

Access to breast cancer screening — perception, and perceived barriers among older Bhutanese refugee women resettled in Australia: a qualitative study

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Abstract

Background The use of breast cancer screening mammogram is proven to be beneficial for the early detection and prevention of breast cancer. Despite the free availability of this service in Australia, it has not been fully used by many migrants and refugee women.

Objective To explore the perception and perceived barriers of Bhutanese refugee women to the access and use of breast-screening service.

Methods We used qualitative methods with an in-depth interview and Interpretative Phenomenological Analysis (IPA).

Results Our findings suggest that there is a low level of screening services use among Bhutanese refugee women. From the interpretative phenomenological analysis of the interview data, four main themes were apparent as barriers to accessing breast cancer screening: lack of knowledge about the importance of the screening; lack of motivational factors; problem-triggered health seeking behaviour due to strong cultural factors; and communication difficulties due to poor literacy and limited English language proficiency — all have contributed to low-level use of breast-screening mammograms.

Conclusion Older Bhutanese refugee women resettled in Australia did not seek preventive screening without symptoms or their doctor's advice. Women in this study followed their doctor's lead. Recommendations for screening and follow-up from their doctor were followed, and lack of advice from them was interpreted by the women that no action was required.

Introduction

Breast-screening is considered one of the most effective methods of improving survival of breast cancer. A national breast-screening program has existed in Australia for more than two decades¹. In Australia, biennial breast-screening is recommended, free of charge, for women aged 40 or more, while women aged 50–74 years are sent invitations from BreastScreen Australia². The aim of the screening program is to improve health outcomes in an asymptomatic population by detecting conditions associated with elevated cancer risk and early-stage cancers, where treatment will be effective¹. Over the 20 years since the full implementation of the breast-screening

program in Australia, it has been estimated that this program reduced breast cancer mortality by 21 to 28 per cent³. However, the service access and utilisation rate in Australia among migrant and refugee women is significantly lower compared to rates in the host population^{3,4}.

Breast cancer is the most common cancer diagnosed in women and accounts for approximately 28% of all cancers in Australian women⁵. Though early detection and appropriate treatment can effectively improve breast cancer survival, marked disparities have been documented in the uptake of breast-screening among ethnic minority populations⁶.

Australia has resettled more than 6000 Bhutanese refugees under the United Nations' humanitarian program as part of a coordinated international strategy⁷. We could find no studies that have explored breast cancer and the Bhutanese refugee population in Australia, but studies in the United States (US) have highlighted the low rate of participation in cervical and/or breast-screening programs among this group⁸⁻¹⁰.

Several reasons have been suggested as contributing to low screening rates among refugee women, including poor comprehension of the concept of screening when such services are not available in the home country or country of asylum^{6,11}. The aim of this paper was to explore Bhutanese women's perceptions and perceived barriers to accessing breast-screening programs in Australia.

Theoretical framework

This study was underpinned by an intersectionality theoretical framework where intersectionality as a theoretical framework creates a space for the exploration of how multiple social identities of women intersect to influence their own health behaviour¹². Intersectionality allows exploration of multiple social identities among women through a multi-axial approach by taking account of their different roles¹². The application of intersectionality in this study explored the interconnected factors affecting Bhutanese refugee women that can influence their health-seeking behaviour after resettlement. The types of factors that intersect include their race, their education level, their caste, traditional beliefs and practices, and socio-economic and refugee status. The interplay of these intersections is significant when exploring their health-seeking behaviours.

Methods

Data collection

Face-to-face, in-depth interviews were conducted in the Nepali language by the primary author (JP) between April 2016 and December 2016 in a separate room of the homes of study participants, with only the interviewer and interviewee present. The interviewer, who is a Nepalese Australian, worked as a refugee health nurse and previously worked in refugee camps in Nepal.

