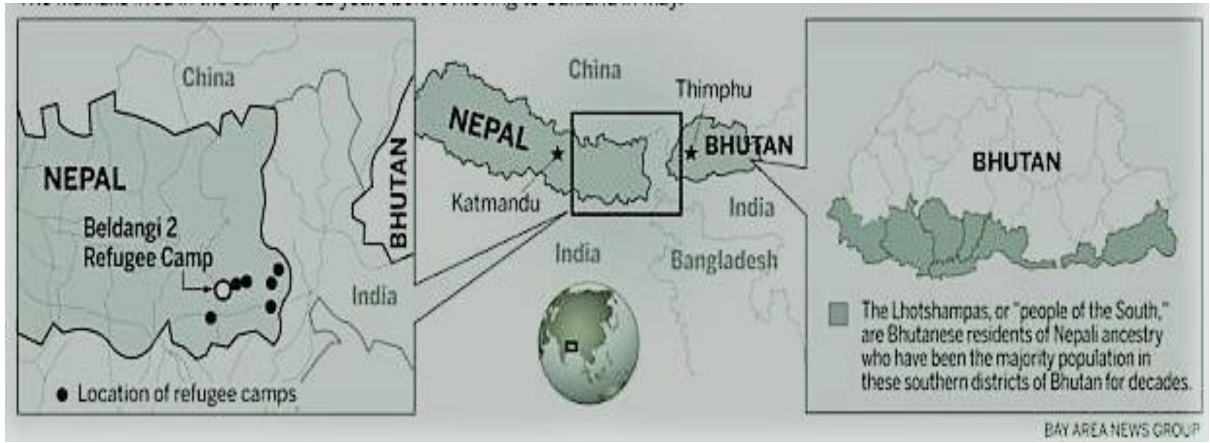
Barriers to accessing cervical and breast cancer screening: A qualitative study of Bhutanese Refugee women in Australia

