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Breaking the Silence: Breast Cancer Knowledge and Beliefs Among Somali Muslim Women in Seattle, Washington

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Abstract

We elicited the perspectives of Somali women in Seattle, Washington, about breast cancer. We conducted a focus group of 14 Somali immigrant women at a community center in Seattle, Washington. Participants reported barriers to seeking cancer screening, including fear of pain, difficulty with transport, and lack of knowledge. Participants explained that Somali women tended not to discuss breast cancer or breast cancer screening, and said religion played a central role in their care and treatment decisions and coping mechanisms. If such barriers are addressed, fewer women may present with late-stage breast cancer, resulting in greater chances for long-term breast cancer survival.

BACKGROUND

Breast cancer is the most common form of cancer in women worldwide. An estimated 1.38 million new cancer cases were diagnosed in 2008 (Ferlay et al., 2010). Differences in breast cancer incidence and mortality in developed countries versus developing countries are well documented: Incidence rates are generally higher and mortality rates are generally lower in developed countries than developing countries. Women in developing countries typically present with late-stage disease, making treatment options limited (Ferlay et al., 2010). Immigrants to the United States from developing countries are more likely to present with late-stage disease and have a lower rate of participation in breast cancer early

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detection programs than nonimmigrants (Li, Malone, & Daling, 2003). In this study, we used qualitative methods to explore the attitudes and beliefs of a group of Somali women who were recent immigrants to Washington state. There are increasing African immigrants to the United States; thus, it is important to learn about their perceptions of breast cancer and breast cancer screening. The results of this study may be useful in promoting breast cancer screening and reducing late-stage breast cancer among women in African populations.

Many states, including Washington state, have experienced an influx of Somali immigrants in recent years. The vast majority of Somalis arrived in the United States after 1990 as refugees due to civil war and clan violence that has crippled Somalia's infrastructure and economy (Dixon, 2006). Prior to the civil war, the majority of Somalia's population lived nomadically in rural areas and had limited educational opportunities. Illiteracy among females is estimated to be 86% in Somalia (Dixon, 2006; Goel et al., 2003), and only approximately 16% of Somali immigrants have a college degree (Dixon, 2006). Before immigrating to the United States, Somali refugees typically spent years in refugee camps in Kenya or Ethiopia, where the ability of health systems to respond is limited, and where access to cancer prevention, care, and treatment programs is nearly nonexistent. Immigrant women have a lower rate of cancer screening than nonimmigrants, especially those who have immigrated within 10 years, such as the Somali population in Washington state (Goel et al., 2003; Swan, Breen, Coates, Rimer, & Lee, 2003). In a 2009 study, the authors noted that Muslim Somali immigrant women in Maine were even less likely to be screened for breast, cervical, and colorectal cancer than other immigrant groups (Samuel, Pringle, Fielding, & Fairfield, 2009). Muslim women in the other cities in the United States have low rates of health care utilization in general, especially breast and cervical cancer care (Matin & LeBaron, 2004; Underwood, Shaikha, & Bakr, 1999).

In a number of studies, Muslim immigrant populations in the United States have noted that there are several possible reasons why immigrant women have higher mortality rates and lower rates of cancer screening in the United States. Cultural sensitivities (Banning & Hafeez, 2010; Hammoud, White, & Fetters, 2005), religious beliefs (Haji-Mahmoodi et al., 2002; Harandy et al., 2009; Li et al., 2003), and level of knowledge and awareness of cancer and cancer screening needs are all associated with rates of screening among immigrant populations, including Muslim Somalis (Carroll et al., 2007; Underwood et al., 1999). In addition to barriers and facilitators to early detection and cancer care, Muslim immigrants and specifically Muslim Somali immigrants in Maine, New York, Minnesota, and California have provided information about screening knowledge and health beliefs and attitudes of these female Muslim Somali immigrants (Carroll et al., 2007; Matin & LeBaron, 2004; Pavlish, Noor, & Brandt, 2010). Little research has been conducted, however, with the steadily growing Somali immigrant and refugee population in Washington state, particularly King County. In this study, we sought to provide additional insight into the knowledge and beliefs about breast cancer and breast cancer screening among immigrant Somali Muslim women in Seattle, Washington.

