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Article

Breast cancer presentation delays among Arab and national women in the UAE: a qualitative study

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ABSTRACT

Breast cancer (BC) is a disease that has improved prospects for survival if detected and treated early. Delayed help-seeking behavior, with poor survival as a consequence, is an important public health issue in the Middle East. More than 75% of breast cancer patients in the United Arab Emirates (UAE) seek medical advice after experiencing a sign or symptom of the disease and many seek such advice late. Our aim was to explore factors influencing delayed presentation for treatment after self-discovery of symptoms consistent with breast cancer in Arab women in the United Arab Emirates (UAE), and to explore facilitators and barriers of women's health seeking behavior in the complex religiously dominated society of the UAE. A qualitative descriptive approach using semi-structured interviews was used. We interviewed nineteen BC survivors aged 35–70 who have experienced delayed presentation to treatment after symptomatic recognition of BC. The time interval between initial experience of symptoms consistent with BC, and taking action to seek medical help was between three months to three years. The key themes that emerged from the interviews were varying responses to symptom recognition, fear of societal stigmatization, and concerns regarding abandonment by spouse because of BC. Culture has a strong influence on the decisions of women in the UAE society. The lack of awareness about signs and symptoms of BC and routine screening has an important effect on symptom appraisal and subsequently decision making regarding options for treatment.

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1. Introduction

Delays between recognition of symptoms suggesting breast malignancy and seeking help or advice from healthcare professionals vary between different communities and countries (O'Mahony & Hegarty, 2009). Various factors such as culture, gender roles and socio-economic status influence the decision making of women to seek medical attention (O'Mahony & Hegarty, 2009). BC is a disease that has improved prospects for survival if detected and treated early. Any delay in presentation for symptomatic BC is associated with larger tumors, more advanced stages of disease and consequently poorer prospects for survival (Richards, Westcombe, Love, Ramirez, & Johns, 1999). Delay in BC treatment has been categorized into:

a) Patient delay-defined as waiting three or more months to seek help (e.g. consulting a physician) after self-discovery of breast signs or symptom;
b) Provider delay-defined as one month or more from the time of first patient visit to the physician and the beginning of treatment (Pack & Gallo, 1938).

Among the top ten sites for cancer diagnosed in the United Arab Emirates (UAE), BC is at the top of the list. It constitutes 43% of cancers diagnosed among females and 25% of all cases of cancer (Cancer Registry Report, 2012). It is the second leading cause of death among women with an incidence rate of approximately 38 per 100,000 (Cancer Registry Report, 2012). The annual incidence is more than 130 new cases of BC diagnosed in the emirate of Abu Dhabi (Cancer Registry Report, 2012). Despite having access to the national screening programs and the coverage of cancer screening by the health insurance, only around 75% of BC patients in the United Arab Emirates (UAE) seek medical advice after experiencing a sign or symptom of the disease (Cancer Registry Report, 2009). The introduction of mandatory health insurance in 2007 in the emirate of Abu Dhabi has provided all residents access to high quality care (Taher, Al Neyadi, & Sabih, 2008).

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Late detection of BC has historically led to significant increases in mortality. Female adult nationals between 40 and 69 are being given an option for BC screening as part of their insurance card renewal process. For non-UAE nationals, screening campaigns have helped in early detection of BC, however, screening is not performed on an organized basis and some insurance companies do not cover screening cost (Taher et al., 2008). Some preventive medicine centers provide free screening, but its availability is not widely publicized.

In the Middle East, late diagnosis has been attributed to the lack of knowledge about BC, and to the limited access to information on screening programs (Altwalbeh, El Dahshan, & Yassin, 2015; Lodhi, Ahmad, Shah, & Naeem, 2010). However, there is scant published literature from this region on the reasons for delayed presentation of female BC (Lannin et al., 1998). There has been also little comparison between communities and countries about similarities and differences in reasons for such delays.

The aim of our study was to explore factors influencing delayed presentation for advice in BC patients, and their health seeking behavior regarding treatment after self-discovery of symptomatic breast disease among Arab women in the United Arab Emirates. The results can contribute to improvement of the standards and quality of BC screening for early detection and prompt follow-up in the UAE.

2. Methods

2.1. Design

A qualitative approach using thematic analysis was used to explore UAE women's reasons for delay in seeking advice for BC symptoms, and their help seeking trajectories. The process involved in-depth confidential person-to-person interviews. This was the preferred method for acquiring data, as it involved questions that may be perceived to be 'sensitive' (Kvale, 1996).

