

# BARRIERS TO BREAST CANCER SCREENING AND TREATMENT AMONG WOMEN IN EMIRATE OF ABU DHABI

**Objectives:** The objectives of this study were to explore attitudes and beliefs among major national groups of women resident in the Emirate of Abu Dhabi (EAD) in relation to breast cancer screening and treatment.

**Design:** A qualitative study utilizing age and nationality specific focus group discussions and interviews in all parts of EAD.

**Setting:** Study was conducted among women living in various areas of EAD during April-September 2009.

**Participants:** A total of 329 participants divided into four nationality groups and categorized into two functional groups (well women and regular screeners) were included in this study and participated in 46 focus groups and 30 personal interviews.

**Results:** Some differences in beliefs, perceptions and opinions related to stated causes of breast cancer, preferences regarding breast care services, financial considerations, trust in health services and cultural attitudes towards breast cancer were observed across nationality and age groups.

**Conclusions:** New information has been obtained that will shape more focused awareness messages, emphasizing on decreasing fear and shame, discouraging use of cauterization and herbal preparations in delaying care, and activating the role of older female peers in favor of breast screening. Ensuring a sufficient number of trained female health care providers and devising creative approaches to ensure preventive health care costs to reimburse non-nationals are structural changes to the health care system which may further improve breast health for all women in EAD. (*Ethn Dis.* 2012;22(2): 148-154)

**Key Words:** Focus Groups, Interviews, Social Stigma, Insurance, Qualitative, UAE, Arab

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## INTRODUCTION

Breast cancer is the most frequent cancer affecting women globally and is a major public health problem in many developed and developing countries.<sup>1-3</sup> Public health data indicate that the global burden of breast cancer in women, measured by incidence, mortality and economic costs is substantial and on the increase.<sup>2</sup> Although breast cancer is responsible for the highest number of cancer-related deaths in women globally, the burden of breast cancer differs between countries and regions showing variations in incidence, mortality and survival.<sup>4,5</sup>

In the United Arab Emirates (UAE), the breast cancer incidence rate is relatively low. In the Emirate of Abu Dhabi (EAD), the largest and most populated of the seven emirates composing the UAE, recent estimates were of 26 new cases per 100,000 among women.<sup>6</sup> The impact of breast cancer can be reduced through breast health practices such as breast-self examination (BSE), clinical breast examination (CBE) or obtaining a mammogram. The likelihood to engage in those practices depends on a large array of determinants such as demographics, socioeconomic status, medical insurance,<sup>7</sup> access,<sup>8</sup> social, cultural beliefs<sup>9</sup> and fatalistic views.<sup>10</sup> The Health Authority Abu Dhabi (HAAD) has undertaken multiple initiatives to promote breast cancer screening. Despite these initiatives, screening rates have not yet reached levels of best practice countries. The HAAD recommends monthly BSE and CBE every three years for all women aged 20-39, and monthly BSE, annual CBE and screening mammograms every 2 years from age 40.<sup>11</sup>

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The association between cultural beliefs and breast health behaviors in the UAE in general, and in EAD in particular, is complex in view of the ethnic diversity of the population. The HAAD 2010 population demographics show that women constitute 28.3% of the total population, of which 65.1% fall within the target age-group for breast health screening, (ie, 20-69 years).<sup>12</sup>

Of the approximate total of 2.3 million residents, only 18.7% are UAE nationals.<sup>12</sup> The remaining include 3 large subgroups: 1) non-UAE Arabs, 2) Asians from the various countries of the Indian subcontinent, and 3) populations from Southeast Asia (SEA) - predominantly Filipinos, but also Malaysians and Indonesians. Other ethnic groups, while present, are of lesser demographic importance.<sup>13</sup> While these subgroups are not homogenous, they share several cultural features including languages, religious beliefs and food habits.

## METHODS

In an effort to identify cultural barriers affecting women's choice for breast health behaviors, and to provide information for health planners and educators, a qualitative study was conducted in 2009 among

women from the four largest ethnic groups including native UAE Arab women. We believe this article is the first reporting on structured qualitative research on breast health behaviors in the UAE among various ethnic groups.