METHODS

Sixteen Somali immigrant women residing in Seattle, Washington, were invited to participate in a 90-minute focus group discussion about breast cancer; the focus group was held in July 2011. Volunteer participants were solicited by the leader of a community center with whom the Fred Hutchinson Cancer Research Center has connections. The leader of the community center recruited a diverse group of Somali women who regularly attend community center functions. Participants were invited if they were female Somalis between the ages of 30 and 69 years of age, Muslim, and living in the Seattle area. The focus group was facilitated by the principal investigator (B.T.) and coinvestigator (S.A.) in English. A Somali nurse provided verbatim translation of Somali to the approximately one-third of women who were not proficient in the English language. With the consent of the participants, the focus group discussion was audio recorded.

Although participants were eager to share their perspectives verbally with the group, they did not want their names recorded. To acknowledge these concerns, participants were assured that the information would only be used for research purposes, and that their names would not be connected to any quotes included in publication. Written informed consent was obtained from all participants and a copy of the form was given to each woman; one copy was kept with the principal investigator (BT). An incentive in the form of a Visa gift card valued at \$25 was offered to each participant for her time.

The focus group script consisted of the following topics: (a) knowledge about breast cancer, including perceived causes, cures, and availability of cures; (b) sources of breast cancer information; (c) religious, traditional, and medical beliefs about breast cancer; (d) health care experiences with physicians; (e) barriers to seeking a mammogram; and (f) support for breast cancer patients.

The audiotape recording captured both Somali and the English translation; the tape was transcribed into English and reviewed for themes and subthemes. The research team discussed preliminary findings immediately following the focus group. The team reviewed both the audio files and the English transcriptions and created a matrix of the six main topics. Three researchers then independently identified and coded key words and common themes from the transcripts and notes, based on the matrix. The researchers met to review key words and themes and reach a consensus. Selected sentences or phrases were chosen to represent recurring key concepts.

The protocol and all documents were reviewed and approved by the Institutional Review Board at the Fred Hutchinson Cancer Research Center.

RESULTS

Fourteen adult Muslim Somali women participated in the focus group discussion. Five major themes related to breast cancer and breast cancer screening emerged from the discussion and the responses provided by the focus group participants: silence, knowledge of breast cancer and screening, barriers to seeking screening, traditional beliefs, and religion as a coping mechanism.

Silence

Silence around the topic of breast cancer was very pronounced in this group. In the discussion, very little was said about breast cancer among Somali Muslim women. When we probed for information about perceptions of breast cancer in Somalia, focus group participants reported that they never talked about breast cancer in Somalia, even among family members. “My uncle’s wife had breast cancer; we know only when somebody dies.” Further, nothing was said about screening for breast cancer. Women did not discuss the topic with anyone: “We never talk about it there.” Another woman who had some experience with breast cancer noted, “We do not mention a thing.”

Further probing about breast cancer information available in the United States led one participant to respond, “*When in Somalia, we never talk or heard about it, only when we came here.*” When asked what they had heard about breast cancer in the United States, the women were mostly silent. Further examination of the response about talking about breast cancer when the women came to the United States, led to a discussion about who they would talk to about breast cancer. The women mentioned physicians, but they were not sure they would talk to friends or relatives. As one woman noted, “We never talk about it with our husbands; we will give them [a] hernia!”

Knowledge of Breast Cancer and Screening

Only one woman had heard of breast cancer or breast cancer screening before immigrating to the United States. “In Somalia, we don’t have breast cancer awareness like here.” Focus group women knew breast cancer “*is not a good disease*” but did not understand much more about it. One woman mentioned that an injury to the breast could cause breast cancer: “Because she has injury trauma and there is blood and milk and it [the breast] gets infected.”

