



Understanding the experiences and quality of life issues of Bahraini women with breast cancer



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ABSTRACT

We explored the experiences of Bahraini women who have survived breast cancer and their perception of quality of life after diagnosis. We conducted in depth, semi-structured face-to-face interviews with twelve women diagnosed with breast cancer. A qualitative method using semi-structured interviews on a purposive sample of 12 Bahraini women with breast cancer was conducted. Similarities and differences in women's experience were identified through thematic analysis of interview transcripts using a constant comparative approach. The themes identified were meaning of cancer and quality of life, spirituality and beliefs about causes of breast cancer, coping mechanisms, impact of illness and change in relationships. Quality of life was framed in terms of the ability to perform daily duties with emphasis on the physical component of quality of life. Themes that differed from previous western studies included a heavy emphasis on spiritual practices for comfort; the use of traditional clothing (hijab and abaya) to hide hair and body changes; the important role played by the family and husband in treatment decisions and concerns regarding satisfying the sexual needs of the husband, which were related to a fear of losing the husband to a second wife. Evil eye, stress and God's punishment were believed to be fundamental causes of the disease. The emotional shock of the initial diagnosis, concerns about whether to reveal the diagnosis and a desire to live a normal life were consistent with previous studies. However, cultural and religious issues such as role of the husband and impact of prayers were also important here. These themes are important to healthcare professionals for ensuring an individualized approach to the treatment of women with breast cancer.

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Introduction

Breast cancer is the most common form of cancer among women worldwide (Global Health Estimates WHO, 2013). There is a wide variation of breast cancer age standardized incidence rates around the world, with some countries reporting high rates per 100,000 population (for instance Belgium 109.4, Ireland 93.9, UK87.9, and USA 76.0. On the other hand, some countries report a low incidence of breast cancer (e.g. China 22.4, Saudi Arabia 21.6, Iran 18.4 and Mongolia 8.0) (Globocan cancer fact sheet, 2008). Bahrain lies in the middle with an age-standardized incidence rate of 54.4 per 100,000 population. This is by far the highest among Arabian Gulf countries (Ministry of Health publication, 2011). In the Arab world, surgeons and oncologists dealing with breast cancer tend to believe that it presents at an earlier age with a more advanced stage at presentation (Najjar & Easson, 2010).

The psychological impact of breast cancer has been extensively studied and indicates high levels of psychological morbidities among breast cancer survivors (Mehnert & Koch, 2008). Depression and anxiety are the most commonly studied mood disorders (Fann et al., 2008). Rates of major depression or anxiety in breast cancer patients have been estimated to range from 20% to 30% in the initial six months following breast cancer diagnosis in women with early stage breast cancer (Akechi, Okuyama, Imoto, Yamawaki, & Uchitomi, 2001; Fallowfield, Hall, Maguire, & Baum, 1990).

In addition, there is considerable information available about the quality of life of women with breast cancer at various stages and courses of the disease (Ganz et al., 2002, 2004; Montazeri, 2008). The majority of these studies are primarily quantitative in nature utilizing structured validated tools to measure quality of life among women with breast cancer (Montazeri, 2008). The most bothersome symptoms identified by the quantitative literature and having a significant impact on women's quality of life were hair loss and arm symptoms (Engel et al., 2003; Heiney et al., 2007; Lemieux, Maunsell, & Provencher, 2008; Thomas-Maclean et al., 2008). However, even well-constructed and reliable measures may not capture all aspects

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of QoL in breast cancer survivors and might not be culturally specific (Shelby, Lamdan, Siegel, Hrywna, & Taylor, 2006). This has led to a call for more qualitative studies to be carried out in order to gain a deeper understanding of the cultural influences on quality of life of women with breast cancer (Montazeri, 2008).

Qualitative studies providing insight into quality of life issues of women with breast cancer are relatively few (Ashing-Giwa et al., 2004; Coreil, Corvin, Nupp, Dyer, & Noble, 2012; Fatone, Moadel, Foley, Fleming, & Jandorf, 2007; Luoma & Hakamies-Blomqvist, 2004; Yusuf, Ab Hadi, Mahamood, Ahmad, & Keng, 2013). The prevailing concerns revealed in these studies were overall health, cancer recurrence or metastases, concerns related to the children and burden on the family, body image, sexual concerns, cultural sensitivity of providers and beliefs about the illness (Ashing-Giwa et al., 2004). More importantly, qualitative reports showed remarkable variation between cultural and ethnic groups. Of note, African Americans, Latina, Hispanic and Asian women voiced their views that spiritual practices and faith were essential to their coping with the disease (Ashing-Giwa et al., 2004; Coreil et al., 2012; Fatone et al., 2007). A systematic review of qualitative evidence showed that spirituality emerged robustly as a coping mechanism in qualitative studies of quality of life of women with breast cancer (Devi & Hegney, 2011). The same review reported lack of similar studies in the Asian context (Devi & Hegney, 2011). Moreover, treatment decisions differed across cultures; for example Asian and Latina women were more likely to receive mastectomies (Yanez, Thompson, & Stanton, 2011) and African Americans were least likely to receive adjuvant therapy (Ashing-Giwa et al., 2004).