### Study Design and Target Population

Focus group discussions (FGD) and structured interviews (SI) were used to obtain women's knowledge, perspectives and attitudes about breast cancer and breast health behaviors.<sup>14,15</sup> This study was conducted with women residing in 3 EAD administrative regions in decreasing order of population density: Central region (capital city), Al Ain "eastern region" (suburban) and Al Gharbia "western region" (mostly rural). In each region, women were included from four ethnic subgroups: UAE nationals (UAE), non-UAE Arabs (Arabs), Asians and SEA. The FGD were conducted with consecutive groups of women until the research questions were saturated. In each ethnic group, women were selected to either the younger (20–39) or older (40–69) group. Participants were divided into two main groups, healthy women (well-women [WW]) free of breast cancer who did not necessarily conduct regular breast health screening and regular screeners (RS), women free of breast cancer who practiced regular breast health screening including routine mammography every 2 years. Any woman who worked in breast cancer related fields was excluded.

### Study Procedures

This study was conducted as part of the HAAD Public Health mandate and ongoing program and is Institutional Review Board exempt.

Women for the FGDs were conveniently recruited by the researchers through embassies, businesses, churches, women's clubs, women's societies, schools, NGOs. The FGDs were held in private, convenient locations, at

times corresponding to the preference of ethnically and age-defined groups. At the beginning of each FGD, the interviewers introduced themselves, presented the aims of the study and described how the session would be conducted; assuring that attendance would be anonymous and voluntary. Verbal consent was a general rule and any woman who did not feel comfortable in participating was allowed to leave at any time.

Consent to use a recorder for the group to tape the setting was also obtained. Each FGD included a facilitator and a note-taker and usually lasted for 60–90 minutes depending on the number of women and their interaction. Before ending each FG session, responses of participants were reviewed between the researchers and participants.

It was difficult to find a sufficient number of demographically similar RS for FGDs in one single setting. Those participants had to be recruited in face-to-face and one-on-one telephone SI. Contact was established through mammogram centers where the women were screened. Interviews took approximately 45–60 minutes to complete depending on the dynamics of the interaction. Telephone interviews were not recorded.

Opening questions to the FG or SI included questions as to where the location of breast health services were in their specific region of EAD and their definition of breast health screening. Regular screeners were also asked about their motivation for adopting a regular pattern of screening.

Languages used in the FGD and SI were Arabic for UAE and non-UAE Arabs and English for other ethnicities. The lead researcher transcribed all recorded conversations, and translated Arabic ones into English.

The research team reviewed the transcripts and reached a consensus on grouping each response into key themes. Those key themes were subsequently analyzed for the four ethnic groups and the two age groups separately. Participants

were provided with clear recommendations and evidence-based information regarding breast health issues.

## RESULTS

### General Characteristics of Participants

A total of 46 focus group discussions were conducted with well women (WW); 27 in Central Abu Dhabi, 12 in Al Ain and 7 in Al Gharbia. The total number of participants involved in the focus groups was 299, with an average group size of 7 participants per group, ranging from 6–10. A total of 30 regular screeners (RS) were involved in the structured interviews.

Demographic details are presented in Table 1. As a result of the analysis, 4 themes were identified: 1) beliefs about breast cancer causes and symptoms; 2) access and preferences regarding breast care services; 3) cognitive barriers to screening; and 4) perceived cultural and societal attitudes towards breast cancer.

### Beliefs about Breast Cancer Causes and Symptoms

When asked, "What are the most common causes of breast cancer?" Well women, regardless of nationality, generally believed that the main causes of breast cancer were having a family history of breast cancer, genes, and unhealthy foods described by the participants as: fatty processed foods, food preservatives, canned foods, junk foods and insecticides and fertilizers in the food.