Many help seeking models have been developed to understand why women delay in seeking clinical help (Andersen, Cappioca, & Roberts, 1995; Bish, Ramirez, Burgess, et al., 2005; De Nooijer, Lechner, & de Vries, 2003; Facione, Miasckowski, & Dodd, 2002; O'Mahony, Hegarty, & McCarthy, 2010; Rauscher, Ferrans, Kaiser, et al., 2010; Reifenstein, 2007). The constructs of these models can be used in the development of new models appropriate for another culture (Unger-Saldaña & Infante-Castañeda, 2011). In this study, a conceptual framework was used to guide the analysis based on two previously developed models: the understanding delayed presentation model by Bish et al. (2005) and the grounded model of seeking help for breast symptoms (GMHSB) by Unger-Saldaña and Infante-Castañeda (2011). The framework shows the interactions of the BC patient at three levels, (a) the individual level; including symptom recognition and symptom appraisal, (b) the community and social network level, and (c) the healthcare delivery system level (Fig. 1). The first level uses four aspects identified in Bish et al., (2005) model: (1) knowledge and symptom appraisal, (2) attitude to help seeking, (3) disclosure of symptoms and (4) intention to seek help. These four aspects interact together to influence patient behavior. At level one, the individual evaluates and interprets the recognized symptom(s) and her perception as being sick or unwell as a prelude to seeking help. At the second level, the social and community network is represented within the environment. This includes the woman's family, her husband (for married women), neighbors and friends. The interaction of the first two levels: the individual level and the community-social network level in the environment guides the woman in decision making, i.e. whether to seek help or to ignore the symptom(s). In the UAE, we assume that there are no issues with access to healthcare due to the presence of primary health services in the community and the wide coverage of health insurance of different services including cancer screening and treatment. If the woman decides to seek help, then the third level; the healthcare services utilization (healthcare delivery level) will influence the two previous levels. The third level includes aspects such as acceptability and satisfaction of the health services by women, errors in diagnosis and the referral process.

2.2. Study setting

United Arab Emirates (UAE) is a fast developing country with an estimated population of 9.35 million (Trading Economics/World Bank, 2014), located in the southeastern corner of the Arabian Peninsula. It was formed in 1971 as a federation of seven emirates – with Abu Dhabi and Dubai being the two most well-resourced and developed. Abu Dhabi is the capital of the UAE, with an estimated population of 2.58 million residents, 18% are UAE-nationals (Health Statistics, 2012). The basic elements of the traditional UAE society are an emphasis on the importance of Islam, the tribe and the family. The tribe and family values influence the society and continue to shape the beliefs and behavior of UAE nationals and UAE

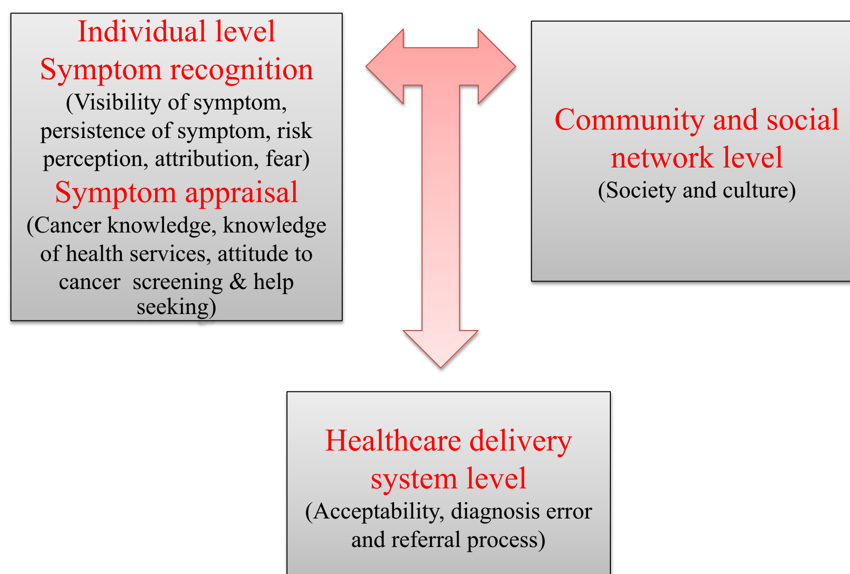

Fig. 1. Conceptual framework (the help seeking model).

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