Barriers to accessing cervical and breast cancer screening: A qualitative study of Bhutanese Refugee women in Australia

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Background: Bhutanese refugees

- Fled Bhutan in early 1990 after changes to government policy that created conflict
- Lived in refugee camps in Eastern Nepal for nearly two decades
- Repatriations and permanent host country resettlement was not possible
- Third country resettlement started in 2007 under UNHCR global humanitarian program
- More than 110,000 Bhutanese now resettled in 8 developed countries including ~6,000 in Australia
- Over 1,500 Bhutanese refugees now live in Victoria
Bhutanese Refugees women’s status
Vulnerable population and sensitive topic

Compounded chain of vulnerability

Chain of vulnerability among Bhutanese refugee women

- Generation of cultural domination
- Difficult life experience in refugee camps
- Challenges of resettlement
Aim of the study

To explore perceptions, experiences and perceived barriers in accessing cervical and breast cancer screening services among Bhutanese refugee women after resettlement.

The study also aimed to identify appropriate models of care to enhance the access and utilisation of these cancer screening services.
Research Questions

What are the perceptions and experience of Bhutanese refugee women in accessing and using cervical and breast cancer screening services in Melbourne?

What are the perceived barriers in accessing cervical and breast cancer screening services?

What is the women’s preferred model of care to enhance the accessibility and use of cervical and breast cancer screening services?
Background - Literature review


**Key findings:** The review included 12 qualitative studies published between 2006 and 2017 involving more than 500 participants. Using a meta-synthesis approach, we compared and combined findings. Most studies identified gaps in knowledge and skills. Specifically, lack of cultural knowledge, poor cultural competency, and poor communication skills were raised. Health service barriers were also identified and these largely focussed on time constraints. Continuity of care, assisting with wider needs, taking an interest, compassion/empathy, and explaining roles and responsibilities were seen as facilitators for health service utilisation.

Barriers related to refugee: language and cultural barriers; health beliefs, low health literacy, refugee experiences, financial constraints, employment, and types of physical health issues. Barriers related to health services: lack of cultural competency, lack of knowledge about refugee health issues, difficulties working with interpreters, and time constraints. Barriers related to the context of resettlement: health systems and flexibility, location of services, transport, different layers of service provision, continuity of care, assisting with wider needs, taking an interest, compassion/empathy, and explaining roles and responsibilities were seen as facilitators for health service utilisation.
Theoretical framework: Intersectionality

- Looks at issues with multi-axial approach
- Intersectionality **enables exploration** of various aspects of social identity such as gender, race, ethnic, social class, education, geographical location, language and citizenship status and how these interconnect to influence health behaviours and outcomes of refugee women.
- Intersectionality **recognises that women have multiple identities** that are not limited to race and gender and that these multiple identities may influence individual behaviours, beliefs, decision making and subsequent outcomes in the lives of individuals.
- My study recognised the multiple identities of Bhutanese refugee women and how these could, either individually or by their inter-connection, affect access to cervical and breast cancer screening services.
Research Methodology

Qualitative research methods

Phenomenology
* Focuses on “lived experience”

Uncovers hidden aspects of lives that would not surface during the everyday conversation
Promotes rigorous process to access difficult phenomena that
Influences how:
* Recruitment occurs
* Data are collected
* Data are validated

Feminist research
* Values women’s stories, opinions and experiences respectfully

* Recognizes women’s own perspectives on bringing about desired changes through their combined effort and actions

* Considers women's perspectives

* Allows women to have power to advocate for their own needs.
Data collection and analysis

In-depth interviews
This method also called qualitative interviewing. I interviewed 30 Bhutanese refugee women.

Photo elicitation
Uses photographs to start data gathering conversation by asking about what participants see or think of a specific photograph.
Photo elicitation used for those women who said that they had never heard about screening or didn't have any idea of a screening test.

6 step IPA process for data analysis
Research findings

Publications


Evidences - data

- 13 of 30 women in the study had never heard of cervical and breast screening
- 15 women had undergone the test at least once but only 2 had followed up
- Average time of using first time cervical and breast screening service was 5 years after arrival
- 21 out of 30 women were illiterate in their own language
- All women accessed GPs for other health conditions, but screening was not offered or discussed or asked about
Barriers to cervical and breast cancer screening

Barriers to Cervical Cancer Screening among refugee women in Australia

- Changing awareness
- Sacred body
- Stigma
- Refugee experience
- Low or no concept of preventative health services
- Symptoms based health-seeking
- 'no symptoms-no check up
- Cultural motivation
- Faith in doctors
- Poor knowledge
- Low health literacy
- Lack of information

Health professional behaviours

- Screening not offered
- Opportunistic screening without education
- Interpreter not used
- Use of family members as interpreters
Women said ... 

many times I went to the doctor and doctor didn’t tell me about it. I think, if the doctor didn't tell us to do it, it means it's not very important to do for us. GP never told me to do this test. (Madhavi 55-60 years)

I have not done it because I was very shy and also I do not have any problem related to this, no pain, no burning, no discharge. I believe I do not have this problem and I won’t have this problem. When I get a doubt about it I will do it. (Phulmaya 55-60 years)

Nobody told me where or why we need to do this; I have been to the doctor many times. (Leela 50-54 years)

But the doctor does not use an interpreter at all. It is a problem for a mother to talk about any women's health problem when her son is acting as the interpreter. (Sita 30-34 years)

I do not understand about it much. The doctor who did it, didn’t tell me anything about it. Doing without knowing is painful. (Chandrawati 40-44 years)

If the doctor asks me, I will do it. (Thulidid 45-49 years)
Resettlement Drivers

Concern for children’s future

• Almost every woman spoke about their children’s future. Opportunities for them was the main reason for their resettlement decision.

