Breast cancer awareness among Afghan refugee women in Turkey

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Summary

Background Refugees and asylum-seekers have lower levels of cancer awareness and this contributes to low rates of screening and more advanced cancers at diagnosis, compared to non-refugee populations, due largely to reduced access to medical information and care. The global Afghan refugee population is rapidly increasing with the ongoing Afghan political crisis. The present study investigates breast cancer (BC) awareness among Afghan refugee women.

Methods A cross-sectional survey of Afghan refugee women residing in Turkey was performed in September 2021. A validated BC patient awareness assessment, the Breast Cancer Awareness Measure (BCAM), was used to assess participants' knowledge of seven domains of BC: symptoms, self-examination, ability to notice breast changes, age-related risk of BC, urgency of addressing changes in the breast, BC risk factors, and BC screening. BCAM was translated into patients' native language and administered verbally by a physician with the assistance of an official interpreter. Routine statistical methods were employed for data analysis.

Findings A total of 430 patients were recruited to the study. The response rate was 97·7% (420 patients). The median participant age was 35 years (range: 18 to 68 years). The majority of participants (84%) had no formal education. Most participants (96%) were married, and most (95%) were not employed. Awareness of warning signs of BC was low: only seven to 18% of participants recognized 11 common warning signs of BC. Participant use of breast self-exam (BSE) was low, with 82% of participants stating they rarely or never complete BSE. Zero of 420 patients reported ever seeing a physician for a change in their breasts. Awareness of risk factors for BC was also low: only 15% of participants recognized increasing age as a risk factor for BC, and other risk factors were only recognized by four to 39% of participants.

Interpretation BC awareness among Afghan refugee women is critically low. There is an urgent need to target this population for practical interventions to increase BC awareness, in addition to screening and earlier diagnosis. Evidence-based interventions include educational sessions in patients' native language and use of BSE and clinical breast examination for screening.

Funding American Society for Radiation Oncology (ASTRO) − Association of Residents in Radiation Oncology (ARRO) Global Health Scholar Grant, Dana-Farber Cancer Institute Jay Harris Junior Faculty Research Grant.

Keywords: Afghanistan; Turkey; Refugee; Global health; Breast cancer; Cancer awareness; Screening

Introduction

The plight of refugees and asylum-seekers is one of the most urgent modern global health issues. The confluence of unrelenting geopolitical conflict and the coronavirus disease-19 (COVID-19) pandemic have created, per the United Nations' assessment, the world's gravest humanitarian challenges since World War II.[1] Five decades of geopolitical conflict in Afghanistan has resulted in the world's largest and longest displacement crisis: nearly 6 million Afghan refugees and asylum-seekers have fled to countries around the world.[2] Iran,

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Research in context

Evidence before this study

We searched PubMed on October 1, 2021 for all publications, without date restrictions, using the search "Refugee cancer awareness" OR "Afghan refugee cancer awareness." We found a limited number of qualitative studies, each with a sample size of less than 100 participants, but none of them was focused on cancer awareness in Afghan refugees.

Added value of this study

To the best of our knowledge, this study is the first to report on cancer awareness among Afghan refugees using a validated questionnaire. Only a small minority of women were aware of common signs of breast cancer (BC), such as breast lumps and skin changes. Further, the majority of women were not aware of important risk factors for BC, such as increasing age and lifestyle factors. Utilization of breast self-examination and clinical breast exam within this population was also critically low, and none of the participants had any prior screening mammogram.

Implications of all the available evidence

Cancer awareness among refugee populations is low, also within the Afghan refugee population. More opportunities to increase awareness should be offered by implementing educational programs and clinical monitoring, to facilitate screening and early diagnosis.

Pakistan, Germany, and Turkey host the largest populations of Afghan refugees, and significant numbers reside in other European and North American countries, including the United Kingdom, the United States, France, and Canada.[3] The collapse of the Afghan government in August 2021 has acutely worsened this crisis, with over 120,000 Afghans airlifted out of the country in August alone[3]; the United Nations High Commissioner for Refugees (UNHCR) estimates that by the end of 2021, this number will exceed 500,000.[2] Therefore, attention to the specific needs of Afghan refugees is critical.

