

**Barriers to Accessing Cervical and Breast Cancer Screening:  
A Qualitative Study of Bhutanese Refugee Women in  
Australia**

**Submitted by**

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This thesis is dedicated:

**To my late Grandmother Hari Maya Parajuli**, who unconditionally loved me and supported my education by removing me from circumstances where girls were criticised for their education and made me the person who I am today. She was my guiding light, whose wisdom and sacrifices taught me the importance of love, humility, giving, self-reliance and hard work.

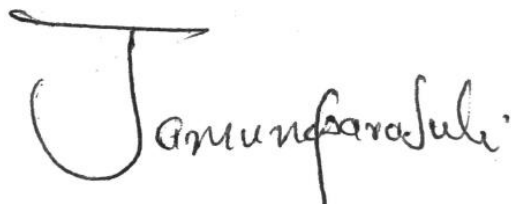
**To my late sister Nirmala Parajuli**, whose death has been a great loss in our family with her sudden departure from this world at a young age. Her strengths, her notion of obedience, and her acts of confidence as a young girl are imprinted in me forever. Even after 22 years, those memories of childhood are still fresh in my mind. I feel as if she is always walking beside me.

## STATEMENT OF AUTHORSHIP

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This thesis includes work by the author that has been published or accepted for publication, as described in the text. Except where reference is made in the body of the text, this thesis contains no other material published elsewhere or extracted in whole or in part from the thesis or from any other degree or diploma. No other person's work has been used without acknowledgement in the main text of the thesis. This thesis has not been submitted for the award of any degree or diploma. All research procedures reported in the thesis were approved by the relevant Ethics Committee.

The research underpinning the publications was undertaken while completing a PhD at La Trobe University, Melbourne, Victoria. I am the primary author for all included publications. Associate Professor Dell Horey is a co-author for all publications as my primary supervisor and my co-supervisor Dr Maria-Irini Avgoulas is co-author for four publications included in the thesis. Details of their contributions are mentioned in each chapter.

A handwritten signature in black ink, reading 'Jamuna Parajuli'. The signature is written in a cursive style with a large, stylized 'J' at the beginning.

Jamuna Parajuli

29<sup>th</sup> of October 2019

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---

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My extended family members, in Australia and in Nepal, my uncles, aunties, cousins and in-laws, I am very thankful and deeply humbled for all your support and encouragement.

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## ACRONYMS

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GP:	General Practitioners
UNHCR:	United Nations High Commissioners for Refugees
CST:	Cervical Screening Test
CDC:	Centre for Disease Control
UN:	United Nation
IPA:	Interpretative Phenomenological Analysis
UHEC:	University of Human Ethics Committee
HBM:	Health Belief Model
TIS:	Translation and Interpretation Services

## ABSTRACT

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**Background:** Over 6000 Bhutanese refugees have resettled in Australia since 2008 after nearly two decades in refugee camps in Nepal. However, resettlement is not the end of refugees' stories as it brings new challenges with new opportunities. Refugee women are particularly vulnerable. Despite the free and readily available cervical and breast cancer screening services in Australia, many refugees including Bhutanese refugee women who are also at increased risk do not access these services.

**Objective:** This study aimed to explore the experiences and perception of Bhutanese refugee women regarding the barriers to accessing cervical and breast cancer screening in Melbourne. The secondary aim was to explore women's own preferred model of care to enhance the use of these screening services.

**Method:** In-depth interviews with 30 Bhutanese refugee women following resettlement. An Interpretative Phenomenological Analysis (IPA) framework was used for the analysis.

**Findings:**

The health-seeking behaviour of Bhutanese refugee women was strongly based on the presence of symptoms and can be described as 'no symptoms-no check-up'. Poor knowledge, low literacy, cultural beliefs and stigma were major contributors to this behaviour. In the experiences that women recounted, some health professional's behaviours were identified as barriers including screening not being offered, no education with opportunistic screening, and failure to use publicly available professional interpreters. Two practice models were suggested by refugee women: doctor-initiated or group screening models both with essential education and supportive environments.

Interlinking challenges and dilemmas were apparent in the women's experiences and appeared to influence health service utilisation: despondency and contentment, gratitude and regret; and identifying as either Australian or as a refugee.

**Conclusion:** Symptoms-based health-seeking was common and opportunities for health professionals to raise awareness or educate women about preventative screening appeared to be missed. Some simple strategies could improve the uptake of cervical and breast cancer screening among refugee women.



## RESEARCH DISSEMINATIONS

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### Paper published or submitted for publications

1. 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* doi: <https://doi.org/10.1071/AH18108> <https://www.publish.csiro.au/ah/pdf/AH18108> Published online 18<sup>th</sup> January 2019
2. 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* doi:10.1071/PY18120 <https://www.ncbi.nlm.nih.gov/pubmed/31239028> Published online 26 June 2019
3. 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* - Revised Submitted and accepted on 6<sup>th</sup> of August 2019 to publish in December 2019.
4. Parajuli, J., Horey, D., & Avgoulas, M.-I. (2019). Perceived barriers to cervical cancer screening among refugee women after resettlement: A qualitative study. *Contemporary Nurse* First submission was 29<sup>th</sup> August 2018. Revised version submitted on 10<sup>th</sup> of September 2019
5. 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. *The Australian Journal of Cancer Nursing*, pp. 14-18. doi:10.33235/ajcn.20.1.14-18 - Published in May 2019
6. Parajuli, J., Horey, D., & Avgoulas, M.-I. (2019). Best practice models recommended by Bhutanese refugee women for cervical and breast cancer screening in Australia: A qualitative study *Health Promotion Journal of Australia* First submission was in 12<sup>th</sup> of March 2019. The Revised version submitted to the journal on 27<sup>th</sup> Aug 2019.

## LIST OF THE PRESENTATIONS

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1. Parajuli, J. Access to cervical and breast cancer screening: Experiences of Bhutanese refugee women living in Melbourne. Northern American Refugee Health Conference, Toronto Canada; June 2017
2. Parajuli, J. Looking through their Lense: refugee women own ideas for cervical and Breast cancer screening Program in Australia. A qualitative study. Refugee Alternative Conference, Academic forum, Adelaide, Australia
3. Parajuli, J. Refugee women identity and health service utilisation. A qualitative study. Refugee Health Network forum, Melbourne, Victoria Australia. May 2019
4. Parajuli, J. Looking through their Lense: refugee women's recommendation for cervical and Breast cancer screening Program in Australia. A qualitative study. PHA conference, Melbourne, Victoria, Australia July 2019
5. Parajuli, J. Barriers to accessing cervical and breast cancer screening: A qualitative study of Bhutanese Refugee women in Australia. Research review panel, Latrobe University, Bundoora Victoria September 2019

## MY MOTIVATION TO DO THIS STUDY

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As a female child in a traditional Hindu family in Nepal, I had to fight to be allowed to continue my education beyond primary school in the 1980s. I told myself ‘the girls are as intelligent and as worth educating as boys’ and I promised myself I would attain the highest level of education possible to make others in my family and community aware of the possibilities for girl’s educations. This thesis is the result of that promise.

As a young woman I faced many obstacles: not only did I break the ‘glass ceiling’ of female expectations in my home village, but also became a role model for many other girls and women within that discriminatory society. By my late teens, I had finished university with a nursing degree and started working in the Bhutanese refugee camps in Nepal under the umbrella of the United Nations High Commissioner for Refugees (UNHCR). As a registered nurse my focus was the health of women and girls as I knew that women in Nepal were of low status and had no decision-making power in their family or in society. In the refugee camps I found that a female child would be given less priority for food, education and health care and as a consequence girls suffered higher childhood mortality. Over the six years that I worked in refugee camps, I came to have no fear in raising concerns about gender discrimination in health care and its impact. During this time, I conducted several action research projects, and implemented a gender equality policy in the recruitment, employment, provision of services and training at various levels of the organisation. I also designed and implemented various ‘women’s empowerment’ programs among the refugee women in the camps and in the Nepali community, teaching women about their health and what they could do to improve it.

I moved to Australia in 2001 to undertake further studies and completed my second master’s degree at the University of Melbourne in 2005 in women’s health. Following this I started my first job in women’s health in Australia where I conducted a sexual and reproductive health training program for young Hmong women based on the empowerment model that I had used in Nepal and my own lived experiences. My next project was an action research study to identify health issues among women caring for disabled children at home. This study was eye-opening, as I did not expect to find such disempowerment among

women in Australia. I came to realise that women's needs can be neglected, and their voices ignored, no matter what country they are in.

For over ten years, I have worked as a Refugee Health Nurse in Victoria. As a Refugee Health Nurse, I work in a multidisciplinary team in a Victorian Government service, where I provide support to newly arrived refugees and asylum seekers, helping them access and use health services. As I have been involved with refugees for such a long time, I have observed diverse experiences working with different cohorts of refugees from many countries.

A critical event that occurred for me one day was when I was providing health education to a group of young African women. I used the word 'refugee' many times while I was talking when suddenly a young woman stood up and said, 'I am no longer a refugee, I am an Australian citizen, don't call me a refugee if you are referring to me'. This particular response made me question my own feelings and attitudes as a professional wanting to provide culturally sensitive services to refugees. It also forced me into re-thinking on my own migrant identity.

From this point there was no doubt I wanted to learn more about refugee women, their attitude to accessing healthcare, and their patterns of changing identity. I was also establishing my new life in Australia as a migrant, building my career and family, I looked for the right time to pursue study in this area. As a result, I commenced this study to fulfil my childhood dream of 'a girl obtaining the highest level of education' and at the same time contribute to refugee women's health in the Australian context. Ultimately, in this thesis I am seeking to contribute to the advancement of refugee 'women's health services' not only with Bhutanese refugee women, but also for the broader refugee populations in Australia.

## STRUCTURE OF THESIS

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According to La Trobe University guidelines, when a thesis contains articles or book chapters, these should be thematically linked to reflect a sustained and cohesive theme of the study; preferably with a separate Introduction, general discussion, and conclusion. As I have intended to publish six papers as a result of my study, this thesis is structured according to 'thesis by publication' guideline.

To give the readers a thematic view, the publications have been incorporated into the main body of the thesis document with linking texts. The papers published are inserted as is, and papers which are submitted or accepted for publications are formatted in line with the journal requirements within the body of the thesis. The thesis is structured as outlined as below.

### **Chapter one**

This introductory chapter provides an overview of refugee resettlement with particular focus on Bhutanese refugees. This chapter also explains the relevance of my personal background, working in refugee health in Australia and in refugee camps in Nepal, to the development of this study. The chapter discusses the significance of this thesis including the research aim, and research questions.

### **Chapter two**

As a background of the thesis, this chapter describes the research population; Bhutanese refugee women and their refugee journey and explores the factors contributing to their compounded vulnerability in accessing preventive health services following resettlement focusing on the cervical and breast cancer screening.

### **Chapter three**

This chapter provides an overview of literature examining service access barriers, and facilitator and challenges for refugees in resettlement countries including roles of health professionals. The chapter includes two published papers: an overview of systematic reviews conducted across the world and a meta-synthesis of qualitative studies conducted in Australia.

Citation	Aim	Study Design
Parajuli, J., & Horey, D. (2019). Barriers to and facilitators of health services utilisation by refugees in resettlement countries: an overview of systematic reviews. <i>Australian Health Review</i> doi: <a href="https://doi.org/10.1071/AH18108">https://doi.org/10.1071/AH18108</a> <a href="https://www.publish.csiro.au/ah/pdf/AH18108">https://www.publish.csiro.au/ah/pdf/AH18108</a>	To provide an overview of previously reviewed research literature to identify barriers and facilitators to health service utilisation by refugees in resettlement countries.	Overview of systematic and other reviews with search strategies
Citation	Aim	Study Design
Parajuli, J., & Horey, D. (2019). How can health care professionals address poor health service utilisation among refugees after resettlement in Australia? A narrative systematic review of recent evidence. <i>Australian Journal of Primary Health</i> doi:10.1071/PY18120 <a href="https://www.ncbi.nlm.nih.gov/pubmed/31239028">https://www.ncbi.nlm.nih.gov/pubmed/31239028</a>	To examine studies conducted in Australia to see what type of health service barriers and facilitators have been identified as affecting the health service use of refugees in this country.	A systematic narrative review of qualitative studies in Australia

#### **Chapter four**

This chapter describes the theoretical framework that informs this research. I discuss the use of intersectionality theory in responding to women's multiple identities and its relationship and influences to use and access preventative health services including cervical and breast cancer screening services.

#### **Chapter five**

This chapter describes the methodology underpinning this research, and the method used for this study including research design that informs this research on how the study was undertaken, how the sample was selected, and how the data was collected and analysed

## **Chapter six**

Chapter six briefly describes the study sample and explores findings specific to Bhutanese refugee women's perceived identities and related dilemmas, and their behavioural response to the use of preventative health services in resettlement. Chapter six present as manuscript that has been accepted for potential publication in the Australian Journal of Anthropology in December 2019.

<b>Citation</b>	<b>Aim</b>	<b>Study Design</b>
Parajuli, J., Horey, D., & Avgoulas, M.-I. (2019). Resettlement challenges and Dilemmas: An in-depth case study of Bhutanese refugee women in Australia <i>The Australian Journal of Anthropology</i> - Revised Submitted and accepted on 6th of August 2019 to publish in December 2019.	This paper explores Bhutanese refugee women's perceptions of their changing identity; associated challenges and dilemmas and their behavioural response to the use of preventive health services following resettlement in Australia by gaining an understanding of their lived experiences.	In-depth interviews with 30 women

## **Chapter seven**

This chapter explores the Bhutanese refugee women's perceptions and perceived barriers to cervical and breast cancer screening services. It includes one manuscript and one published article detailing the health seeking barriers of Bhutanese refugee women to the different cancer types screenings.

<b>Citation</b>	<b>Aim</b>	<b>Study Design</b>
Parajuli, J., Horey, D., & Avgoulas, M.-I. (2019). Perceived barriers to cervical cancer screening among refugee women after resettlement: A qualitative study. <i>Contemporary Nurse</i> . First submission was	To explore the perception and perceived barriers to accessing cervical cancer screening services among Bhutanese refugee women	In-depth interviews with 30 women

29th August 2018. Revised version submitted on 10th of September 2019	in Australia	
Citation	Aim	Study Design
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. <i>The Australian Journal of Cancer Nursing</i> , pp. 14-18. doi:10.33235/ajcn.20.1.14-18 - Published in May 2019	To explore Bhutanese refugee women's perceptions and their perceived barriers to accessing Breast cancer screening services	In-depth interviews with 30 women

### Chapter eight

This chapter explains the possible solution as suggested by the refugee women to enhance their participation in cervical and breast cancer screening services. In other words, the chapter describes their desired model of care.

Citation	Aim	Study Design
Parajuli, J., Horey, D., & Avgoulas, M.-I. (2019). Best practice models recommended by Bhutanese refugee women for cervical and breast cancer screening in Australia: A qualitative study <i>Health Promotion Journal of Australia</i>  First submission was in 12th of March 2019. The Revised version submitted to the journal on 27th Aug 2019.	To explore the views of refugee women about the types of health screening services that would improve access to cervical and breast cancer screening services	In-depth interviews with 30 women



## **Chapter nine**

This chapter provides the discussion and summary of research findings in the broader context of refugee health care and refugee resettlement in Australia and describes the contributions this research has made. The chapter concludes with strength, limitation, practice implication and recommendations along with proposal of future research.

# 1. INTRODUCTION

---

## Background

In 2018 70.8 million children, women, and men were forcibly displaced as a result of persecution, conflict, violence, or human rights violations, the highest number in the 70-year history of the United Nations High Commission for Refugees (United Nations High Commission for Refugees, 2019). The 1951 refugee convention defines the term refugee as 'a person who has fled their country of origin and sought protection in another country due to profound fear of persecution for a reason of their race, religion, nationality, political opinion and membership of particular social group' (United Nation High Commission for Refugee, 2010, p. 14). The UNHCR supports the resettlement of people determined to be refugees into a third country when repatriation into their home country is not possible (United Nation High Commission for Refugee, 2019).

However, resettlement is not the end of a refugee's story. Resettlement can come with many challenges, being in an unfamiliar country and starting a new life can be very overwhelming (Colucci, Minas, Szwarc, Guerra, & Paxton, 2015). Encountering new people with different languages and social ways (Mosselson, 2006), frequently demands that refugees adapt to new social realities while trying to maintain a coherent sense of their own histories, traditions and cultures (Marlowe, 2011).

## The notion of the study

The idea for this study slowly emerged from my experience working in health in refugee camps in Nepal and with resettled refugee populations in Australia, specifically I wanted to understand why some refugee women fail to use preventative health services, particularly cervical and breast cancer screening. After several years working as a Refugee Health Nurse in Australia, I still observe that even though preventative health services are readily available to refugee women, these women have difficulty in accessing these services. As I was thinking about my study plan, Bhutanese refugees were undergoing resettlement in third countries, including Australia. The resettlement of Bhutanese refugees in Australia resonated with me personally as I was already aware of their refugee journey through my

time working in camps in Nepal. I knew about their culture and language and about the disadvantageous position of women in Bhutanese society.

Cervical and breast cancer have particular relevance to Bhutanese women as these are among the most common female cancers in Bhutan and Nepal. In 2014, over ten per cent of all female deaths in Bhutan (11.1%) and nearly 20 percent in Nepal (18.4%) were attributed to cervical cancer alone (World Health Organization, 2014). Unfortunately, the Human Papilloma Virus (HPV) vaccine, which is now recommended for the prevention of cervical cancer, was not available when the refugee camps were established. Limited funds for health care in refugee camps in Nepal meant the HPV vaccination program was never introduced in the camps. In these circumstances, the reluctance of Bhutanese refugee women to access the cervical and breast cancer screening programs available in Melbourne determined the aim of this thesis, which was to explore the perceptions and experiences of these screening programs among Bhutanese refugee women.

This chapter provides further context for this thesis by briefly looking at the history of refugee resettlement in Australia and refugee access to health services following resettlement. The chapter also includes information about cervical and breast screening in Australia, the research questions, study significance and an outline of the structure of the thesis.

## **Refugee resettlement in Australia**

Australia has a long history of accepting refugees for resettlement, resulting in over 800,000 refugees being resettled in Australia since 1945 (Neumann, 2016). As a signatory of the 1951 Refugee Convention, Australia receives and resettles 13,750 refugees every year under its humanitarian program (Koser, 2015). Based on previous data, an estimated 140,000 refugees are likely to resettle in Australia each decade (Australian Government, 2018a). While the make-up of nationalities included in the Australian resettlement program varies over time, several countries have appeared consistently in recent years: Myanmar, Iraq, Afghanistan, Bhutan, Ethiopia, Democratic Republic of Congo, and Syria (Australian Government, 2018a). The emergence of new instances of human rights violations in the world has 'flow-on' effects to countries such as Australia. For example, as a consequence of

the Syrian Civil War, an extra 12,000 Syrian refugees have been admitted into Australia since 2013 (United Nation High Commission for Refugee, 2016).

With regard to Bhutanese refugees, Australia was one of eight countries taking part in the resettlement program, a process that began in 2007. By November 2017, Australia had become the home to 6204 Bhutanese refugees (Corcoran, 2017) (see Chapter 2).

### **Refugee access to health services after resettlement**

Several studies in different countries have noted that despite the poor health status of refugees, their use of health services is often lower than that of the host populations (Morris, Popper, Rodwell, Brodine, & Brouwer, 2009; Shawyer, Enticott, Block, I-Hao, & Meadows, 2017). However, there is variation between countries and not a lot is known about the reasons for this. A systematic review of 32 quantitative and qualitative studies assessing the utilisation of healthcare services among refugees and asylum seekers, found that annual attendance at primary care was considerably higher in Switzerland (average 5.8 visits per year) and the United Kingdom (5.2) compared with only 3.4 visits per year in Australia (Hadgkiss & Renzaho, 2014).

The relatively low use of health services by refugees settling in Australia occurs despite commonly found health issues that include communicable diseases, poor states of nutrition, poorly managed chronic diseases, dental and/or optical health problems and the physical consequences of torture and trauma (Milosevic, Cheng, & Smith, 2012). This is important as these health conditions can be exacerbated if access to, or utilisation of, health services is restricted or not taken up (Hadgkiss & Renzaho, 2014).

Prior to their resettlement, Bhutanese refugees had little access to preventive health services in the refugee camps apart from basic vaccinations for infectious diseases (Martin et al., 1994). Preventive health services are likely to be unfamiliar to many refugees and this unfamiliarity may lead to poor comprehension of the concept of screening among this group and explain low uptake rates (Saadi, Bond, & Percac-Lima, 2015). Continuous reinforcement of appropriate information is likely to be important to sustainable health behaviour. (Clark, Gilbert, Rao, & Kerr, 2014; Jiwrarka, Mahmoud, & Uppal, 2017)

In Australia, refugees are given priority access to health care and have full entitlements to Medicare, Australia's universal health insurance scheme (Taylor & Lamaro Haintz, 2017).

Priority access means, for example, that refugees have shorter waiting times to access any health service compared with the host population including dental and allied health services (Department of Health and Human Services, 2019). Despite this, many refugee families still experience difficulties in accessing health services in a timely way (Cheng I. H, Drillich, & Schattner, 2015; Szajna & Ward, 2015).

### **Cervical and breast cancer screening in Australia**

The cervical and breast screening programs in Australia have been very successful. Since their implementation over 20 years ago it has been estimated that the incidence of, and mortality from, cervical and breast cancer has decreased significantly (Aminisani, Armstrong, Egger, & Canfell, 2012; Australian Institute of Health and Welfare, 2018; BreastScreen Australia, 2018; Weber et al., 2014). However, despite its successes, disparities persist for both diseases for immigrant women. Unlike the United States, Australia's cervical and breast cancer screening services are free, yet a significant number of refugee and migrant women choose not to access these services (Kagotho & Pandey, 2010).

Participation of women from low socioeconomic groups is lower. In 2015-2016, 62% of women in the highest socioeconomic group took part in screening programs compared with only 50% of women in the lowest socioeconomic group (Australian Institute of Health and Welfare, 2018). Screening participation rates are also higher in Australian-born women compared with women from Asia and Europe (Weber et al., 2014) and with migrant and refugee women (Henderson & Kendall, 2011; Manderson & Allotey, 2003). There is a clear link between cancer screening disparities and the incidence of cervical and breast cancer-morbidity and mortality, which is significantly higher among women from low income and ethnic minorities (Lu et al., 2012; Menon, Szalacha, & Prabhughate, 2012).