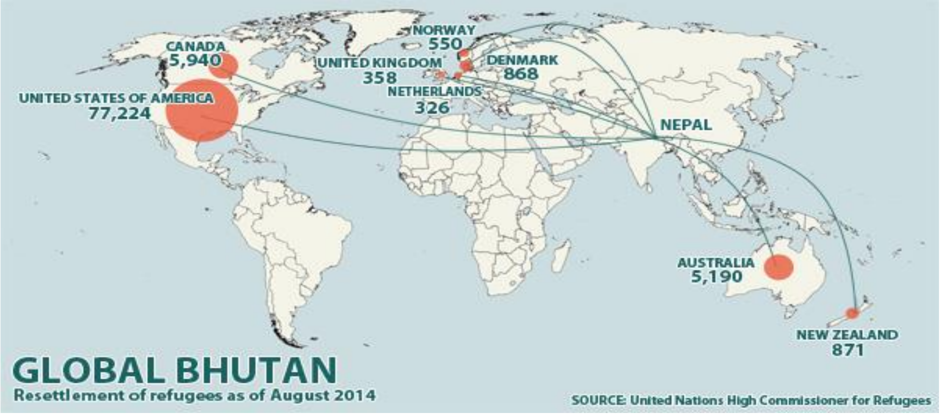
Jamuna Parajuli PhD
RHN

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



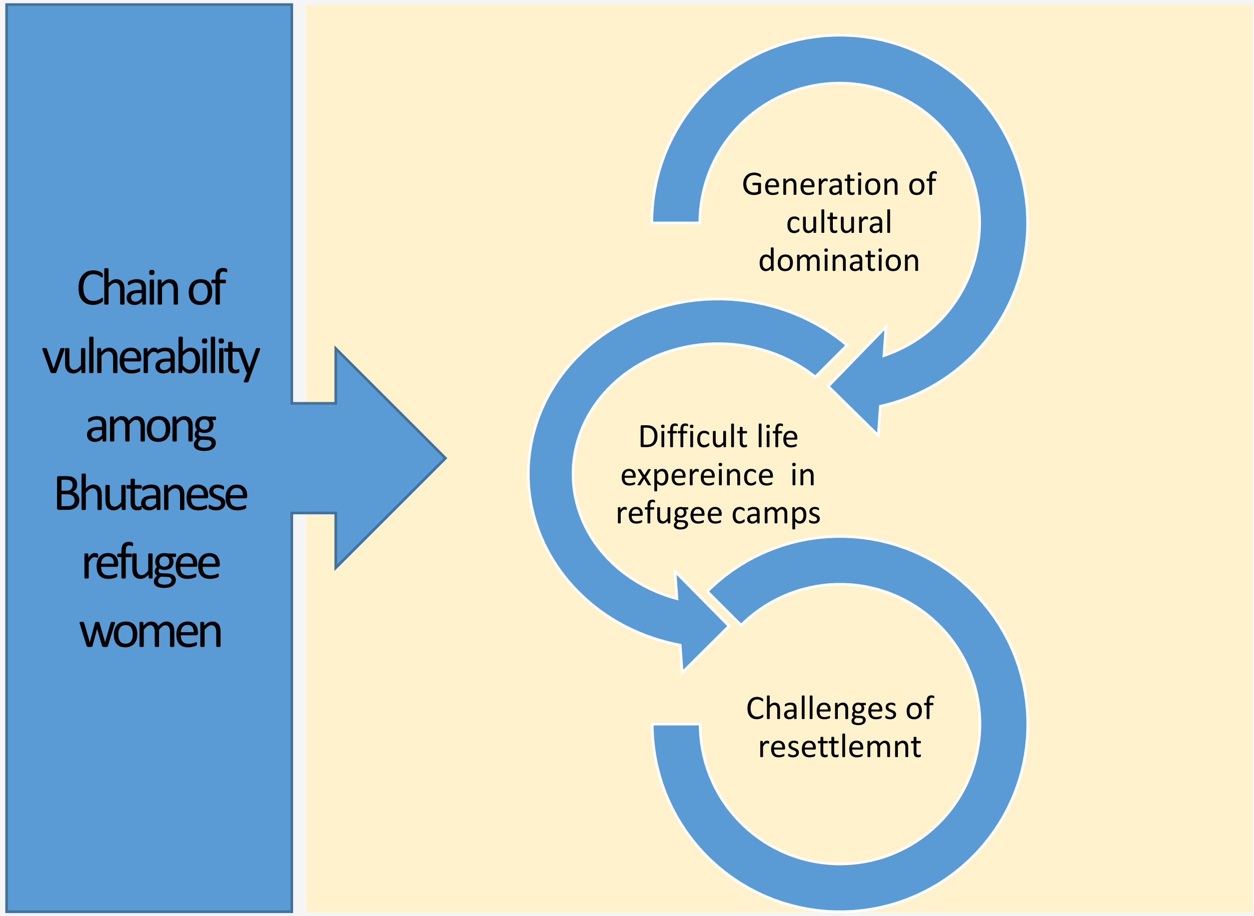
(Human Rights Watch 2005 and UNHCR)



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 expereince in refugee camps

Challenges of resettlemnt

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 accesss 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

✓**Overview:** Parajuli, J., & Horey, D. (2019). Barriers to and facilitators of health services utilisation by refugees in resettlement countries: an overview of systematic reviews. *Australian Health Review*.

✓ **Systematic review:** Parajuli, J., & Horey, D. (2019). How can healthcare professionals address poor health service utilisation among refugees after resettlement in Australia? A narrative systematic review of recent evidence. *Australian Journal of Primary Health*, *25*(3), 205-213.

Key findings : 12 papers were reviewed. The review establishe the
barriers to health service utilisation are falling into three di trums
that are related to refugee, related to health service a lement
context. Barriers related to refugees are language alth
beliefs, low health literacy, refugee experienc
employment, and types of physical healt to health
services are lack of cultural compete bout refugee
health issues, difficulties workin ne constraints. Barriers
related to the context of re tems and flexibility, a
location of services, tr service provision. Continuity of
care, assisting wit nterest, compassion/empathy,
explaining roles seen as facilitators for health service
utilisation.

Barriers related to refugee, barriers related to health services, barriers related to resettlement context