Participants also mentioned breast feeding practices that led to accumulation of milk in the breast as a causative factor for breast cancer (eg, clogged milk in breasts, milk collects in breast and becomes old and molds especially if stopped suddenly before the recommended period of 2 years). While breastfeeding was not mentioned among the SEA women they were united in attributing trauma to the breast (eg, too much handling by the husband/partner,

**Table 1. Demographic characteristics of women participating in the study**

Characteristics	Well women 20–39 years <sup>a</sup>	Well women 40–69 years <sup>a</sup>	Regular screeners
Age, years			
Mean (SD)	29.7 (5.2)	46.1 (5.4)	48.3 (7.1)
Range	20–39	40–69	37–73
Nationality, <i>n</i> (%)			
UAE	46 (28.4)	36 (26.3)	9 (30)
Arab	35 (21.6)	34 (24.8)	10 (33.3)
Asian	42 (25.9)	33 (24.1)	7 (23.3)
SEA	39 (24.1)	34 (24.8)	4 (13.4)
Total	162 (100)	137 (100)	30 (100)
Marital status, <i>n</i> (%)			
Married	109 (67.3)	111 (81)	28 (93.4)
Unmarried	48 (29.6)	13 (9.5)	0 (0)
Divorced	2 (1.2)	2 (1.5)	1 (3.3)
Widowed	3 (1.9)	10 (7.3)	1 (3.3)
Single mother	0 (0)	1 (0.7)	0 (0)
Total	162 (100)	137 (100)	30 (100)
Educational level, <i>n</i> (%)			
Basic	6 (3.7)	36 (26.3)	6 (20)
Primary school	14 (8.6)	9 (6.6)	1 (3.3)
Middle school	17 (10.5)	4 (2.9)	1 (3.3)
Secondary school	17 (10.5)	27 (19.7)	5 (16.8)
Graduate	99 (61.1)	57 (41.6)	16 (53.3)
Postgraduate	9 (5.6)	4 (2.9)	1 (3.3)
Total	162 (100)	137 (100)	30 (100)

<sup>a</sup> Age groups as per HAAD breast cancer screening recommendations.

pressing the breast like in breastfeeding, tight bras, bumping into the door) as major contributing factors for developing breast cancer.

A number of young Asian women agreed that “padded brassieres especially if black” caused breast cancer since “they cause friction and absorb all the sunrays.” Smoking, alcohol, and overweight were also three causative factors mentioned inconsistently. United Arab Emirates nationals did not mention them at all, but rather were particular in attributing cancer to the usage of perfumes and creams. Apart from the SEA group of women, a fatalistic outlook, believing that events are fixed in advance so that human beings are powerless to change them, was also identified by all (eg, “it is God’s will,” “it is from God,” “God knows”).

Regular screeners obtained mammograms but had rarely practiced breast self-examination. All of them, regardless of nationality, mentioned food items

such as beef, fast foods, preserved foods, caffeine, and Chinese salt as possible causes for breast cancer. Arabs and UAE RS mentioned breastfeeding practices as causes (eg, when milk is left in the breast, it makes lumps or no breastfeeding). Other possible causes included pollution (Asians and Arabs), mental stress (Arabs), tight bras and contraceptives (UAE). Hereditary factors were mentioned by all except UAE nationals.

When asked about most common signs and symptoms of breast disease, pain as a sign of cancer was mentioned more often by younger WW. Finding a lump or lumpiness was an important sign as reported by a UAE national, older women, “Lumpiness is more dangerous without pain.”

Among RS, the most commonly mentioned symptom was feeling a lump; “hard, stone like lump” (SEA), “small painless lump” (Asians), “a big pimple in the breast” (UAE). Pain was also mentioned among the 4 national

groups as well as “any changes in the breast or nipple” (Arab nationals). Nipple discharge was mentioned by all nationalities, educational levels and age groups.

Breast cancer was equated with phrases such as: losing a breast; torture; an ugly body; pain that never ends; my hair will fall; suffering and death; and better to die not knowing. They described breast cancer as a disaster, an agonizing disease, death, a woman walking with a single breast, and continuous treatment, painful and fearful.