Refugee populations are well-known to suffer from poor health outcomes in every category of disease and to have lower access to medical care.[4] This deficit is due to socioeconomic disadvantage, language and cultural barriers, lack of knowledge about how and where to obtain medical care, and, importantly, reduced health awareness.[5] Refugee health programs traditionally emphasize prevention and treatment of communicable diseases, given their tendency to spread rapidly through refugee communities.[6] As a result, resources for intensive education, prevention, and screening for noncommunicable diseases such as cancer are not widely available.[6] Therefore, limitations in knowledge and

care-seeking amongst refugees are likely even more pronounced with regard to cancer and other noncommunicable diseases.

These limitations have fatal consequences. Numerous studies have shown that refugee populations have dismally low rates of cancer screening and overwhelmingly present with advanced-stage disease.[7−12] Low rates of cancer awareness are a major contributor to these low screening rates and poorer outcomes. Previous studies have found lower cancer-related knowledge in refugee populations compared to both citizen and non-refugee immigrant populations in their host countries, and there is an inverse correlation between cancer awareness and use of screening within these populations.[13−16] In limited-resource populations, where mammography-based breast cancer (BC) screening programs are not readily available, breast cancer awareness, patient use of breast self-exam (BSE), and clinical breast exam (CBE) are of critical importance. Patient use of BSE can increase breast-related healthcare seeking among patients and promote earlier-stage presentation. Furthermore, the effectiveness of annual CBE is nearly as effective as biennial screening mammography and more affordable for both individuals and national healthcare systems; therefore, increasing the use of BSE and CBE in these populations is a crucial global health goal.[17−19]

The combination of a population with low cancer awareness and screening, a high burden of advanced disease, and a rapid increase in that population's size amounts to an impending global health crisis. A better understanding of cancer awareness among Afghan refugees is critical to allow the appropriate implementation of interventions to improve screening and diagnosis. Interventions that promote earlier diagnosis and lower the proportion of individuals with advanced disease will lessen the suffering of individual patients, improve outcomes, and reduce the financial burden on host countries.

Prior studies of non-Afghan refugee populations are helpful to guide investigations of Afghan refugee populations but are not a substitute for research devoted to Afghan refugees. Notably, several studies of Syrian refugees' cancer awareness and trends in screening and diagnosis exist, and it may be tempting to extrapolate to the Afghan refugee population given similarities between these groups: Muslim-majority groups from geopolitically unstable states. However, stark differences exist between these populations. For example, the adult literacy rate is 81% in Syria, but only 43% in Afghanistan.[20] Given the well-demonstrated correlation between lower literacy and education levels and lower health-related knowledge,[21] a concerning possibility is that cancer awareness may be even lower among Afghan refugees than among Syrian refugees. Additionally, cancer screening programs are poorly organized in Afghanistan compared to Syria and other countries. For

example, the country of Syria has an organized BC screening program acknowledged by the World Health Organization (WHO); Afghanistan has no equivalent program.[22] Afghan refugees may thus be at even higher risk of undetected cancers than refugees from other nations. Formal data regarding breast cancer diagnoses in Afghanistan are severely limited, but a recent study found a mean age at breast cancer diagnosis of only 43 years old, significantly lower than global average of approximately 62 years old.[23,24] Therefore, an assessment of cancer awareness specifically among Afghan refugees is critically needed. The present study begins to address this urgent need by investigating the level of awareness of BC among Afghan refugees in Turkey.

Methods

Study design and participants: A cross-sectional survey of Afghan refugee women residing in Turkey was conducted in September 2021. Data were collected from women aged 18 or older with refugee status who presented for care at the outpatient departments of a public health care facility in a metropolitan area. Patients with a personal history of BC were excluded from the study. Critically-ill patients were also excluded.