Our children may feel more Australian here because they are young and have more time to learn a language, educate themselves and they can give more to this country later. We have to be happy in their happiness.

(Devi, 50-52 years)
Resettlement challenges

Dependency in children

Women expressed concern about how dependencies had changed. They had lost authority without language proficiency and with communication difficulties.

Our voice is not heard, I feel very dependent here, for every small thing, I need to ask for chhora-chhori [children] to communicate. They have their own life routine; they are not available all the time. At times I don’t feel secure as well because my husband is sick. When it is just him and me at home, I always feel scared that if there is an emergency I can’t speak. I feel stuck without having children around. ... I can’t express what I feel, I can’t tell my problems, I need to expose all my privacy to my children or an interpreter. This is a sad thing for me and may be so for others. Without children, it’s hard to live here. I feel I am a child, not a mother (Maya 50-54 years)
Resettlement challenges

Strange neighbourhood, no connection to next door neighbour

Sita, who is educated and fluent in English, explicitly differentiated the cultural context in which she found herself and its impact on her sense of belonging.

We do not have that environment where we stay in the courtyard and yell out next door neighbour demanding for a cup of tea, which we could easily do at back home. We need to be always mindful that what next door neighbour think of us, think about our behaviour that hinders us for doing ...... (Sita 30-34 years)
Research question 3

What is the women’s preferred model of care to enhance the accessibility and use of cervical and breast cancer screening services?

What do refugee women want in health screening programs to encourage them to use these services?

Why this question?
- Most studies in the past have focused on barriers to access
- Little research attention given to identifying women’s ideas or preferences for cancer screening programs
- Incorporating consumers’ views into the design of any health program shown to be more effective than services designed only by policy-makers.
**Women’s desired models**

**GP-initiated model**

*GPs as a means for opportunistic screening*

*If the doctor asks me, nothing bothers me, I will do it* (Thulidid 45-49 years)

*GP as an authoritative source*

*I would do anything if GP asked me to do and I also think all women will do it if GP tells them* (Narayani 61-64 years)

*The GP asked me to do it and due to the GP’s suggestion, I made my decision* (Madhavi 55-59 years)

*GPs as potential educators*

*I think the GP is the best and authentic person to tell about this. We all are dependent on the GP for our health* (Devi 51-55 years)

**Group screening model**

*Group screening supported by community education and peers’ networks*

*The first experience, in the room there was an English sister [nurse] and Nepali didi [sister-interpreter]. The settlement worker took us to the clinic. so it felt secure and easy.*

*There was the [nurse] and our own didibahini [sisters], there was no male present, and I could speak my language.* (Kumari 40-44 years)

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**Community Education**

- More education from people who know the community – there was high value given to the person like me to organise education program

**Peer Education**

- One to one teaching or peer education - seems to be very effective to talk about these sensitive issues

**Supportive Environment**

- Supportive environment – more prompting, reminding and reinforcing from relevant authority, families and friends.
Important questions from the research

• As health professionals, do we provide needs-based care to people with special needs, such as refugees?

• Do GPs understand the expectations of Bhutanese refugee women and their influence on them?

• How can we incorporate women’s ideas and preferences into our practice?

• How can GPs address refugee women’s needs? Are they ready to do so?

• What would a group-screening model look like? How would it fit into current processes, including follow-up? How feasible is a group screening model in Australia?

• How can we improve access and health literacy in illiterate populations?
Conclusion

The study highlighted a perceived limited value in preventative screening-Symptoms-based health behaviour or the phenomenon of ‘No symptoms-no check-up’ as a central barrier in accessing preventive services, where health professional fail to provide opportunistic education and services required for them and they need to self-educate on the barriers to health-seeking of this vulnerable groups and their multifaceted nature of identities.

Refugee women's' own suggestions of GP initiated model or groups screening model has been highlighted as the way to go.
Recommendations

Implementation of women’s recommendations

Opportunistic tests and education from GP

One stop specialised services for refugees

Bilingual co-worker

Cultural competency training for health professional

Cultural competency self-evaluation tool

Interpreter use as the criteria for accreditation for GP practice

An active bi- or multicultural neighbourhoods

While lack of cultural competency has been stated as a major issue in this study, further training of health professionals to provide culturally competent care for refugee and asylum seekers is essential. The increasing multicultural diversity in Australia requires embedding cultural competency training into the curriculum of medical and other health professional courses with periodic supplement of cultural competency self-evaluation tool as a reminder to health professionals.

The importance of neighbour relationships was a repeating finding from this study. Currently the formal environments of neighbourhood aren’t perceived as friendly and don’t make for smooth transitions and integration for Bhutanese refugees into Australian society. Establishing an active bi- or multicultural neighbourhoods are likely to enhance social inclusion and foster linguistic ability.

Bilingual co-worker and appointing them into the major health care services would be beneficial to bridge the gap.
Moving forward/desirable change?

How can we (as health professionals) support refugee women experiencing resettlement?

- Identify gaps in our knowledge and/or understanding
- Reflect on own cultural assumptions and expectations
- Take opportunities to educate and explain
- Ask about preferences and values important to women.
Future research

- The relationship between time spent in resettlement country and incurring and continuing barriers of health service access.

- Research on what are the factors that actually hindering GP not using an interpreter while seeing refugee population.

- Research on how health professionals especially GP can support refugee families to encourage and retain in the health care system.

- Action research on how to promote health literacy on illiterate population with language barriers.

- Research that uses innovative methodologies to investigate emotional and cognitive responses to a symptoms-based approach vs a preventative approach.
Thank you