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Public and Professional Educational Needs for Downstaging Breast Cancer in Egypt

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Abstract

We conducted focus groups with women from urban and rural areas in the Nile Delta region to investigate their attitudes regarding breast cancer diagnosis, treatment, and screening. Six 60-min focus groups, each group comprised of 6–10 women with ages between 20–69 years, were conducted. Discussions included breast health, breast cancer diagnosis, treatment, early detection and screening, and communication for breast health. Almost all urban and rural women reported that women do not see physicians until they are seriously ill or have advanced cancer. They reported that oncologists or gynecologists were important to be seen first if a woman suspected breast cancer and primary care physician are not the primary line of cancer diagnosis. Other deterring factors besides distrust in primary care physicians included attitude that breast cancer equals death and lack of knowledge of early detection and screening techniques. Women felt that public education campaigns must be implemented to improve early detection and screening

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methods for breast cancer. The majority of beliefs regarding breast cancer and screening were common among urban and rural women. Culture-specific and tailored professional and public education programs in developing countries are essential for achieving downstaging cancer.

Keywords

Urban/rural; Breast cancer; Attitudes; Egypt

Introduction

Breast is the most common cancer site among women in Egypt, accounting for nearly 35% of all cancers in women [1]. Although early detection of the disease plays a large role in improved prognosis, majority of breast cancers in Egypt are detected at advanced stages [1, 2], when chances of survival are diminished.

Studies from the two largest cities of Cairo and Alexandria showed that about 10% of women reported having some knowledge about breast cancer and breast self-examination (BSE) [3] or conducting BSE [4]. Women who were diagnosed at advanced stages rather than early stages were less likely to have knowledge of BSE, and those who had knowledge of BSE were less likely to present at later stages [5]. With increasing breast cancer rates in Egypt and other developing countries [6], there is an important need for understanding the underlying reasons for late diagnosis of breast cancer, which is becoming an emerging public health problem.

In addition to the possible lack of knowledge regarding early detection, other factors may contribute to the rising rates of breast cancer and the variable disease distribution in urban and rural areas in Egypt. Aging of the population, declining fertility rates, and a possible age–cohort effects are all factors that may be responsible for the current and future increasing breast cancer rates [7]. Our recent studies from the only Egyptian population-based cancer registry in the Nile Delta region revealed a two to four times higher incidence of breast cancer and estrogen receptor-positive breast cancer in urban than rural areas [2, 8]. As reported in our recent studies, this significant difference in incidence could be attributed to a possible higher exposure to environmental sources of estrogens in urban than rural areas and/or cultural barriers to seeking medical care for breast cancer diagnosis and treatment in rural than urban areas [2, 8].

The aim of this qualitative study was to investigate the knowledge and perceptions of women in urban and rural areas toward breast cancer diagnosis, treatment, early detection, and screening in the Nile Delta region of Egypt. The study also aimed to explore if cultural barriers may account for the significant difference in urban–rural breast cancer incidence. Understanding the attitudes and cultural barriers is essential in developing future cancer education programs.

Methods

We conducted six focus groups in the Gharbiah Province in the center of the Nile Delta of Egypt (located 100 km north of Cairo). The participants included 48 Egyptian women ranging from 20 to 69 years of age. Two sessions were held in Tanta city, and another four in two different villages outside Tanta. The participants in the two urban sessions were recruited by a simple random sample from the Tanta Social Club, which is a middle-class level community in the urban capital city of Tanta. After selection, all participants were invited and came for the focus group discussion at the Gharbiah Cancer Society conference room. Participants for the remaining four focus groups were personally invited door to door from the villages and discussions were held in a local home of each respective village. This study was approved by the University of Michigan Institutional Review Board and the Gharbiah Cancer Society's Ethics Committee.

Each focus group included 6–10 participants and lasted about 60 min. All discussions were conducted in Arabic and led by one of the coauthors (EF). The majority of women included in the study were married and had children. All of the women were Muslims, and most of them were unemployed (Table 1).

Two bilingual coauthors (NU and EF) were present at each session: one acted as the moderator (EF) while the other took notes and observed nonverbal cues (NU). A research assistant was present to transcribe sessions and monitor tape recordings after subjects' informed consent was taken. Everyone present in the room was female to create a comfortable atmosphere. Each session began with the moderator introducing herself and the team, a brief overview of what to expect from the session, and a request for verbal consents to participate in the study and audiotape the session.