Australia's screening programs for cervical and breast cancer are free of charge for all eligible women (Australian Institute of Health and Welfare, 2018; Olver & Roder, 2017); eligibility is based on the national guidelines. Biennial breast screening mammogram is recommended for all women from 40 years of age. General Practitioners (GPs) are expected to make referrals and all women aged 50-74 years are sent invitations to attend breast screening programs (BreastScreen Australia, 2018). Cervical Screening Tests (CST) can be carried out by the GP or a registered nurse accredited for screening. Screenings take place in

various primary healthcare settings including doctors' clinics, family planning and sexual health clinics, community health centres and Aboriginal medical services (Australian Government, 2018b). The recently updated national guidelines for cervical screening reduced the frequency of screening, which are now recommended to occur every five years (previously two years) for women aged from 25 to 74 years (Australian Government, 2018b).

Australia is not the only country where disparities in breast cancer screening exist for immigrant women. A study in America amongst South Asian women, including Bhutanese women highlighted the low rate of participation in cervical and breast screening programs (Menon et al., 2012). A recent Canadian study examining mammogram rates among 183,332 eligible immigrant women from eight regions identified that Asian women had the lowest rate of screening, and that factors affecting low screening rates included refugee status, living in low socio-economic neighborhoods, not attending primary health care, having a male physician and not having regular physical examinations (Vahabi, Lofters, Kumar, & Glazier, 2016). In another study looking at screening programs in the United Kingdom (UK), Canada and United States (US), a lack of knowledge of benefits, how to access services and not having heard about cancer and its consequences were major reasons that women didn't participant (Crawford, Ahmad, Beaton, & Bierman, 2016; Saadi et al., 2015). However, it is unclear whether similar factors apply to refugee women in Australia, where the effectiveness of organised cervical and breast cancer screening programs specifically for refugee populations in Australia has not been done. Little is known about the experience and perceptions of preventive screening for refugee women in Australia, nor do we know what sort of services they would prefer.

## **Research aim and questions**

The aim of this thesis was to explore the perceptions and experiences of Bhutanese refugee women in accessing cervical and breast cancer screening services following resettlement in Australia. Specifically, the study asked the following research questions:

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

2. What are the perceived barriers in accessing cervical and breast cancer screening services?
3. What are the women's preferred model of care to enhance the accessibility and use of cervical and breast cancer screening services?

## **Study Significance**

The findings of this study are essential to providing improved insight into the issue of Bhutanese refugee women's health behaviours. It also informs health researchers and social scientists about Bhutanese culture and its influences on Bhutanese women's behaviour in accessing and using women's health services before and after resettlement. It also adds to the body of literature; specifically, the research findings have identified the needs of Bhutanese women in relation to accessing cervical and breast cancer screening services. In addition, the research further supports devising ways to ameliorate the situation and promote the delivery of culturally sensitive services to refugee women using a tailored approach that is effective for service providers and for refugee women themselves.

## **Thesis overview**

The thesis is comprised of nine chapters. Chapter one introduces the research. Chapter two describes the challenge of researching a vulnerable population, such as Bhutanese refugee women, and describes the background of this population. Chapter three presents two published reviews on what is known in the literature about barriers to health care access for refugees internationally and in Australia. Chapter four discusses intersectionality which forms the underpinning theoretical framework for this study. Chapter five discusses the methodological frameworks and methods used in the research. The findings are presented in Chapters six, seven and eight in the form of published papers. Chapter six is about resettlement dilemmas and how that affects the health seeking behaviour. Chapter seven talks about cervical and breast cancer screening barriers and Chapter eight discusses Bhutanese refugee women's desired model of care. Chapter nine presents a discussion of the findings and describes the contributions this research makes. and the thesis concludes with implications of study and recommendations along with proposal of future research.

## Summary

This chapter provides a broad background of refugee resettlement and subsequent use of health services, with a focus on cervical and breast cancer screening in Australia and on Bhutanese refugee women. I introduced my personal background working in the area of refugee health in Australia and in refugee camps in Nepal as the key to the idea of research. The research questions are clearly presented. The significance of the study and the overview of the thesis briefly mentioned. In the next chapter I discuss the challenges of studying a vulnerable population and present Bhutanese refugee women's story of exile, their refugee journey, resettlement in Australia and the impact of their vulnerability on researching this group.



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## **2. BHUTANESE REFUGEE WOMEN: STORIES OF EXILE AND RESEARCHING VENERABLE POPULATION**

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The purpose of this chapter is to explore issues associated with researching a vulnerable population, focusing on Bhutanese refugee women who have resettled in Australia.

Understanding the causes of vulnerabilities is important to enable the research to progress in a way that the voices of those vulnerable people are heard. This understanding also assists addressing the challenges of researching vulnerable populations including the correct use of research design and strategies to ensure that findings are relevant and robust.

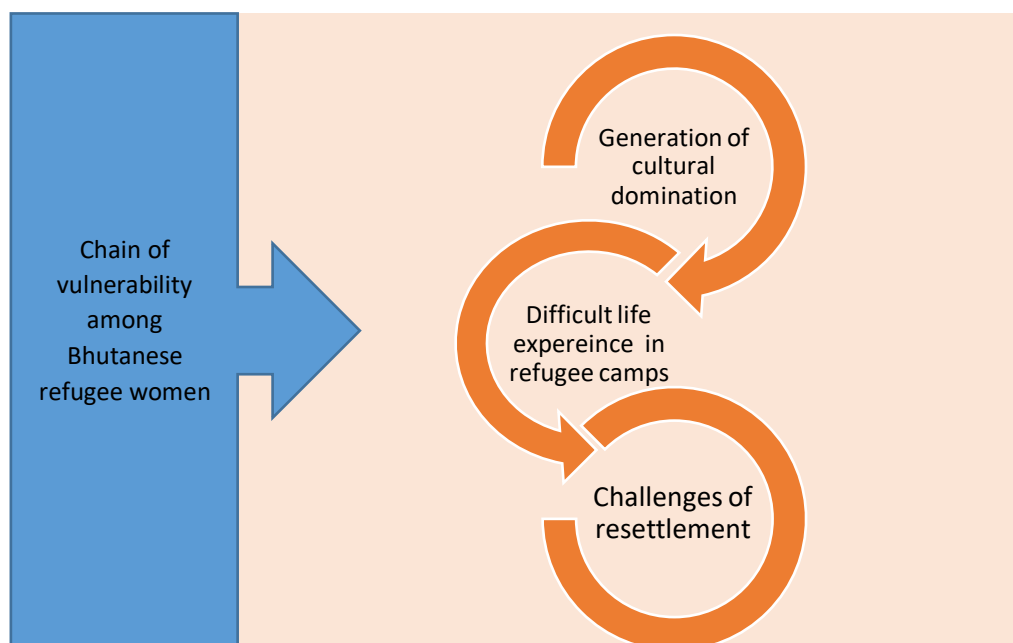
In this chapter I look at the issue of researching a vulnerable population more broadly, then examine the issues of vulnerability that contribute to research in more detailed descriptions of Bhutanese refugee women's stories. This provides both background and deep insight on the issue of vulnerability, which is important if research into these populations is to be useful in making change. Further, I discuss the challenges and critical roles of the researchers researching vulnerable populations with regards to my own research position in this research.

### **Vulnerability and Bhutanese refugee women**

Refugee populations are often described as vulnerable due to the numerous difficulties they face both in resettled countries and in their refugee journeys. For example, similar Bhutanese refugee women to those in my study have been described this way (Shrestha, 2011). They are considered vulnerable usually because of difficult and traumatic life experiences (Taylor, Nicolle, & Maguire, 2013; Von Benzon & Van Blerk, 2017). For example, one study that explored a story of a Rohingya refugee's journey in Australia supported a similar notion of vulnerability in resettlement (Jiwrajka, Mahmoud, & Uppal, 2017). This view was also documented in another study with reference to European and African refugee resettlement in Australia, where the authors contemplated the vulnerability of refugees in a novel way (Colic-Peisker & Tilbury, 2003). Their findings refer to previous fragmented lived experiences including living in refugee camps with scarce resources, gender discriminatory policies and unbalanced gender roles. The impact of prolonged protracted situations on

vulnerability is also evident in other literature (Corcoran, 2017; Donini, 2008; Evans, 2010; Ferguson, 2011).

In similar ways, the Bhutanese refugee women in my study could be considered vulnerable due to generations of cultural domination prior to their life in the camps, their difficult life experiences, and the challenges they have faced in resettlement. The combination of these situations in the lives of the Bhutanese women created a chain of compounded vulnerabilities (see Figure 1). Recognising the manifestation of compounded vulnerabilities as shown in Figure 1 is important for researchers of this population. Through my own involvement in the lives of many refugee women in Australia, I believe that vulnerability does not end with resettlement.



**Figure 1: Chain of compounded vulnerabilities of Bhutanese refugee women**

Research involving any group that has low status in the community raises several challenges for researchers. The social position of women in the Bhutanese-Nepalese cultural context means that women's health issues are often hidden and not widely discussed (Menon, Szalacha, & Prabhugate, 2012). This means that many health issues are not discussed and treatment may be delayed, which can have implications including long-term morbidity and early mortality. Studies undertaken in refugee camps prior to resettlement established the cultural dominance of men, who were the household heads, the decision-makers and exercised all economic power (Donini, 2008; Human Rights Watch, 2003). Men were seen to

have the right to control the lives of their families in all areas including education, employment, health care, social participation, economic decisions and even personal care (Donini, 2008). Such patriarchal cultures are likely to remain in Bhutanese groups even after resettlement. The participation of Bhutanese women in research may need the agreement of Bhutanese men, and research regarding women's health issues in this population could be contentious and needs careful consideration.

As in Nepal, daughters in Bhutanese families are considered burdens and are counted as assets of others, not as someone who belongs to the family of their birth. Sons carry the family name and legacy and so are more important than daughters. Bhutanese and Nepali family homes and family life revolve around sons. Consequently, females experience discrimination and are less likely to be given access to opportunities and may even be prohibited from attaining education, economic independence, and social autonomy (Tamang, 2000). Lack of education has important consequences for literacy, which can affect several aspects of research participation, including how consent is obtained and conveyed and how data are collected.

The male dominance embedded in Bhutanese societies continued in the refugee camps, where gender-based violence and discrimination against women continued adding to their vulnerability. For example, the registration process that allowed admittance to a camp and access to food rations meant that ration cards were only given in the husband's name. Women suffering domestic violence could not access basic humanitarian aids independently, which meant that many women continued living in violent situations to get access to basic needs. Separate housing was not available to women, and women who left violent relationships had to rely on friends or family members for protection and safety (Donini, 2008; Human Rights Watch, 2003). Reports of rape, sexual assault, polygamy, girls' trafficking, domestic violence, and child marriage in the camps were common (Human Rights Watch, 2003). These issues were raised in Human Rights Watch reports even after the camps had existed for a decade and more. As part of the data gathering for the Human Rights Watch reports, women in the camps were interviewed. One woman recounted her experiences as follows:

Sometimes I was beaten so badly I bled. My husband took a second wife. I didn't agree.... He said, 'If you don't allow me to take a second wife, then the ration card

is in my name, and I'll take everything.' I have asked my husband for the health card and ration card and they don't give it to me.... I have not gotten approval to get a separate ration card. Geeta M. (not her real name, Bhutanese refugee camps, Nepal, March 26, 2003). (Human Rights Watch, 2003)

While experiences such as these are likely to increase the vulnerability of Bhutanese refugee women, through highlighting their stories of exile, I examine the issues that contribute to vulnerability in more detail.

## **The Journey of Bhutanese Refugees**

### **Background: Fleeing Bhutan**

Bhutan is a small monarchy in South Asia bordered by India and China. It has a rugged mountainous landscape with fertile valleys and forests covering nearly 50,000 square kilometres and a population of 810,000 people (CDC 2014). Bhutan is an ethnically diverse nation. Four main ethnicities are officially recognised: Drukpa, in the north; Lhotsampas, in the south; Sharchop, in the east; and Ngalong, in the west (Hutt, 2005). Of these ethnic groups Lhotsampas are the only Bhutanese who speak a Nepali dialect.

In 1989 the government of Bhutan announced a 'one nation one people policy', which had the ambition of creating a homogeneous Bhutanese nation. An important consequence of this policy was to enforce the practices of the northern Drukpa culture (Hutt, 2005), which is the ethnic culture of the Buddhist Bhutanese monarch. Cultural laws and policies, based on Buddhist religious principles formulated by the ruling government discriminated against the Lhotsampas, who were mostly Hindu. These policies enforced Druk dress code, Buddhist religious practices and the use of Drukpa language on all Bhutanese people regardless of their cultural heritage (Mills, Singh, Roach, & Chong, 2008). The cultural prohibition meant that many Nepali speaking Hindu people could not follow or perform the cultural practices belonging to their religion (Hutt, 2005).

The 1985 citizenship requirements specific to the Lhotsampas people, required proof of existing Bhutanese citizenship cards as citizenship acquired after 1958 was now invalid. For example, the Lhotsampas had to produce 1958 land tax receipts to take part in the 1988 census (Hutt, 2005; Lui, 2007). Village elders who had been in Bhutan long before 1958

attempted to accommodate the citizenship law by pledging their residency, but the government responded by imprisoning them. In prison they were tortured, and release from prison was only obtained by completing a volunteer migration form and undertaking to leave the country (Lui, 2007).

From 1989 Nepali-speaking schools were closed and Lhotsampas who occupied government positions were dismissed (Lui, 2007). Businesses, hospitals and post offices in the south were forced to close. Many lost their jobs as a result. Military rule was imposed in the south. In response to the abuses related to this policy, Lhotsampas protested against the government and formed political and human rights groups to defend their rights and cultural and linguistic identity (Evans, 2010). Lhotsampas wanted to follow their Hindu culture and speak their own language; however, the response of the Bhutanese government was violent. Schools were closed and health services in the southern region of Bhutan were suspended. Allegations of terrorism and anti-nationalism followed with erratic arrests, home invasions and random attacks leading to the detention and torture of Lhotsampas. Reports of rape, arrest and torture in these Lhotsampas villages were common when there was failure to follow the imposed Druk cultural practices, which including wearing Druk dress, speaking Druk language, and following the Buddhist religion (Human Rights Watch, 2003; Hutt, 2005; Mills et al., 2008). Eventually these activities led many Lhotsampas to flee to another country in fear of their lives (Lui, 2007). Between 1991 and 1993 over 100,000 Nepali speaking Lhotsampas had been forcefully expelled from Bhutan with many of these arriving in eastern Nepal. In this 500 kilometre journey the Lhotsampas crossed two borders as they moved crossed India into Nepal in the hope of finding a safe place in country with a common language (Lui, 2007), (Evans, 2010; Human Rights Watch, 2003; Hutt, 2005) (see Figure 2).





**Figure 2: Bhutan to Nepal: Map of refugee camps** (*Human Rights Watch 2005 and UNHCR*)

## Establishing refugee camps in Nepal

From late 1991 the first temporary camp was established on the bank of the Kankai River in Jhapa, Nepal under very harsh conditions. Soon after the first refugee arrivals, the Nepalese government sought support from the United Nations High Commission for Refugees (UNHCR) to help deal with the unexpected emergency situation (Hutt, 2005). The role of the UNHCR can be considered in three main stages: addressing the emergency crisis, ensuring on-going safe food, water and health resources, and resolving the refugee settlement issue (Hutt, 2005).

The influx of refugees from Bhutan reached its height in mid-1992 with nearly 600 people arriving every day. By the end of 1993 seven camps had been established in the nearby jungle to house more than 85,000 refugees (see Figure 3). Sanitation, hygiene, water supply, waste management, food supply, and health care were all important issues to be addressed in the emergency stage of establishing the camps (United Nations High Commissioner for Refugees, 1994). Eventually the refugees moved from temporary tents to basic huts with thatched roofs and earth floors. Food was distributed through ration distribution centres which supplied rice, pulses, vegetable oil, salt, sugar, and seasonal vegetables. As time passed families also started to grow vegetables in gardens adjacent to their huts to supplement their daily diet (Centre for Disease Control and Prevention, 2014)

All seven camps had primary health care centres where minor sicknesses and injuries were treated. In each camp these centres were run by health assistants and nurses (both registered and unregistered) who provided immunisation, addressed malnourishment in children, and gave pregnancy and post-natal care to women. In the early days of the camps

health care was often supported by visiting doctors, but over time protocols were established to refer more serious cases to local or regional hospitals and 24-hour ambulance services were available (Centre for Disease Control and Prevention, 2014; Human Rights Watch, 2003).

### **Life in the refugee camps**

An emergency situation was declared by the UNHCR soon after the refugee camps were established as many adults and children were dying from communicable diseases and malnutrition. There were mass outbreaks of cholera and measles and emergency health care protocols were implemented by Save the Children UK (Martin et al., 1994).

By the end of 1993, the situation in the camps became more stabilised and the health of the refugee population improved. As the camps shifted from the emergency to maintenance phase, more preventative health care strategies were implemented including immunisation, maternal and child health, the provision of supplementary and fortified foods and safe drinking water, and regular monitoring of the sanitation systems. Public health campaigns including health education around simple health behaviours were critical.

During this period, support mechanisms were introduced including schooling for children, non-formal education including skill development for adults, vocational training for health volunteers, and the encouragement of income generating activities among refugees.

Despite the focus on education and skill development this period saw increased prevalence of hopelessness and frustration, fuelled by the history of torture and trauma. Mental health problems became more common as the Bhutanese spent a longer time in the refugee camps and the situation became protracted (Ferguson, 2011; Lui, 2007; Van Ommeren et al., 2002). Traditional approaches to health care such as traditional healers and herbal remedies were common among the refugees who tended to seek out health care only when serious problems arose. The value of preventative health care practices was not well-understood and such practices only occurred when initiated by health professionals (Centre for Disease Control and Prevention, 2014). The use of home remedies and traditional healers were common practice and the port of first call for any health problem (Maxym, 2010).



**Figure 3: Bhutanese refugee camps in Nepal 2007**

The refugee camps as shown in Figure 3 in eastern Nepal remained home for these Bhutanese refugees for more than two decades. Before resettlement options were given (Lui, 2007), the camps had grown to reach a peak population of around 120,000 Bhutanese refugees (Bonney, 2013).

### **Options for resolution**

Once the maintenance phase was established, attention turned to resolution. Three options to resolve the refugee situation were proposed by the UNHCR:

1. repatriation to Bhutan
2. host country settlement in Nepal
3. third country resettlement.

According to the UNHCR, resettlement involves ‘the selection and transfer of refugees from a State in which they have sought protection to a third State which has agreed to admit them – as refugees – with permanent residence status’ (Ferguson, 2011).

The first of these options, repatriation, was preferred by most refugees, but despite several bilateral talks between the Bhutanese and Nepalese governments successful negotiation towards this outcome could not be reached (Lui, 2007). The second option, host country settlement, also could not be achieved as the Nepal government was unwilling to give citizenship to such a large group. Eventually, the option of third country resettlement was

accepted by the majority of Bhutanese refugees in the camps (Maxym, 2010) and a resettlement program was agreed in 2007 with the UNHCR by eight countries, including, Australia, United States (US), Canada, Denmark, Netherland, New Zealand, United Kingdom (UK) and Norway (Gurung, Baidya, & Purvis, 2009). The Bhutanese refugee resettlement program is one of the largest UNHCR-supported resettlement programs (Benson G, Sun, Hodge R, & Androff K, 2012). By the end of 2017, 10 years after the third country resettlement program began around 111,000 Bhutanese refugees, nearly nine out of ten refugees, in the Nepal camps had resettled in a third country with 8,500 Bhutanese remaining in two camps in Nepal (Corcoran, 2017).

The large majority of Bhutanese refugees resettled in the United States (92,323, 76.9%) followed by Canada (6773, 5.6%), Australia (6204, 5.17 %), New Zealand (1075, 1.75%), Denmark (875, 0.89 %), United Kingdom (358, 0.29 %), and The Netherlands (329, 0.27%) (Corcoran, 2017). (See Figure 4)



**Figure 4: Global resettlement of Bhutanese refugee (UNHCR 2017)**

Source: UNHCR and US Refugee Processing Centre

## Early resettlement experiences

Resettling in a new country and starting a new life can be overwhelming for anyone (Colucci, Minas, Szwarc, Guerra, & Paxton, 2015), but adjusting to a new culture and new language can be even harder for refugees (Clark, Gilbert, Rao, & Kerr, 2014; Lawrence & Kearns,

2005). There are few studies describing resettlement from the perspective of refugees. However, as one study undertaken in New Zealand in relation to Bhutanese refugee resettlement described the difficulties faced when they first arrived. After living in camps for many years they did not know how to fulfil basic daily needs, such as shopping, using public transport, or finding their way around their neighbourhood (Ferguson, 2011). Volunteers who spoke the same language and helped them were highly valued. The type of help provided including taking the refugees to appointments and showing them how services worked. Many expressed diverse feelings following resettlement including feeling lost, feeling excited for the future, and feelings of happiness. One woman said; “I never imagined I would be able to stay in this beautiful house” (Ferguson, 2011, p. 40). However, simple things posed challenges after resettlement. Communication difficulties were common as refugees were unable to understand signs, labels, or addresses. There were problems in communicating with other people in the community, including health care workers, shopkeepers, teachers at their children’s schools. They also had no knowledge of societal rules or systems, Challenges such as these fostered feelings of vulnerability (Ferguson, 2011).

## **Challenges at Resettlement**

Resettlement can offer many opportunities for refugees such as access to education, reliable food supplies, safe shelter, good medical treatment and better opportunities for employment, but can also create new challenges. In Australia, refugees are recognised as vulnerable groups, or group with special needs (Health.Vic, 2019) and as a consequence they are given priority for health care service provision (Health.Vic, 2019).

Even after resettlement, Bhutanese refugees in other countries have displayed vulnerability in multiple ways (Ferguson, 2011; Shrestha, 2011). In a study involving 110 Bhutanese refugees that looked at their coping strategies to promote psychological well-being it was found that refugees of any age can be at risk of developing psychological distress based on pre-migration experiences (Subedi, Edge, Goldie, & Sawhney, 2019). Other studies highlight the fact that the social factors that can influence mental health are as critical as treating diseases and injuries. Bhutanese refugees are disadvantaged in terms of health and economic outcomes (Marsh, Browne, Taylor, & Davis, 2017; Praetorius, Mitschke, Avila, Kelly, & Henderson, 2016).

Several studies of resettled Bhutanese refugees in the United States have found that their health and social outcomes are poorer compared with other refugee groups (Bhatta, Assad, & Shakya, 2014; Griffiths & Loy, 2018; Haworth, Margalit, Ross, Nepal, & Soliman, 2014). Past traumatic experienced by Bhutanese refugees can make it difficult for them to integrate their traditional cultural beliefs, behaviours and values with those of their new country and create new stresses that affect their mental health and wellbeing (Benson G et al., 2012; Bonney, 2013; Centre for Disease Control and Prevention, 2014)

The practice of using home remedies and traditional healing continued even after resettlement (Centre for Disease Control and Prevention, 2014). They also have a tendency to use health care for serious illnesses rather than seeking preventative care (Maxym, 2010). This may be due to their greater exposure to acute health care systems in the refugee camps; furthermore, continued imbalance gender roles, low literacy and language barriers attributed to further marginalisation of Bhutanese refugee women in resettled counties. (Maxym, 2010).