Data collection tool: The Breast Cancer Awareness Measure (BCAM) was developed by the Cancer Research UK group of Kings College London in 2009.[25] BCAM is a questionnaire that assesses seven domains of BC awareness: knowledge of BC symptoms, breast self-examination, confidence of noticing a change in the breasts, age and lifetime risk of BC, urgency if a change in breast is noticed, BC risk factors, and BC screening. The questionnaire can be administered face-to-face or via telephone.[26] BCAM is highly readable for patients, has good test-retest reliability, good construct validity, and is sensitive to changes in awareness. BCAM has been validated in Muslim and Middle Eastern populations.[27−29] For the present study, BCAM was translated from English into Pashto and Dari by an official translator, and participant responses were translated back to English. BCAM was administered verbally via telephone. For each participant, the administration of the survey was conducted by a physician with an interpreter present on the call for assistance.

Ethics statement: This study was approved by the Institutional Review Board of Kanuni Sultan Süleyman Training and Research Hospital. Informed consent was obtained from each participant prior to the interviews.

Data collection: The sample size was calculated using OpenEpi software (Emory University, Atlanta, Georgia, United States of America [USA]) with a confidence interval of 95%, margin of error 5%, and assuming 50% prevalence of BC awareness. An additional 10% sample was added as non-response rate, yielding a final sample size of 430. A pilot with 20 participants was initially performed. The questionnaire and the

logistical arrangements were found feasible by the participants.

Statistical analysis: Statistical analyses were performed using Statistical Package for the Social Sciences (SPSS) statistical software version 25 (International Business Machines (IBM) Corporation, Armonk, New York, USA). Results are presented as frequencies and percentages for categorical variables and as the median and range for continuous variables.

Role of the funding source: The study's funding source did not participate in study design, collection of data, analysis of data, interpretation of data, or report writing. MCK, MAB, OS, and MS had access to the dataset. The decision to submit for publication was made jointly by all of the authors.

Results

A total of 430 patients were recruited to the study. All patients were of female biological sex and self-identified as female gender. Four hundred and twenty participants completed the questionnaire, yielding a response rate of 97·7%. The median participant age was 35 years (range: 18 to 68 years). Of these, 142 (34%) were aged 40 or older. The majority of participants (84%) had no formal education. Most participants (96%) were married, and most (95%) were not employed. No patient had ever had a screening mammogram in their lifetime. The demographic characteristics of the cohort are displayed in Table 1.

Participant responses regarding knowledge of the warning signs of BC are displayed in Table 2. Only a small fraction of participants displayed awareness of common signs of BC. Pain in breast or armpit was the most recognized, with 18% of participants recognizing this sign. Nipple bleeding or discharge was the least recognized, with only 7% of participants recognizing this

	n (%)
Age	
Median, years (range)	35 (18−68)
Education	
No formal education	352 (84)
Primary school	42 (10)
Secondary school	26 (6)
Marital status	
Single	17 (4)
Married	403 (96)
Employment status	
Employed	21 (5)
Housewife	399 (95

Table 1: **Demographic characteristics of participants. This table displays the median and range of ages, as well as the educational, marital, and employment statuses of participants.**

	Yes (%)	No (%)	Do not Know (%)
Lump or thickening in the breast	54 (13)	50 (12)	316 (75)
Lump or thickening under the armpit	50 (12)	54 (13)	316 (75)
Bleeding or discharge from the nipple	30 (7)	40 (10)	350 (83)
Pulling in of the nipple	35 (8)	50 (12)	335 (80)
Change in the position of the nipple	37 (9)	52 (12)	331 (79)
Rash on or around the nipple	60 (14)	32 (8)	328 (78)
Redness of the breast skin	70 (17)	42 (20)	308 (73)
Change in the size of the breast or nipple	52 (12)	60 (14)	308 (73)
Change in the shape of the breast or nipple	48 (11)	63 (15)	309 (74)
Pain in one of the breasts or armpit	76 (18)	49 (12)	295 (70)
Dimpling of the breast skin	44 (10)	55 (14)	321 (76)

Table 2: **Participant awareness of warning signs of BC. This table displays the responses of participants regarding awareness of various signs of BC.**

sign. For each of the 11 signs of BC assessed, most participants assessed their awareness as "Do not Know" rather than declaring that signs did or did not warn of BC. "Do not know" rates ranged from 70 to 83%. However, a small fraction of participants incorrectly assessed each sign as not being a warning sign of BC. For example, 12% of participants responded that a lump in the breast is not a warning sign, and 20% of participants responded that redness of the breast skin is not a warning sign.

