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ORIGINAL PAPER

Perspectives on Preventive Health Care and Barriers to Breast Cancer Screening Among Iraqi Women Refugees

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Abstract Since the Iraq war began in 2003, over 4 million Iraqis have been displaced. Little is known about preventive cancer care in this population, but stark disparities have been documented. The purpose of this study was to assess the perspectives of Iraqi women refugees on preventive care and perceived barriers to breast cancer screening. Interviews were conducted in Arabic with twenty Iraqi refugee women by a bilingual (English/Arabic) medical student, transcribed, translated and coded according to established qualitative content and thematic analysis procedures. Psychosocial barriers, culturally mediated beliefs, and health consequences of war were identified as major themes, ultimately showing what factors, alone and collectively, have impeded Iraqi refugee women's ability and motivation to obtain breast cancer screening. To improve cancer prevention and decrease disparities in care in this most vulnerable population, culturally appropriate health education and outreach programs, as well as further community-level targeted studies, are needed.

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Background

In 2010 more than 207,000 women were diagnosed with breast cancer in the US, and over 40,000 died from the disease [1]. Refugee women, a uniquely vulnerable population, face many healthcare challenges—not speaking English, dealing with physical and/or emotional trauma, resettling in an unfamiliar culture, and having few medical services prior to coming to the US. Although few studies differentiate between refugees and immigrants, all indicate disparities in preventive screening in these groups. A 2004 study of 283 Vietnamese, Cuban and Bosnian refugees revealed that 86% never had a mammogram as compared to 33% of American women [2], and a study of 189 Korean immigrant women revealed only 38.6% had had a mammogram within the year [3]. Reduced screening rates are also reported in Cambodian [4], South Asian [5], Arabic [6], Filipino [7], and Afghan communities [8]. The 2000 National Health Interview Survey revealed that women in the US for 10 years or less were less likely to have had a mammogram within the last 2 years than non-immigrants [9], and other studies reveal that more time in the US is associated with a greater number of mammograms [10]. These disparities result in increased breast cancer risk, presentation at a later stage of breast cancer, and increased mortality and morbidity following a breast cancer diagnosis [11–14].

The studies show great variability among ethnic communities with a variety of socio-demographic, access, and

cultural belief factors along with limited knowledge [15, 16], racial discrimination [15, 17], embarrassment [18], fear of diagnosis [17], underestimation of risk [17], and lack of insurance [19], and culturally appropriate health resources described as barriers [20–22]. One understudied group of refugee and immigrant women are Arabs. A survey of 365 Arab women in Detroit revealed decreased mammography screening with lack of insurance contributing to inadequate follow-up [6]. No study has investigated Arab refugees or explored subpopulation variation among the Arab countries, which have varying levels of health care infrastructures.

Since the 2003 Iraq war, over 4 million Iraqis have been displaced. Many resettled in the US, with 32,661 admitted just in 2008–2009 [23]. The Massachusetts General Hospital Chelsea HealthCare Center (MGH Chelsea) is a Massachusetts Department of Public Health designated refugee health assessment site, providing a comprehensive health assessment for newly arriving refugees. This urban, multi-specialty community health center serves a multiethnic, low-income, heavily immigrant and refugee community. Since 2001, over 1,600 refugees have had their initial immigration exams at MGH Chelsea. In 2009, Iraqis made up 43% (n = 63) of the 147 incoming refugees.

Breast cancer screening rates for Arabic-speaking (mostly Iraqi) women refugees receiving care at MGH Chelsea showed only 44% had received a mammogram in the last 2 years, as compared to 87% of Spanish or English speaking patients. To address this health disparity, it was important to better understand their perceived barriers to screening and health beliefs. The study's purpose was to explore Iraqi refugee women's perspectives on preventive health, assess perceived barriers to screening and describe factors that may influence screening rates and behaviors. The goal was to deliver a culturally tailored patient navigator program to increase screening and improve outcomes in Iraqi and other Arabic-speaking women.

Methods

Study Design

This was an MGH IRB approved qualitative interview study of Iraqi women refugees designed to obtain in-depth information about their perspectives on preventative health, and explore potential barriers to breast cancer screening. The interviewer was a bilingual medical student of Iraqi heritage. She approached participants by telephone to gauge their interest in the study and scheduled an in-person interview at a mutually agreeable time and location. Interviews were conducted from June to August of 2010.