The discussion around knowledge led to comments about mammography. There was some limited awareness of mammography, with a comment that “It is a prevention.” Further, there was some awareness of the mammography method, with a woman noting that “It puts a bit of pressure.” Another woman stated, “It will be hurting me.”

Barriers to Seeking Screening

Despite visiting a doctor regularly for other health conditions, study participants reported not receiving a recommendation for breast cancer screening from their physicians: “If [the] doctor does not [tell me], then I do not know where to go.” Another woman commented that “I go to the doctor every 3 months because I have diabetes and they never mentioned it to go [for a mammogram].” We probed about the reasons women had not had a mammogram and what, beside the pain previously mentioned by two respondents, prevented them from receiving a mammogram. Lack of information about where to go was one response: “We do not know where to go for this treatment; we do not know.” Others said that the “language is sometimes hard.” Still another noted that “[It is] very hard because the doctor is in one place and the exam in another.” Finally, the women expressed preferences for health care providers, observing that “It is hard to get a Muslim doctor or a woman doctor.”

Traditional Beliefs

Although the women knew breast cancer was not contagious, they had misconceptions about the etiology of the disease, probably due to the prevalence of some traditional beliefs: “We do not have breast cancer in Somalia maybe because we eat the camel meat and drink camel milk.” Added to that was the statement that camel meat and milk were treatments for breast cancer: “Camel milk and camel meat will protect, and is a treatment for cancer.” A woman commented that she went back to Jordan and “brought the milk of camel back here to drink—preventative.” Another woman thought that exposure to the sun might be protective. Women also thought that breast cancer rates in Somalia were “less than in other people.” Finally, one participant thought breast cancer might be caused by “not breastfeeding, maybe.”

Religion as Coping Mechanism

Religious beliefs played a significant role in the women’s perception of disease; their explanation for its occurrence; and their measures for coping with illness: “We know all diseases come from God.” “We believe God gave us the disease and God can take it away.” Religious belief also plays a role in women’s attitude toward treatment: “If someone got it, we pray for her.” “We read the prayers to God. After all, it is God’s will that will help.” A combination of reading the Qur’an, reciting Islamic prayers, and utilizing Western medicine was identified as important treatments for disease: “God we will use, but [also] traditional medicine and Western medicine. Both.” The focus group readily acknowledged the need for support for breast cancer patients, including providing food, praying for the women, and offering emotional support.

DISCUSSION

The findings from this focus group discussion validate research conducted in other parts of the United States with similar Somali Muslim immigrant populations. The silence—or women’s reluctance to discuss breast health or breast cancer—identified as a theme in this focus group discussion complements Banning and Hafeez’s findings that breast care presents a unique challenge for women from cultures where discussion of female anatomy may be a taboo or awkward topic, where breasts are considered private organs not to be discussed in public, or where symbolic meaning of the breast are associated with child bearing and rearing or with negative experiences (Banning & Hafeez, 2010).

What is unique about this investigation is that all the women were from Somalia and were recent immigrants. As such, many did not have experiences in the United States to change some of the issues around breast cancer that were prevalent in their homeland. This appeared to be especially true for the concept of silence. Early in the focus group, participants sat in silence, showing a sense of awkwardness in discussing the topic of breast cancer. Yet, later in the focus group, a few women noted that they had heard of breast cancer in the United States, through the television medium. Silence may have been the initial response to a socially difficult topic.

Underwood and colleagues reported that lack of knowledge is a key barrier for immigrant women to participate in cancer screening activities (Underwood et al., 1999), and Carroll and colleagues found that few Somali refugee women in New York understood little about cancer screening services, although they were aware of vaccinations and routine health exams (Carroll et al., 2007). In our study, we also confirmed that knowledge of breast cancer is limited among immigrants from this developing country. Women in this focus group discussion had not previously been exposed to breast cancer awareness programs in Somalia. They were unable to communicate the purpose of mammograms and did not know when or where a woman should be screened for breast cancer. By the end of the focus group, however, participants were eager to learn more about breast health, and were interested in attending future awareness campaigns and screening activities. Indeed, at the end of the focus group, we offered Arabic language materials, and each woman requested a copy of the materials.