Participant responses regarding breast self-exam, breast changes, and BC risk based on age are displayed in Table 3. The majority of participants (82%) reported that they rarely or never complete breast self-examination (BSE). Despite the low rate of use of breast self-exam, 70% of patients rated their confidence in noticing a change in their breasts as "Fairly confident" or "Very confident." Notably, all 420 participants stated that they had never visited a doctor for a change in their breasts. Only 15% of participants correctly identified a 70-year-old woman as having the highest age-based risk of BC.

Participant responses regarding BC risk factors are displayed in Table 4. For each of the nine criteria assessed, only a small minority of patients correctly identified each criterion as being a risk factor for BC. The most well-recognized risk factor was personal history of BC, which 39% of participants agreed or strongly agreed was a risk factor for BC; recognition of other risk factors ranged from 29% for alcohol use to as low as 4% for late or no childbearing.

Discussion

We found dismally low rates of BC awareness among Afghan refugee women with regard to every aspect assessed. Of 11 different warning signs of BC, only 18% of participants, at best, and 7%, at worst, identified the finding as a warning sign of BC. The overwhelmingly most common response to each warning sign was "Do not know," suggesting that a lack of knowledge, rather

than inaccurate beliefs, is the most important contributor to low BC warning sign awareness in this population.

The present study is the first to employ a validated questionnaire and to offer quantitative assessment of cancer awareness among Afghan refugee women. Two small prior studies performed in 2013 and 2020 presented qualitative interviews with Afghan refugee women in California, USA and identified similar themes to the present study, including low rates of BC awareness and a lack of accessible health education information for Afghan refugees.[30,31] However, these studies were small (53 and 19 participants, respectively), did not use a validated method for assessing cancer awareness, and did

	n (%)
Breast self-exam	
Rarely or never	344 (82)
At least once every 6 months	60 (14)
At least once a month	11 (3)
At least once a week	5 (1)
Confidence in noticing a change in the breasts	
Not at all confident	12 (3)
Not very confident	111 (27)
Fairly confident	220 (52)
Very confident	77 (18)
History of doctor visit about a change noticed in the breasts	
Yes	0
No	0
Never noticed a change in one of my breasts	420 (100)
Who is most likely to develop breast cancer?	
A 30-year-old woman	124 (30)
A 50-year-old woman	79 (19)
A 70-year-old woman	62 (15)
A woman of any age	155 (37)

Table 3: **Participant confidence, skills and behavior regarding BC. This table displays participant responses regarding breast self-exam behaviors, ability to notice a change in the breasts, and physician visits for breast-related issues.**

	Strongly disagree (%)	Disagree (%)	Not sure (%)	Agree (%)	Strongly agree (%)
Having a history of breast cancer	5 (1)	32 (8)	218 (52)	126 (30)	39 (9)
Using hormone replacement therapy	10 (2)	41 (10)	315 (75)	46 (11)	8 (2)
Drinking more than 1 unit of alcohol a day	12 (3)	30 (7)	256 (61)	102 (24)	20 (5)
Being overweight (BMI over 25)	39 (9)	40 (10)	287 (68)	42 (10)	12 (3)
Having a close relative with breast cancer	5 (1)	59 (14)	324 (77)	22 (5)	10 (2)
Having children later in life or not at all	43 (10)	69 (16)	291 (69)	12 (3)	5 (1)
Starting your periods at an early age	20 (5)	58 (14)	306 (73)	24 (6)	12 (3)
Having a late menopause	14 (3)	22 (5)	326 (78)	42 (10)	16 (4)
Doing less than 30 mins of moderate physical activity 5 times a week	9 (2)	32 (8)	338 (80)	29 (7)	12 (3)

Table 4: Participant awareness of BC risk factors. This table displays participant awareness of various risk factors for BC.