Participants

Women eligible for the study were Iraqi refugees receiving care at MGH Chelsea. A convenience sample was identified using MGH patient registry data. Twenty interviews were conducted in Arabic at MGH Chelsea or at the patient's home. Interviews were audio recorded, translated and transcribed. A fact sheet about the study was given to participants and consent was received from all. Two women declined interviews and two refused audio recording.

Interviews

The interviewer was trained to conduct semi-structured one-on-one patient interviews of approximately 30 min. The interview guide (Text Box 1) used was based on previously validated studies of breast cancer screening in ethnic minorities [17], and informal interviews with MGH Chelsea patient navigators and providers. Initial questions aimed at eliciting women's prior experiences with medical care and views on preventative health. The second part explored women's knowledge about breast cancer screening and barriers to screening. Basic demographic data were obtained from MGH patient's registry or elicited in the interview. After questions were asked, the interviewer provided women with brief education about mammography.

Analysis

The first two authors reviewed the transcripts, identified preliminary themes and developed a codebook, using thematic analysis described by Tuckett [24] and the hybrid procedure described by Fereday and Muir-Cochrane [25]. Transcripts were coded and additional themes noted. The analysis team met after coding, reviewed their data, discussed new insights, confirmed existing themes, and generated new themes when appropriate. Relevant quotes anchoring the data were taken directly from the transcripts. After analyzing 13 transcripts, coding saturation was achieved with no new themes emerging from the last seven interviews. Inter-rater reliability was >90%. Disagreements were resolved through discussion until consensus was achieved. A third reviewer read the combined transcripts, confirming the coding of themes.

Results

Study Participants

Sociodemographic characteristics of participants are shown in Table 1. Average age of interviewees was 41.25 (range

Text Box 1 Interview guide

1. When you have gone to the doctor in your home country, or in this country, was it a good or bad experience? Please tell us about it.
2. Is there any reason that you would go to the clinic or the doctor if you are *not* sick?
3. Sometimes there are cultural treatments—like herbs, traditional medicines, or people in the community whose opinions are trusted about health conditions, who are not doctors, that people turn to. Do you or anyone you know ever use these things or consult these people?
4. When women go to their doctor for check-ups, what do you think are the sorts of things that are most important to have checked?
5. What do you know about "preventive health care" and screening exams for women's health?
6. What do you know about mammography or mammograms? What is it?
   Why is it important to get it?
   Who should get it?
   How old should they be when they get it?
   Have you or would you have one?
   Would you recommend it to your sister/mother/friend? Why or why not?
7. What problems stop you from getting a mammogram?
8. Is there anything else you want to tell us?

Thank you very much for participating!

23–55 years) and seven women were under 40 years old. Most (55%, n = 11) spoke no English, and 75% (n = 15) were married. 55% (n = 11) had lived in the US for less than 1 year, with a range of 1 month to 3 years. 95% were Muslim (n = 19). Although education status was not explicitly solicited, information provided revealed an education range of middle school to college; most women had lower levels of educational attainment.

Table 1 Patient demographic characteristics

	N
Age (years)	
<30	3
30–39	4
40–59	9
>55	4
Range 23–55	
Marital status	
Married	15
Single/divorced/widowed	5
English proficiency	
None	11
Low	7
Intermediate	2
Years lived in US	
<1 year	11
1 year or more	9
Religion	
Muslim	19
Christian	1

Themes

Three major themes emerged:

1. Culturally mediated beliefs about illness and preventive care.
2. Knowledge about breast cancer screening.
3. Barriers to obtaining mammography screening:
   - Psychosocial barriers
   - Health consequences of war
   - Religiously influenced concerns

Health Beliefs on Illness and Prevention

The majority of women defined illness as symptomatic and did not talk about preventive care. As one participant said, "If I am not sick, why would I go to the doctor? I don't go to the doctor if I am not sick!" Women identified "focus on health" as a major difference between the Iraqi and American health care systems, and pointed to reliance on God in preventing illness. According to one participant: "In Iraq, only if we were really in need, we would we go to the doctor… but in day-to-day things, I'd leave it up to God and say, God is watching over." Women recognized different health practices in the US: "here, I've noticed that routine check-ups and preventive exams are very important and the doctor is always reminding you of them."