Barriers to seeking care identified in the study included language, fear of pain, preference for a female or Muslim doctor, and lack of knowledge about where to obtain services. This poses a great problem for the refugee women. On more than one occasion the respondents stated that they would have a mammogram if their doctor recommended it. It is not clear why this was not the case in clinics in which Somali women were seen. It may be that members of the population present with a number of acute problems, so that it is difficult to address preventive care measures. The role of health care providers in shaping women's perception of screening cannot be overemphasized. It is imperative that clinics treating non-English-speaking refugees pay attention to the barriers experienced by this population. Further, it is critical that health care providers understand that sociocultural factors can prevent women from being seen and diagnosed when their cancers are still early, when treatment is more easily tolerated, and when favorable cancer outcomes are more easily achievable. Failure to recognize the cultural beliefs, ethnic taboos, and scientific misconceptions in immigrant populations can doom the success of cancer care programs, even if adequate resources are provided. If health care delivery is not structured in a way that addresses these language, cultural, and religious barriers, Muslim women may not participate despite understanding the benefits of screening (Underwood et al., 1999).

Religious beliefs may also influence a woman's health care seeking behavior, though studies of religiosity and health-seeking behavior among Muslim women have reached mixed conclusions (Haji-Mahmoodi et al., 2002; Harandy et al., 2009; Li et al., 2003). These differences may reflect the diversity of Muslim cultural and religious communities, which should be considered when targeting disparate populations with cancer education, care, and treatment. The women in our focus group emphasized the importance of religion as a coping mechanism for their illness, but they agreed that a combination of Western medicine and Muslim practices would help treat those afflicted with disease.

The "silence" theme identified in this study is common among many Muslim groups (Sheppard, Christopher, & Nwabukwu, 2010). The silence that exists around breast cancer may have much to do with the perception that the woman's body is a taboo aspect of conversation (Sheppard et al., 2010). This was supported by our focus group findings that in Somalia, breast cancer was simply not discussed. In recent years, however, there are

movements in developing Muslim countries to break the silence and begin activities around women's empowerment for breast health (World Health Organization, 2013).

Public awareness that breast cancer outcomes are improved through early detection is critical to improving participation in early detection programs. This can be challenging to implement in immigrant populations for multiple reasons. Women may be uneducated about breast cancer risk or may have major misconceptions about the nature or curability of the disease. They may feel uncomfortable discussing breast health with health care providers, or they may have religious or traditional customs that need to be recognized and accommodated in order to fully participate in breast cancer screening programs. For Somali refugees, the problem is particularly striking as these women not only fled a country rife with discord, but they also spent years in refugee camps where health care was severely limited. In other developing countries, the particular hardships of these Somali refugees may not exist, making it easier to break the silence.

Study findings are limited by the small size of the study and by the type of data collected. Due to participants' unfamiliarity with research and fear of their names being connected with the information they provided, demographics were not collected. This was done to make the community of women feel comfortable with the research process as such information may be considered too private to share with researchers during their first exposure to study protocol. Our limited data, however, suggested trends that could be confirmed by a larger sample and more extensive data collection.

Most of the Somali women we spoke to were genuinely interested in learning about breast cancer screening, a similar finding in other studies. Our study findings support the importance and efficacy of breast cancer educational programs targeted to immigrant women who may be especially vulnerable to presenting with late-stage disease because of lack of screening.

Conclusions

In this study, we conducted a focus group among Somali women who immigrated to the United States as a result of the conflict in their country. We found a number of themes around breast cancer, including a reluctance to address the topic characterized by silence; this silence existed in their native country and extended to their reluctance to talk about the topic in the United States. Traditional beliefs, especially religious beliefs, played a role in how the women would cope with breast cancer. Very few of the participants had received breast cancer screening, and intentions to be screened were hampered by lack of physician advice, not knowing where or how to get to screening, and gender discordance with providers. The results indicate that women would receive screening if it were recommended by their providers. More must be done to eliminate the barriers to screening faced by this group.

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