### Access and Preferences Regarding Breast Care Services

When asked, “Do you know where breast check up services are in your region?” we found that WW had poor screening practices, with a majority failing to perform any type of screening exams regardless of nationality or age. Some of the younger SEA women felt that it was not important for them to

conduct BSE, while some younger Asian women did practice BSE. Generally, younger women were unaware that CBE was a recommendation for their age and unaware where services were available. Older WW knew better than younger ones where to access screening services for CBE and mammography. Asians and UAE nationals were more knowledgeable about breast screening facilities, regardless of age, across the regions.

When asked, "If there is only a male doctor, will this affect your decision to get diagnosed/ treated?" the majority of women stated they preferred to visit a female physician first. This was true for WW and RS, especially women <40, regardless of national group; sample responses included: I will wait (for a female doctor) even if for 1 month; will go to another emirate; will go to another country; and would search for a female doctor in other clinics. Arab nationals suggested they might consider accepting "if examined unexposed" and "if someone/my husband accompanied me in the examination room" given no other choice. However, some younger UAE women agreed that seeing a male physician for treatment was "better than dying." The SEAs tended to be more lenient in this issue stating that, "He is a doctor and that is his job." Asians stated that "they would go back home" even for treatment if they couldn't be seen by female physicians.

Regular UAE screeners in Al Gharbia and Al Ain unanimously stated that first line treatment for breast cancer would be cauterization or herbs by a "healer," "No woman would try conventional medicine before decreasing the size of the tumor by cautery and prevent local spread." Visiting a "local healer who has learned from her forefathers" first is the practice of choice. In other subgroups, only one younger SEA woman, stated that she would, "Visit a herbal healer first." Many women preferred to obtain friendly advice prior to a formal one.

The SEA women were more likely to consult a friend or their mother first. A group of UAE women in Al Ain concurred that "if their mother or sister decided nothing was wrong with them, they wouldn't see the doctor." Regular screeners screened routinely regardless of nationality and age as evidenced by comments: to clear any doubts, to take care of myself, and early discovery means cure/survival. Nevertheless, even among RS, approximately a third of the women would still consult family and friends for advice first.

Financial concerns may not be an issue among the UAE women covered by Thiqa (Arabic for trust) insurance which provides free coverage of breast cancer screening and treatment to UAE nationals. However such concerns may exist and were mentioned by a number of Arab, Asian and SEA women, especially in the younger Asian and SEA group with lowest wages whose insurance coverage, when present, rarely covers screening procedures. They reported having breast screening before coming to the UAE and although they paid for it, they would screen when they returned to their country three years later as it was cheaper.

A few women from the Al Gharbia region complained of distance or transportation as issues limiting their access to screening due to lack of services in the region.

### Cognitive Barriers to Screening

The most important barrier among WW to obtaining a screening mammography across all nationalities, ages and educational levels was the fear of discovering they might have breast cancer. Members of all subgroups replied with phrases such as: fear of discovering the disease, fear of knowing I have breast cancer, it's a scary disease, I'm afraid of knowing, I prefer not to know and I don't want others to know. Fear of dying and fear of radiation from the mammogram were other fears mentioned by Arabs.

Embarrassment was also a deterrent to screening. Arabs, Asians and SEAs regardless of age mentioned "they would feel shame" or were "too shy to show their breast." This theme was often linked to the preference for seeing female care providers.

A common theme among the UAE WW was distrust of the insurance system which they felt as being "manipulated" by professionals and that the insurance system was "making treatment in general more difficult." This perception stems from comparing practices a decade ago when walk-ins were possible for all and for all services, without any paperwork. They also expressed distrust in the health care staff and facilities in EAD and preferred to go abroad; "giving into doctors is giving into death. We do not trust treatment." In contrast, RS already using the service felt that "mandating screening mammography by Thiqa [trust] is better for women's health."

Most women who received services were satisfied, principally with mammography. Only two women in Al Ain complained that it was a painful procedure and that this may be a deterrent for the future. All others did not express misgivings about health care in the UAE.