Therefore, it is critical to understand that ‘vulnerability does not stop with resettlement’, and it is an essential consideration to make by researchers to conduct research ethically in vulnerable groups. The nature of the vulnerabilities is continuously changing and often affected by the societal structures. For example, the notion of ‘visible migrant’ can make a person’s status more evident and more exposed in ways that refugees have not previously experienced and can pose vulnerability in different ways (Edge, Newbold, & McKeary, 2014; Merry, Gagnon, Kalim, & Bouris, 2011). Visible migrants are distinct through their appearance that can be skin colour or cultural clothing such as saris and hijabs, or head scarves, which could be the problem prior to resettlement. Another important example can be illiteracy and language which were not seen as barriers for Bhutanese refugee women prior to resettlement along with their heightened dependency on their children. Challenges such as these raised by resettlement can be confronting and unanticipated, and can be the causes for vulnerability (Hugman, Pittaway, & Bartolomei, 2011; Wilson & Neville, 2009).

## **Researching vulnerable people**

Despite apparent widespread agreement on the importance of recognising vulnerability in research groups there is no consensus on the definition of the term which is used in various ways. Vulnerability has been described as a relative state or condition that occurs as a result of external or structural factors, or as a consequence of social dynamics such as inequality and social exclusion (Johnstone & Kanitsaki, 2007). Vulnerability has also been described as a perception of social groups and of individuals, and so is seen as a condition dependent on how someone sees themselves in relation to a dominant social group(s), or in relation to culturally marginal groups (Aldridge, 2015). Vulnerability is also associated with those at risk of exploitation because of demographic, social or economic circumstances (Pyer & Campbell, 2012), and the term is used to describe people who experience social injustice, discrimination and inequality. People who are powerless, excluded and marginalised can be deemed vulnerable (Liamputtong, 2007; Wilson & Neville, 2009) and vulnerable people may also be those at risk of harm or death, or those that have experienced ongoing hunger or poverty, or they may be people who are unable to make personal life choices independently (Aldridge, 2015).

Research involving topics that are deeply personal and private combined with a vulnerable population can be practically and ethically challenging and complex for researchers at every step from planning, data collection, data validation and dissemination (Marsh et al., 2017). Procedural issues associated with access and the ethics in research with groups perceived to be vulnerable, raises further vulnerabilities and may interrupt or distort the way research is able to be carried out (Von Benzon & Van Blerk, 2017).

As stated by National Health and Medical Council's qualitative researchers, when wanting to explore the lived experiences of populations considered vulnerable, special account of their specific vulnerabilities when designing and conducting studies is needed (National Health and Medical Research Council, 2018).

Bhutanese refugee women in this study are largely illiterate and bound by a high level of cultural religiosity that increases their vulnerability and limits their ability to access services. These issues are also like to affect their participation in research. Talking about women's health issues to this group of women is likely to be confronting and very sensitive. Low cultural status in families is strongly associated with poor or little education (Ferguson,

2011; Yun et al., 2016). Illiteracy has important implications for study design. It can affect how a study might be explained to participants, how data are collected, and how findings are validated (Liamputtong, 2010).

## **Situating researcher in researching vulnerable population**

A researcher's position in undertaking research in vulnerable population is integral. In the context of population explained earlier, researchers need to create spaces to develop a critical understanding of the sociocultural realities of those vulnerable people being researched. For example, a researcher should think of their own positioning and presence in the research process and how that could influence the research findings. One way of doing this is through 'researcher's reflexivity' which is also critical to rigor as it is fundamental to understanding the researcher's position in relation to the population under study. Reflexivity requires ongoing critical self-reflection that considers how the research process may itself influence a study's findings (Berger, 2013; Hewitt, 2007). When researching vulnerable people, researchers may need to extend their understanding to the roots of vulnerability which can be complex and demanding. However, this process is important because it can lead to a better understanding that can guide a researcher in ways to recruit participants and seek consent from them, design possible interventions, and collect and analyse data (Berger, 2013). Sound knowledge of vulnerable populations and understanding of the root causes of their vulnerability can also be key to ensuring that findings are relevant and robust (Clift, Hatchard, & Gore, 2018; Pyer & Campbell, 2012). These issues were important to recognise in designing my research study, how I would recruit participants, and how I collected and validated my data and findings (Marsh et al., 2017).

The central goal of any research with vulnerable groups needs to put participants at the centre of the research process, and to find ways that enables them to speak or tell their stories in their own ways (Aldridge, 2015). All research should aim to carry benefits and should contribute to the understanding of unique experiences. In health research, there should be an attempt to include exploration of any possible interventions or strategies to improve health services and health outcomes (Pacquiao, 2014; Pyer & Campbell, 2012; Wilson & Neville, 2009). Undertaking research with vulnerable populations without identifying possible ways to address the issues underlying their vulnerability could risk creating increased



vulnerability. For example, the process and outcomes of a research study may make participants more aware of issues pertaining to their daily life that have a negative impact on them. Leaving such a group without any plan of action after the research is complete could increase insecurity and added vulnerability among them. (Marsh et al., 2017; Von Benzon & Van Blerk, 2017; Wilson & Neville, 2009)

My position as researcher in this study can be influenced due to my presence in the community. As a Nepalese woman I share many social, cultural and linguistic characteristics with my Bhutanese research participants, and my roles can be considered instrumental and critical to my study (Ramji, 2008; Rowland, 2011). This is not unusual; undertaking research with people and communities who share a common background, language, race, ethnicity, nationality or heritage is common as evident in other studies (Dwyer & Buckle, 2009). My personal experience is outlined in Chapter 1 which describes how I came to do this study and my long-term connection to this population meant that it promotes easy interaction and trust during the interview.

I worked as a registered nurse from June 1992 to September 1999 in Bhutanese Refugee camps. During this time, I was directly involved in service provision in the field and undertook several roles including feeding centre nurse, health trainer, maternal and child health nurse coordinator and health information manager. Throughout my six years working in the camps I was active in many health education activities and public health campaigns, all of which were designed for people with low literacy. These intense experiences of direct involvement with this population made me acutely aware of their health care needs and support they require in resettlement and had an enormous influence on me while I was planning this research. My deeper understanding of the causes of vulnerability in this population specifically among women helped me to consider the right use of research design and appropriate methods to enable participation to ensure that findings are relevant and robust to give these women a voice that would be heard.

## **Summary**

In this chapter I described the issues researching a vulnerable group with an example of Bhutanese refugee women and their difficult journey. The chain of compounded vulnerability of the Bhutanese refugee women was explained—arising from a tradition of

cultural patriarchy, a difficult life journey as a refugee and the processes of resettlement. Understanding the challenges of researching a vulnerable population, such as refugee women, is important for researchers to make sure that the research is successful in making the voice of vulnerable people heard with the right use of research design and strategies to ensuring the findings are relevant and robust. While this chapter provides both the background and deep insight on the critical roles of the researcher in researching vulnerable populations, in the next chapter I present and discuss the relevant evidence from the literature that reinforce and support to build up the base for this research in the form of publication.

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### 3. LITERATURE REVIEW

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This chapter provides an overview of the literature pertaining to service access barriers and facilitators, and challenges for refugees in resettlement countries. The chapter includes two published papers: an overview of systematic reviews conducted across the world and a meta-synthesis of qualitative studies conducted in Australia.

The overview paper titled 'Barriers to and facilitators of health services utilisation by refugees in resettlement countries: an overview of systematic reviews' published in Australian Health Review in January 2019 provides an overview of the previously reviewed research literatures to identify barriers and facilitators to health service utilisation by refugees in resettlement countries.

The meta-synthesis of qualitative studies titled 'How can healthcare professionals address poor health service utilisation among refugees after resettlement in Australia? A narrative systematic review of recent evidence', was published in the Australian Journal of Primary Health in June 2019 and examined qualitative studies conducted in Australia to ascertain what types of health service barriers and facilitators have been identified as affecting the health service use of refugees after resettlement.

## Published article

### Barriers to and facilitator of health service utilisation by refugee in resettlement countries

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Intended audience	Journal [2018 Impact Factor]	Publication status	Extent and nature of candidate's contributions	Extent and nature of co-authors contributions
Health professionals, broader Audience including policy maker and service providers	<i>Australian Health Review</i> [1.228]	Published online 18 <sup>th</sup> January 2019	Contribution of candidate: 80%.  This includes data collection, data analysis, drafting and revision of manuscript; submission to journal	Contribution of co-author: 20%.  This includes discussion of ideas expressed in paper and critical review

# Barriers to and facilitators of health services utilisation by refugees in resettlement countries: an overview of systematic reviews

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## Abstract

**Objective.** The aim of this study was to provide an overview of the previously reviewed research literature to identify barriers and facilitators to health service utilisation by refugees in resettlement countries.

**Methods.** An overview of systematic reviews was conducted. Seven electronic databases (Medline, Cumulative Index to Nursing and Allied Health Literature (CINAHL), PsycINFO, ProQuest Central, Scopus, EBSCO and Google Scholar) were searched for systematic reviews of barriers and facilitators to health-seeking behaviour and utilisation of health services by refugees following resettlement. The two authors independently undertook data selection, data extraction and quality assessment using a validated tool.

**Results.** Nine systematic reviews covered a range of study areas and refugee populations. Barriers to health service utilisation fell into three broad areas: (1) issues related to refugees, including refugee characteristics, sociocultural factors and the effects of previous experiences; (2) issues related to health services, including practice issues and the knowledge and skills of health professionals; and (3) issues related to the resettlement context, including policies and practical issues. Few facilitators were identified or evaluated, but these included approaches to care, health service responses and behaviours of health professionals.

**Conclusions.** Barriers to accessing health care include refugee characteristics, practice issues in health services, including the knowledge and skills of health professionals, and the resettlement context. Health services need to identify barriers to culturally sensitive care. Improvements in service delivery are needed that meet the needs of refugees. More research is needed to evaluate facilitators to improving health care accessibility for these vulnerable groups.

**What is known about the topic?** Refugee health after resettlement is poor, yet health service use is low.

**What does this paper add?** Barriers to accessing health services in resettlement countries are related not only to refugees, but also to issues regarding health service practices and health professionals' knowledge and skill, as well as the context of resettlement. Few facilitators to improving refugee access to health services have been identified.

**What are the implications for practitioners?** The barriers associated with health professionals and health services have been linked to trust building, and these need to be addressed to improve accessibility of care for refugees.

**Additional keywords:** access to care, developed countries, health-seeking behaviour, service access.

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## Introduction

The current forced global displacement of people is unprecedented and accelerating. The displacement grew 40% in just over 3 years from 42.4 million people in 2011 to 59.5 million in 2014.<sup>1</sup> By the end of 2015, the United Nations High Commissioner for Refugees (UNHCR) estimated that 65.3 million people had been forcibly displaced; of these, 21.3 million people were designated as refugees and 3.2 million were designated

as asylum seekers, whose status as refugees is yet to be assessed.<sup>2</sup> The future of these people is uncertain, with many living for protracted periods in refugee camps in poor conditions.<sup>3</sup> When return to their home country is not possible, the goal for many refugees is resettlement in a high-income country.<sup>4</sup>

However, resettlement in a high-income country is not the end of a refugee's story. Often health remains poor, yet health service use is low. Globally, the use of health services by



refugee groups in high-income countries after resettlement is lower than host populations, despite the poorer health status of refugees. For example, among refugees settling in Australia, common health issues include communicable diseases, poor states of nutrition, poorly managed chronic, dental and/or optical health and the physical consequences of torture and trauma.<sup>5</sup> Such health issues can be exacerbated if access to and utilisation of health services is restricted or not taken up.<sup>6</sup>

Health service use is an important issue for resettlement. Prearrival health checks for a limited range of conditions are routine for refugees before departure from transit countries to countries of resettlement. However, some conditions are not appropriately screened for due to difficult conditions in transit countries,<sup>7,8</sup> such as anaemia, schistosomiasis and vitamin D deficiencies, which respond well to early detection and treatment, and are not universally included in prearrival checks. Further, prearrival health checks do not include many of the chronic and infectious diseases that are relatively common in refugee populations. This means that on arrival some refugees can have immediate health needs that are treatable and warrant medical care.<sup>9</sup> Without timely treatment, many conditions worsen, subsequently requiring more expensive interventions.<sup>10,11</sup>

Those healthcare professionals responsible for refugees after resettlement face several obstacles in meeting the needs of many refugees in a culturally appropriate way despite long recognition of these needs and challenges. Several reasons have been suggested as to why problems persist in this area, including lack of familiarity with health issues that are specific to country of origin or transit countries<sup>12</sup> and deferral of health assessments by the refugees themselves after their arrival in resettlement countries, which delays diagnosis.<sup>13</sup>

Several systematic reviews have explored possible reasons explaining the phenomenon of poor health service use by refugees following resettlement.<sup>11,14–16</sup> These reviews have covered a range of resettlement countries and have focused on different population groups,<sup>14</sup> health issues<sup>15,17,18</sup> and types of health services.<sup>15,16,19</sup> To better understand common barriers and facilitators to the access of health services by refugees in resettlement countries, we undertook an overview of systematic reviews that have explored these issues with the goal of developing a conceptual map that could be used to help plan services and identify gaps in the research.

## Methods

### Search strategy

With the help of a senior university librarian at La Trobe University, a search strategy was devised based on the STAR-LITE acronym<sup>20</sup> to identify systematic reviews that reported barriers and facilitators to health-seeking behaviour and utilisation of health services by refugees following resettlement. Search terms were determined on the basis of the PICO acronym (population, intervention, comparison and outcome). The approach is detailed in Table 1.

Seven electronic databases were searched for any review article published in English (Medline, Cumulative Index to Nursing and Allied Health Literature (CINAHL), PsycINFO, ProQuest Central, Scopus, EBSCO and Google Scholar). No date

**Table 1. STARLITE approach used in the literature search**  
CINAHL, Cumulative Index to Nursing and Allied Health Literature

<b>Sampling strategy</b>
Comprehensive: attempts to identify all relevant studies on the topic
<b>Type of studies</b>
Systematic reviews or literature reviews with a clear search strategy
<b>Approaches</b>
Six electronic databases; hand searching (reference lists and forward citations)
<b>Range of years</b>
No date limits
<b>Limits</b>
English language, developed country
<b>Inclusions and exclusions</b>
<b>Inclusions</b>
• Refugee and/or asylum seeker population
• Barriers to health service use, access or service provision identified
• Facilitators to health service use, access or service provision identified
• High-income countries
• Search strategy described
<b>Exclusion</b>
• Empirical research
• Refugee camps and transit countries
<b>Terms used</b>
Refugee*, Asylum seekers* AND health-seeking behaviour*, service use, access to health services, health service utilisation, access to care, resettled countries, high-income countries*
<b>Electronic sources</b>
Medline, CINAHL, PsycINFO, ProQuest Central, Scopus, EBSCO, Google Scholar

limit was set and specific search strategies were used for each database with keywords based on the inclusion criteria (see Table 1). The final searches were conducted on 13 March 2018. In addition to the electronic database searches, the reference lists of included articles were scanned and examination of forward citations conducted using Google Scholar.

### Data extraction and management

The Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines were followed for data extraction to enhance transparency.<sup>21</sup>

All search results were imported into EndNote X8 (Clarivate Analytics (Australia) Pty Ltd, Sydney, NSW, Australia) and duplicates removed. Titles and abstracts were screened for potential inclusion, with all potentially relevant full-text articles retrieved for full-text review. The inclusion criteria were applied independently by the two authors to assess eligibility, with discrepancies resolved by discussion. The following data were extracted from the studies included and tabulated: study name and year of publication, review objectives, databases searched, years searched, inclusion and exclusion criteria, number and types of studies and key findings. Directed content analysis was used to categorise findings from each review as either identified barriers and/or facilitators to health service use.<sup>22</sup>

The quality of each review was independently assessed by the two authors using the Assessment of Multiple Systematic Reviews (AMSTAR) tool.<sup>23</sup> The quality of the reviews was classified as high (AMSTAR score 9–11), medium (6–8) or low (0–5). Any disagreements were resolved through discussion.

## Results

The search strategy resulted in the identification of 125 potentially relevant titles. After duplicates had been removed, 102 records were screened and 39 full-text articles were retrieved and assessed for inclusion. Of these, nine review articles<sup>6,11,15–19,24,25</sup> met the inclusion criteria for eligibility and were included for the overview (Fig. 1). Table 2 provides a summary of the systematic reviews included in this study and their quality rating.

### Characteristics of reviews included in this study

The key characteristics of the nine reviews included in this study are given in Table 2. One review focused on pharmacy-related issues,<sup>24</sup> six were focused on general issues of settlement, including problems with disability, physical health issues and women's health,<sup>6,11,16,17,19,25</sup> and two reviews focused on mental health.<sup>15,18</sup>

Populations identified in the reviews included refugees, asylum seekers and healthcare professionals (nurses, midwives, pharmacists and general practitioners (GPs)). The number of papers included in the systematic reviews ranged

from eight to 32, with between three and 12 databases searched. The most commonly searched databases were CINAHL (eight of nine reviews), Medline (seven of nine reviews) and PsycINFO (seven of nine reviews). All reviews included in this analysis were published between 2010 and 2017, with a total of 95 reported papers reviewed, however it was not possible to determine the extent of overlap because three reviews did not list the studies they included.<sup>18,19,25</sup> In the six reviews that listed the studies included, 95 individual papers were listed, with only four studies reported in more than one review.<sup>6,11,15–17,24</sup>

### Methodological quality

Based on AMSTAR ratings,<sup>23</sup> two reviews were judged to be of high quality, two were considered to be of medium quality and five were considered to be of low quality (Table 2). Ratings of poor quality were due to the lack of a list of included and excluded studies, cross-checking of data extraction and differences due to study methodology. Other factors affecting quality ratings included lack of information about publication bias or how findings were analysed.

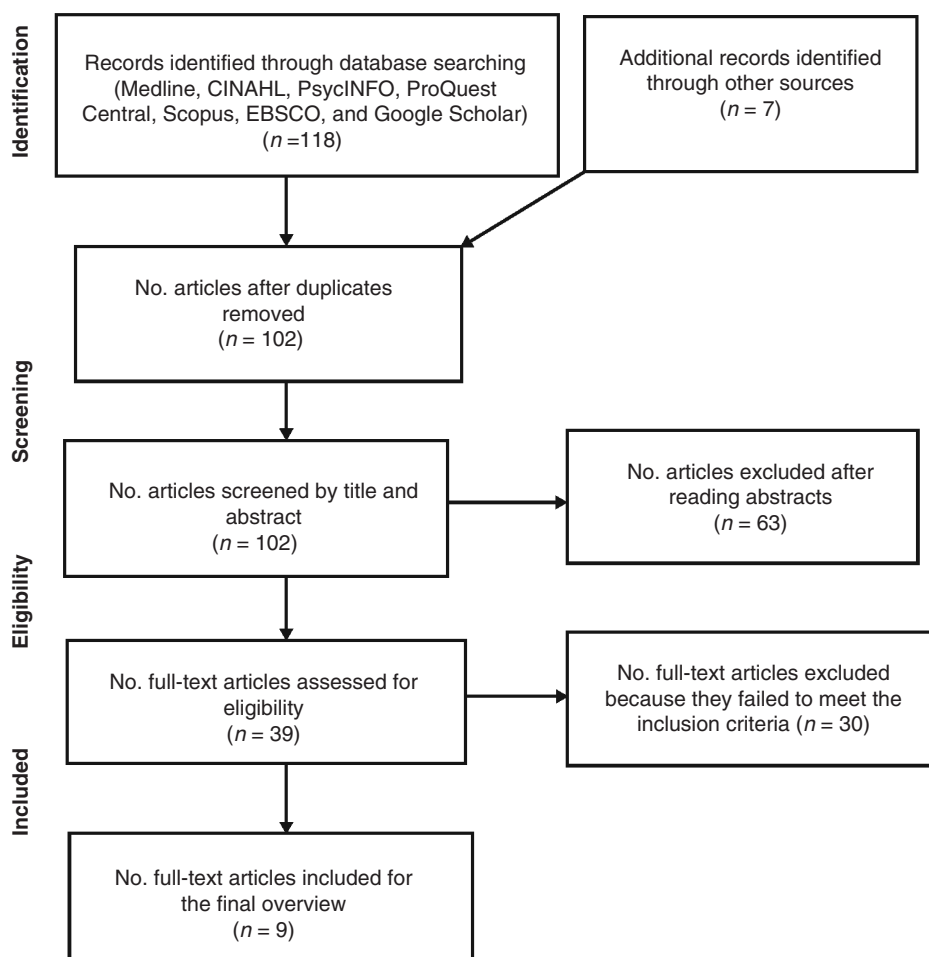


Fig. 1. Flowchart of search results and study selection. CINAHL, Cumulative Index to Nursing and Allied Health Literature.

