer patients (Landmark et al. 2002; Henderson et al. 2003).

Thomas (2006) conducted a qualitative study to explore women’s memories and feelings concerning their breast and breast cancer screening behaviours. Twelve African American black women shared their experiences with breast cancer, which generated narratives and individual interviews. Silent and societal contraindications were the two main themes that emerged from these women’s stories. This finding emphasizes the important role of social reflection on the breast cancer women’s self-perception and feelings (Thomas 2006).

Barton-Burke et al. (2006) applied a literature review concerning black women and breast cancer. Five dimensions, namely physical, psychological, social, economic, and spiritual and existential, form the guiding framework of their paper.

Qualitative research by Johnson (1999) aimed to gain a greater understanding of the female patient with breast cancer experiences of radiotherapy. A phenomenological approach was employed using semi-structured interviews undertaken in the patient’s home approximately 2 weeks after completion of their treatment course. Data analysis resulted in the description of five
important categories of experience for the women. The discus-
sion concludes that it is paramount for all healthcare profession-
als and therapy radiographers, in particular, to undertake and
promote this type of research in order for them to establish and
maintain a true sense of empathy and understanding with their
patients. It also helps healthcare professionals maintain a sense of
the importance of the ‘whole experience’ for those in their care.
This type of enquiry provides a valuable and yet all too rare
insight into aspects of attending for radiotherapy, which would
otherwise remain buried beneath the bustle of a busy radio-
therapy department (Johnson 1999).

In current study, the researchers as a team are working with
breast cancer patients in a non-government organization
for supporting Iranian breast cancer women, to empower them
for self-care and a high-level quality of life after breast cancer
diagnosis.

Working with breast cancer women and feeling Iranian
women’s fears and worries of losing their feminine appearance
and attraction particularly for their spouse, and subsequently
losing their marriage bounds, was the main motivation for
researchers to investigate and try to explore the meaning of living
with breast cancer for Iranian women.

Method
A phenomenological approach was used to explore the meaning
of living with breast cancer for Iranian women. According to
Corbin & Strauss (2008), the research question dictates the
methodological approach for conducting the research. Van
Mannen (2006) believes that when the research question is
regarding people’s lived experience of a phenomenon and seeks
the deep feelings and emotions, phenomenology is the best
approach (p. 40–41).

The women’s feelings and lived experiences with breast cancer
were elicited using semi-structured interviews with probing
questions with women between 34 and 67 years old, in a private
breast cancer clinic. Data saturation was obtained after inter-
viewing 13 women.

Ethics
This research proposal was approved by the ‘Tehran Committee
against Breast Cancer’ ethics committee. In this study, all partici-
pants had a mastectomy/lumpectomy experience and had passed
the period of chemotherapy/radiotherapy. They were informed
about the purpose of the interviews, and oral consent was
obtained before participating in the interview.

The participants were given a chance to describe their feelings
regarding living with breast cancer in their own words, from
their unique perspective and based on their lived experiences.
Each interview was tape-recorded and lasted between 60 and
90 min, and in case the women intended to continue the story, a
further interview session would be planned. The interviews were
then transcribed, and the texts were analyzed utilizing Van Man-
nen’s thematic analysis approach. The transcribed interviews
were checked with the participants when there was any ambigu-
ity in the text, so not in all cases, but in four, we member checked
the text with the participants.

Data gathering and analysis were conducted simultaneously.
Each transcribed interview was read several times until capturing
a whole meaning of the text (holistic thematic analysis). Then the
meaning units were highlighted and categorized as the cluster of
themes. This was done according to Van Mannen’s selective the-
matic analysis. The clusters of themes were then changed and
reconstructed according to the similarities.

Findings
Two main clusters of themes were finally captured from the
analysis of transcribed interviews as (1) negative and (2) positive
aspects of breast cancer. The participants explained their experi-
ences of living with breast cancer as losing something important,
uncertainty, living with fear, emotional dizziness, and the need
for support as negative aspects of breast cancer and exploring
new aspects of life as positive aspects of this condition.

Negative aspects of breast cancer
This included the majority of the emerging themes because
according to the participants lived experiences, their life has been
more negatively affected by the disease.

Losing something important
The first feeling most participants explained was the feeling of
loss. These women felt that not only they had lost their health but
also something important in their body and perhaps their mind.
This was the feeling of functioning as a woman in their private
life with their family. They explained the feeling of loss particu-
larly in relation to their spouse. One woman said:

When I look at myself in the mirror, I just want to cry. I feel it
is not me. Where is the good looking woman whom I knew?
How my spouse will even look at me now?

Another woman was fully disappointed with her spouse who
was reminding her about the changes in her body as a reason for
divorce.