### Perceived Cultural and Societal Attitudes Toward Breast Cancer

When asked, "What are the community (family, friends) impressions of women with breast cancer?" Well women generally agreed that the community would sympathize with the patient, pity and eventually support her. The UAE women in Al Gharbia voiced their concern that no one would marry their daughters if they knew that the mother had breast cancer. Some UAE nationals and Arab women were concerned they would lose their husbands if they were diagnosed with breast cancer. Among the regular screeners, UAE national women in Al Ain also worried that "a woman may risk losing

her husband should he know that she had breast cancer.”

Regular screeners' outlook toward the community was more positive and specific. They too felt the community would show sympathy, pity, prayers and well wishes, would give a sick woman strength and raise her morale. Two RS in Al Ain, one Arab and one Asian, mentioned social stigmatization should people know that she had gone for mammography especially if diagnosed with cancer, “What would the society say if they knew she had done a mammogram or gone to see the doctor?”

When asked, “Do men play a role in influencing women to do breast screening?” the unanimous response for all WW was that it would be a major influence on a woman's decision to do breast screening, with comments such as: “If he loves his wife, he will encourage her, the choice is hers”(UAE nationals, AL Gharbia). Arabs and UAE nationals in Al Ain felt that, “It depends on his level of education but they will generally not object.” Asians stated that, “They can force hesitant women.” emphasizing the role of husbands. Generally, brothers and fathers were excused as women's health issues were more easily discussed with their husbands or elder women in the family.

## DISCUSSION

To our knowledge, this is the first qualitative study that targets multiple national groups of women from various educational and age backgrounds in the community. While aiming for a large spectrum of profiles, this study certainly did not obtain all the knowledge regarding breast health perceptions in the Emirate. The widespread diversity of nationalities and educational levels present in the Emirate limited outreach. Most messages, although crafted in Arabic and English, may not reach a relatively small group of women, who are not fluent in either one.

In this study, participants were all free of breast cancer, and were either non- to low-performers of breast screening practices or regular ones. More focus groups/interviews are under implementation for cancer survivors, and also for men's views on breast health issues in women.

It has been stated that screening behavior is governed by level of knowledge and perceived risk.<sup>16</sup> Our results show that the women were generally unaware of the common risk factors for breast cancer regardless of nationality, age and educational level and have poor screening practices. Although regular screeners suggested more various factors for breast cancer, neither sex or age or reproductive risk factors were mentioned in any of the focus groups or interviews. Poor screening practices among SEA women might be attributed to their fear of excessive touching of the breast as a cause of cancer.

Many qualitative studies have explored women's knowledge and perceptions of breast cancer in relation to screening practices and have found that lack of knowledge about breast cancer and screening programs as well as fear and a fatalistic belief are deterrents that prevent women from adopting a positive breast cancer screening attitude.<sup>9,10,16-20</sup> Results of this study indicate the persistence of fatalistic views, but much less than previously believed. On the other hand, the attribution of cancer to excessive breast handling/trauma is new and should be revisited for its implication on women's perception of risk for breast cancer.

Across all subgroups, breast cancer was attributed to insufficient breast feeding practices. The protective role of breastfeeding has been a field of extensive study in many reports with various results ranging from no protective effect to an inverse dose response relationship between breastfeeding duration and risk of breast cancer.<sup>21-26</sup> However, the contribution of not breastfeeding remains much less important

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than the late age at first pregnancy and the lower number of pregnancies. Encouraging breast feeding seems therefore to be a desirable message, building on existing perceptions, and aiming at the larger context of child and women's health.

Regular screeners were more knowledgeable than WW with respect to common signs and symptoms of breast cancer, and they offered a more vivid description of breast cancer. They had overcome the obstacle of fear and shyness, a common theme among WW, and were positively motivated to screen based on knowledge that early detection meant cure.

Unveiling the major role of female family members, older friends, reliance on local or herbal healers and cauterization in shaping the decision to engage in breast screening was also a very important and interesting finding in our study, indicating a venue for future health awareness messages in Abu Dhabi. The delay caused by cauterization/herbal treatment of lumps on obtaining good care should be highlighted and discouraged.