Preventing disease was seen as the function of nutrition and cleanliness, not doctors. As one said, "The most important thing is the vegetables and fruits." Women's notions of a healthy diet were multidimensional, and most did not rely on herbal remedies except for nominal

remedies like chamomile tea. Women linked health maintenance to strict cleanliness: "Of course cleanliness is the most important thing. If a person is clean and adhering to healthy habits and cleanliness then, of course, this is the biggest prevention from disease."

Understanding/Awareness of Breast Cancer Screening (Mammogram)

The majority of interviewees knew about mammograms. Many mentioned that screening for disease was not the norm in their home countries and because screening centers were typically far away, testing was done only when breast cancer was suspected. Those who had not heard about mammography before settling in the US cited their physician as their primary source of education. Most had learned that regular mammography screening is critical for early detection and considered it an important behavior which they encouraged for their friends and family. They expressed gratitude over having access to mammography services unavailable in their home country.

> [Mammography] is something we haven't seen in our countries. We used to see it on television… that this is something you should do to detect, God forbid, that illness because if you delay, in that hour, you will lose your health… we used to dream for services like this. So when we came here, and we found these [services], thank God. We are lucky.

All women said they would not follow the advice of anyone other than a doctor's as in this comment: "No, how would I get advice from someone who's not a doctor? Do I want to bring harm to myself?"

Barriers to Breast Cancer Screening

Psychosocial Barriers

Women identified psychosocial barriers of fear: fear of pain during mammography and fear associated with receiving a cancer diagnosis. As several echoed: "When I had my mammogram last year, I had heard from people that it hurts a lot so I was nervous" However, many noted the importance of overcoming this fear. According to one: "they are bothered by [the mammogram] because it's painful. But isn't it better to endure it than to have to endure the illness?" Fear of cancer diagnosis and fear of the unknown were often mentioned, as described by this participant: "I went with my hand over my heart; I was so worried and scared. And not until the results were sent home saying there wasn't anything wrong that I was fine."

Health Consequences of War

Another theme was "health consequences of war", with danger and decrease in quality and availability of Iraqi medical care, making day-to-day survival paramount. As one said:

> [Iraqis] are living… in a state that has forced them to forget about their own lives. Here, no. An individual will pay attention to his health more… to his food, to his health, to his sleep, to his appointments… all these things, here, you have the luxury to pay attention to this.

Almost all the women stated that health services in the US were significantly better than in Iraq, and have influenced their health behavior: "Here in America, it's much better than in Iraq. Here, there is peace, security… and mentally you're more at peace… not like in Iraq."

This woman's words are especially telling of how focus on immediate survival can continue even after resettlement:

> Back in our country, death was so close because of the war and violence. Every day, you think you can die that day and death is always there. Because of this, you don't pay attention to your personal health. That's why a lot of people don't go to the doctor unless it gets very serious… Many people have carried this mentality to the United States. I think that's why many women may not get it here.

Women had a heightened awareness of breast cancer due to years of biological and chemical warfare leaving high levels of radiation throughout Iraq and increasing cancer prevalence. A typical comment: "I mean, we have had wars and the uranium and the radiation everywhere, and bombs… all these things have effects. [Breast cancer] is actually something common we have in Iraq now."

Religious Concerns

Modesty issues were mentioned by a few women, both in mammography and other health care situations. Women preferred female doctors: "I don't go to a doctor who is male. That's a bit of an embarrassment as Muslims. One said: "you know, I am a covering woman and don't want [a male doctor]." Despite this preference for female doctors, it was not the most significant problem—ultimately, their Muslim faith complemented rather than obscured their health-conscious efforts. As one woman said:

> I've heard from some people… that this is not our way. We are Muslims. We can't go do something [inappropriate] like this [mammography]… but, I

> think, the doctor gives this advice, this order, and it becomes your duty to follow through with it. Even religiously, something relates to a sickness, you can't say… it's *haram* [religiously impermissible]… I think this is something that is necessary. It's a must for women. I was actually approached by someone who asked [whether it's *haram*] but I said, 'no, in our religion, it is obligatory to do something that is beneficial to your health.' And this is something that is necessary. Our religion doesn't prohibit it.

System barriers such as insurance and transportation were the least commonly reported. All of interviewed women were insured under the Massachusetts universal health care regulations and transportation was not an issue illustrated by these two quotes: "It is not a burden… bus or train, I come and go." "Oh, [transportation is] so easy. In the summer, the shuttles and hospitals are kept cold and in the winter, they're kept warm and we enjoy riding on a bus, going out."