Table 2. Summary of systematic reviews included in overview

AMSTAR, Assessment of Multiple Systematic Reviews; ERIC, Education Resources Information Center; GP, general practitioner; IBSS, International Bibliography of the Social Sciences; MM, mixed-methods study; Qual, qualitative study; Quant, quantitative study; SocioAbs, Sociological Abstracts; SWA, Social Work Abstracts; WHO, World Health Organization

Study	Objectives	Databases searched (years of search; date of search) and other searches	Inclusion and exclusion criteria	No. studies included	Participants	Main findings: barriers and facilitators to health seeking	AMSTAR quality rating
Bellamy <i>et al.</i> <sup>24</sup>	To explore barriers and/or facilitators to accessing medication and pharmacy services for resettled refugees	Scopus, ProQuest, Sociological Abstracts, PubMed, EMBASE and APAIS Health (1990–2014; March 2014) Other searches: government websites, TROVE and refugee organisation websites, The Grey Literature Report, OALister, Open Grey, Mednar, WHO, Google Scholar	Inclusion: refugees accessing medication and pharmacy services Exclusion: non-English language, refugee camps, migrants and immigrants, and major focus on asylum seekers	9 (5 Qual, 4 Quant)	793 refugees, most from South-east Asia (at least 573)  One study included a mix of refugees from African and Asian countries ( <i>n</i> = 36)	Refugees: difficulties with language and navigating Western healthcare system, cultural barriers and discordant illness beliefs, use of traditional medicines, effects of family, peers and communities on health behaviour and adherence, illness beliefs affecting health-seeking behaviours and understanding, low levels of education and literacy  Health services: inconsistent use of interpreter services, lack of information about local services  Context: Western medication considered 'too strong', stigma associated with disease, role of preventive care	Low
Cheng <i>et al.</i> <sup>19</sup>	To explore the experiences of refugees and asylum seekers using general practice services in resettlement countries	Embase, Ovid MEDLINE, PsycINFO, CSA SocioAbs, and CINAHL (1990 and 2013; date of search not reported)	Inclusion: primary data describing individual refugees or asylum seekers' personal experiences of GP services  Exclusion: experiences of mixed populations beyond refugee and asylum seekers	23 papers (13 focusing on refugees, 3 focusing on asylum seekers, 7 focusing on both; all Qual)	864 refugees and asylum seekers in 11 countries	Refugees: language barriers, poor doctor–patient relationships, problems with cultural acceptability of medical care, lack of knowledge of health system, including role of GPs and how to make appointments and access after-hours care  Health services: lack of available interpreter services, inadequate cultural competency, high cost of medical care	Low

Colucci *et al.*<sup>15</sup>

To summarise issues with the use of mental health services by children and young people with refugee backgrounds, and to identify obstructions to service users and facilitators of access and engagement	PsycINFO, PubMed, Medline, CINAHL, SocioAbs, IBSS, ISI: Web of Science (from inception: 1966 for Medline, 1960 for PsycINFO; May 2011)	Inclusion: original research published in scientific journal or book with data relating to access or use of mental health services where data on refugees could be extracted (or if aggregated data for refugees and asylum seekers only reported)	11 papers reporting 10 studies (8 Quant, 1 Qual, 1 MM)	At least 2193 participants (998 unaccompanied refugee minors, 105 refugee children (source country not reported); 537 refugee adolescents or young adults (from Middle East and Africa); 304 Sudanese (age not reported); 249 Palestinian refugee families)	Refugees: poor knowledge of mental health, low priority for mental health care, stigma and tendency to hide problems, lack of trust, lack of confidence to seek help, cultural factors including previous traumatic experiences Health services: lack of experience and confidence among staff, issues with training and/or time to recognise and manage complex needs and problems among refugees, language difficulties including translation or interpreter issues, gender issues, issues with appointments (e.g. booking systems, missed appointments, schedules, waiting periods, transport difficulties) Context: absence of partnerships or collaboration between agencies and service providers (effects continuity of care), high geographical mobility of refugees	Low
To assess physical health problems of asylum seekers and their issues with to access health services during settlement	MEDLINE, PsycINFO, Embase, CINAHL (2002–October 2012; date of search not reported)	Inclusion: adult asylum seekers residing in the community of high-income countries, published in peer-reviewed journal in English  Exclusion: studies focusing on mental health or assessing burden of disease	32 papers for 30 studies (21 Quant, 9 Qual)	>20 000 asylum seekers settled in high-income countries	Asylum seekers: inability to pay for medical consultations, unable to navigate healthcare system, inadequate knowledge of availability and eligibility for health services, language and cultural factors Health services: long waiting times for all types of services and lack of continuity of care, mistrust over degree of confidentiality and security	High

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Table 2. (continued)

Study	Objectives	Databases searched (years of search; date of search) and other searches	Inclusion and exclusion criteria	No. studies included	Participants	Main findings: barriers and facilitators to health seeking	AMSTAR quality rating
Hoffman and Robertson <sup>17</sup>	To provide a comprehensive perspective of documented physical and mental health issues of Karen refugees from Burma	Medline, PsycINFO, SWA, Scopus, and CINAHL (from 1966 for Medline, from 1978 for PsycINFO, from 1986 for SWA, from 1823 for Scopus and from 1937 for CINAHL; 2014)	Inclusion: Qualitative studies exploring experiences of Karen refugees on resettlement or quantitative studies of Karen refugee health and migration experiences Exclusion: if focus did not extend to after resettlement or if mental, physical or psychosocial health not included	18 papers (12 Qual, 6 Quant)	>3000 resettled refugees from Burma	for health information, discrimination and poor attitudes among health professionals Refugees: inadequate shelter, inaccessible education, unemployment, health care, communication issues, cultural factors, lack of education, gender norms, language problems, sense of powerlessness and disillusionment Health services: programs and services not targeted to meet specific health needs of Karen community	Medium
O'Mahony and Donnelly <sup>18</sup>	To gain an understanding of the mental health needs of immigrant and refugee women during the postpartum period	CINAHL, PsycINFO, MEDLINE (Ovid), EBM Reviews, Cochrane Database of Systematic Reviews (years of search not reported; date of search not reported)	Not reported	Not reported	Not reported	Refugees: language difficulties, unfamiliarity with accessing healthcare services, childcare issues, cultural factors leading to fear of stigma, lack of awareness of postpartum depression, disproportionate domestic work for women Health services: lack of social support, transportation difficulties, financial cost, lack of information about healthcare services	Low
Robertshaw <i>et al.</i> <sup>16</sup>	To explore challenges and facilitators for health professionals providing primary health care for refugees and asylum seekers in high-income countries	MEDLINE, EMBASE, PsycINFO, CINAHL, Web of Science (years of search not reported; March 2016)	Inclusion: qualitative studies involving GPs, nurses, pharmacists and midwives working with refugees in developed countries	26 papers reporting 21 primary studies (19 Qual, 2 MM)	469 healthcare professionals (including GPs, nurses, pharmacists, midwives)	Refugees: lack of trust in relationships, communication difficulties, poor health and social conditions, suspicion of authorities, unique physical health problems (including communicable diseases,	Medium

<p>female genital mutilation, injuries and psychological trauma from torture, abuse, social difficulties, somatisation)</p> <p>Health services: lack of training or guidance, time constraints, deficiency of professional support (supporting traumatised patients without support), isolation, referral difficulties</p> <p>Context: transience of refugees or asylum seekers, cultural values, health and social conditions, lack of language-specific resources</p> <p>Facilitators: continuity of care, assistance with wider needs, interest in refugee issues, compassion and empathy, explanation of roles of health professionals, using professionally trained interpreters, using visual aids, awareness of cultural values and body language, training and professional support, appropriate referral pathways, collaboration with other services, codelivery of services, service provision through multiagency teams</p>	<p>Exclusion: studies with mental health professionals, studies reporting service users as migrants or illegal migrants, studies published in languages other than English</p>	<p>CINAHL, Scopus, and PsycINFO (2002–2011; date of search not reported)</p>	<p>To determine access to healthcare services by the resettled refugee population using dimensional analysis</p>	<p>Inclusion: studies on resettled refugees in English-speaking countries</p> <p>Exclusion: general migrants, illegal migrants</p>	<p>20 articles (types not reported)</p> <p>Resettled refugees in English-speaking countries</p>	<p>Refugees: culture (including spirituality and religion), language, fear of discrimination and stigmatisation, and logistical concerns</p> <p>Healthcare providers: uncertainty over the cultural appropriateness of examination and feelings of apprehension when explaining reproductive procedures such as Pap</p> <p>Low</p>
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Table 2. (continued)

Study	Objectives	Databases searched (years of search; date of search) and other searches	Inclusion and exclusion criteria	No. studies included	Participants	Main findings: barriers and facilitators to health seeking	AMSTAR quality rating
Taylor and Lamaro Haintz <sup>11</sup>	To study the effects of social determinants of health on refugees in accessing healthcare services in Australia	EBSCO, MEDLINE Complete, Health Policy Reference Center, SocINDEX, CINAHL Complete, Global Health, PsycINFO, ERIC (from 2006; date of search not reported)	Inclusion: studies published in English, specific to refugees, based in Australia, peer-reviewed studies, at least one measurement relating to refugee healthcare access  Exclusion: international studies, studies focused on migrants, asylum seekers or mixed groups	8 studies (6 Qual cross-sectional studies, 1 MM cohort study, 1 systematic review)	Participants from refugee backgrounds	smears, gender-related issues when counselling refugees on birth control and consent for treatments  Refugees: language difficulties (verbal and written), low health literacy, low trust in healthcare providers, transport difficulties, cost of healthcare services, poor navigation of healthcare systems, low literacy levels  Health service: long waiting times, poor use of professional interpreter services, lack of culturally appropriate health information and communication, lack of cultural understanding, lack of knowledge about the refugee experiences	High



**Table 3. Summary of key findings**  
GPs, general practitioners

Refugee and asylum seekers issues	Barriers		Facilitators/recommendations
	Health services or systemic issues	Context of resettlement	
Characteristics <ul style="list-style-type: none"> <li>• Communication or language difficulties</li> <li>• Types of health issues</li> <li>• Low health literacy</li> <li>• Lack of confidence to access services</li> <li>• Financial constraints and employment status</li> <li>• Unfamiliarity or poor knowledge of available services</li> </ul>	Practice issues <ul style="list-style-type: none"> <li>• Working with interpreters, including inconsistency in their use</li> <li>• Time constraints to address communication issues with patients</li> <li>• Complexity of paperwork and administrative processes</li> <li>• Referral difficulties, including geographical location and relationships with refugee organisations</li> <li>• Lack of professional support in supporting traumatised patients</li> <li>• Lack of collaboration between agencies and service providers for continuity of care</li> </ul>	Policy issues <ul style="list-style-type: none"> <li>• Design of health system including different layers of service provision</li> <li>• Funding limits</li> <li>• Lack of refugee-specific resources</li> </ul> Practical issues <ul style="list-style-type: none"> <li>• Location of services</li> <li>• Availability of transport</li> </ul>	Approaches to care <ul style="list-style-type: none"> <li>• Community-based approach</li> <li>• Family-centred and strength-based approach</li> <li>• Flexible primary healthcare system</li> </ul> Health service responses <ul style="list-style-type: none"> <li>• Cultural competency training</li> <li>• Support for GPs and refugee families</li> </ul>
Social/cultural <ul style="list-style-type: none"> <li>• Influence of family and peers</li> <li>• Health beliefs and stigma</li> <li>• Cultural acceptability</li> </ul> Effects of previous experiences <ul style="list-style-type: none"> <li>• Distrust in services and service providers</li> <li>• Fear of judgment and discrimination</li> <li>• Previous exposure, torture or trauma</li> <li>• Pessimism and sense of powerlessness</li> </ul>	Knowledge <ul style="list-style-type: none"> <li>• Lack of cultural competency or cultural understanding</li> <li>• Lack of knowledge about refugee health issues and experiences</li> <li>• Lack of training on how to manage complex needs</li> <li>• Lack of proper information system for refugees</li> </ul>	<ul style="list-style-type: none"> <li>• Connections between service organisations</li> <li>• Transience of refugee and asylum seekers</li> <li>• Different cultural values</li> </ul>	<ul style="list-style-type: none"> <li>• Universal access to health services</li> <li>• Flexible appointment times</li> <li>• Explain roles of health professionals</li> <li>• Colocated services: English classes, GP practices, pathology, pharmacy and specialist care</li> <li>• Refugee mentor programs</li> <li>• Health professional behaviours</li> <li>• Use of effective communication, resources and techniques</li> <li>• Use of demonstration to ensure understanding</li> <li>• Avoid refugee stereotypes and value individuals, focusing on their needs</li> <li>• Develop personal qualities of sensitivity, empathy and cultural humility</li> </ul>

### *Barriers and facilitators to health service access and utilisation*

The barriers to accessing health services for refugees after resettlement fell into three broad domains: (1) refugee issues; (2) health service issues; and (3) the context of resettlement. Refugee issues related to the specific characteristics of the refugees, social or cultural factors and the effects of previous experiences. Health service issues focused on practice issues and the knowledge base of health providers. The context of resettlement could be grouped into policy or practice issues (Table 3). Only one study<sup>16</sup> looked at facilitators, and these included approaches to care, types of health service responses and behaviours of health professionals.

### **Discussion**

This overview provides a synthesis of the current evidence of the barriers and facilitators to health service access by refugees following resettlement. The overview included nine

systematic reviews, of which six comprised more than 90 unique studies covering a broad range of settings and population groups. In this body of literature, many more barriers to accessing healthcare services by refugees were identified than facilitators. A clear finding of the overview is that more attention has been given to describing problems with refugee health services than in finding solutions in this area. Only one systematic review identified interventions designed to improve refugee access to health services after resettlement,<sup>16</sup> although other studies recommended different strategies.<sup>6,11,14,15,17–19,24–27</sup>

Barriers to health care access fell into three distinct domains, namely refugee characteristics, health service or systemic issues and the context of resettlement, and these are interlinked. The most commonly reported barriers related to communication and cultural understanding and involved both refugees and those providing care. Refugees experienced language difficulties,<sup>1,18–20,25,26</sup> whereas health professionals used interpreters inconsistently and/or inappropriately in their



practice<sup>11,15,18,19,24,27</sup> and lacked the knowledge needed to provide culturally competent care.<sup>6,11,15,19,25,27</sup>

Despite the diversity of study settings, factors affecting access to health care were common across the systematic reviews. For example, refugees were described as lacking the capacity and/or confidence to navigate health services,<sup>6,11,15,18,24–26</sup> which was attributed to characteristics of the refugees, including communication difficulties due to language barriers,<sup>11,14,16–19,24,25,27</sup> low health literacy<sup>6,11,19,24,26</sup> and lack of knowledge and/or unfamiliarity with the services available.<sup>6,11,17–19,24,26</sup>

The issues related to healthcare providers and services were less frequently directly identified as barriers to health care access, but were acknowledged as key to developing trusting relationships with refugee groups in several reviews.<sup>6,11,16,19,24–27</sup> Factors associated with trust in these reviews included lack of cultural competency,<sup>16,25,27</sup> inadequate training or guidance,<sup>16,27</sup> lack of professional support,<sup>14–16,24</sup> poor communication between services<sup>24</sup> and insufficient time to address complex and sensitive issues.<sup>15,18,19,27</sup>

The resettlement of refugees to different countries, where different health systems and policies apply, means that some barriers to and facilitators of health care accessibility will necessarily be contextual.<sup>27</sup> The type and quality of resources available to refugees will be variable,<sup>16</sup> as will the level of support and political goodwill.<sup>15</sup>

Possible facilitators for improving refugee access to health care services were identified by Robertshaw *et al.*<sup>16</sup> and can be categorised as approaches to care and the response and behaviours of individual healthcare providers. Similar strategies to improving access to care were included as recommendations in other reviews<sup>16,25,27</sup> and appear to be based on the application of simple human principles, such as taking interest in refugees as individuals, showing compassion and empathy, explaining professional roles and asking and assisting refugees with their needs beyond their presenting health condition. Other recommendations to facilitate access to health care for refugees included in the reviews are the provision of ongoing social support, building capacity and confidence among refugees, establishing community networks and the appropriate use of interpreters.<sup>19,24,25</sup>

Support for integration of health and other services was a strong theme across the systematic reviews.<sup>6,19,24,26</sup> Other studies outside this overview have also proposed that indicators of integration, such as language acquisition,<sup>28</sup> access to labour markets<sup>29</sup> and the use of health and education systems over time,<sup>30</sup> are effective pathways to the better utilisation of services generally. Similar findings are found in systematic reviews that focus on immigrant populations.<sup>16,25,27</sup> The findings of the present overview highlight the need to support and build capacity in healthcare providers and health services, as well as in the refugees themselves.

### Study limitations

This overview has several limitations. First, it was reliant on the quality and content of the systematic reviews included in the analysis. A minority of the reviews included were rated as high quality and the reviews covered a broad area of practice. Few reviews addressed facilitators for improving access to

health care, and there was little evaluation of strategies that would make a difference. Nevertheless, the overview offers a useful picture of the topic and shows that these barriers are common across a broad range of areas and groups.

### Conclusion

Appropriate access to health services is an important issue for refugees after resettlement. This overview shows that the barriers to accessing care involve more than issues associated with the refugees themselves and include practice issues in health services, the knowledge and skills of health professionals and the policies and systems of the resettlement country. Improvements in refugee health following resettlement will need strategies that address this broad spectrum of issues. Health services need to identify barriers within their control and consider how to implement culturally sensitive care for this vulnerable population. Improvements in service delivery that meet the needs of refugees are also likely to improve care for others from culturally and linguistically diverse backgrounds. Health professionals also need to consider how they may overcome their own practice and knowledge shortcomings to better meet the needs of their clients. More research is needed on evaluating the effectiveness of different facilitators to improving health care accessibility for refugees.

### Competing interests

The authors declare that they have no competing interests.

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## Published article

### How can health professional address poor health service utilisation among refugee after resettlement

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# How can healthcare professionals address poor health service utilisation among refugees after resettlement in Australia? A narrative systematic review of recent evidence

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**Abstract.** This systematic narrative review of qualitative studies examined health service barriers and facilitators in Australia for refugees after resettlement. Twelve qualitative studies published between 2006 and 2017 involving more than 500 participants were included in the review. Approximately half of all participants were healthcare professionals. A meta-synthesis approach was used to compare and combine findings from across studies. Few facilitators were identified. Barriers to accessing health services were commonly attributed to refugees, but several barriers were associated with healthcare professionals and health services. Barriers attributed to healthcare professionals included gaps in knowledge and skills; poor cultural competency; poor communication skills; and time constraints. Understanding such barriers is the first step in developing strategies to overcome them. The skills and knowledge of healthcare professionals are important to facilitating access to healthcare among this vulnerable population.

**Additional keywords:** access to healthcare, asylum seeker, health-seeking behaviour, service access.

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## Introduction

As a signatory of the 1951 Refugee Convention, Australia is one of 26 countries participating in the United Nations High Commissioner for Refugees (UNHCR) resettlement program (Koser 2015) taking ~14 000 refugees every year under its Humanitarian Program with additional special provision places (Department of Immigration and Border Protection 2017). Under this resettlement program, ~83 000 people have settled in Australia over the last 5 years (Department of Home Affairs 2019). Nationalities making up the program vary over time, but several countries appear consistently in recent years (Department of Immigration and Border Protection 2017). Australia has taken an extra 12 000 Syrian refugees since 2013 (United Nations High Commissioner for Refugees 2016).

Large resettlement numbers within short time periods can create particular challenges for health service providers unfamiliar with the particular physical and psychological stresses refugees face. Resettlement can also bring new difficulties in accessing services for refugees (Morris *et al.* 2009; Shawyer *et al.* 2017). In Australia, despite high levels of satisfaction with the quality of healthcare services available among refugees, many families experience difficulties in accessing timely services (Cheng *et al.* 2015a; Szajna and Ward 2015).

A recent overview of nine systematic reviews (Parajuli and Horey 2019), including more than 200 published articles,

looked at global barriers and facilitators to health service use by refugees after resettlement. Three broad barriers were identified: those relating to refugees; those relating to health services; and those relating to the context of resettlement. Common refugee-related barriers were language; cultural and health beliefs; low literacy; refugee experiences; financial constraints; employment and physical health issues (O'Mahony and Donnelly 2010; Colucci *et al.* 2014; Hadgkiss and Renzaho 2014; Bellamy *et al.* 2015; Cheng *et al.* 2015a; Szajna and Ward 2015; Hoffman and Robertson 2016; Robertshaw *et al.* 2017; Taylor and Lamaro Haintz 2018). Health service-related barriers included lack of cultural competency; lack of knowledge about refugee health issues; difficulties working with interpreters; and time constraints (Szajna and Ward 2015; Robertshaw *et al.* 2017). Barriers in the context of resettlement included the type of health system and its flexibility; the location of services; and transport accessibility. Fewer facilitators were identified. Facilitators included continuity of care; contextualising needs; healthcare professional attitudes; and providing information about the roles of healthcare professionals (O'Mahony and Donnelly 2010; Colucci *et al.* 2014).

The nine systematic reviews included in the overview incorporated studies from developed countries with different health systems.

**What is known about the topic?**

- Barriers to accessing health care by refugees are commonly attributed to refugees themselves.

**What does this paper add?**

- Barriers related to healthcare professionals and health services that can be attributed to poor accessibility of health services by refugees were common across different studies and refugee populations.

The main aim of this narrative review was to examine Australian studies to identify any barriers and facilitators affecting the health service use of refugees in Australia. A secondary aim was to consider how healthcare professionals could address poor health service utilisation among refugees after resettlement in Australia.

**Methods**

A systematic narrative review of qualitative studies, or qualitative meta-synthesis, involves a systematic approach to synthesising findings from qualitative research and using an analytical process where findings of included studies are aggregated and interpreted as a whole (Hsieh and Shannon 2005). There are four stages: searching, screening, data extraction and analysis (Moher *et al.* 2010).

The search strategy was devised with the help of a senior university librarian and the use of the STARLITE approach, a standard for reporting literature searches (Booth 2006; Table 1).

Seven electronic databases were searched for studies published in English between 2006 and 2017. The 10-year limit was to ensure that studies reflected contemporary refugee policy in Australia. The searches were conducted twice (1 July 2017 and 21 December 2017), with search results imported into EndNote (EndNote X8, Clarivate Analytics, Philadelphia, PA, USA) and duplicates removed. Titles and abstracts were screened for

potential inclusion, and full-text articles identified for retrieval. The inclusion criteria were applied independently by two authors, with discrepancies resolved by discussion. Reference lists of included articles were scanned, and Google Scholar used to identify forward citations of included papers.

The Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines were followed to enhance transparency (Moher *et al.* 2010). The following data were extracted and tabulated: study name and year of publication; objectives; study population; data collection method; data analysis; and key findings, including any concepts, themes or metaphors that could be deemed barriers or facilitators to healthcare access (Pace *et al.* 2012). Directed content analysis was used to categorise findings as either health service barriers, refugee barriers or health service use facilitators.

Methodological quality assessment of all eligible studies was performed independently by two reviewers using the Mixed-Methods Appraisal Tool (MMAT) (Pace *et al.* 2012). Studies were assessed to be: low-average (25% of MMAT criteria met); average (50%); good (75%); or high quality (100%). Differences were resolved by discussion.

**Results**

The search strategy resulted in 297 potentially relevant titles. After duplicates were removed, 132 records were screened and 75 full-text articles retrieved and assessed for inclusion. Of these, 12 original articles met the inclusion criteria (Fig. 1). No study was discarded as the result of quality appraisal outcome.