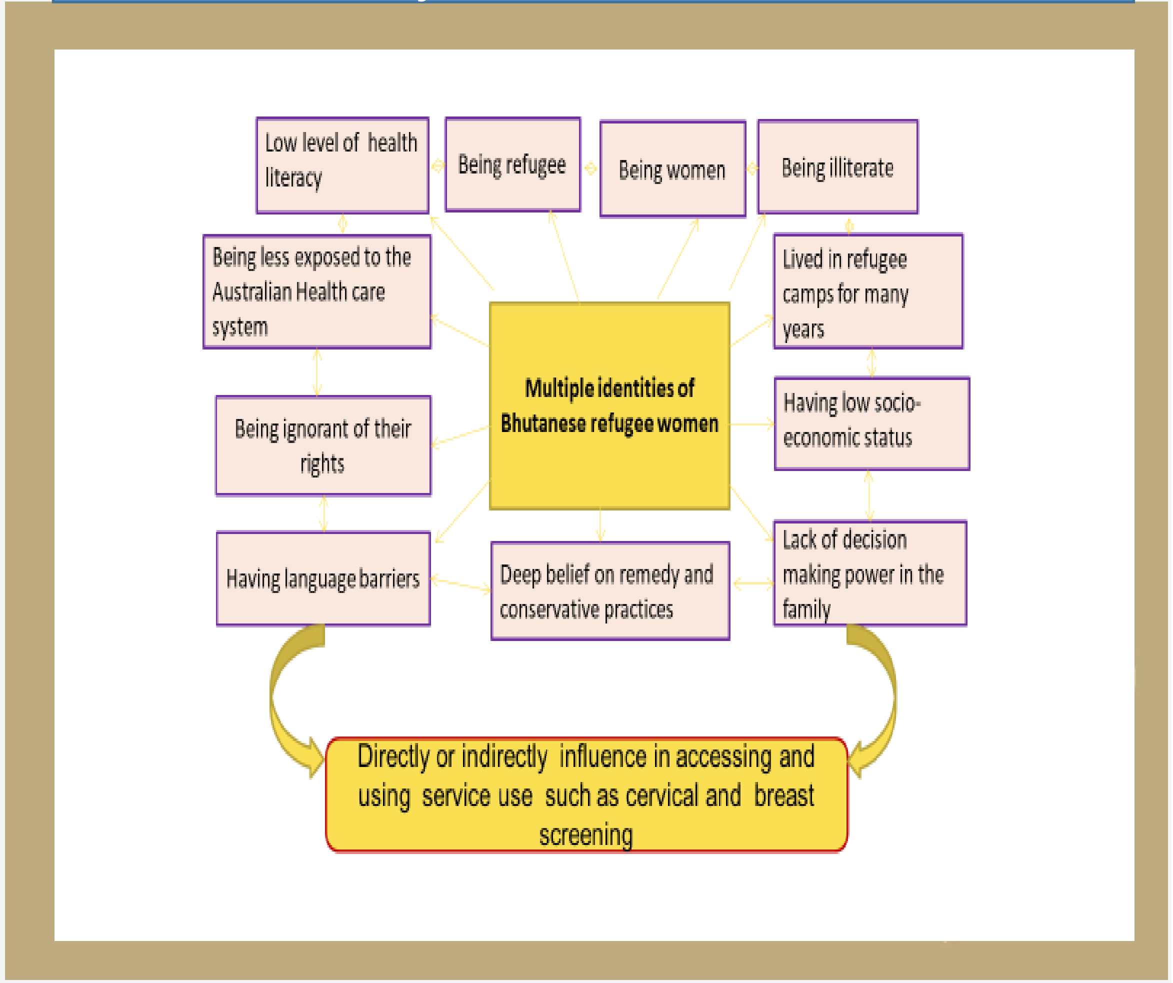
Key findings: The rev w included 12 qualitative studie Australia
published between 2006 and 2017 involving more About
half of all participants were health professional esis
approach, we compared and combined fi studies largely
focussed on barriers relating refugee als, however this
paper reports only those barrier rofessionals. Most
studies identified gaps in k ecifically, lack of cultural
knowledge, poor cultur or communication skills were
raised. Health serv entified and these largely focussed
on time const derstanding between refugees and health
professional k of trust. Simple strategies may be useful in
overcoming lo ues

Health professionals' poor cultural competency and time constraints

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.

Intersections of Bhutanese refugee women's perceived identity and health service access



Low level of health literacy

Being refugee

Being women

Being illiterate

Being less exposed to the Australian Health care system

Lived in refugee camps for many years

Multiple identities of Bhutanese refugee women

Being ignorant of their rights

Having low socio-economic status

Having language barriers

Deep belief on remedy and conservative practices

Lack of decision making power in the family

Directly or indirectly influence in accessing and using service use such as cervical and breast screening

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

- Looking for themes
- Looking for a connections
- Producing a table of themes
- Continuing the analysis with other case
- Creating master list of themes
- Writing up the findings