Little is known about the experiences of Arab women with breast cancer and their perceptions of QoL. The diagnosis of breast cancer in the Arab population may have spiritual, social and cultural aspects that differ from those of Western populations, that have largely been studied and described to date (Jassim & Whitford, 2013). We carried out this qualitative study in order to explore the experiences, beliefs, perceptions and attitudes of Bahraini women with breast cancer towards their quality of life.

Methods

Study design

Due to the paucity of information about breast cancer experiences of Bahraini women, we decided to use a qualitative approach to allow for a deeper, richer understanding of the research question via open dialog (Waxler-Morrison, Doll, & Hislop, 1995). In depth, semi structured interviews were conducted with Bahraini women with breast cancer. Depth interviewing is a data gathering process designed to generate narratives that focus on fairly specific research questions (Miller & Crabtree, 1999). It focuses on facilitating a shared understanding of the topic of interest and not necessarily on the context of that understanding. The depth interview is personal and intimate, with an emphasis on “depth, detail, vividness, and nuance” (Rubin & Rubin, 1995). Depth interviews primarily use open, direct, verbal questions that elicit stories and case-oriented narratives.

Participants and recruitment

Our goal was to interview women with differing experiences of breast cancer. We therefore used purposive sampling in order to ensure a wide range of experience and views among the women with breast cancer (Kuzel, 1999; Silverman, 2000). Participants were recruited from the Oncology Centre in Salmaniya Medical Complex. This is the only specialized oncology center on the island that offers oncology services and additional adjuvant therapy to

women with breast cancer. We determined that the health professionals in the center were most likely to be able to identify women with differing experiences and views of breast cancer. With the help of doctors and nurses in the oncology center we identified women with breast cancer who were deemed to have coped to differing degrees both during and following their initial diagnosis with breast cancer. Only Bahraini women were included and no limitations were placed on either the length of time since diagnosis or the stage of their disease.

Once the woman was identified by the health care provider and after she attended her scheduled appointment with the oncologist, the first author approached her, introduced herself and explained the purpose of the research in a private room in the oncology center. If the woman expressed her wish to participate in the research a signed informed consent form was taken. All interviews were conducted in Arabic by the first author who is a bilingual female family physician. Interviews lasted about 30 min. All interviews were audio-recorded and additional notes were written.

We constructed an interview guide based on the mapping we had previously carried out (Miller & Crabtree, 1999). This started with some simple biographical questions about the women and their breast cancer. These were followed by an open question asking them to describe experiences and feelings about their breast cancer. Further main questions were open and designed to elicit understanding and feelings about her experiences (Werner & Schoepfle, 1987). These questions covered the following topics: the meaning of cancer and breast cancer to the woman prior to diagnosis, the meaning of cancer and breast cancer following diagnosis, the impact of the diagnosis of breast cancer on the woman, family and friends, coping mechanisms, understanding of QoL, the meaning of QoL and the impact of breast cancer on the woman's QoL.

Topics were often raised spontaneously by the interviewee. Probes and follow up questions were used to serve two purposes: first, to obtain additional information and specific examples of more general statements and second, to ensure that specific dimensions were explored in all interviews (Sandelowski, 2000).

Data analysis

Verbatim transcription of the audio-recorded interviews was prepared in Arabic by the first author. All transcripts were sent to a professional translation center to be translated to English. All translated transcripts were reviewed by the interviewer to ensure that the linguistic meaning was preserved and to enhance the trustworthiness of the data (Mays & Pope, 1995). Translated transcripts were entered into NVivo 8 software. The narratives from these transcripts were analyzed using a constant comparative approach to identify common concepts and themes that provide a structured framework for organizing the data. We adopted an iterative approach to the data analysis, with the analysis beginning after the first interviews, allowing emerging themes to be further explored in subsequent interviews in line with the grounded theory approach. We added and altered questions to the interview guide as the interview process progressed.

The co-author of this study was continuously involved in the analysis process. To ensure validity, the co-author independently analyzed the translated transcripts and then discussed the results with the first author. We resolved ambiguities in discussion.

Data saturation was used to determine the final number of participants (Morse, 2000; Sandelowski, 2000). We stopped conducting interviews when no new themes were emerging, in line with the grounded theory approach (Glaser & Strauss, 1967; Krueger, 1994). After the 10th interview, there were no new themes generated from the interviews. Therefore, it was deemed

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