The key characteristics of the included studies are shown in Table 2. Six studies were judged to be high quality, four good, one average and one low quality. The studies covered a range of health areas: three studies involved mental health (Gifford *et al.* 2007; Yelland *et al.* 2014; Colucci *et al.* 2015) and two studies each looked at each of the following areas: general practice (Cheng *et al.* 2015b; Jiwrajka *et al.* 2017), primary health (Omeri *et al.* 2006; Clark *et al.* 2014) and pharmacy (Kay *et al.* 2016; Bellamy *et al.* 2017). The remaining studies focussed on

**Table 1. STARLITE approach applied to reporting of the literature search**

S: Sampling strategy	<i>Comprehensive</i> : attempts to identify all relevant studies on the topic
T: Type of studies	Qualitative studies and mixed-method studies where qualitative data could be extracted
A: Approaches	Seven electronic databases; hand searching (reference lists and forward citations)
R: Range of years (start date–end date)	2006–17
L: Limits	English language, human
I: Inclusion and exclusions	Inclusion <ul style="list-style-type: none"> <li>• Refugee and/or asylum seeker population</li> <li>• Related to health service use, access or service provision</li> <li>• Australia is the country of resettlement</li> </ul> Exclusion <ul style="list-style-type: none"> <li>• Study did not identify barriers</li> <li>• No empirical data</li> <li>• Studies outside of Australia</li> <li>• Refugee*, refugee women, Asylum seekers* and health seeking behaviour*, service use, access to health services, health service utilisation, access to care, Australia, high income countries*</li> </ul>
T: Terms used	Medline, Cinahl, Psycho-Info, ProQuest Central, ProQuest Social Science and Google Scholar
E: Electronic sources	



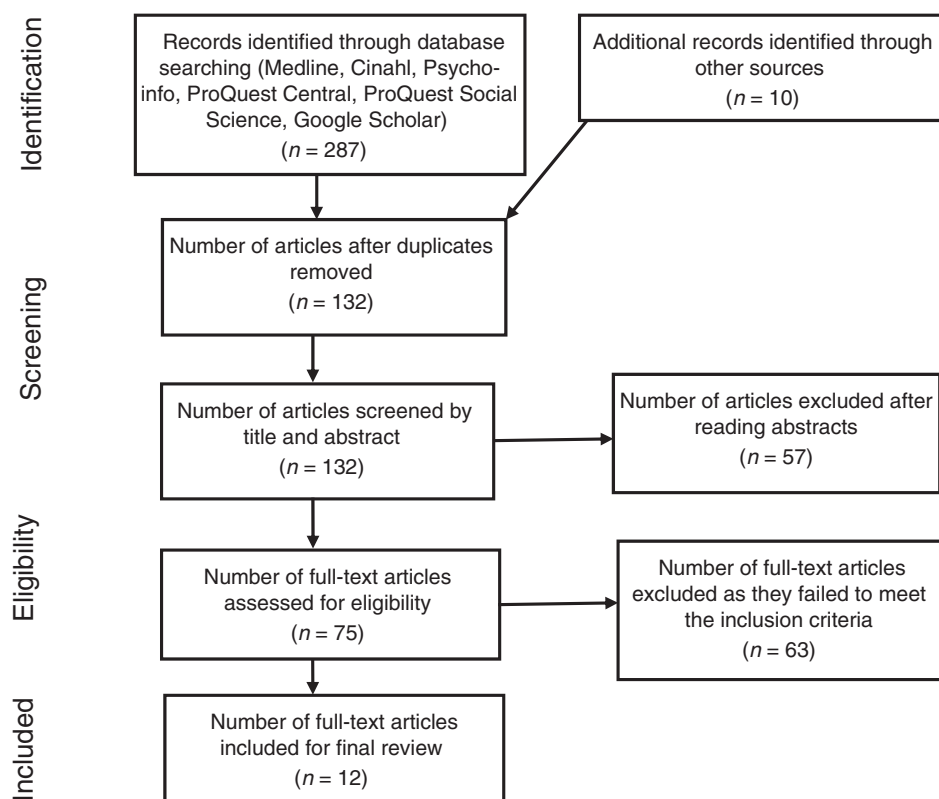


Fig. 1. PRISMA flow diagram of search result and studies selection.

maternal and child health (Riggs *et al.* 2012a), immunisation (Mahimbo *et al.* 2017) and rural health (Sypek *et al.* 2008).

Study participants were not always well described, particularly the type of health worker. More than 500 participants were involved across the 12 studies, including at least 246 health workers and at least 325 refugees.

The most common method of data collection was interviews (seven studies) and focus groups (six studies). One study supplemented interview data with field observations, and three studies collected data in multiple ways (Omeri *et al.* 2006; Cheng *et al.* 2015b; Colucci *et al.* 2015). One study, described as a case study, did not report how data were collected.

### Key findings

More barriers to health service use were identified than those things that facilitated access to health care for refugees after resettlement. Barriers identified by most studies related to gaps in knowledge and skills. Specifically, lack of cultural knowledge, poor cultural competency and poor communication skills were raised. Health service barriers were largely focussed on time constraints, but a range of service constraints and access issues were identified, including inconsistency in the use of interpreters, lack of professional experience with traumatised patients, lack of training in managing complex cases and lack of coordinated approaches to ensure continuity of care.

The issue of poor cultural understanding or cultural competency was raised in all included studies and was seen to

limit the ability of healthcare professionals to offer culturally appropriate services (Omeri *et al.* 2006; Gifford *et al.* 2007; Sypek *et al.* 2008; Riggs *et al.* 2012a; Clark *et al.* 2014; Yelland *et al.* 2014; Cheng *et al.* 2015b; Colucci *et al.* 2015; Kay *et al.* 2016; Bellamy *et al.* 2017; Jiwrajka *et al.* 2017; Mahimbo *et al.* 2017), but several studies described cultural misunderstandings among both refugees and healthcare professionals (Gifford *et al.* 2007; Sypek *et al.* 2008; Riggs *et al.* 2012a; Yelland *et al.* 2014; Cheng *et al.* 2015b; Colucci *et al.* 2015; Kay *et al.* 2016; Bellamy *et al.* 2017; Jiwrajka *et al.* 2017).

Low or poor cultural competency raised several issues. One study directly linked poor understanding of refugees' backgrounds and cultural beliefs to reducing trust (Jiwrajka *et al.* 2017). Several studies included in this review discussed how health service utilisation by refugees was directly or indirectly associated with trust (Omeri *et al.* 2006; Gifford *et al.* 2007; Sypek *et al.* 2008; Clark *et al.* 2014; Jiwrajka *et al.* 2017). For example, a rural study involving interviews with a mix of refugees, healthcare professionals and volunteers found a belief among refugees that doctors were only for very sick people. This cultural misunderstanding had not been addressed and refugees had stopped seeking care (Sypek *et al.* 2008).

Refugees new to Australia have high expectations of doctors, including beliefs that doctors will be familiar with their experiences and cultural beliefs (Sypek *et al.* 2008; Bellamy *et al.* 2017; Mahimbo *et al.* 2017), but several mismatches in cultural expectations around healthcare were evident in preventative and mental healthcare (Omeri *et al.* 2006; Gifford *et al.* 2007;

**Table 2. Key characteristics of the included studies, including health access barriers and facilitators**  
MMAT, Mixed-Methods Appraisal Tool

Reference	Aim	Study population [Data collection method and data analysis]	Barriers – health services	Findings Barriers – refugees	Facilitators	Quality rating (MMAT) <sup>A</sup>
Bellamy 2017	To explore the barriers to accessing medicines and pharmacy services among refugees in Queensland, Australia, from the perspectives of resettled African refugees.	16 refugees from different African countries [Focus group discussion with thematic analysis]	<ul style="list-style-type: none"> <li>• Gap between resettled refugees' expectations of health services and reality of the Australian health system</li> <li>• Location of services not easy to access by public transport</li> <li>• Healthcare professionals lack awareness of translating and interpreter services</li> <li>• Minimal interactive communication</li> <li>• Perceptions that physical health problems led to discrimination from healthcare professionals</li> <li>• Lack of awareness of culture and refugee experiences</li> </ul>	<ul style="list-style-type: none"> <li>• Language barriers</li> <li>• Poor access to translating and interpreter services</li> <li>• Cultural beliefs affecting healthcare-seeking behaviour</li> <li>• Poor understanding of differences in health systems in Australian and country of origin</li> <li>• Preference for traditional medicine</li> <li>• Negative perceptions of doctors</li> <li>• Preference for healthcare professional of same gender</li> </ul>	None reported	****
Clark <i>et al.</i> 2014	To identify the barriers to accessing primary healthcare services and explore medicine-related issues as experienced by refugee women in South Australia	38 refugee women from six countries (Sudan, Burundi, Congo, Burma, Afghanistan, Bhutan) and healthcare providers and experts (number not reported) [Focus groups with framework analysis]	<ul style="list-style-type: none"> <li>• Interpreter services were used inconsistently or not at all</li> <li>• Lack of information about local health services</li> <li>• Support staff not aware of locally available services including those that initiate use of interpreters or bulk bill</li> <li>• Long waiting times</li> <li>• Service location and distance</li> </ul>	<ul style="list-style-type: none"> <li>• Not being able to speak or comprehend English</li> <li>• Many refugee women had little or no education and not literate in own languages</li> <li>• Very low previous exposure to urban centres</li> <li>• Could not understand concept of western medicine and health beliefs</li> </ul>	<ul style="list-style-type: none"> <li>• Educate and support to GPs</li> <li>• Remunerate and incentivise GP clinics</li> <li>• Health literacy education for refugees</li> <li>• Register all GP clinics and pharmacies with translating agencies</li> </ul>	***
Cheng 2015b	To undertake in-depth investigation of factors influencing refugees' access to general practice services in urban general practice in Australia	Six health workers, five settlement workers and six Afghan refugees Total participants 17 [Field observations and semi-structured interviews]	<ul style="list-style-type: none"> <li>• Interpreters used infrequently</li> <li>• Cultural response of not taking health issues seriously</li> <li>• Long waiting times (average 45 min)</li> <li>• Poor access to public transport for service</li> <li>• High staff turnover</li> </ul>	<ul style="list-style-type: none"> <li>• Difficulty in making appointments over telephone due to language difficulties</li> <li>• Written language not understood including appointment cards, forms or SMS reminder message</li> <li>• Not being familiar with area and location</li> <li>• Transport issues – especially for Afghan women</li> </ul>	<ul style="list-style-type: none"> <li>• Co-location of general practice, pathology, pharmacy and counselling services</li> <li>• Coordinate appointment times with regard to transport needs</li> </ul>	***

Colucci <i>et al.</i> 2015	To explore perspectives of service providers on barriers and facilitators to engaging young people from refugee backgrounds with mental health services	115 service providers from various agencies and five key informants [Focus group discussion and key informant interviews with thematic analysis]	<ul style="list-style-type: none"> <li>• No after-hours services.</li> <li>• Service intake restrictions e.g. age</li> <li>• Lack of activity-based programs</li> <li>• Ineffective reminder systems</li> <li>• Service providers overloaded</li> <li>• High staff turnover</li> <li>• Lack of cultural competency</li> </ul>	<ul style="list-style-type: none"> <li>• Differences in time and other concepts (including location and transport)</li> <li>• Trust issue – fear of authority</li> <li>• Different concepts of mental health illness and treatment</li> <li>• Service details not known</li> <li>• Focusing on bad past experience</li> </ul>	<ul style="list-style-type: none"> <li>• Simplified referral process</li> <li>• Flexible appointment systems</li> <li>• Drop-in and outreach services</li> <li>• Key workers</li> </ul>	****
Gifford 2007	To identify the psychosocial factors that assist refugee young people to make a good start in their new country; and to describe processes that support, enhance and facilitate settlement and wellbeing	100 newly arrived refugee young people. Total participants 100 [Longitudinal ethnography study, used mixed methods]	<ul style="list-style-type: none"> <li>• Unable to establish trust</li> <li>• Lack of understanding of refugee culture</li> <li>• Lack of cultural competent services</li> <li>• Service location and transport and distance not coordinated</li> </ul>	<ul style="list-style-type: none"> <li>• Bad past refugee experiences</li> <li>• No vision of a future self among young people</li> <li>• Language and low socio-economic status</li> <li>• Feeling helpless or hopeless about future</li> <li>• Lack of social interaction and connection</li> </ul>	<ul style="list-style-type: none"> <li>• Build positive self-identity and self-esteem</li> <li>• Provide social support and social connections</li> </ul>	***
Jiwajka <i>et al.</i> 2017	To explore language differences as a barrier to health care and its near-fatal consequences, as well as communication breakdown in the context of the misalignment of health goals between the patient and the profession	1 Rohingya refugee [Case study, method of analysis not described]	<ul style="list-style-type: none"> <li>• Doctors not adequately trained to use interpreters</li> <li>• Lack of cultural competency among healthcare providers and services</li> <li>• Discordance between patient and physician's goals of treatment</li> <li>• Service location and transport and distance not coordinated</li> <li>• Untrained workers</li> </ul>	<ul style="list-style-type: none"> <li>• Language difference is a barrier in accessing health care in Australia</li> <li>• Low socioeconomic status and high chronic disease burden</li> <li>• Uncertain about migration</li> <li>• Low health literacy</li> <li>• Traditional health beliefs</li> </ul>	<ul style="list-style-type: none"> <li>• Inclusion of cultural, religious, language and social issues in patient history taking</li> </ul>	**
Kay <i>et al.</i> 2016	To explore barriers and facilitators to quality use of medicines in the primary healthcare setting	Nine primary healthcare providers (two GPs, three practice nurses, four pharmacists) and three refugee health leaders Total participants 12 [Semi-structured interviews with thematic analysis]	<ul style="list-style-type: none"> <li>• Lack of understanding regarding refugee issues</li> <li>• Interpreters not used adequately</li> <li>• Service cost</li> <li>• Lack of inter service coordination and communication</li> <li>• Poor transport links</li> </ul>	<ul style="list-style-type: none"> <li>• Communication and language barriers</li> <li>• Limited health literacy</li> <li>• Financial cost</li> <li>• Types of physical health problems</li> <li>• Lack of trust</li> </ul>	<ul style="list-style-type: none"> <li>• Better coordination between healthcare providers</li> <li>• Improve healthcare provider training</li> <li>• Improve engagement between pharmacists and refugees</li> <li>• Guidance for GPs on refugee catch-up vaccinations</li> </ul>	****
Mahimbo <i>et al.</i> 2017	To explore challenges in the provision of immunisation services to newly arrived refugees among key stakeholders to improve vaccine coverage	30 immunisation providers [In-depth interviews]	<ul style="list-style-type: none"> <li>• Variability in accessing program funding</li> <li>• Lack of national policy for catch-up immunisation for refugees</li> <li>• Unclear roles and responsibilities for catch-up immunisation</li> <li>• Lack of central immunisation register for older children and adults</li> <li>• Insufficient training among GPs</li> <li>• Lack of cultural competence</li> </ul>	<ul style="list-style-type: none"> <li>• None reported</li> </ul>	<ul style="list-style-type: none"> <li>• Guidance for GPs on refugee catch-up vaccinations</li> </ul>	***

(continued next page)



Table 2. (continued)

Reference	Aim	Study population [Data collection method and data analysis]	Barriers – health services	Findings Barriers – refugees	Facilitators	Quality rating (MMAT) <sup>A</sup>
Omeri <i>et al.</i> 2006	To explore and describe health and related resettlement issues and barriers faced by Afghan refugees in New South Wales	61 Afghan community and health service providers [Focus groups and key informant interviews]	<ul style="list-style-type: none"> <li>• Lack of information about services</li> <li>• Costs of travel</li> <li>• Long waiting times for appointments</li> <li>• Inaccessibility to services because of distance</li> <li>• Lack of health-related information</li> <li>• Lack of cultural competency</li> </ul>	<ul style="list-style-type: none"> <li>• Feelings of alienation</li> <li>• Lack of familiarity with health services</li> <li>• Cultural differences and stigma</li> <li>• Changes to roles and gender issue</li> <li>• Language barriers to accessing health services</li> <li>• No recognition of qualifications</li> </ul>	<ul style="list-style-type: none"> <li>• Implement drop-in centre to address emotional health- and settlement-related issues</li> </ul>	****
Riggs 2012a	To explore experiences of using Maternal and Child Health (MCH) services from the perspectives of refugee families and service providers	87 mothers from seven countries (Karen, Iraq, Assyria Chaldean, Lebanon, South Sudan and Bhutan) and 18 service providers Total participants 105 [Focus group discussion and in-depth interview with thematic analysis]	<ul style="list-style-type: none"> <li>• Transport difficulties</li> <li>• Language challenges working with interpreters</li> <li>• Cultural differences</li> <li>• Time constraints</li> <li>• Lack of community engagement</li> </ul>	<ul style="list-style-type: none"> <li>• Lack of awareness of available services</li> <li>• Cultural differences</li> <li>• Lack of trust</li> </ul>	<ul style="list-style-type: none"> <li>• Community engagement,</li> <li>• Central telephone line for MCH service,</li> <li>• Provision of reminders and access to translated information,</li> <li>• Use of bilingual staff</li> <li>• More home visits</li> <li>• Co-located services</li> </ul>	****
Sypek <i>et al.</i> 2008	To explore reported effect of regional resettlement of refugees on rural health services, to identify critical health infrastructure gaps for refugee resettlement	Five refugees, five GPs and practice managers and 12 volunteer support workers Total participants 24 [Case studies, interview and situational description with thematic and descriptive analysis]	<ul style="list-style-type: none"> <li>• Low healthcare practitioner numbers and high turnover of healthcare staff</li> <li>• Lack of subsidised health services</li> <li>• Lack of funding to specialist services</li> <li>• Lack of coordination of early settlement</li> <li>• Underutilisation of interpreting services</li> <li>• Problem with transport</li> </ul>	<ul style="list-style-type: none"> <li>• Mismatch in expectations of health service delivery</li> <li>• Communication difficulties due to language and culture</li> <li>• Financial constraints</li> <li>• Unfamiliarity with Australian healthcare system</li> </ul>	<ul style="list-style-type: none"> <li>• Altruism among volunteer networks</li> </ul>	***
Yelland <i>et al.</i> 2014	To explore responsiveness of health services to the social and mental health of Afghan women and men with new babies	30 Afghan refugees (16 women) and 34 health providers Total participants 64 [Interviews and focus groups discussion with thematic analysis]	<ul style="list-style-type: none"> <li>• Short appointment times</li> <li>• No questions about refugee background</li> <li>• No response to non-clinical needs</li> <li>• Lack of access to interpreters when needed</li> <li>• Lack of capacity to identify families with a refugee background and tailor services to needs</li> </ul>	<ul style="list-style-type: none"> <li>• Limited understanding of context of migration</li> <li>• Dependency of Afghan women on husbands for appointments</li> <li>• Poor access to interpreter services</li> <li>• Different healthcare professionals at each antenatal visit</li> <li>• Financial hardship</li> </ul>	<ul style="list-style-type: none"> <li>• Refugee status identification from the beginning of care</li> <li>• Continuity of care</li> </ul>	****

<sup>A</sup>Quality rating: \* = low-average (25% MMAT criteria met); \*\* = average (50%); \*\*\* = good (75%); \*\*\*\* = high quality (100%).

Sypek *et al.* 2008; Colucci *et al.* 2015; Mahimbo *et al.* 2017). These mismatches were largely differences in understandings or beliefs about disease and healthcare and assumptions about cultural awareness.

Poor knowledge of refugee health and/or culture among healthcare professionals was raised in several studies as a negative influence on appropriate service provision (Riggs *et al.* 2012a; Clark *et al.* 2014; Yelland *et al.* 2014; Colucci *et al.* 2015; Kay *et al.* 2016; Jiwrajka *et al.* 2017). In some studies, refugees reported embarrassment, shame or fear of being judged by others, including the healthcare professionals providing their care. There was fear of diagnosis with infectious disease, which was associated with concerns about the implications for family relationships, employment and the effect on acceptance of residency applications (Clark *et al.* 2014; Bellamy *et al.* 2017; Jiwrajka *et al.* 2017). Refugees were reported to rarely raise sensitive health issues such as sexual abuse, family violence, alcohol or substance abuse, or mental health problems with their care providers (Sypek *et al.* 2008; Clark *et al.* 2014; Colucci *et al.* 2015). One study suggested refugees' concerns about raising sensitive issues could be overcome by ensuring continuity of care and the use of follow-up consultations (Clark *et al.* 2014) but there were also concerns expressed that lack of resources and lack of confidence may cause some healthcare professionals to avoid refugees as clients (Clark *et al.* 2014; Jiwrajka *et al.* 2017).

Communication difficulties between healthcare professionals and refugees were widely recognised and various; consistent reasons for this were reported (Omeri *et al.* 2006; Sypek *et al.* 2008; Riggs *et al.* 2012a; Clark *et al.* 2014; Yelland *et al.* 2014; Cheng *et al.* 2015b; Colucci *et al.* 2015; Kay *et al.* 2016; Bellamy *et al.* 2017; Jiwrajka *et al.* 2017; Mahimbo *et al.* 2017). Problems with language differences continue to exist despite the national Translating and Interpreting Service (TIS), which provides free access for GPs in Australia. Several studies pointed to inconsistent use of this service among healthcare professionals (Omeri *et al.* 2006; Gifford *et al.* 2007; Sypek *et al.* 2008; Riggs *et al.* 2012a; Clark *et al.* 2014; Yelland *et al.* 2014; Colucci *et al.* 2015; Kay *et al.* 2016; Jiwrajka *et al.* 2017). The main reasons given were lack of prior awareness that a refugee would be attending and consultation times too short to facilitate interpreter use (Riggs *et al.* 2012a; Clark *et al.* 2014; Jiwrajka *et al.* 2017).

Service constraints affecting health service use were often interrelated and included transport, location of services, hours of service, waiting times, appointment availability, unavailability or inadequate supply of interpreters, high staff turnover and failure to follow up or attend appointments (Omeri *et al.* 2006; Riggs *et al.* 2012a; Clark *et al.* 2014; Cheng *et al.* 2015b; Colucci *et al.* 2015; Kay *et al.* 2016; Bellamy *et al.* 2017; Jiwrajka *et al.* 2017; Mahimbo *et al.* 2017). Failure to attend was frequently associated with poor reminder and support services (Omeri *et al.* 2006; Sypek *et al.* 2008; Riggs *et al.* 2012a; Clark *et al.* 2014; Yelland *et al.* 2014; Colucci *et al.* 2015; Jiwrajka *et al.* 2017; Mahimbo *et al.* 2017). Such factors adversely affected continuity of care.

Time constraints were raised in the majority of the studies, and related to interpreter use and insufficient time to listen to refugee stories (Gifford *et al.* 2007; Sypek *et al.* 2008; Riggs *et al.* 2012a; Clark *et al.* 2014; Cheng *et al.* 2015b; Colucci *et al.* 2015; Bellamy *et al.* 2017; Jiwrajka *et al.* 2017).

Few facilitators to health service access or utilisation were reported and when they were, these were assumed to be beneficial, without any evaluation occurring. Several unevaluated strategies were recommended including: a simplified referral process, flexible appointment systems and drop-in services (Colucci *et al.* 2015); involvement of social supports and networks, the inclusion of cultural, religious and language in history taking (Jiwrajka *et al.* 2017); training for healthcare professionals (Kay *et al.* 2016); and community engagement programs (Riggs *et al.* 2012a).