Research findings

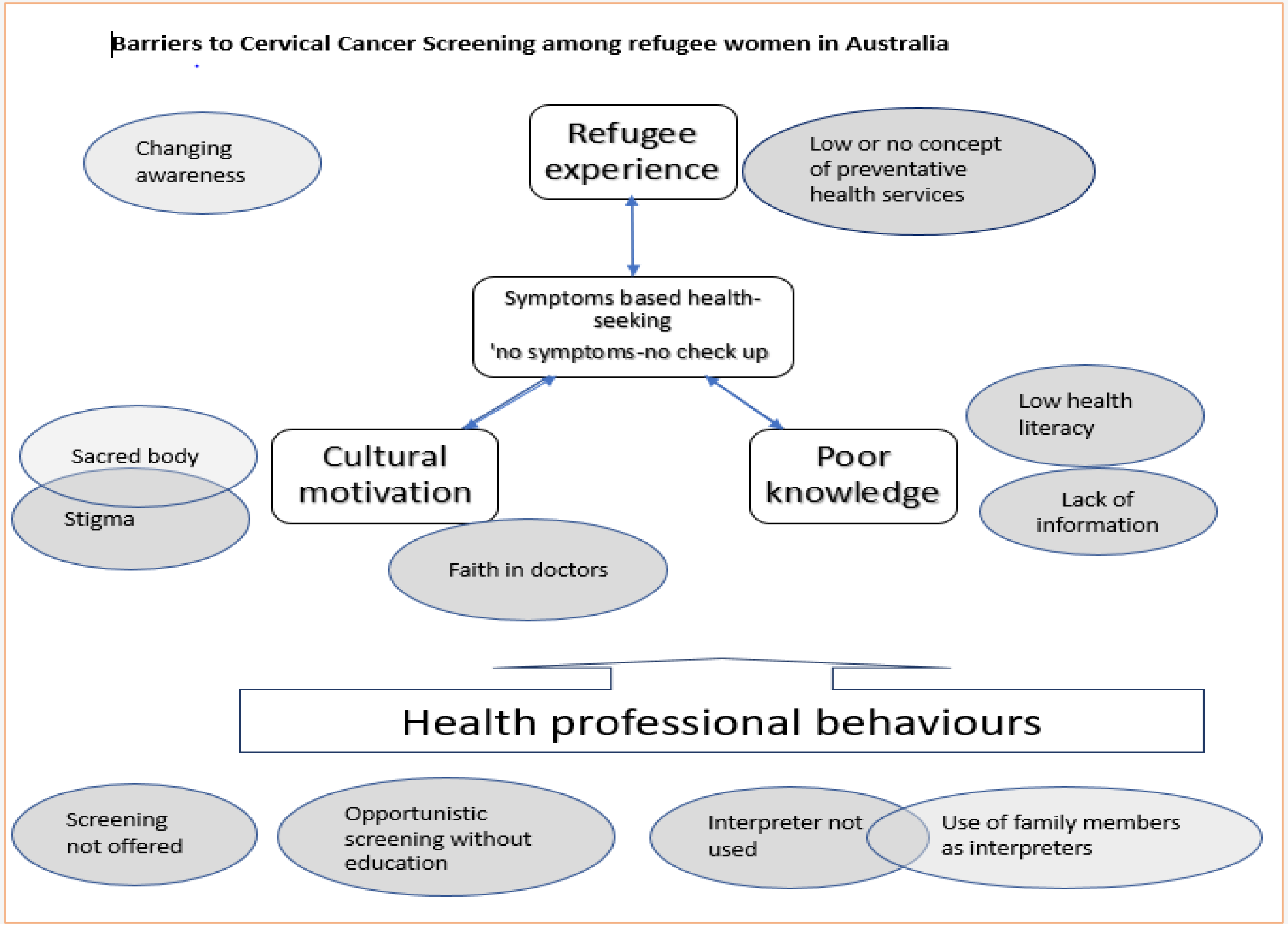
Publications

1. Parajuli, J., Horey, D., & Avgoulas, M. I. (2020). Perceived barriers to cervical cancer screening among refugee women after resettlement: A qualitative study. *Contemporary Nurse*, 1-13.
2. Parajuli, J., Horey, D., & Avgoulas, M. I. (2019). Resettlement challenges and dilemmas: An in-depth case study of Bhutanese refugee women in Australia. *The Australian Journal of Anthropology*, *30*(3), 309-323.
3. Parajuli, J., Horey, D., & Avgoulas, M. I. (2020). Best practice models recommended by Bhutanese refugee women for cervical and breast cancer screening in Australia: A qualitative study. *Health Promotion Journal of Australia*.
4. Parajuli, J., Horey, D., & Avgoulas, M. I. (2019). Access to breast cancer screening-perception, and perceived barriers among older Bhutanese refugee women resettled in Australia: A qualitative study. *Australian Journal of Cancer Nursing, The*, *20*(1), 14.

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

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)

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 educations from GP

opportunistic education from a doctor, which would be very effective, as the doctor is
perceived to be the most authoritative pers… information. One-to-one
education from a do… the most effective way to

One stop specialised services for refugees

One strategy to this end could be the development of … ealth services that focus
specifically on refugees, and tho… e educated regarding
the importance of c…

Bilingual co-worker

Bilingual co-worker and appoi…
into the major health…
would be h… ge the gap.

Cultural competency training for health professional

While lack of cultural competen… der
has been stated as a ma… ther
studies in the…
trai… ught to
prov… efugee and asylum
seeke… the increasing multicultural
divers…

Cultural competency self-evaluation tool

Embedding cultura… o the curriculum
of m… ses with
perio… mpetency self-evaluation
tool a… to health professional.

Interpreter use as the criteria for accreditation for GP practice

Victorian governm…
and int… accreditation
fo…

An active bi- or multi-cultural neighbourhoods

The importance of the neighbour relationshi… repeating
finding from this study. Currently th… ments of
neighbourhood aren't seen… for
smooth transition… e refugees into
Australi… ing an active bi- or
multi-cu… ods are likely to enhance social
inclusion … linguistic ability.

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