not present quantitative results. Our study, with over 400 participants, is by far the largest study to date of Afghan refugee cancer awareness, and it is further strengthened by use of a validated cancer awareness questionnaire. Furthermore, the prior studies were likely not representative of the average Afghan woman with regard to breast health and BC screening: 66% of women in the 2013 study and 63% of the women in the 2020 study had at least one lifetime mammogram, compared to our findings of 0% of participants ever having seen a physician for a breast-related issue, a rate that is more representative of the absence of any formal breast cancer screening program in Afghanistan.[22] Low BC risk factor awareness in this population is particularly alarming given the strong association of BCAM-assessed risk factors with BC, including increasing age, age at menarche, and family history of cancer, validated by recent robust studies in Afghan women.[32] Furthermore, studies of BC in Afghan women suggest that the mean age of diagnosis is younger than the global average, emphasizing the importance of instituting cancer awareness programs for a wide demographic of Afghan women.[23] The mean participant age in our study was 35 years, nearing the Turkish recommended breast cancer screening start age of 40 years, further emphasizing the need for rapid institution of BC awareness initiatives in this population.

The present study demonstrates that Afghan refugees have critically low cancer awareness, similar to reports of other refugee ethnicities in prior studies. A study of cancer awareness among Syrian refugees living in Lebanon compared to Lebanese citizens revealed lower awareness of breast and cervical cancer screening programs in the refugee group compared to the citizen group.[13] A study of BC screening knowledge and use of screening mammography among Syrian refugee women in Saskatchewan, Canada found that this population had only a modest fund of BC knowledge, and that lower knowledge was strongly associated with lower likelihood of any lifetime use of mammography.[15] Furthermore, a meta-analysis of 20 studies of Muslim-majority refugee populations' cancer awareness and attitudes found that refugee patients had lower knowledge

and awareness of cancer even when compared to non-refugee immigrants and ethnic minorities, groups already known to have lower cancer literacy.[16] Of particular relevance to the present investigation, a study of breast and cervical cancer awareness among 60 Syrian refugee women living in Turkey found low understanding of the definitions, screening, and diagnosis of these malignancies.[14]

Low cancer awareness among Afghan refugees as identified in the present study requires urgent intervention, given that low awareness is a major contributor to low screening rates and high incidence of advanced-stage cancer diagnosed in refugee groups, as demonstrated in prior studies in refugee populations. One of the largest studies of cancer screening among refugees examined rates of cervical, breast, and colon cancer screening in a diverse refugee population in Texas, USA and found dismal lifetime screening rates: 33% for cervical cancer, 27% for breast cancer, and 0% for colon cancer.[11] Critically low screening rates have also been noted among diverse immigrant and refugee populations in Canada[8,15,33] and the Northeastern United States.[12,34] Low awareness leads to low screening and in turn to advanced stage disease: a study of immigrant and refugee women compared to Canadian-born women with BC in Ontario, Canada revealed that immigrant and refugee women were statistically significantly less likely to be diagnosed with stage I disease.[10] Similarly, a study of Syrian refugees with cancer living in Turkey revealed that 77% of patients had stage III or IV disease.[7] The same phenomenon was observed in pediatric oncology refugee patients in Turkey, most of whom presented with advanced disease.[35] Among Iraqi refugee and Lebanese citizen patients with BC in Lebanon, the percentage of refugee patients who presented with metastatic disease was nearly double that of Lebanese citizens, and only 4% of refugees' cancers were screen-detected, compared to nearly one-third of Lebanese citizens.[9]

The present study confirms that, similarly to other refugee groups, Afghan refugees have low cancer awareness, which likely contributes to lower screening rates

and increased risk of advanced disease in these patients. This topic is not only of intellectual interest; identification of at-risk populations is of practical importance to allow the implementation of interventions that significantly improve awareness and result in long-lasting improvements in screening rates. The aforementioned study of Syrian refugee women in Turkey implemented a practical and affordable cancer education intervention consisting of an educational video, an oral presentation, and a question-and-answer session, all in the participants' native language of Arabic.[14] This one-time intervention increased participants' scores on a post-education knowledge assessment more than five-fold at eight weeks after the intervention, compared to no increase in score among participants who did not undergo the intervention. A study of cervical and breast cancer screening among refugee women in Toronto, Canada found that screening rates improved after women participated in a cancer education program.[8] Similarly, a breast cancer screening study of refugee women in Massachusetts, USA found that after implementation of a culturally-tailored patient navigation program, screening mammography rates remained persistently high and approximated rates in non-refugee patients even five years after the conclusion of the program.[12] Peer health education-based programs to increase cancer awareness have also had excellent results among immigrant populations, and offer both affordability and language accessibility.[36]