A structured interview guide consisting of seven sections was developed and reviewed by all coauthors before the focus groups and was then used to facilitate the discussion to ensure consistency among sessions. The discussion began with a series of questions pertaining to general attitudes of Egyptians and their health. As the session proceeded, the questions became more specifically related to breast cancer and included the following sections: perception of breast cancer as disease, where women go for medical treatment if they notice an abnormality in their breast, knowledge regarding screening and early detection, knowledge of girls regarding pubertal changes, cultural perceptions regarding breast cancer, and future changes that women would like to see implemented to improve breast health (Table 2). All questions were asked in an indirect manner and in third person point of view so women would feel comfortable discussing a culturally sensitive topic in a group.

All the sessions were transcribed in Arabic through notes taken during the interview and in audiotapes and later translated into English. Similar themes that emerged in all the sessions were then grouped together, and the urban and rural sessions were compared to look for similarities and differences.

Results

Most of the cultural perceptions regarding breast cancer and screening were shared between the urban and rural women.

Attitudes About General Health

The majority of women in this study felt that men paid more attention to their own health than women in this region: “Women don’t care about themselves. They only care about their husbands and children.” Another reason given was,“ A woman can bear it if it is a serious disease but a man says ‘No I cannot, I must see a doctor quickly’.” A point of agreement amongst all the women was that Egyptians did not see a doctor until they were in state of severe, intolerable pain: “If we don’t feel pain, we shouldn’t see the doctor.” The only instance mentioned for going to regular checkups was if one had a chronic condition, such as diabetes. Some of the reasons women listed for waiting to be seen by a doctor included financial burden, lack of time, lack of education, and absence of pain. However, the two illnesses the women noted that caused them to seek medical attention immediately included breast cancer and gynecological-related conditions such as infertility, irregular menses, and vaginal or uterine pain or bleeding.

Knowledge About Breast Cancer

All the women agreed that breast cancer was a common disease. In all but one focus group discussion from a village, women knew personal stories of a family member, relative, neighbor, or friend who had breast cancer. The most common treatment option provided for these women was mastectomy, followed by chemotherapy. Their stories made it clear that the women understood that the aforementioned treatment can improve mortality rates: “A large portion of patients who had a mastectomy survived.” There was a difference of opinion among the sessions about whether breast cancer was more widespread in villages or cities. Those who noted higher incidence of breast cancer in rural areas were from the village and attributed it to lack of knowledge of the disease, resulting in advanced stage: “In the village, people have no awareness and don’t know what the symptoms of the disease are or what to do.” The women who stated that a higher incidence of breast cancer is in the urban areas were from a different village and attributed the higher incidence to environmental causes, including higher pollution and hormones used in fruits and vegetables. When asked about various characteristics of the disease, almost all the women agreed breast cancer was not heritable or infectious. The symptoms women listed included swelling around the breast or axilla, lump, discharge, heat, redness, and shape disfigurement (e.g., inverted nipple). All of the women agreed that breastfeeding can cause some of these symptoms without cancer. In three of six sessions, women understood that the early phases of breast cancer are painless and attributed this to delay in seeking medical care: “Tumors don’t cause pain.”

Seeking Medical Care

Majority of women stated that if women suspected an abnormality in their breast, they would go to an oncologist directly. An OB/GYN doctor was the next most common doctor of choice. One of the sessions highlighted the pivotal role of the pharmacy in Egyptian health care system and stated that a woman who suspected breast cancer would go to the

pharmacy: “The pharmacist is more important than the doctor that treats us.” Majority of women preferred seeing a female doctor for examination because of the level of comfort: “It is embarrassing to have a breast examination by a male doctor.” However, the women who preferred seeing a female doctor stated that they would still see a male physician if they were more knowledgeable or skilled, specifically if surgery is required. When asked about whether women go to a cancer center, all of the women agreed that there is a general taboo associated with going to a cancer center. One woman mentioned that she went to visit someone who was sick at the cancer center but could not get herself to enter: “I was nervous even though I was in front of the center.” This taboo stems directly from their fear of cancer itself: “People think that this disease ends with death and that is it.” Because the word cancer provokes anxiety, the women mentioned that other expressions have been coined and are used instead of breast cancer, such as “malignant swelling” and “the bad disease.”

Knowledge About Screening

Women in all the sessions understood the role of early detection in reducing mortality: “The tumor will be smaller in size and can be treated.” However, they noted that lack of knowledge about etiology of the disease prevents women from taking action: “Because they do not know the symptoms when [they] appear, they neglect them or say it is not serious.” Similar uncertainty was expressed about screening tests. Most of the women had never heard of mammograms, and those who did hear about it were unsure about its role in diagnosing breast cancer. Similarly, most women did not know about BSE, and if they had heard about it, were unsure of how to perform it. The few women who knew about BSE stated that it should be done monthly after menstruation and learned about it from watching television, from a nursing or medical school, or from a doctor. There was also confusion about at what age screening should begin.