## Discussion

This meta-synthesis provides an overview of contemporary barriers and facilitators to health service access for refugees after resettlement in Australia. Barriers were consistent across a range of different types of health services. A common theme was poor cultural understanding between refugees and healthcare professionals, which was seen to inhibit trust. Lack of trust also inhibits refugees reporting of sensitive, yet important issues. This is important as lack of trust appeared to play a significant role in hindering refugees' access to appropriate and timely health care.

A mismatch in expectations between refugee clients and care providers was common, adding to other challenges (Sypek *et al.* 2008; Morris *et al.* 2009; Riggs *et al.* 2012b; Clark *et al.* 2014; Cheng *et al.* 2015b; Kay *et al.* 2016; Bellamy *et al.* 2017). The high quality of health services available in Australia impresses refugees (Taylor and Lamaro Haintz 2018); however, it also creates high expectations, particularly with medical doctors. Such expectations can be unrealistic in the Australian context; for example, some refugees assume that doctors will know how to identify and treat all exotic or rare health conditions common in their home country (Tiong *et al.* 2006; Johnston *et al.* 2012). When expectations are not met, disillusionment can follow (Khan and Amatya 2017). Refugees need explanations when this occurs, and to know how the health system will provide care for them. Healthcare professionals need to explain the processes involved in healthcare: diagnosis, treatment and how health services work, including referrals and investigations. Care plans for refugees could involve more than treatment and address social and practical issues. This can be valuable for long-term care and could help develop trust and facilitate continuity of care. When trust is lost, and when refugees don't know how to seek further care, more health problems are created (Pavlish *et al.* 2010; Fleischman *et al.* 2015).

Communication difficulties remain a significant issue for health care access among refugees (Gifford *et al.* 2007; Sypek *et al.* 2008; Correa-Velez and Ryan 2012; Clark *et al.* 2014; Colucci *et al.* 2015; Jiwrajka *et al.* 2017). A couple of potential solutions were suggested. Greater involvement of bilingual co-workers or nurses was beneficial in mental healthcare (Raval 2006), and may have a role in other areas of healthcare. More consistent use of interpreters could be achieved by better flagging of individual patient needs in appointment systems, which enable interpreter service bookings to coincide with refugee appointments (Gifford *et al.* 2007; Sypek *et al.* 2008; Correa-Velez and Ryan 2012; Clark *et al.* 2014; Colucci *et al.* 2015; Jiwrajka *et al.* 2017).

Healthcare professionals' attitudes towards their patients can be adversely affected once they are aware of their health status (Pavlish *et al.* 2010; O'Mahony *et al.* 2012). Healthcare professionals in Australia need to recognise their own cultural expectations, particularly regarding Western constructs of healthcare. Lack of acknowledgement or respect for different health beliefs and practices can hinder trust building, which delays health seeking (Grove and Zwi 2006; Metusela *et al.* 2017). All Australian healthcare professionals should be trained in basic cultural understanding (Davidson *et al.* 2004; Grove and Zwi 2006; Sypek *et al.* 2008; Correa-Velez and Ryan 2012; O'Mahony *et al.* 2012; Clark *et al.* 2014; Truong *et al.* 2017).

Continuity of care and team approaches seem to be important to refugee health. The latter requires the involvement of community organisations and specific agencies (e.g. torture and trauma services). One strategy to this end has been the development of specialised health services that focus specifically on refugees (Davidson *et al.* 2004; Correa-Velez and Ryan 2012). Some studies emphasise the need for clear referral processes, flexible appointment systems and drop-in and outreach services (Sypek *et al.* 2008; Colucci *et al.* 2015). Future studies should evaluate the effectiveness of these approaches.

The review highlights several important implications for practice. Healthcare professionals working with refugees need more support and training. Health services need to better facilitate integration across systems; for example, general practice clinics and pharmacies should be registered with translating services. Patient records should include information relevant to supporting holistic care, such as cultural, language and social needs.

The review also offers several recommendations for policymakers. Consideration should be given to how health services are expected to operate, including the development of different care models, such as drop-in and outreach services and the involvement of key workers, flexible appointments and appropriate reminder systems. Remuneration that incentivises services that meet refugees' needs should be promoted, and the location of refugee services should take into account transport issues and access to other support, particularly pharmacies and counselling. This meta-synthesis has several limitations. We included contemporary studies in Australia to get a recent picture of current practice, but there were relatively few refugee-specific qualitative studies published in the chosen period and it is possible that the search strategy may have not captured all relevant articles. It is also likely that more data may be available in the 'grey' or unpublished literature. Our restriction to qualitative studies will have reduced the number of studies eligible for inclusion. Despite these issues, the included studies involved a relatively high number of participants, and common issues were evident across different areas of practice, which suggests that the barriers identified are widespread. Understanding the issues involved is a necessary step that precedes quantitative studies.

## Conclusion

This qualitative meta-synthesis literature review was prepared with the goal of recognising and reducing barriers to health service access for refugees who have resettled in Australia.

Several implications for practice are evident that could improve healthcare experiences of refugees in Australia. This review shifts the focus from problems with refugees to shortcomings in health service delivery.

## Conflicts of interest

The authors declare no conflicts of interest.

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## **Summary**

In this chapter, through two published systematic reviews of literatures, I have outlined the trend of refugee resettlement around the world and the Australian humanitarian refugee resettlement program and its challenges. Both the papers raised the issue of health service access and utilisation of refugees in the context of resettlement and the factors affecting to health seeking behaviours of refugee and potential solutions to the issues. It was interesting to know that health service access barriers were highly apparent in the Australian literature. While these barriers appear obvious, in the next chapter, I will outline the basic concept of intersectionality theory and how this concept embrace this research from identifying the accounts of intersectional identities to the design and the discussion of the research findings.

## 4. INTERSECTIONALITY: THE THEORETICAL FRAMEWORK

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### Introduction

In this chapter I describe the concept of intersectionality which is the theoretical framework underpinning my study. I begin by briefly outlining the rationale of using this theory in my research, the historical emergence and spread of this concept, and discuss how I have applied it in my study. Using an intersectional approach allowed me to explore the multiple identities of Bhutanese refugee women and consider how such identities interact and intersect to influence behaviours in terms of accessing health care services.

The different chain of vulnerabilities that exist for Bhutanese refugee women are described in Chapter 2 and are extended into the resettlement context. The vulnerability of Bhutanese refugee women can be explained as a chain arising from a tradition of cultural patriarchy, difficult life experiences in refugee camps and the processes of resettlement.

Intersectionality helps to identify—and recognise—that this chain contains intersections of the different identities of these women, which are held both simultaneously and at different points in time in their lives.

Intersectionality supports the use of qualitative methods and a multi-axial approach in research design to understand the complexity of women's roles and status (Hankivsky & Christoffersen, 2008), which makes it suitable to exploring my research questions. An important issue that intersectionality raises is that people with multiple influences on their behaviour may appear to act in ways that appear inconsistent if a single lens is applied to analysis. For example, sometimes my behaviours are determined by my cultural background, as a Nepali woman, or my status as an educated health professional, and sometimes they are determined by a combination of these. This means that outsiders may have expectations based on one identity, which can differ from the influences in place at the time. Intersectionality recognises the impact of these influences, and analyses the different influences separately and combinedly.

This understanding is important to my thesis because it helps me to reflect on what I observe and how I interpret what I see. Using an intersectional lens, I can consider the



strategies that may be enacted to shift women's behaviours, which may be or may not be effective as expected, or may be distorted when other influences may come into play.

For this reason, it was important to have a broader view of the barriers refugees face when accessing healthcare (see Chapter 3, literature review) , and to understand systematic barriers as well as individual barriers (Parajuli & Horey, 2019a). Greater understanding of the complexity of any situation enables more effective approaches to be conceived and implemented, and to support development of appropriate policies and practices that can lead to desirable health outcomes for this group. To do this I looked at women's various identities and their associated characteristics and intersections of those, to explore the connections between women's social positions, their lived experiences, and their perceptions in accessing cervical and breast cancer screening services in a resettlement context.

## **Intersectionality**

Intersectionality emerged as a theory from the African-American feminist Kimberle Crenshaw (Crenshaw, 1989), who considered western feminist theories to be too focused on the experiences of middle-class white women and excluded race, ethnicity and cultural issues faced by women of colour, in addition to those of gender and general racial discrimination. Other feminist theorists have acknowledged the limitation of looking only at issues from a gendered perspective and support the multi-axial approach of intersectionality (Collins, 1998). Although the concept of intersectionality originally focused on black women, it has been used for women of all colours and across the broad range of different identities where they exist (Nash, 2008; Lynn Weber & Parra-Medina, 2003).

Crenshaw (1989) described intersectionality as referring to the intersection between gender, race, and other categories of difference in individual lives, in social practices, across institutional arrangements and cultural ideologies. The outcomes of such interactions in power differentials leads to various forms of oppression for individuals, families, community and social-cultural spheres (Crenshaw, 1989; Garry, 2011).

The particular intent of Crenshaw (1989) in using the term 'intersectionality' was to draw attention to the marginalisation of black women's experiences within the single-axis frameworks used in antidiscrimination laws, feminist theories and anti-racist politics which

refer to only one point of difference, either gender *or* race where Crenshaw pointed out the multiplier effect of gender *and* race. According to Crenshaw, the intersection of such characteristics is a crossroad where all aspects of identity simultaneously are separate and joined, and multiple identities, or social locations, exist. Through this crossroads metaphor, Crenshaw explained that the more social locations a person occupies—defined by their race, their gender, their class or even their age—the more difficult it can be to cross the intersections and exist free of obstruction or oppression. Crenshaw argued that an intersectional analysis should include both feminist *and* anti-racist theories (Crenshaw, 1989). She illustrates this idea through an analogy with traffic:

Discrimination, like traffic through an intersection, may flow in one direction, and it may flow in another. If an accident happens in an intersection, it can be caused by cars traveling from any number of directions and, sometimes, from all of them. Similarly, if a Black woman is harmed because she is at the intersection, her injury could result from sex discrimination or race discrimination (Crenshaw, 1989, p. 149).

Crenshaw encouraged examination of how different systems of oppression intersect and affect any group of women in different ways, ways that all contribute to discrimination, resulting in inequalities and inequities (Crenshaw, 1989; Davis, 2008; S. Guruge & N. Khanlou, 2004; Phoenix, 2006). The chain of vulnerability described in Chapter 2 shows how this occurs for Bhutanese refugee women. Garry (2011) supported Crenshaw's approach and added that oppression and privilege by race, ethnicity, gender, sexual orientation, class, and nationality do not act independently in individual lives, or in group dynamics and social structures, rather they are intermeshed within our social relations, in our own experiences of each person's identity and shared interests—even among members of the same group (Crenshaw, 1989; Garry, 2011).

In her essay, Ann Garry claimed that intersectionality is inclusive, modest, and capable of providing a plan of action to meet the theoretical and practical needs of women in general (Garry, 2011). Failure to use an intersectional approach often leads to unsatisfactory outcomes as there is no consideration of how the multiple characteristics of women interact to affect implementation (Garry, 2011; Krieger, 2014).



Simply defining people by their differences, such as their race, class, age or gender, can also create oppressive processes. Intersectionality shows that rather than seeing people as simple categories, these characteristics interconnect to form social identities that influence outcomes. For example, in case examples of pre and post migration health of refugee and immigrant women, the intersection of their pre-migration history and post-migration status remains a major predictor of better health outcomes (Sepali Guruge & Nazilla Khanlou, 2004; Parajuli & Horey, 2019a). By recognising the different layers of, and the extent to which, various factors contribute to discrimination, intersectionality adds to our understanding of the causes of inequalities and inequities (Nash, 2008; Phoenix, 2006). Intersectionality does not limit identities to just race or gender, but helps to show that individual behaviours, beliefs, and other factors may also influence the identities of people (Hankivsky & Christoffersen, 2008; Springer, Hankivsky, & Bates, 2012). For Bhutanese refugee women, this multiplier effect is evident in the exploration of their vulnerabilities (as shown in Chapter 2).

The concept of intersectionality initiated as a critique of feminist works to show that women are positioned by several different identities, which up until that time were invisible (Crenshaw, 1989). Since then, intersectionality has provided a lens to 'see' the multiple identities of women and helped to better understand women's experience of discrimination beyond that of race and gender alone. Migration experience, language, sexual orientation and social class have all been shown to play important identity roles, and to influence how people see themselves, how others see them and how their behaviour is determined (Davis, 2008; Phoenix, 2006). Such multiple identities, commonly mentioned in relation to intersectionality, are said to interact by mutually *strengthening* or *weakening* each other and the consequent degree of inequality (Bowleg, 2012; Crenshaw, 1989; Phoenix, 2006). For example, Bhutanese refugee women's gender is highly relevant as they are from a strongly patriarchal system, where female access to education is commonly limited in their home. Their refugee identity in the camps also reinforces this aspect of their vulnerability. Access to education in the refugee camps is limited and there is little to counteract information from traditional sources such as healing beliefs and remedies. Such factors may strengthen how Bhutanese refugee women see themselves and influence their health seeking behaviours even after resettlement.

## **Critiques of intersectionality**

Despite the status of intersectionality as the 'gold standard' multidisciplinary approach for analysing women's lived experiences (Phoenix, 2006; Springer et al., 2012) the concept has been criticised for its potential to create confusion, and for inconsistency and ambiguity in the use of the term (Davis, 2008). Intersectionality has even been described as too open (Phoenix, 2006), yet ironically, it is the openness and inclusive nature of intersectionality that are considered major strengths, because it enables several theoretical frameworks to be used when researching the experiences of women with diverse backgrounds (Samuels & Ross-Sheriff, 2008; Trahan, 2010). The ambiguity of the term mirrors the identities of the women it seeks to understand.

Phoenix (2006) concluded that 'no concept is perfect and none can ever accomplish the understanding and explanation of all that needs to be understood and explained within the field of women studies' (Phoenix, 2006, p. 191). Imperfections of intersectionality are unavoidable, but its lack of specific parameters has enabled it to be used in nearly any kind of inquiry where new intersections and new connections may emerge, and where previously hidden conclusions may come to light. Davis (2008) summarised it this way:

intersectionality, by virtue of its vagueness and inherent open-endedness, initiates a process of discovery which not only is potentially interminable but promises to yield new and more comprehensive and reflexively critical insights (Davis, 2008, p. 77).

Over recent years, intersectionality has become a popular way to understand co-constituted differences that exist in feminism, and in doing so has become not only a theory, but also a research paradigm, as noted by Hancock (Hancock, 2007). By going beyond the initial scope of the study of non-white women, intersectionality is now considered a research standard for the study of marginalised identities and is applied more widely to the study of different social groups (Dhamoon, 2010; Moradi & Grzanka, 2017; Patil, 2013). In many ways intersectionality stimulates the creation of new questions and encourages complexity and the exploration of new areas and old areas in new ways (Davis, 2008; Krieger, 2014; Muntinga, Krajenbrink, Peerdeman, Croiset, & Verdonk, 2016; Phoenix, 2006). An intersectional approach has been used in research to examine the areas of gender and race, in recognising that society has multiple systems of social stratification, where every

individual's position has an associated identity (Giritli & Olofsson, 2014; Patil, 2013) for example in the patriarchal Bhutanese culture, where male domination is strong, and impact of gender discrimination is likely to be far reaching.

### **The use of intersectionality in my research context**

My research population group, Bhutanese refugee women who resettled in Melbourne within the last decade, provides such a field for an intersectional approach. These women have come from conditions very different to resettlement context in Australia and their culturally lived experiences intersect and interact in a situation where they spent long time without proper access to basic needs such as housing, food, and education (Ferguson, 2011). High-income countries such as Australia bring new challenges for these women, including a culture that promotes and values individuality, self-expression, and independence.

The use of intersectionality provides a way for me as a researcher to gain insight beyond my professional role as a nurse as it allows for a more complex and dynamic framework to analyse human experiences (Marecek, 2016). This is important in my understanding of Bhutanese refugees which has evolved from the refugee camps in Nepal to my role now: seeing similar women who have resettled in Melbourne. Some differences between us remain, for example they are refugees, I am not. In Australia other differences place us both apart from the dominant Anglo population. Both myself and Bhutanese refugees have become 'non-white', which was not an identity for any of us in Nepal or Bhutan. Adaptation of identity is a developmental process that can be understood from a multi-axial approach and is influenced by self-identity and by personal affiliations within a social group (Bauer, 2014). Bhutanese refugee women are part of a social community in Melbourne which reinforces one common identity across the group with common cultural interests and values, that can interact in ways that impact their health and wellbeing. An intersectional approach offered a way to differentiate between the experiences of refugee women and the perceptions of those holding social positions such as myself (L. Weber & Hilfinger Messias, 2012).

### **Intersectionality and women's health research**

Women's health research strives to make changes by seeking knowledge that promotes action affecting women's health. The use of gender as a health determinant has motivated

researchers to question social norms and structures, and to investigate variation in how women experience and reflect on different aspects of their health, including access to preventative and curative measures, the burden of ill health, and quality of care (Hankivsky O et al., 2010). Adding an intersectional approach to women's health research enriches the attention given to inequalities (Hankivsky & Christoffersen, 2008). An intersectional approach encourages a contextual analysis that goes beyond the single identities and experiences of women, and considers numerous factors that are at play that influence health outcomes of the disadvantaged (Hankivsky & Christoffersen, 2008)

Intersectionality has been used in health research and it can be group-, process- or system-centred (Choo & Ferree, 2010; Giritli & Olofsson, 2014). Pragmatic intersectional studies are largely group-centred, where lived experiences of oppression cannot be separated into single issues of class, race, or gender, as they are actually intertwined (Giritli & Olofsson, 2014). A process-centred approach views intersectionality as relational, and looks at the relationships between processes and power, where interaction between variables increases oppression. A process-centred approach is used mainly in comparative, multi-level analysis to draw attention to a previously unidentified issue. A system-centred approach of intersectionality considers where gender and race are embedded in the framework of an organisation's or system's structures (Giritli & Olofsson, 2014). These three approaches have been used independently (Choo & Ferree, 2010), or in combination within the same study (Choo & Ferree, 2010; Giritli & Olofsson, 2014). In thinking about planning future research, the approach practiced would depend on the actual research question, but insights from one approach may further understandings of where changes are needed in other areas. For example, a group-approach may reveal the need for process or system changes (Choo & Ferree, 2010; Giritli & Olofsson, 2014), or a systems approach may show that more attention is needed on the experiences of individuals.

An intersectional approach to women's health research can enrich the attention given to the inequalities between women that are caused by various factors, and help to focus on differences between women and to analyse interacting social factors affecting their lives (Hankivsky & Christoffersen, 2008). By questioning of the meanings and relationships that exist between different social groups, intersectionality can help to disclose the dynamics of

power, and in doing so reveal new knowledge about health disparities across different critical dimensions of social inequality (Green, Evans, & Subramanian, 2017; Hankivsky O et al., 2010), including experiences of oppression or disadvantage (Choo & Ferree, 2010; Collins, 1998). These contributors to inequality in health care are important to consider when thinking about refugees as similar issues contribute to their sense of vulnerability after resettlement (Parajuli & Horey, 2019a)

An intersectional approach has been shown to be particularly useful in terms of women's health research (S. Guruge & N. Khanlou, 2004; Tastsoglou, Abidi, Brigham, & Lange, 2014). For example, despite female gender being commonly resilient in terms of health outcomes, in some societies, the roles of women place them at greater risk. In cultures where women are expected to perform the vast majority of household work there are often expectations or controls around what women can eat, wear, where they can go and with whom they can interact. Such gender roles imposed on women can inhibit their freedom, foster poor self-esteem, encourage lower levels of achievement and consequently, lead to poorer health outcomes (Collins, 1998; Garry, 2011; L. Weber & Hilfinger Messias, 2012). Women who are disadvantaged tend to be disadvantaged in multiple ways.

Similarly, in my study intersectionality offers the grounds in which to explore the intersections of the multiple identities of Bhutanese women that manifest within their self-perceptions, in their homes, and in their communities. This means that intersectionality allows an examination of women's individual experiences within the complex socio-economic, historical, political, social and family structures and dynamics in their pre- (refugee camps) and post- (Australia) resettlement conditions.

As I needed to consider not only the social groups these women inhabit, but also those from which they are excluded, intersectionality logically guided the development of my study, where intersections that are usually to be difficult for women in this study. I needed to take a view of the potential differences among women and their behavioural response to accessing preventive cancer screening services in a resettlement context.

## **Summary**

As the concept of intersectionality has become common application in recent research work—specifically when it involves researching a specific phenomenon in a specific group of people. In this chapter, I highlighted how intersectionality with its multi-axial approach, is relevant to conceptualise, theorise and analyse Bhutanese refugee women's own lived experiences before, during, and after resettlement. I provided examples of other research that used this conceptual framework and aligned those examples and the notion of intersectionality to the examination of connections between the multiple identities of Bhutanese refugee women, and their intersections in the study design, analysis and in interpretations of study findings. While, the application of intersectionality theory to this study would answer the question of how these interconnected identities influence Bhutanese refugee women's health-seeking behaviour in the resettlement context, in the next chapter I will discuss the methodology that goes along with this concept and informs this research.

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## 5. STUDY DESIGN AND METHODOLOGY

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This chapter outlines the methodology and research design that I used to address my research questions which relate to the lived experiences of a group of vulnerable people and is a potentially sensitive topic.

- What are the perceptions and experiences 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 are the women's preferred model of care to enhance the accessibility and use of cervical and breast cancer screening services?

These questions raised important methodological challenges and considerations for me as a researcher. These challenges and the methodological frameworks used to inform the research design are discussed in this chapter.

First, I must address the influence of my multiple roles on my research approach. These roles which are woven into my personal history, were raised in earlier chapters but in this chapter, I reflect on how these roles were likely to impact this research.

### **My multiple roles: Nepalese migrant woman, refugee health nurse and researcher**

I came into this study with three significant roles (or identities). I am a Nepalese migrant woman, a refugee health nurse and a women's health researcher.

My personal journey is outlined in Chapter 1, which describes how I came to do this study. My Nepalese background means that there are common elements between my life and those of the Bhutanese refugee women I came to include in my study. We share the same religion, the same language and the same culture and we have all resettled in Melbourne, Australia.

As a Nepalese woman I share many social, cultural and linguistic characteristics with my Bhutanese research participants, and my roles can be considered instrumental and critical

to my study (Ramji, 2008; Rowland, 2011). These shared characteristics meant that as a researcher I am an 'insider' with cultural commonality and socialisation that can reduce cultural and linguistic barriers (Maylor, 2009; Ramji, 2008). This is not unusual, undertaking research with people and communities who share a common background, language, race, ethnicity, nationality or heritage (Dwyer & Buckle, 2009).