Unexpectedly, most women denied that the role of men can be anything but beneficial in promoting a decision for screening. Men, especially husbands, were not considered a barrier among all groups. Overall it appeared that mothers' and other older female relatives' support and opinions counted more in the attitudes and practices of women than husbands'. If this information continues

to appear in future results, it should put to rest the often-repeated assumption that men may be an obstacle for women's access to health care in more traditional societies. Women, on the other hand, should be encouraged not only to act for their own health but also be responsible for information they impart to their younger peers.

Availability and access to breast care services in Abu Dhabi did not seem to be an obstacle for screening or management of a breast problem, although UAE national women had their doubts about the quality of care. Mistrust of health care has been reported previously by a study conducted in Al Ain by Bener et al about 10 years ago, among women who did not suffer from breast cancer.<sup>20</sup> In our study, regular screeners were satisfied with the quality of care they received. Once more, it appears that a first trial is an important determinant of repeated action, and therefore future messages should put more emphasis on encouraging that first step.

The level of education or nationality did not affect the overwhelming preference of all women to visit a female physician first. Privacy and modesty are characteristics that may prevent women from seeking medical help when they suspect that they may have breast cancer, especially if the examiner is a male physician.<sup>19</sup> Physician sex in respect to counselling and health services, even in more liberal societies, has been reviewed by other authors.<sup>27,28</sup> The importance of providing female practitioners to women seeking prevention and screening services becomes apparent as a result of our study.

Cost and insurance as barriers to women seeking screening services has been cited by other authors.<sup>27,29</sup> The UAE nationals are covered by Thiqqa insurance that covers all health care costs. Enlarging the insurance coverage for expatriates' breast cancer screening, diagnosis and treatment should be a priority for public health advocates in EAD.

One of the greatest barriers to screening mammography expressed by women in this study was their worry about what people would say and the social stigma that would impact their lives and their families. In other studies women have also expressed their fear of social stigmatization,<sup>30</sup> reported feeling alienated by their communities due to their cancer status,<sup>31</sup> and that breast cancer is often viewed as a socially unacceptable disease that may result in a negative response from family members. It might be possible that the UAE nationals and Arabs are so particularly concerned about the stigma of breast cancer and privacy issues that they would be prompted to go abroad for care to preserve a sense of anonymity. As a consequence, women may be discouraged from seeking active medical treatment for the disease or they may attempt to hide the diagnosis as the disease will affect the whole family, especially as it may impact their marriage or their daughter's future marriage plans. Reports indicate that social unacceptability is not unique to one specific country. In Korea, for example, breast cancer is associated with perceptions of bad luck for the family members.<sup>19</sup>

In conclusion, valuable new information has been obtained from our study that will help shape more focused awareness messages for women, encouraging formal care actions rather than delaying ones, emphasizing decreasing fear and shame and promoting the role of female peers in favor of screening. Ensuring a sufficient number of trained female health care providers and devising creative approaches to ensure preventive health care costs to reimburse non-nationals are structural changes to the health care system which may further improve breast health for all women in Abu Dhabi.

### Limitations of the Study

The logistical requirements for recruitment in this study were complex, as some women preferred daytime meetings,

while others preferred nights, after completing house chores and cooking. The SEA women were particularly difficult to recruit as they are often employed as domestic helpers and may not have the time to engage in non-job related activities. Older SEA women were especially difficult to identify and recruit in Al Gharbia. However, there is no reason to believe that beliefs and attitudes would drastically differ between expatriates residing in one area of EAD compared to another.

Obtaining written consent from women in the FGDs as well as taping telephone interviews proved to be unacceptable by the participants, regardless of nationality, fearing they would be identified (through signatures) and that either method would hold some kind of legal responsibility. However, they did agree to verbally consent. Methods to overcome this issue for future research are being reviewed.

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## BARRIERS TO BREAST CANCER SCREENING - Sabih et al

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