The issue of cancer screening for refugees is especially relevant given the financial implications of supporting refugee populations. With regard to Turkey, in 2020, the United Nations High Commissioner for Refugees (UNHCR)'s budget for refugees and asylum-seekers in Turkey was 365 million United States dollars (USD); however, the sum of all available funds was only 131 million USD, a gap of 234 million USD.[2] This deficit is a longstanding phenomenon: according to official Turkish governmental data, the total spending on Syrian refugees in Turkey from 2011 to 2014 was 4.5 billion USD, but aid from the UN and European countries amounted to only 246 million USD.[37] By investing in cancer education and screening programs for refugees, host countries and international organizations will lessen the economic burden on the host country of cancer care for patients with advanced and metastatic disease.

The low use of BSE and CBE among Afghan refugees identified in this study is another area in critical need of improvement. In developed countries such as the USA, guidelines from several national organizations recommend against BSE given the lack of impact on BC mortality and the widespread availability of a better screening intervention (mammography). In contrast, the Breast Health Global Initiative strongly recommends BSE and CBE as a screening modality in countries such as Afghanistan that have only limited health resources.[18] An essential principle of global health is

"Doing the best we can with the resources that we have."[17,18] Therefore, a financially and logistically feasible target for intervention to improve cancer screening is increasing the rate of BSE and CBE among Afghan refugee women. In fact, in lower- and middle-resource countries, annual CBE for patients aged 40 to 60 is close in effectiveness to biennial screening mammography in terms of BC mortality reduction, but significantly lower in cost.[19] BSE and CBE require only basic skills on the part of the patient and do not demand significant resources from healthcare workers and systems, and can be implemented quickly in the interim while more time- and resource-intense interventions, such as patient education programs and mammography programs, are developed.

The present study is an important reminder of the systemic barriers faced by Afghan women, particularly refugee women. Only 10% of participants had a primary school education, and six percent had a secondary school education. These rates are poor even in comparison to prior estimates of schooling completion in Afghanistan: in 2015, completion rates among women were 40% for primary school and 14% for upper secondary school.[38] These findings raise concern that the population of Afghan refugee women are comparatively even more disadvantaged than the average Afghan woman citizen, and reinforce the importance of interventions targeted specifically for their levels of literacy, education, and background knowledge, which are likely lower than comparable populations from previous studies. Furthermore, previous studies of Muslim women have identified cultural barriers related to healthcare for private body parts.[39] These cultural factors likely contribute to the systemic barriers preventing adequate BC screening in Afghan women.

BCAM is a focused clinical tool. As a result, only limited demographic, socioeconomic, and health information was collected for each participant. Knowledge of additional characteristics, such as family history of BC among participants, would be useful for understanding how these factors contribute to BC awareness. The median age of participants was relatively young (35 years), concordant with the fact that refugees and asylum-seekers who are able to leave their home countries are frequently younger in age.[2] Our results therefore may not be generalizable to older refugee women. Our study was also restricted to women living in a metropolitan area, and therefore may not be generalizable to the entire Afghan refugee population, some of whom live in more rural areas. Given that the present study population consists of women who actively sought medical care, the general population of Afghan refugees in Turkey may have even lower cancer awareness than this relatively motivated, care-seeking population. The length of residence in Turkey for each participant is unknown, and is an important variable that may influence cancer awareness.

Among Afghan refugee women in Turkey, BC awareness is critically low in all domains assessed: warning signs, risk factors, and BSE/CBE. This low level of awareness occurs in the setting of a highly vulnerable population with low education and literacy levels. Native-language interventions to increase BC awareness in this population should be implemented expediently with the ultimate goal of increasing screening, early diagnosis, and treatment rates.

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