Cultural Attitudes

When asked about effects after a woman discovers she has cancer, many of the women mentioned emotional turmoil as a common reaction and felt that it was crucial for breast cancer patients to have support from their loved ones: “[They become] emotionally devastated and they need someone to encourage them.” The women in all groups agreed that traditional medicine had no effect in curing cancer, but can play a role in everyday illnesses like a cough or cold.

Communication About Reproductive and Gynecological Health

The majority of the women stated that their mothers never informed them about pubertal changes nor was such information taught in schools. Moreover, most women approached an older sister or colleague when they got their first menstruation because they did not understand what was occurring to their bodies. Despite this lack of communication between mothers and daughters, all women agreed that communication was improving with the new generation and puberty was no longer deemed a sensitive topic: “Mothers and daughters are like friends now.”

Public Education

There was a consensus among all groups that more education was needed on breast cancer and screening. They felt that government's role should be to improve health education, which should begin while girls are in primary schools. Some ideas as to how this can be done included having female physicians visit schools to discuss women's health topics, such as changes to expect during puberty and how to do BSE. There was a general feeling that the new generation is different and more open minded about learning: "I swear, people now… want to know about any new thing or new information. They are not like the people of the old days." The women also felt that media, in collaboration with the government, can play an important role in teaching women about breast health because of easy access to television through an advertisement, a show, or soap opera. As one village woman reported, "It is the most widespread form of media that has entered homes." A few women mentioned that the media has played a role in educating Egyptians about the harm of female circumcision and therefore can do the same with breast health awareness. Topics that women stated they would like to know more about included: etiology of breast cancer, why it is widespread, chemotherapy, screening techniques, and what role positive attitude if any plays on outcome. Women would like physicians to offer more empathy and hope.

Urban–Rural Differences

Overall, the knowledge and attitudes regarding breast cancer were similar between urban and rural groups. However, there were a few differences, but cannot be generalized due to the qualitative nature of the study. The women in both villages were not content by their health care services. Some reasons were lack of qualified and experienced doctors and lack of doctors that respect and care for the patients. One woman stated that the doctor just hands patients a prescription. Another stated, "Even when children are sick we don't go there." Hence, they felt that one of the duties of the government to improve the situation for the future was to provide the villages with more trained physicians and better medical equipment. They also felt that the best way to disseminate accurate information about breast health was by having educational health seminars in their village: "One would attend and tell another [that] we heard and learned such and such." Moreover, only women in the villages mentioned the role faith can play in coping with the disease: "Some women get upset and some do not. It depends if she knows Allah and prays to Him or not." One woman mentioned how a woman she knew improved after having the Quran recited upon her: "She thought it was the end but she became fine."

Discussion

Most of the perceptions and attitudes regarding breast cancer and screening were shared among all women, which contradicted our hypothesis that significant cultural differences exist in attitudes towards breast cancer between women in urban and rural settings in this region in Egypt. The findings of the focus group study supports the literature that majority of breast cancer cases in Egypt are detected in advanced stages [1, 2]. Several aspects of the narratives mentioned support this point. Majority of women known to the focus groups' participants did not seek help until they experienced intolerable pain, which was also noted in our recent study in Egypt [5]. Moreover, total mastectomy was the primary treatment

choice, which is usually done if cancer has progressed to advanced stages [9]. Thirdly, retracted nipple was an associated symptom of breast cancer, which also occurs more often in advanced stages of the disease [10].

The findings of this study have important implications for how breast cancer screening programs should be tailored in Egypt and similar countries. Firstly, primary health care physicians must increase the awareness of their female patients regarding breast screening techniques and encourage women to report unusual changes early on. The dichotomy that women lacked an understanding of breast screening techniques yet understood the vital role early detection can play in saving lives mirrors findings of previous studies in developing countries that not enough education is being imparted at the primary health care level [11–13].

Moreover, since the majority of women stated that they would go to an oncologist as their first line of seeking medical care if they suspected they had breast cancer shows a general distrust in the primary health care physicians, who should be the major role players in detecting breast cancer. The lack of knowledge of primary care physicians in breast cancer diagnosis and management was reported in our study from the same region [14]. Another study we conducted in the same region revealed that only one third of the patients who initially visited primary care providers reached the Gharbiah Cancer Society by the second facility visit, whereas the majority of patients who initially visited oncologists reached this center by the second visit [15]. This highlights the need for increased awareness of proper screening methods and referral practices among primary care physicians. The findings of this focus group study also confirmed the importance of the gynecologist's knowledge in detecting breast cancer since they were second preferred doctors of choice among the women [16].