An interview guide, which had been developed, based on the literature, had minor modifications after the first three interviews to incorporate additional information recorded in the field notes. The interviews covered a broad range of questions relating to experiences of accessing cervical and breast-screening services. Photo elicitation was used to facilitate data gathering when women were unfamiliar with screening, with photographs of screening activities used to prompt understanding¹³. Data collection continued until data saturation was reached. There were no repeat interviews. Interviews took 30–60 minutes and were recorded, transcribed and translated into English. A sample of the interviews (10%) were independently translated

by a second Nepalese-Australian PhD student enrolled at another institution. No discrepancies between translations were identified.

This paper is confined to a sub-sample of a larger study of 30 Bhutanese refugee women and to questions about breast-screening.

Study participants

Participants were purposively selected through information provided by Bhutanese community leaders. No one approached refused to take part. This sub-sample included 14 women aged 50–70 years. All had lived in Melbourne for at least four years (range 4–7 years), were born in Bhutan and lived in refugee camps in Nepal for at least 18 years (range 18–23 years). Most had never gone to school and were illiterate in their own language. All participants were married and had at least two children. Participants provided their own pseudonym, which confirmed their understanding that others would read their responses. Two women chose the same pseudonym, so superscript numbers were used to distinguish these.

Analysis

Transcripts were read and reread. Interpretative Phenomenological Analysis (IPA) was undertaken with the assistance of NVivo 11¹⁴ for coding and data management. The six-step IPA process includes: looking for themes; looking for connections; producing a table of themes; continuing analysis with next case; creating a master list of themes; and writing up findings¹⁵. In the two-part interpretation process participants were asked to clarify or explain and the researcher interpreted how participants made meaning of their experience¹⁶. The primary researcher undertook the analysis as part of her PhD studies, with the co-authors coding subsets of the data for checking.

Ethics

Before each interview, participants were given a study information sheet in Nepalese, describing the study with information about confidentiality. This was explained in detail. Ethics approval was obtained from the University Human Ethics Committee (UHEC), at La Trobe University, Melbourne, Australia.

Results

Four main themes contributed reasons for low utilisation of routine breast cancer-screening mammograms among Bhutanese refugee women in Australia: lack of knowledge about the importance of screening; lack of encouragement; communication difficulties; and problem-triggered health-seeking behaviour. Those who had attended the services also talked about their experiences with breast-screening mammogram, which further clarified their perceived barriers to accessing services.

Lack of knowledge about importance of screening

Most participants knew little about breast-screening, and

despite being in Australia for five years, only nine of the 14 women had had a mammogram. All nine had done so following a recommendation by their doctor, but there was still little understanding of the importance of screening, and only one of those who had a mammogram had followed up after two years. The five women who had never had a mammogram had also never heard about breast-screening.

"I do not know anything. You know, nobody tells us. I can't talk, read, it's like being dumb and blind here in this country. Not able to talk is the most hurtful thing in your life. Nothing is known about it." (Madhavi)

Most women knew something about breast cancer, but some were unaware of the disease, including women who had been screened. A few women initially said that they didn't know about breast-screening but when shown photographs of mammogram screening responded "yes, I did this test".

"... It was hard to know what has been done. There was no interpreter." (Madhavi)

Most women had no knowledge that screening tests are done to detect problems and saw no need for investigative tests if no symptoms were present.

"No feeling of pain, no discharge, felt no need to do it. Nobody told me about the importance of doing it. I didn't know this is for cancer prevention." (Rathi)

Lack of encouragement

A common view among the women in the study was that as their doctor had not raised breast-screening it must not be important or relevant to them.

"When we go to the doctor, a doctor does not talk to us other than the problem. No one told us about this service and asked us to do it." (Sanu)

The failure to hear about screening services from someone who the women saw as significant, like their doctor or informed family members or friends, meant that women did not see the importance of screening services, and so did not feel encouraged to use them.

"Firstly, I don't know about the service and no one is informing and encouraging us to do it." (Amma²)

"If women are informed by their doctor they would do it." (Leela)

Most women who had accessed services had used them only once. Only one woman had followed up after two years and done so on the advice of her doctor. When others were asked why they had not followed up, the women said they had not been told about the importance of regular follow-up.