He looked at my eyes straight and told me that he is going to
leave because I am not a complete woman any more . . . and I
could see that I had to forgo my all rights as a woman (she was
telling this with the tears in her eyes).
Uncertainty
Uncertainty was another theme emerged through the women’s lived experiences. This was mainly presented in relation to physical functioning. One of the participants explained her story about the feeling as follow:

I feel I’m not able to start something and be sure that I can finish it successfully. Even when I plan to do a very little job such as gathering some friends, I think I will not probably be able to do that. I think each moment can be the messenger of other bad news about my life.

Another participant described the feeling of uncertainty as:

I can’t rely on my previous abilities anymore. . . . I’m too weak to start and finish something . . .

Living with fear
The feeling of fear was another theme related to the experience of living with breast cancer among Iranian women with breast cancer. The following examples are some of participants’ experiences:

Something is behind the door, something which can make everything worse. I’m always waiting, but unfortunately not for a good thing.

This was seen in another woman’s experience with different words:

Nobody can escape from death, but my situation is different. I’m always in worry about the way I will die. I like to die in peace, and I’m afraid that my death occurs during the process of fighting with cancer.

A recently diagnosed woman said:

This is an intolerable feeling that you are always expecting unknown tragic events. You sleep with fear, wake up with fear, look at yourself with fear, touch yourself with fear and finally leave with fear. Constant fear is your life background.

Another young woman explained this fear with other words:

I don’t like to be exposed to the community, particularly between them who know me. I’m afraid of people, of my family and also of myself. I’m always afraid of hearing something new.

Emotional dizziness
Emotional dizziness was another theme emerged from women’s experiences:

I’m confused. I don’t know their compassion is because of my illness or they really love me for my own. I don’t like their pity. I can’t understand their emotions.

This confusion was seen in another woman’s words:

My husband shows different emotions. He comes home so late but he also tries to show me compassion. I can’t believe that he is really impacted by my suffering, rather I think he wants to flight and is looking for a proper opportunity.

This emotional dizziness is seen in another woman’s experience who was hanging between good and bad mood.

I was starting to find my new body. Nothing was on its place, and I didn’t know if I should complain and explain my thoughts with my family. They were always nice to me but those days were so vital for me to be stable. I would like to listen to their whispers to realize do they still love me or their compassion is just because of the pity. This was one of my concerns during all these times from my cancer diagnosis date.

Need to support
This was another theme captured from Iranian women’s experiences with breast cancer. This was explained sometimes as negative or positive experience. From the first group, one said:

My everyday life is full of need. I just have to ask and the others have to supply. This is not a good thing and sometimes makes me feel that I’m just a trouble and nothing more. . . .

This was sometimes explained in positive terms such as:

I really need the others to understand me. . . . And they usually do. (They (my family) try to make me feel that I’m still being loved and they are supporting me. I’ve been always serving them. Perhaps this is an opportunity for me to ask and for them to supply . . .

There were also good experiences in Iranian breast cancer women that could help them to feel better with themselves and their illness, which was categorized under the positive aspects.

Positive aspects of breast cancer
This was shown with explaining how a new look at the life could provide the women with breast cancer a wider angle of the human life. The main theme in this area is described along with some participants’ statements.

Exploring new aspects of life
‘It’s better not to look at life just for ourselves’, a middle-aged woman said, and a 70-year-old woman’s experience was so confirming:
I’m not thinking about life and death any more . . . these are our every day’s concerns when we think we can manipulate the situation. But I’ve found more invaluable feelings these days. I feel I can help other people who are suffering from cancer with informing them about their abilities and strengths. Who can talk about my disease and tell I’ll die earlier than someone else? I should live all my life. I should thank God for this opportunity who provided to me to come to the world on time and go whenever there is no more place for me to live.

This theme was also seen in the participants’ experiences finding God closer than ever to them. Their religious beliefs could help them to acquiesce to the God’s will and to adapt better with their situation.

I can see that God is watching me . . . and this lulls my fears. I wasn’t a religious person, but now I need this. I can see the things I could never before and this is amazing.

Another woman explained that she found some different feelings in herself and in the world:

My world has absolutely changed. I could hardly feel how valuable my health was, but now I want to devour any single moment of my life. Everything is important, even simple natural event such as rain, sunshine . . . in everyday life can be a message to help me discover the meaning of life.

These experiences were all examples of how the illness makes the women find new aspects of their life, both emotional and spiritual aspects.

**Discussion**

The advances in breast cancer screening and treatment technologies allow many women to survive for years after they are diagnosed with breast cancer. However, their experiences of suffering throughout the journey for this illness are not yet clearly understood.

This phenomenological study purposed to explore the meaning of living with breast cancer for Iranian women.

Despite some cultural differences, Iranian and Western women’s feelings and experiences seem to have some general similarities.

The participants of this study explained some positive and negative feelings regarding their situation. This was also shown in Browall et al.’s (2006) qualitative study that found the women with breast cancer who are in chemotherapy phase, experience two contradictory set of feelings; negative (such as the fear of uncertainties) and positive (such as receiving support from significant others) (Browall et al. 2006).