However, I am neither from Bhutan, nor a humanitarian refugee. I arrived in Australia approximately five years ago as a migrant before the resettlement of the first Bhutanese refugees. I am educated, both in my home country of Nepal and in my adopted country, Australia. My experience of refugee camps was as an employed registered nurse. During my 6 years working in refugee camps, that I gained valuable insights into refugees' journeys (see Chapter 2). In Melbourne, I am active in the Nepalese community, but my relationships with refugees are through my professional role as a refugee health nurse in a local community health centre.

Unlike the women in my study, I haven't experienced the difficulties of being a refugee. I have not lived in refugee camps for many years with scarce resources such as food and healthcare. Many Bhutanese refugee women are uneducated, but I am tertiary educated. My social networks include people from many different backgrounds, whereas many refugees, particularly women, have limited social contacts (O'Mahony & Donnelly, 2010). While English is my second language, I didn't face the same language barriers settling in Australia as many Bhutanese refugees have done.

These differences mean that I also consider myself an 'outsider' in the context of this research (Dwyer & Buckle, 2009). Sharan Marram and colleagues 2001, suggest that 'being an insider means easy access, the ability to ask more meaningful questions, and read non-verbal cues and most importantly be able to project a more truthful, authentic understanding of the culture under study' (Liamputtong 2010, p.112). Whereas 'becoming an outsider also has its own usefulness, such as providing different perspectives on cultural and community norms, asking questions that require more detailed explanations and developing other forms of interaction often relegated to non-members.' (Liamputtong 2010 p.115).

My multiple roles could offer several advantages, there could be opportunities for study participants to accept and trust me as one of their own, so as an insider they would be more open to sharing their experiences. My previous experiences working in refugee camps could enhance open communication during interviews, particularly as a woman who places concern on women's health issues; many participants have never talked about women's health issues to anyone before. In practice, the refugee women in my study simply addressed me as 'sister' as a way of expressing the close relationship we shared culturally. Their stories were shared without hesitation. They trusted me to share very sensitive issues as I was not insider enough to know their immediate family members or close social relatives and networks. I was enough of an outsider for the women to feel that there was no risk of their stories being shared with other community members (C. Marsh, Browne, Taylor, & Davis, 2017).

My position as insider/outsider provided benefits as it afforded me easy access and provided common ground to begin the research. I had some risks as there was the potential to impede the research process as it progressed (Dwyer & Buckle, 2009). Hence, I was conscious during the whole interviewing process to avoid participant's familiarity with me which could hinder their individual stories and experiences.

## **Researching a vulnerable group**

Issues relating to researching vulnerable groups are discussed in Chapter 2. In essence, methodologies concerned with researching vulnerable people will depend on how a specific type of vulnerability is perceived by individuals and by social groups (Aldridge, 2015)

In general, vulnerability can be grouped in different ways and people can be susceptible to vulnerability at any given time in their life (Aldridge, 2015; Plummer & Young, 2010; Rowland, 2011). For some people recognition of their vulnerability could mean developing strategies to meet their needs and eventually alleviate their vulnerability. This is particularly true in health and social care contexts. In Australia, refugee and asylum seekers are recognised as vulnerable groups, giving them higher priority in the provision of healthcare services (Department of Health and Human Services, 2019). However, self-perceptions of vulnerability may not always accord with the views of others (Rose, 2016; Wangdahl, Lytsy,

Martensson, & Westerling, 2015), and vulnerabilities attributed to populations may not apply to individuals within that group. For example, many refugees see themselves as resilient (Pyer & Campbell, 2012) whereas for others vulnerabilities can compound and some people are described as doubly vulnerable (Aldridge, 2015).

Compounded vulnerabilities (See Chapter 2, Figure 1) exist for many Bhutanese refugee women and need to be considered in many aspects of research involving this population group such as recruitment, data collection and the processes related to data interpretation. As Chapter 2 showed, the chain of compounded vulnerability for Bhutanese refugee women arises from a tradition of cultural patriarchy, difficult life journeys and the process of resettlement, and so a study that focuses on their lived experiences needs to ensure that the needs of the study participants are at the centre of the research process and enables them to tell their stories in their own way (Wilson & Neville, 2009).

An important contributor to vulnerability can be low literacy. Research involving a population with low literacy encounters challenges that need to be addressed, for example, in how consent to participate is achieved and in how data are collected. Strategies used to gain consent in low-literacy populations often require one-on-one conversations and built-in checks to confirm understanding. Clearly separating different components of complex decisions into simple steps and using diagrams and photographs can all facilitate understanding (Kraft 2018).

## **Photograph elicitation**

Collecting data through in-depth interviews is a common practice in qualitative research. However, there can be times when additional strategies are needed. Photo elicitation, which involves the use of photographs to initiate data gathering conversations, is commonly used to overcome the hurdle of illiteracy, for example Muhamad (2019) used photograph elicitation to help women discuss sexual experiences that they found hard to talk about (Muhamad, Horey, Liamputtong, Low, & Sidi, 2019). In this study I used this method to initiate discussions with participants by using some relevant photographs to provide some idea to the participants about cervical and breast cancer screening.

Photographs are used to either prompt responses or to address gaps in knowledge and cultural experiences (Harper, 2002; Liamputtong, 2007); photographs are also used by researchers as a tool to expand on questions, and by participants to identify images that can communicate their experiences visually (Clark-Ibanez, 2004; Harper, 2002). Photographs can enable participants to visualise and confirm their experiences, which can be empowering for them (Liamputtong, 2007; Oliffe & Bottorff, 2007).

In his paper outlining the history of photo elicitation, Douglas Harper (2002) reported that the photo elicitation method was first named in a paper by researcher John Collier in 1957 when he used this method to examine the mental health in changing communities in Canada. Collier later noted that when he used photographs in interviews, the interviews were longer and more comprehensive. He concluded that using this approach allowed researchers to explore latent memories by stimulating individual emotional statements about an informant's life (Harper, 2002).

## **Researching a sensitive topic**

Similar to vulnerability, the sensitivity of a research topic depends on the particular groups or populations involved. This can be particularly apparent in research into women's health issues. For example, women who hold conservative views in relation to talking about their bodies are more likely to find it difficult to share their lived experiences, even the use of particular health services can be very sensitive, and difficult, for them to talk about (Dickson-Swift, James, Kippen, & Liamputtong, 2007; Muhamad et al., 2019).

Research commonly deemed to be sensitive includes studies where participants need to disclose behaviours or viewpoints that under normal circumstances would be considered private and personal, and that when revealed could cause discomfort or disapproval (Liamputtong, 2007; McCosker, Barnard, & Gerber, 2001). Sensitive topics are usually defined in reference to context and place, where population, culture, political situation or other phenomenon are associated with potential fear of stigmatisation (Dickson-Swift et al., 2007; C. A. Marsh, Browne, Taylor, & Davis, 2016). Research can be seen as sensitive when it potentially poses a substantial threat to those who are, or have been, involved in it. Many phenomena within specific cultural and social contexts can be seen as sensitive not only to

the participants, but also to the researcher and research team (Dickson-Swift et al., 2007). Therefore, researchers undertaking qualitative research on sensitive topics need to reflect on the impact of the topic, and participants' potential response to it, and be alert to the possibility that difficult issues may be raised.

Sensitive topics and sensitive content can create barriers to participation in research, even when the study focus recounts only indirectly, such as with preventive health screening. This can be because of the nature of the screening process, or because of the potential consequences that screening can lead to (Fahie, 2014). Culturally women may not be able to freely share their viewpoints due to the 'sacred' value given to their body or body parts, the importance of shyness and reluctance to talk about issues for which they may not have language to describe (Muhamad et al., 2019). A research topic that is considered sensitive may affect recruitment, and researchers need to consider how to approach the right group in the best way.

Data collection processes can also be influenced when research looks at sensitive topics. Researchers need to take particular care to demonstrate to potential participants that they are trustworthy, and to create safe environments when collecting data. Care with using the appropriate language and phrases with relevant cultural understanding is critical. The gender, social status and occupation of the researcher can also be significant. Health professionals can often collect data not available or appropriate for others to gather (Muhamad et al., 2019).

A methodological framework for research involving a sensitive topic and/or a vulnerable group can be helpful in ensuring study rigor. For example qualitative research is more suited to the study of sensitive topics as it does not assume prior knowledge of people's experiences and seeks to understand the world view of research participants based on the interpretative paradigm that participants often share private information about certain aspects of their lives that they would not normally (Dickson-Swift et al., 2007) .

## Methodological frameworks

All research is framed, either implicitly or explicitly by an underpinning theory or conceptual framework. This study was informed by the concept of intersectionality (See Chapter 4) and the research design was based on phenomenological and feminist frameworks. The lens of intersectionality helped clarify the necessity of acknowledging multiple aspects of identity to gain deeper understanding of a person's experience (See Chapter 4). This was very important to my study with its focus on the experiences of refugee women after resettlement, as the study involved multiple layers of complexity. The background of the study population and their multiple vulnerabilities, and their causes, were likely to feature in the interviews.

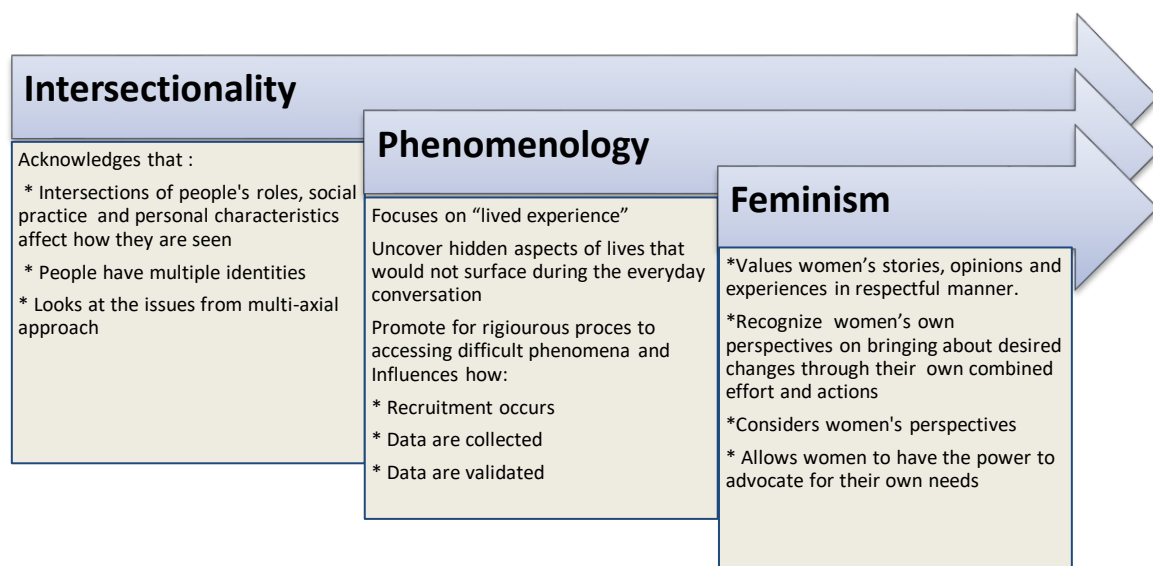
Intersectionality has expanded the views of many feminist scholars to look beyond their interests for ways to use the concept in their research enquiries (Davis, 2008; Springer, Hankivsky, & Bates, 2012). Differences across women have become the leading concerns since the concept of intersectionality emerged, and has brought ways to understand the impact of race, class and gender on women's identities, experiences, and struggles for empowerment (Davis, 2008; Maria, Rees Charlotte E, Monrouxe Lynn V, & Vanita, 2011; Patil, 2013). The marginalisation of poor women and women of colour have become a main concern of intersectionality research inquiry (Bowleg, 2012; Davis, 2008; Green, Evans, & Subramanian, 2017)

My research questions are concerned with access to preventive health services, and it is in situations like this, that multiple identities can interact and possibly even compete to influence behaviours (Bowleg, 2012). To capture the interplay of the different needs of influencing behaviours I used a combination of phenomenology and feminist methodological frameworks to determine what approach my research needed to take.

Phenomenology allows exploration of people's lived experiences and helps to understand how people make meanings of those experiences (Pascal, Johnson, Dore, & Trainor, 2011). It does not necessarily place an explicit value on the role and work of women, whereas a feminist framework explicitly ensures that the value of women's lives is acknowledged and reflected in any analysis (Plummer & Young, 2010). This consideration is particularly

important when researching a vulnerable group of women who come from a strong patriarchal heritage. Particular aspects in the research design that need to be considered are: participant recruitment, data collection, data analysis, interpretation and dissemination.

The combined application of these two methodological frameworks ensures that thought is given to how recruitment for the study is targeted, how data collection and analysis, and interpretation maintain rigor and respect for study participants, and how dissemination of study findings is conducted with safety. Figure 1 shows the relationship between these underpinning concepts and frameworks.



**Figure 1: Overview of methodological framework**

The primary purpose of phenomenology is to investigate and describe 'lived experiences' or phenomena as they are consciously experienced (Pascal et al., 2011) and offers a rigorous descriptive approach for accessing difficult situations (Giorgi, 1997), including sensitive issues (Dickson-Swift et al., 2007; Liamputtong, 2007; Pascal et al., 2011). Phenomenology is seen to open opportunities for study participants 'to see the world again' and discover the meaning and essence of their experiences (Conklin, 2007) Phenomenology does not assume prior understanding, rather it develops understanding and uses the meaning constructed by participants in the moment (Carpenter, 2013) (Giorgi, 2012).

Feminist methodology imposes an explicit value on research by making clear that women's lives and experiences are important and that the body of knowledge gained from women's



experience can be used for women's own benefit (Varcoe & Thorne 1998), and that women's life experiences should be treated in a respectful manner (Carpenter, 2013).

Traditionally research is considered to have ignored the importance of women's issues, denied women's experiences and silenced women's voices (Routledge, 2007; Varcoe & Thorne 1998). The introduction of feminist methodology has shifted women's experiences to the forefront and has focused inquiry on these life experiences and the impact of oppression in cultural contexts (Campbell & Wasco, 2000; Carpenter, 2013). Feminist research generally calls for qualitative enquiry that is less structured and more flexible than others, allowing women to have the power to advocate for their own needs (Campbell & Wasco, 2000; Liamputtong, 2012).

Gender differences in health have been a major factor in the prevalence of disease for many reasons. Gender-based roles are socially constructed, as are the roles men and women play within their families and in subsequent relationships, and often produces unexpected health risks due to social roles and social expectations (Collins, 1998; Garry, 2011; Guruge, Hunter, Barker, McNally, & Magalhaes, 2010; Samuels & Ross-Sheriff, 2008). For example, deeply held cultural views about masculinity in western culture and the behavioural patterns developed from such beliefs can have adverse consequences for health. Compared to women, men are more likely to smoke, and twice as likely to consume higher volumes of alcohol regularly as a result, men have death rates that are at least twice as high as those of women (Bauer, 2014; Collins, 1998).

Despite female gender being commonly protective in terms of health outcomes, in some societies, the roles of women place them at greater risk. In cultures where women are expected to perform the vast majority of household work there are often expectations or controls around what women can eat, wear, where they can go and with whom they can interact. Such gender roles imposed on women can inhibit their freedom, foster poor self-esteem, encourage lower levels of achievement and consequently, lead to poorer health outcomes (Collins, 1998; Garry, 2011; Weber & Hilfinger Messias, 2012). Women who are disadvantaged tend to be disadvantaged in multiple ways.

Race, gender, class, and sexuality are contextual and continuously changing. These characteristics have never been static or fixed throughout history (Bonstead-Bruns & Weber, 2002; Maria et al., 2011; Patil, 2013). Their meaning varies not only across historical time periods, but also across national and regional boundaries within the same period. On the other hand, they are social constructs whose meaning develops out of groups (Bonstead-Bruns & Weber, 2002; Maria et al., 2011). Despite this race, class and gender relations are embedded culturally and have meaning in the everyday lives of individuals, and at the broader levels of community and social institutions. (Bonstead-Bruns & Weber, 2002; Collins, 1998).

My goal in this research was to follow the basic principle of feminist theory by putting women's perspectives at the centre of my study by highlighting their experiences, their ideas and their awareness (Routledge, 2007). Meanings related to their viewpoints are likely to influence the various forces surrounding them (Tindall, 2009). This will affect issues like their relationship to cervical and breast cancer screening services. Understanding the alignment of a feminist approach with phenomenology would allow me to consider how to approach women to take part in the study and conduct interviews in ways that deliver richness in the data (Plummer & Young, 2010), rigor and reflexivity in my research practice (Wuest, 1995).

## **Research Method**

This study used in-depth interviews to explore the lived experiences of accessing cervical and breast cancer screening services in Australia of Bhutanese refugee women who had resettled in that country.

The women were asked about their participation in cancer screening programs, their knowledge and understanding of the importance of cervical and breast cancer screening, the health risks and benefits of doing screening tests, barriers to accessing these types of services, and their ideas for a possible 'best practice' model that would increase participation of Bhutanese women in cancer screening programs.

The application of a phenomenological framework was relevant to my study for the following reasons:

- Bhutanese refugee women are a newly emerging population in Australia who are bound within their own society and almost entirely affected by their own societal and cultural norms. As a hard-to-reach population, phenomenology allows inclusion and acknowledgement of their life experiences and the meanings that they make of them (Carpenter, 2013; Pascal et al., 2011).
- The research topic is sensitive, particularly given the cultural context of the Bhutanese community, where talking about women's bodies is taboo. Phenomenology enables engagement, interpretation and reflection on women's experiences without judgement (Conklin, 2007; Pascal et al., 2011)
- Phenomenology allows exploration of individuals and groups of people, explaining those changes and uncovering hidden aspects of lives that would not surface during the course of everyday conversation (Carpenter, 2013), regardless of the long-term cultural status of women as second-class citizens, which hinders communication patterns and decision-making processes. This is particularly important in relation to my research questions about seeking health information and accessing health services.

## **Research participants**

Bhutanese refugee women settled in Melbourne aged 18-72 years of age who were married or, who had been married, were identified as potential study participants. This age range was chosen to align with the national cervical and breast cancer screening protocols. At the time of recruitment to my study the protocol for cervical cancer screening recommended women aged 18-72 years undertake screening. This recommended was amended in 2017 to women aged 25-72 years. The protocol for breast cancer screening recommends that women aged between 50-72 years have two-yearly mammograms. In Australia, screening mammograms are freely available for this group.

The inclusion criteria for my study were:

- For cervical cancer screening – married women aged between 18-72 years.
- For breast cancer screening – women aged between 50–72 years.

Unmarried women were excluded from inclusion to avoid cultural stigmatisation related to sexual activity outside marriage.

## **Sampling strategies**

### **Purposive sampling**

A purposive sampling technique was adopted. Recruitment continued until data saturation occurred (Tuckett, 2004).

### **Participant selection**

Brief information about the study in the Nepali language and English was widely disseminated in the Bhutanese community by using locally available resources and networks prior to commencing the study. Feedback and suggestions from the community members were incorporated into the recruitment strategies. Community leaders collected the names and contact phone numbers of women who indicated interest in taking part in the study. I contacted each woman directly and explained the study to them. At this stage, some women also nominated someone else who was also interested. I was given 15–20 names with a further 10–15 women identified through snowballing. Only one woman declined to participate after being contacted.

### **Data collection procedure**

This study took place in Melbourne, Australia. All interviews took place in the homes of participants in separate rooms, as this is where they felt most comfortable although all were offered the option of another location.

Prior to the interviews, a study information sheet in Nepali language was given to potential participants with a full verbal explanation of the research process, including how confidentiality would be managed. I conducted all interviews myself and only after informed consent was obtained.

All participants were provided with consent forms and plain language statements in Nepali prior to the interviews, explaining the details and significance of the research. I re-explained the research verbally to make sure that they understood, and they could withdraw their

participation at any time during the interview. This explanation was particularly important to this group of women who were mostly illiterate. All participants chose their own pseudonyms to ensure and maintain their confidentiality.

Each interview took between 45 and 90 minutes and was based on an interview guide which had been trialled and modified after the first three interviews. The interview guide focussed on perceived identity, resettlement experiences, and barriers and experiences of accessing and using women's health services, in particular cervical and breast cancer screening.

Women were also asked about their ideas for improving these types of services. The guide was developed from the literature and modified after the three initial interviews by incorporating field notes taken during the interviews.

Photo elicitation methods were employed when women were unsure of the questions. This included when women didn't have any concept of breast or cervical cancer screening.

Photographs were used to explain what questions referred to and to prompt recall of events (Liamputtong, 2007). Photo-elicitation was used for seven women. All women were asked about cervical cancer screening. Women aged 50 years or older were also asked about breast cancer screening. I conducted all interviews and recorded them on two devices.

### **Data collection methods**

In-depth interviews were used to elicit rich information. I wanted the women I interviewed to be able to express their real feelings and their thoughts in their own way.

I used photo elicitation to supplement the in-depth interviews and to overcome poor health literacy. The relevant photographs I used related to cervical cancer screening and breast cancer screening (mammogram). The images included: women getting ready for and undergoing cervical and breast cancer screening, a normal breast; a breast with lumps; and a diagram of female reproductive organs.

The photographs were used to initiate discussions with the women, to confirm whether the women had ever attended cervical and breast cancer screening services, and to explore their knowledge and experiences, and the meanings they gave to them. Simultaneously, this method is enabling and liberating to participants by making their experience visible and by decentralizing researcher authority in the process of gathering information (Liamputtong,

2007; Oliffe & Bottorff, 2007). Using photo elicitation as a method empowers research participants and provides them with more authority than the researcher. As a consequence, this method is considered suitable for vulnerable people (Liamputtong, 2007), and has also attracted modest interest in health research, especially when it comes to researching within vulnerable populations about sensitive topics (Liamputtong, 2007; Oliffe & Bottorff, 2007).