Discussion

Addressing health disparities in breast cancer screening requires understanding why women do not get screened and what health beliefs inform women's attitudes. We focused specifically on the population of Iraqi refugees because of their recent influx to the US and reported disparities in screening. This study explored Iraqi refugee women's beliefs regarding preventive care and breast cancer screening—information not previously documented in the literature.

Results of our study revealed some perceived barriers similar to those reported in other refugee and immigrant communities and others starkly different. As in the Kobetz et al. [26] study of Haitian immigrants, we found that fear around diagnosis/results and fear of pain during mammography is a common barrier. Sociocultural notions of illness as symptomatic were similarly found in this refugee community. However, several system barriers of other studies [27], such as low English proficiency, no health insurance, and transportation, were not mentioned by our sample. This may reflect the fact that MGH Chelsea addresses system barriers through its community health programs. It may also reflect a bias of women's demographics not investigated, as well as sample bias inherent in women who agreed to be interviewed. Comments by some women indicated that this may partly be due to relief and pleasure Iraqi women feel in being able to move about safely in US.

Expected barriers that did not emerge in our study were reluctance to receive a mammogram or lack of knowledge of mammography. Results from our sample of Iraqi refugee women indicated that the women were thrilled to finally have access to health care procedures they could only dream of in their war-torn home country. These Iraqi refugee women seemed to have a greater awareness of breast cancer than other refugee groups, where the other groups even associate breast cancer as something that only happens in America [18]. Significantly, studies have identified that perceived seriousness of breast cancer is predictive of mammography [28, 29], which could be relevant to this group.

Another unexpected finding was the perspective on religious modesty as being a surmountable concern. Although a few women mentioned modesty, they provided the important insight that their Islamic faith was ultimately facilitative of their health activities, rather than a hindrance. Indeed, Islamic bioethics emphasizes the importance of preventing illness and stipulates the saving of life as an Islamic duty [30].

Women's reflections revealed that their decision to not go to the doctor should be understood within the context of war, which had impeded physician visits in Iraq, except for dire health emergencies. The belief of illness as symptomatic may be exacerbated by these external factors rather than intrinsically held health beliefs.

Also significant was the positive effect of the health center's outreach programs and physician outreach. They viewed these efforts and physicians very positively, thankful for concern not seen in their home country. The International Rescue Committee (IRC) Commission, who interviewed Iraqi refugees in Atlanta and Phoenix, similarly found them expressing deep gratitude for their safety and freedom in the US [31]. This is important as hospitals are increasingly developing tailored programs for specific low-income, minority communities.

Limitations and Recommendations for Further Research

Our study has several limitations. First, this was a convenience sample of only 20 women identified by MGH Chelsea, affecting the study's generalizability. Second, questions about the women's prior socioeconomic status was not obtained, which could influence whether or not these women had knowledge of mammography. Third, the study setting, a health center in Massachusetts, may result in underestimating the financial challenges faced by Iraqi refugee women elsewhere in the US, because of Massachusetts's universal health care provision. Indeed, other studies among immigrant groups have cited financial barriers as being more salient [6, 19], and legislation such as the most recent 2010 Affordable Care Act, which restricts health access to Medicaid to legal immigrants during their

first 5 years in the US, would make financial considerations significant. Moreover, in as much as financial barriers are linked to citizenship, and as other studies have shown [32], we would expect lack of citizenship also to be a barrier to cancer screening among Iraqi refugee women outside of Massachusetts.

In addition, subgroup variations were not explored, given the preponderance of Iraqi refugees at this community health center. Finally, although we developed an interview guide and used a trained interviewer, the use of multiple interviewers may decrease bias associated with individual style or emphasis of the interviewer.

An important finding was the highly emotional trauma suffered by these women. This was not explored further in the interviews. An aforementioned IRC report revealed high numbers of Iraqi refugees suffering emotional trauma [31]. A deeper understanding of these women's mental health status could provide additional insight to their motivation for obtaining screening, and is recommended for further research.

A major strength of this study is its contribution to the literature on cancer screening and preventative care among Iraqi refugee women. Our findings emphasize the importance of culturally appropriate education and outreach for engaging Iraqi women in health care, and of further community-level, targeted studies of underserved communities. With large numbers of refugee arrivals and numerous barriers to accessing services, coupled with limited resources, it is especially important that resources are efficiently and effectively directed to address the health needs of refugees.

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