In explaining negative feelings, participants’ experience, of losing something important, in this study, is consistent with Landmark & Wahl (2002), who found that loss of a breast and the consequent physical changes, affected the identity of the women. Additionally, losing the support of significant others such as their spouse (in this study) and their partner (in Landmark and Wahl’s 2002 findings) was another issue that was narrated by the breast cancer women.

There is another aspect of losing the support of spouse in Iranian Muslim culture in which the marriage relationships are very important, and a women losing the support of her spouse, particularly in such a suffering circumstance, commonly would not (and also is not allowed to) easily start another relationship with someone else. This is seen to transfer to another theme, emotional dizziness, which shows how these women feel regarding the event of losing their spouse, and probably other significant relatives, and are confused with the different responses they receive from them. Thomas (2006) emphasizes how contradictory messages that the breast cancer women receive from society, both voiced and unvoiced, can have a long-term effect on how they perceive their bodies. These messages can positively or negatively influence their feelings and emotions.

The themes uncertainty and living with fear captured in this study were similar to those of Browall et al. (2006), who identified that breast cancer women experience fear of uncertainties as well as constant worry during the period of chemotherapy.

This is important for all women, but in Iranian culture, it is more significant because the unknowns are related not only to the diagnosis and treatment of the disease but also to the women’s family and their social life. For example, it is usual for a man with a breast cancer-diagnosed wife to divorce and marry another woman. Even though most of men do not do this, the fear of this action constantly scares the women with breast cancer.

Exploring new aspects of life was another theme captured from the participants’ narratives. They explained how they gradually coped with their cancer, accepted their body and not giving up. This is consistent with Jensen et al. (2000), who found themes such as accepting the challenge to go on living, working actively on the healing process and finding something important to live for. These themes are closely related to finding something new in life, which can be seen as utilizing mechanisms to cope with their illness. Sadler-Gerhardt (2010) in her study with breast cancer survivors, in addition to negative changes in their life, found five positive sub-themes under post-traumatic growth: new self-perception, new possibilities, new relations with others, new priorities and new faith (Sadler-Gerhardt 2010). These themes are emphasizing those aspects of the illness that can help the patients to live for and to feel alive.

The experiences of participants in this study indicated that they also could find a new kind of peace and comfort by the
feeling of bowing to God’s will. This was seen in previously religious and non-religious women. In a study by Overcash (2004) of older women, it was found that believing in God was of paramount importance for these women, which could help them in not giving up. Other researchers also suggest that the religious beliefs can be a supportive resource for people with cancer or other incurable diseases (Taleghani et al. 2006& 2008), but in Muslims, this is more pronounced. We believe that everything that happens in our life has come to us according to the God’s discretion, and we should stoop to God’s will. This was a frequently repeated theme, which is mainly highlighted in our study because of our socio-cultural context. Relying on women’s religious/spiritual beliefs might be an opportunity to help them in coping with their health problem. This is an increasingly important issue worldwide, so we should be able to use this opportunity as a worthwhile source for raising women’s coping mechanisms.

Limitations
Even though in qualitative researches sampling is purposeful and participants are selected as key informants, in this study, selecting the key informants from a private clinic may be considered as a further limitation. This was considered by selecting the participants with different backgrounds, different ages and educational levels.

Conclusion
Understanding of the phenomenon of ‘living with breast cancer’ seems to be crucial for nurses in helping women with breast cancer to find themselves in confronting the changes that are a consequence of the illness.

This study has shown that living with breast cancer is a unique experience that affects the women’s lives and makes them take a new look to their life if they want to live at optimal quality. The results of this qualitative research help nurses to be able to help these women by being aware of their feeling and experiences. In this regard, one of the nurses’ tasks is to help women find mechanisms to cope with breast cancer such as providing information, helping them to find other women with similar experiences to share, as well as informing women’s spouses regarding the patients’ emotional and physical needs. This can be done in educational or consultation sessions and can help spouses to understand their wife’s problem better, and consequently this can help the woman.

Because most Iranian breast cancer patients are less than 50 years old and the age of incidence in Iran is less than world’s average, breast cancer should be more considered, and nurses should encourage women to attend in screening tests.

Promoting the patient-to-patient relationship and sharing the illness experiences is another way for softening what can be a terrible experience. This can be supported by nurses to suggest those women share with other women’s challenges. Sharing the experiences of Iranian Muslim women with breast cancer might help the nurses and midwives around the world, who work with clients from different socio-cultural background, to know what the concerns of Iranian Muslim women are. This could also be the voice of Muslim women with breast cancer worldwide and present their internal challenges with the issue, while their spiritual beliefs can help them as a supportive source despite of all negative aspects of the illness.

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Author contributions
A.J.: study conception, design, analysis/interpretation of data and critical revisions for important intellectual content; S.J.: study conception, design, acquisition of data, analysis/interpretation of data, drafting of the manuscript and review of the content; M. Kadivar.: study conception, design, material support and critical revisions for important intellectual content; F.H.: drafting of the manuscript and review of the content.

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