"I used it only one time. Nobody told us to do it again within two years and I didn't know." (Saraswata)

Communication difficulties

Limited English and poor literacy were the major causes of communication problems. Thirteen of the 14 women interviewed had never attended school and did not know how to read or write, making face-to-face communication critical.

"If I was not told by my doctor I would not know to do it." (Devi)

Women expressed frustrations with illiteracy strongly in the interviews. It is really frustrating for women when someone gives them a document to read when they do not know how to read.

"One thing is I feel very bad for is not knowing [how] to read and write. It seems like I have a black tape on my eyes. My parents are already dead, but I am now feeling how important it would be if they have given us some education at least to read and write. I feel like I want to read my own documents." (Saraswata)

Lack of English was also a barrier to participation in screening because the women couldn't clarify any concerns. Several that had mammograms had agreed to the procedure knowing nothing about it.

"Here we don't speak the language. This is the main thing; that we are reluctant to ask any question if a doctor is not using an interpreter. We do whatever [the] doctor asks us to do. Then if the doctor doesn't tell about it, who would know." (Sanu)

A common experience for these women was to have their children act as their interpreters, but the women did not like sharing sensitive health information when their children were present.

"Most of the women of my age go to the doctor with their children who can speak English. If I am going with my son, I do not like to talk about it [sensitive health issues] with him being an interpreter. This is the main problem as well. There is the barrier, no one talks about their personal problems with their kids there. No matter how old they are." (Sanu)

Women disliked having a mammogram with no explanation, as Aama¹ described:

"Well, there was a woman doing this, it was very new, strange, painful and I did not know why I was doing it. Nobody told me why I am doing it. I didn't feel discomfort but when breast was put in the machine I had [a] little pain. There was no interpreter. My son was with me, but he stayed outside, I could not understand what she said, I didn't know why I am doing it. But I was there because I am female, I was told not to worry about it." (Amma)

Problem-triggered health-seeking

Women in this group were motivated to seek health services only when symptoms were apparent. Problem-triggered health-seeking behaviour was a significant barrier to the use of preventative screening services.

"I have not used the service, because there is no pain, no problem." (Rathi)

"I told the doctor that I have a lot of pain, burning sensation over my both breasts, I could not move my arms, the doctor asked me to go to do the x-ray." (Ganga)

"As I was feeling a bit different in my breast, then I went to the GP and GP did some examination and sent me to do an x-ray." (Pabi)

Aama² found lumps in her breast which led to a breast-screening mammogram.

"I started having check-ups after I had a problem. Many lumps appeared in my both breasts. But I was not scared of the problem, because I knew that it was due to the sour drink that I had in English language school." (Aama²)

Strong cultural issues were also attached to various health beliefs, for example, feelings of embarrassment about exposing certain body parts.

"... but initially I had not done this due to extreme shyness but later I did and they did find some abnormal mass in my breast, It means it's worth doing it." (Maya)

Saraswata's experience of a mammogram was typical:

"I felt a bit uneasy, ashamed while exposing my breast, as I never showed this to anyone in the past, I closed my eyes and a woman assisted me to do that. I felt inside me this is only for good thing and that does not last for long. I closed my eyes until it finished. I am really shy." (Saraswata)

Discussion

We explored the perceptions and perceived barriers towards breast-screening among older Bhutanese refugee women. The problem-triggered health-seeking due to their particular cultural values and beliefs was a significant barrier to accessing preventive care services in this study. Like other studies, communication difficulties and lack of knowledge about the importance of services were also prominent barriers to breast-screening^{11,7,18}. Besides these factors, the study also identified poor health professional practices, specifically with the use of interpreters and in failure to communicate the importance of screening, as likely contributors to poor uptake of screening services.