Secondly, health care personnel should take advantage of cultural beliefs to create effective breast cancer educational campaigns and screening programs and community resources. For instance, religious teachings can be used as encouraging factors for women to seek early medical attention, especially in villages where the role of faith in illness was cited. In a society where the faith has an important function in the culture, religious teachings related to health, such as the duties of seeking preventive measures for health, can be used as an encouraging factor [17]. Physicians can also encourage women to conduct BSE at the same time as the cleaning ritual Muslim women are required to do at the end of their menstrual cycle, which mirrors what the women who knew how to do a BSE in this study were doing [18]. Early detection techniques that take into account cultural beliefs are more likely to be applied by women.

Although there is no evidence that suggests that the performance of BSE helps decrease mortality, it is a powerful tool in an effective early detection campaign in developing countries [19, 20]. By teaching women to pay closer attention to symptoms or changes in their breasts, BSE can in the very least allow breast cancers to be detected earlier in a region of the world where access to mammography and frequency of visits to a primary health care provider are limited. Public education is an essential tool in developing countries where

resources for advanced screening tools, such as mammography, are not available or affordable [21].

A third method for education is using the media, which all of the women in this study felt is an important means to disseminate accurate information about breast health, early detection, and screening. Television was the most effective media tool in controlling diarrheal disease in Egypt in 1980s, and it was present in over 90% of homes [22]. In a focus group study evaluating attitudes among Chinese women after watching a short video about screening that included a soap opera and a segment with a physician, the video significantly improved the women's attitudes about screening. The authors argued that creating a culturally tailored video can help in increasing the low mammography use among Chinese women [23].

Yet another means to increase awareness among Egyptian women is the development of support groups for breast cancer patients. The women in this study repeatedly mentioned the importance of having support and a positive outlook throughout treatment. By having a support group, patients can share their experiences with other women going through the same illness, which can be a very powerful coping strategy. The development of this type of support group was proven to be successful in Bahrain and can similarly be beneficial in Egypt [24]. Support groups can also encourage family members of breast cancer patients to seek early detection.

There are a few limitations in this study. With any focus group study, some of the women might agree or disagree with an opinion merely because other women supported it. Because two binary opinions were often cited for the same topic, women were not afraid to voice their thoughts. Another limitation was that all the women were of Muslim faith despite efforts to recruit the participants at random and from two different villages.

These findings also have direct relevance to the USA and other western countries with migrant Arab populations. For example, breast cancer is the leading cause of death among Arab Americans and screening activity, such as mammography, occurs less frequently in Arab Americans than women from other racial/ethnic backgrounds [25, 26]. Future studies to explore cultural attitudes of Arab Americans can help clarify the reasons for low breast cancer screening rates. In conclusion, this study revealed the absence of a difference between women in the urban and rural Nile Delta region of Egypt in attitudes towards breast cancer diagnosis, treatment, or early detection. The study also highlighted the need for educating women and primary care physicians about breast cancer and the importance of using the media in breast cancer education.

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Table 1

Demographic characteristics of participants of focus group study on cultural attitudes of women regarding health care access and related behavior, and breast cancer, Gharbiah, Egypt

Variable	Number	Percent
Age (years)		
Mean 37.5±12.5	–	–
Median 35	–	–
Marital status		
Married	43	89.6
Single/divorced/widow	5	10.4
Number of children		
Mean 3.136±1.6	–	–
Median 3	–	–
Education		
Illiterate	9	18.8
Less than high school	7	14.6
High school diploma or equivalent	17	35.4
Bachelors	14	29.2
Graduate degree	1	2.1
Occupation		
Unemployed	39	81.3
Employed	9	18.8
Religion		
Muslim	48	100.00
Living area		
Urban	18	37.5
Rural	30	62.5

Table 2

Focus group questionnaire topics to elicit cultural attitudes of women regarding health care access and related behavior, and breast cancer, Gharbiah, Egypt

Category	Subtopics
General health	• Gender and health • Frequency of doctor visits and checkups • What illnesses unique to women provoke concern • Barriers to seeking medical care
Knowledge about breast cancer	• Prevalence in Egypt • Characteristics of the disease • Points of concern or clarification
Seeking medical care	• Type of doctor
Knowledge about screening	• Understanding of early detection • Beliefs and attitudes regarding screening
Knowledge about puberty	• Source of information
Cultural attitudes	• Role of traditional medicine • Reaction from society
Future vision of improving awareness	• Role of the government • Role of media