The phenomena of problem-triggered health-seeking was a major theme throughout this study. Women sought health care only when symptoms were present. This behaviour was reinforced by the common belief that 'if it was an important health issue, our doctor should have told us'. Women did not know to ask about preventive screening, and their doctor and other health professionals failed to tell them. Preventative health care was an unknown concept to the women and their education about it was ignored by the health professionals caring for them. Other studies have observed that refugees are

more likely to attend health care services when they are sick and symptoms are present⁸ and that preventative health care is an unfamiliar concept^{19,20}. Lack of education plays a part in this, but so too does extended periods in refugee camps where managing acute illnesses is the priority.

As in other studies^{21,22}, cultural beliefs and stigma were prominent barriers to accessing women's health services in this study. Such findings reinforce the need for healthcare professionals to recognise the importance of cultural norms for women from ethnic groups; for Bhutanese women, for example, shyness and embarrassment about exposing private body parts was clearly evident, and rated highly as barriers to attending screening mammograms, especially while no motivational factors emanate from an authoritative person, such as their doctor.

Our findings about poor knowledge about the importance of screening as a barrier to uptake of services, are consistent with other studies²³, and that knowledge of the link between breast cancer and screening can motivate women to undergo breast-screening⁵. Promoting cancer screening in this population of older refugee women, was obstructed by other factors, including illiteracy and the reliance on family members as interpreters. Women in this group regularly attended medical clinics, but had not been informed about, or offered any discussion of the free breast-screening program available to them. Health professionals need further encouragement to ensure the same level of services are provided to this vulnerable group. This could include training in the use of interpreters and how to provide health information to groups with special literacy needs²⁴. Thirteen of the 14 women in this study were illiterate in their own language.

An important finding from this study was that women did not think that they needed breast-screening as their doctor had not advised them to do so. Women attended breast-screening services, and followed up, when their doctor referred them. However, referrals were made without explanation, which meant that women did not attend screening regularly. These findings are similar to another Australian study involving young refugees accessing mental health services²², and raises questions about the level of cultural sensitivity among Australian health professionals.

Though most of the doctors' practices have various types of leaflets and other information sources available to serve the purpose of informing women, the information of breast-screen is either not given in appropriate ways, or not interpreted to the women in this study. Apparently, many of them did not know and didn't attend the breast screening program. Only one woman out of 14 in the study group was educated and literate, the rest have never gone to school and did not know how to read and write. This evidence indicates that the only way to provide information to these women would be a direct 'verbal communication' to them. One of the best strategies would be

opportunistic education from a doctor, which would be very effective, as the doctor is perceived to be the most authoritative person to provide health information. One-to-one education from a doctor or other health professionals could be the most effective way to optimise screening mammograms uptake for Bhutanese refugee women. Other studies have found that poor health literacy and poor understanding of health care systems can be a prime obstacle for health-seeking generally among refugees after resettlement^{18,25}.

Limitations

The major limitation of this qualitative study was that it involved a specific Bhutanese refugee group of older women. Several of the perceptions and barriers identified to access to breast screen services were attached to the Bhutanese cultural context and beliefs. Although similar themes may be evident in other groups, findings of this study may not be generalisable to other refugee cohorts. The study took place in Australia, which has a universal health system and free interpreter services for refugees, conditions that do not necessarily apply in other high-income countries. Thirteen out of 14 women in this study were illiterate in their own language, had language barriers hence, our study findings may not be representative of those who are literate and with no language issues.

Conclusion

Our study explored perceptions and perceived barriers to breast-screening among older Bhutanese refugee women after resettlement in Australia. The study provides a valuable insight to problem-triggered health-seeking behaviour that was collectively running in this group. Women in this study did not know to ask about screening services and their doctor and other health professionals failed to inform them. The issue of problem-triggered health seeking needs to be countered with effective education strategies that involve health professionals, particularly doctors. Women in this study followed their doctor's lead. Recommendations for screening and follow-up from their doctor were followed, and lack of advice from them was interpreted by the women that no action was required.

Conflict of interest

The authors have no conflicts of interest to declare.

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