### **Data coding and analysis**

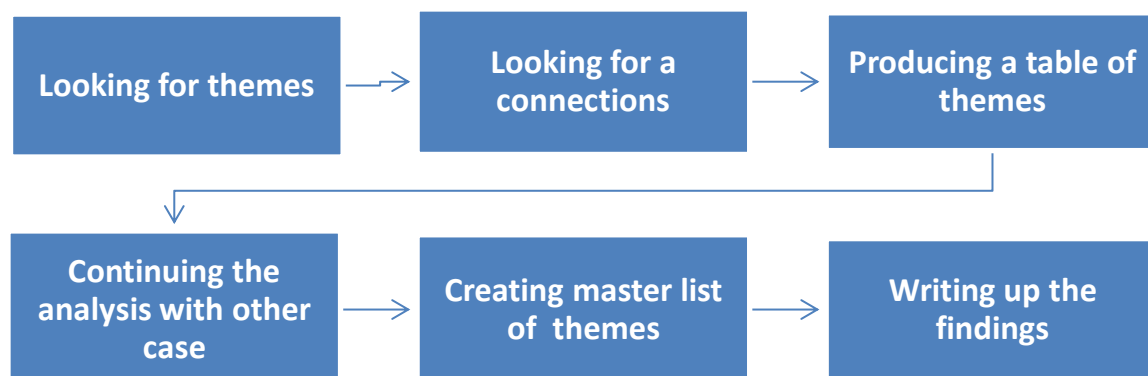
I transcribed all interviews and 10 percent were also transcribed independently by a Nepalese PhD student from another university. No discrepancies in the transcriptions were identified. Interview data were analysed using an Interpretive Phenomenological Analysis (IPA), to capture the actual meaning of the women's experience. IPA is a relatively new qualitative approach to data analysis developed by Jonathan Smith (J. Smith, Jarman, & Osborn, 1999) that has become an increasingly popular approach particularly in health and counselling psychology qualitative research (Biggerstaff & Thompson, 2008; Brocki & Wearden, 2006; Osborn & Smith, 1998; Jonathan A. Smith, 2009)

The primary aim of IPA is to understand how meanings are constructed by individuals, (Jonathan A Smith & Osborn, 2007) and attempts to explore how an individual makes sense of their subjective experience. This requires a dialogue between the participants own understanding of his or her experiences and the researcher's interpretation of it (Jonathan A. Smith, 2009). IPA assumes that a researcher's own views and beliefs inevitably influences the interpretation of any data. This assumption is realistic and is acknowledged in the research process. In other words, IPA allows a researcher to interpret a participant's subjective world. This means that IPA involves a two-stage interpretation process. First, the participant interprets his/her inner world and then the researcher reinterprets how a participant tried to make sense of their world (Jonathan A Smith & Osborn, 2007). IPA can be considered an idiographic case study approach because it starts with in-depth analysis at the individual level, where close attention is given to a particular case and their distinctive characteristics, rather than extensive generalisations (Pietkiewicz & Smith, 2012). An individual case moves towards more general categorisations applicable to an entire group (Jonathan A. Smith, 2009).

Data analysis using IPA framework can be an inspiring activity, although it is complex and time consuming. The primary goal of IPA research is for the researcher to find meaning in the participant's experience (Shaw, Burton, Xuereb, Gibson, & Lane, 2014; Jonathan A. Smith, 2009). To aid my understanding of this, after each in-depth interview, I reflected back to the women to confirm my understanding of their experience and transcribed the interview as soon as possible. This meant that interviews were transcribed one by one and before the next interview was conducted. In this way, the transcription and reflection continued until all individual cases were explored.

The interactive process of coding in qualitative analysis began during the transcribing and continued when using the software, NVivo 11. Individual interviews were coded separately, with codes progressively organised into themes.

Using the six-step analytical process described by (Jonathan A Smith & Mike Osborn, 2008) (see Figure 5.2) I began to understand each person's perspective.



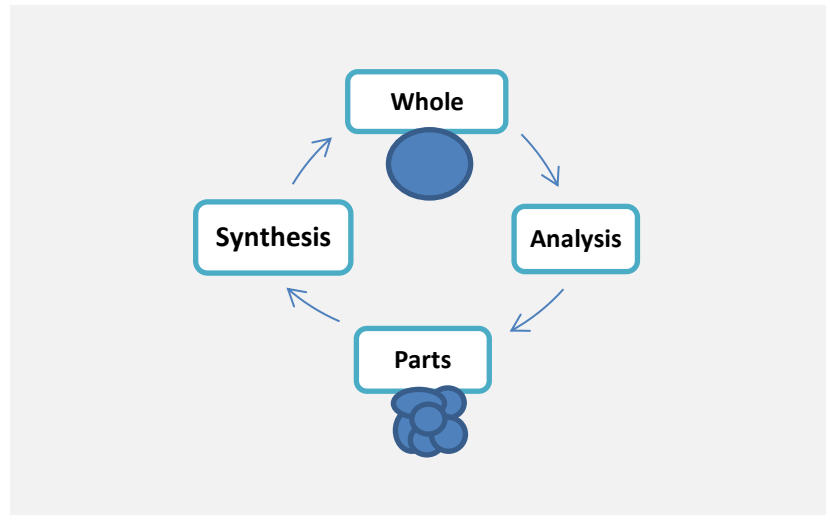
**Figure 2: Six step phenomenological data analysis process**

This process included:

- **Looking for themes in the first case:** I read and re-read the first transcript systematically looking for answers to my research questions. This reading enabled me to gain a global sense for the subsequent analysis. I imported transcripts of individual interview to NVivo to support and aid with my data analysis. I coded individual interviews using NVivo 11 software. I then extracted and compiled key ideas and phrases from the transcript and reviewed them to identify themes.
- **Looking for connections:** As new themes were identified I actively looked for connections and relationships between different and recurrent themes. Connections

helped to clarify the real meanings of experiences and issues as they arose in the interview data.

- **Producing a table of themes:** Starting with the first case a table was created to record themes and overarching clusters, where themes connected. Themes evolved as the analysis continued with appropriate merging and reorganisation into clusters. The table helped to identify connections between themes and facilitated the combination of themes to produce the clusters, or super-ordinate themes.



**Figure 3: Process of creating a master list of themes**

- **Continuing the analysis with subsequent cases:** Using the table of themes created from the first case, I reviewed the rest of the transcripts one-by-one. As new themes emerged in a transcript, they were tested against the first case to see if they fit with an existing theme, could fit with a modified theme or should have a new theme created. Similarly, the impact of each theme on existing clusters was investigated. Under the influence of the hermeneutic circle in IPA I constantly moved back and forth between the parts (individual transcripts) and the whole of the data that I gathered (all transcripts combined) (Shaw et al., 2014).
- **Creating a master list of themes:** As themes emerged from each interview and were combined with those of previous interviews, it was possible to identify sub-themes by grouping themes in the same cluster together according to conceptual similarities to signify certain meanings (Pietkiewicz & Smith, 2012). As themes were compiled, some were dropped if the evidence was weak. Other themes were put aside, when the data was unconnected or a connection with other emerging themes could not be



established (Jonathan A. Smith & Mike Osborn, 2008). As I developed the final master list of themes and sub-themes, the analysis revealed the real meanings of participants' experiences and a coordinated list of master themes was produced (30 cases).

- **Writing up an IPA study:** To develop a comprehensive narrative, I used the master list of themes and associated participant quotes. Transferring quotes into a specific domain of a theme, I worked to assure participants confidentiality without losing the expressive value of the data. While writing my narrative report, I again examined, probed, redescribed, and coordinated the themes in a way that supported the rigorous process in the study transparently to retain the voice of participants. In the process of writing my narrative report I engaged vigorously from low level interpretation of my data to a highly detailed interpretative and theoretical level as I tried to generate new insights. This approach is typical in an IPA study, where analysis is followed by discussion that can include reflection, implications, limitations, and ideas for future development (Pietkiewicz & Smith, 2012)

### **How I maintained rigour and trustworthiness in my study?**

Rigour was maintained before and during the interview process by using a scientific methodological procedure to collect and analyse my data. I wanted to ensure that the experiences of the participants in my study were accurately represented. The process I used to achieve the four criteria commonly used to assure rigour and trustworthiness of data, credibility, transferability, dependability, and confirmability (Liamputtong, 2013b), are described below.

- **Credibility:** or internal validity, was achieved by the careful and purposeful selection of participants and a consistent approach to data collection. I only collected data from participants who met the pre-defined inclusion criteria, who were informed about the study and who signed the consent form. I assured that I identified and described participants' viewpoints correctly (Liamputtong, 2013a).
- **Transferability;** or external validity (Creswell, 2013), was enhanced ensuring that I described and documented the study participants' experiences and views in a way that was consistent with interpretations by others, and in ways that the knowledge

obtained from this study could be applied to other similar individuals, groups, or situations (Given, 2008; Liangputtong, 2013a).

- **Dependability:** or the consistency of findings was established using data triangulation by comparing the experiences of participants gathered in the interviews, with the accounts of others, with my own observations and other documented information.
- **Confirmability** denotes that findings and their interpretation are clearly linked to the data and are not derived from the imagination of researcher (Given, 2008; Liangputtong, 2013a). To enhance confirmability, during interviews I used a consistent approach with all participants. I was mindful to observe and to clarify rather than dictate the direction of an interview. My interpretations were confirmed by another person, and my research findings were checked to ensure that they reflected the data.

### **Ethics consideration and confidentiality**

Ethics approval was obtained from the University Human Ethics Committee (UHEC), at La Trobe University. The study participants were Bhutanese refugee women and participation in the study was entirely voluntary. All participants were provided with consent forms and plain language statements in Nepali, explaining the details and significance of the research. Participants were informed that they could withdraw from the study at any time during the interview, had the right to decline to answer any question(s) and could ask the researcher not to use any information they provided in an interview. Anonymity was assured.

Privacy was very important considering the research topic, which is potentially very sensitive and personal for this group. Confidentiality and consent forms were signed by all participants at the start of an interview. All participants chose their own pseudonyms to ensure confidentiality, and to clarify that participants understood that others may read what they said in their interview. Age ranges were also used to describe participants to maximise anonymity.

If a participant were to become upset when recalling certain information during the interview, I was prepared to pause an interview, provide enough time for a woman to settle,

and then explore if they would like to talk to a professional counsellor. A list of professional counselling services was prepared and I was ready to provide it if a woman said that she wished to attend such services. The list was comprised of agencies that had policies that gave priority access to refugees, were locally available, and were free of cost for refugees.

No participant reported experiencing harm or difficulty from taking part in the study and I did not need to provide this information.

## **Summary**

In this chapter, I discussed the methodological framework for my research and explained how the theory of intersectionality fit with phenomenology and a feminist methodological framework. I briefly described the research design that informs this research, how the study was undertaken, the sample was selected, and data was collected and analysed. I conducted in-depth interviews with 30 Bhutanese refugee women who had resettled in Melbourne, Australia in average of 4-7 years. The interviews were supported by photo-elicitation as required to prompt understanding of terms used. The analysis of qualitative data was enriched by Interpretative Phenomenological Analysis. I maintained rigor, credibility and trustworthiness of my research from the start of the study, from participant recruitment to the final data analysis and interpretation.

As a Nepali woman, nurse and researcher, exploring a topic that was sensitive with a group of women who were vulnerable was both rewarding and challenging. In this chapter I described my multiple roles and positions and how these influenced the research process. In the following chapters, I present the findings from the interviews in the form of published and/or submitted manuscripts.

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## 6. STUDY SAMPLE & SUMMARY OF FINDINGS

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This chapter is divided in two parts. The first part provides a brief description of the study sample and presents a summary of the findings and the second part presents in the form of accepted manuscript.

### Part I: Study sample

The study participants were 30 Bhutanese refugee women aged between 26 and 72 years. All women were asked about cervical cancer screening and 16 women aged 50 years or more were also asked about breast cancer screening (see Table 1). At the time of the interviews, Australian guidelines recommended cervical cancer screening occurs every two years for women aged 18 to 69 who ever been sexually active, and breast cancer screening occurs every two years for women in the age group 50-70 years. Recent changes to the cervical cancer screening guidelines have reduced the frequency of screening to every five years for women aged from 25 to 74 years (Australian Government, 2018).

**Table 1: Study participants by age range, and their participation in cervical and breast cancer screening**

Age group (Years)	Number	Asked about cervical screening?	At least one cervical screening Test?	Asked about breast screening?	At least one mammogram <sup>b</sup>
18-49 <sup>a</sup>	14	YES	11 (79%)	No	0
50- 70	16	YES	5 (31%)	Yes	9 (56%)*
Total	30		15 (50%)*		

<sup>a</sup> One woman reported regular cervical screening

<sup>b</sup> No done second time or regular mammogram.

\* The first screening attended in average after 4 years of arrival in Australia

Individual characteristics of the study participants are presented in Table 2, who were aged between 26 and 72 years (average 48 years). The average number of children for the women was 3.7 (range 1-10). All but one woman had been married prior to their arrival in Australia, and all had been married at least 3 years (average 30.5 years, range 3-53 years). The average length

of time spent in refugee camps was 18.6 years (range 16-23 years) and in Australia was 6.1 years (range 2-8 years). Just over half of the study population had acquired Australian citizenship (16, 53%). Younger women (under 40 years) were much more likely to be educated and to be employed. Study participants were not asked whether they had received the HPV vaccine, which was not available in the refugee camps, as most women who participated in my study were over the age limit for the catch up HPV vaccination when they arrived in Australia (Brotherton, Gertig, Chappell, Rowlands, & Saville, 2011).

**Table 2: Study participants by age range, and their participation in cervical and breast cancer screening**

Age (years)	No. of children	Length of marriage (years)	Years in refugee camp	Years in Australia	Australian citizen?	Highest education level	Employment status
26	2	3	17	8	Yes	Year 12	Non-working
30	1	8	20	7	Yes	Year 12	Employed
31	2	9	20	7	Yes	Year 12	Maternity-leave
32	3	17	18	7	Yes	Year 9	Maternity-leave
34	1	11	18	7	Yes	Tertiary	Employed
36	2	9	17	7	Yes	Year 12	No
39	2	9	18	6	Yes	Tertiary	Employed
39	3	20	18	5	No	None	No
40	3	26	18	7	Yes	None	No
42	3	21	18	8	Yes	Year 8	No
43	3	25	18	6	No	None	No
44	3	30	20	4	No	None	No
46	6	30	18	4	No	None	No-
49	2	37	20	5	No	None	No
50	4	30	18	6	Yes	None	No
52	3	36	18	6	Yes	Year 9	No
52	4	33	23	2	No	None	No
53	3	38	16	8	No	None	No
53	6	35	19	4	No	None	No

53	3	41	16	8	No	None	No
54	5	45	18	6	No	None	No
55	5	39	18	7	Yes	None	No
56	5	40	22	3	No	None	No
57	3	37	20	5	No	None	No
57	5	45	18	6	Yes	None	No
57	4	40	20	6	No	None	No
60	5	53	18	7	No	None	No
63	7	46	20	7	Yes	None	No
67	10	52	18	7	Yes	None	No
72	4	50	18	7	Yes	None	No
<b>SUMMARY DATA</b>							
Mean: 48 years Range: 26-73	Mean: 3.7 Range: 1- 10 children	Mean: 30.5 years Range: 3- 53	Mean: 18.6 years Range: 16-23	Mean: 6.1 years Range: 2-8	53% Australian citizens (16/30)	70 % Illiterate (21/30)	83% Unemployed (25/30)

## Part II: Resettlement Challenges and Dilemmas

This section of the chapter explores findings specific to Bhutanese refugee women's perceived identities and related dilemmas and their behavioural response to the use of preventative health services in resettlement and is presented as manuscripts that have been accepted for publication in the Australian Journal of Anthropology in December 2019. The manuscript summary includes the proposed citation, the abstract, keywords and tabulated information that includes: the intended audience, the target journal and its 2018 impact factor, current publication status, and the nature and extent of the contributions of the candidate and co-authors.

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Intended audience	Journal [2018 Impact Factor]	Publication status	Extent and nature of candidate's contributions	Extent and nature of co-authors contributions
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## Accepted Manuscripts

### Resettlement challenges and dilemmas: An in-depth case study of Bhutanese refugee women in Australia

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In this paper the perceptions of Bhutanese refugee women were explored in relation to their changing identity and their behavioural responses in the use of preventive health services following resettlement. Interviews with 30 Bhutanese refugee women in Melbourne revealed resettlement drivers, challenges and dilemmas. There was no option for women other than resettlement, women wanted to escape from bad conditions and hopes for a better future for their children was critical in their thinking. Resettlement introduced new unexpected challenges including cultural discontinuity, changed dependency and a sense of not belonging. Dilemmas were apparent in their experiences including: despondency and contentment, gratitude and regret; and identifying as either Australian or refugee. Motherhood was important to women in this study and was challenged by changed dependency with their children in resettlement. Challenges of cultural discontinuity included the impact of communication difficulties and illiteracy and the absence of social connections with neighbours. A better understanding of how changing identities of women interact should lead to more effective strategies including tailored programs and activities.

**Key words:** refugees, identity, resettlement, women, challenges, dilemma

## INTRODUCTION

Resettlement in a new country can be overwhelming (Colucci et al. 2015) and is a disruptive encounter for people and their social ways of being (Mosselson 2006). Starting a new life in a new country inevitably demands adaptation to social realities while trying to maintain a coherent sense of one's own histories, traditions and culture (Marlowe 2011). For refugees, resettlement often involves little choice, including selecting the country of resettlement, so adjusting to a new culture and language can be even harder (Clark et al. 2014). Even when well-supported, the process of resettlement for refugees can involve a rollercoaster of emotions (Ferguson 2011; Hauck et al. 2014).

With forced migration, the resettlement of refugees has important political, social, economic and personal implications, one of which is the rebuilding of new identities (Colic-Peisker & Walker 2003). This is because identities are relative; they are culturally and structurally determined, despite common replication in social roles, networks, groups and status. Refugees arriving in a new country of permanent resettlement frequently face the daunting task of acculturation and reshaping disconnected and shattered histories (Colic-Peisker & Tilbury 2003). With the loss of their former lives, their identities as 'refugees', can become fixed, even though unwelcomed by those on whom it is bestowed (Colic-Peisker 2009).

Identity as a refugee may have important implications for long-term health and the adoption of healthy behaviours. Resettlement processes involve building connections to home and neighbourhoods, re-establishing connections to friends, family and ethno-cultural and other

communities that help generate feelings of belonging. These are important determinants of psychosocial wellbeing in resettlement (Gifford et al. 2007, Jiwarzka et al. 2017, Zwi et al. 2015). These activities also help to re-calibrate identity in new settings. However, while several meta-synthesis studies have strongly promoted the need for social connectedness for refugees after resettlement, they have also recognised inadequacies in current policies and systems (Lawrence & Kearns 2005; Grove & Zwi 2006; Davidson et al. 2004; Riggs et al. 2012). Despite its long history, the impact of such shortcomings on refugee identity following resettlement is not well understood (Danso 2002; Milner & Khawaja 2010).

Intersectionality has been used to explore dimensions of refugee's social identity, particularly the way different dimensions intersect to influence health and wellbeing (Guruge & Khanlou 2004). Intersectionality aims to analyse human experience beyond single categories of difference and has been recommended as a way to critically investigate the complexity of groups with multiple similarities and differences (Hankivsky et al. 2010). It has also been applied to understand the impact of race, class and gender on women's identities, experiences and struggles for empowerment (Davis 2008).

Identity has particular importance for the Bhutanese ethnic group, referred to as Lhotshampa, who lived in the southern part of Bhutan prior to the early 1990s. These were the only Nepali speaking Bhutanese recognised at that time (Hutt 2005). This term was applied by the Buddhist Bhutanese Government, and became prominent in 1989 when a 'one nation one people' policy was imposed in the country. The policy enforced practices of Drukpa culture, dress, religion and language on all Bhutanese regardless of their cultural heritage (Mills et al. 2008). These laws led to discrimination against the Lhotsampas, who were mostly Hindu. The Government

closed Nepali-speaking schools and dismissed many Lhotsampas who were occupying government positions (Lui 2007). Daily business activities, hospitals and post offices in the south were also forced to close, and many others lost their jobs as a result. Eventually many Nepalese-ethnic Bhutanese fled to Nepal (Lui 2007) and by 1993 over 100,000 people had settled in refugee camps in eastern Nepal initiating a humanitarian emergency (Evans 2010; Hutt 2005; Human Rights Watch 2003).

The refugee camps were home to these Nepali-speaking Bhutanese refugees for more than two decades, after which three resolution options were considered by the United Nations High Commission for Refugees (UNHCR); namely repatriation, host country settlement, or third country resettlement. Although repatriation was preferred by most refugees, several bilateral talks between the Bhutanese and Nepalese governments ruled this option out. Nepal was also unwilling to give citizenship to such a large population group. Eventually, the protracted refugee situation led to the third country resettlement option (Maxym 2010), with a program agreed to in 2007 involving eight countries: Australia, the United States, Canada, Denmark, Netherland, New Zealand, the United Kingdom and Norway (Gurung *et al.* 2009). The Bhutanese refugee resettlement program is one of the largest worldwide resettlement programs supported by the UNHCR (Benson *et al.* 2012). By the end of 2017, ten years after the third country resettlement program began, nearly 111,000 Bhutanese refugees have been resettled in a third country (Corcoran 2017).

As a signatory to the United Nations (UN) 1951 Refugee Convention, Australia is one of 26 countries participating in the UNHCR resettlement program (Koser 2015). Some 65,000 people



have resettled in Australia over the last five years and numbers fluctuate year to year as different international challenges emerge (Australian Government 2017; UNHCR 2016).

More than 6,000 Bhutanese refugees have been included in the humanitarian resettlement program of Australia as a part of a coordinated international strategy to resolve the long-standing impasse that led Bhutanese refugees to spend nearly two decades in Nepali refugee camps (Corcoran 2017). Prior to their resettlement beginning in 2007 (Commonwealth of Australia 2007), this refugee cohort had little access to preventive health services in the refugee camps, apart from basic vaccinations for infectious diseases. The social position of Bhutanese-Nepalese women often means that women's health issues are hidden because of cultural constraints (Menon et al. 2012). This is contrary to the situation in Australia where women's health issues are openly discussed, and women's health care is publicly encouraged.

Many of the Bhutanese refugee women who lived in the refugee camps in Nepal experienced personal and social hardships, including violence and ongoing gender discrimination. For example, ration cards were given out only in the names of men, which meant that women could not access basic aid independently. Consequently, many women remained in violent domestic situations or lived without basic essentials such as housing or food and had to rely on the mercy of friends or family members for protection and safety (Donini 2008).

Traditional gender roles are common in many refugee populations from patriarchal societies where women's status is low. Poor education and stigmatised beliefs about women's health and bodies are also common in these groups (Maxym 2010; Parajuli & Horey 2019) and women

often rely on male family members to make their health decisions (Maxym 2010; Centre for Disease Control and Prevention 2014).

Understanding how the concept of intersectionality applies to individuals gave insight into the changing influences on people's identity(s). For example, the primary author, as a researcher and Nepali could see beyond her professional role as a refugee health nurse to analyse human experiences beyond single categories of difference, such as age, gender and ethnicity (Marecek 2016). Specifically, the needs and motives of Bhutanese refugees in the camps in Nepal required different understanding as a Nepalese nurse than as an Australian-Nepalese nurse seeing similar women who had resettled in Melbourne. Contrary to what might be expected, access to health services was easier for Bhutanese women in the refugee camps than in Australia, because services in the camps were designed to meet their specific needs. Lack of literacy and language creates additional barriers to access in Australia. An intersectional lens helps when considering the types of strategies that can be enacted to shift behaviours and why some strategies may not deliver the expected impact. This paper explores Bhutanese refugee women's perceptions of their changing identity; associated challenges and dilemmas and their behavioural response to the use of preventive health services following resettlement.

## **METHODS**

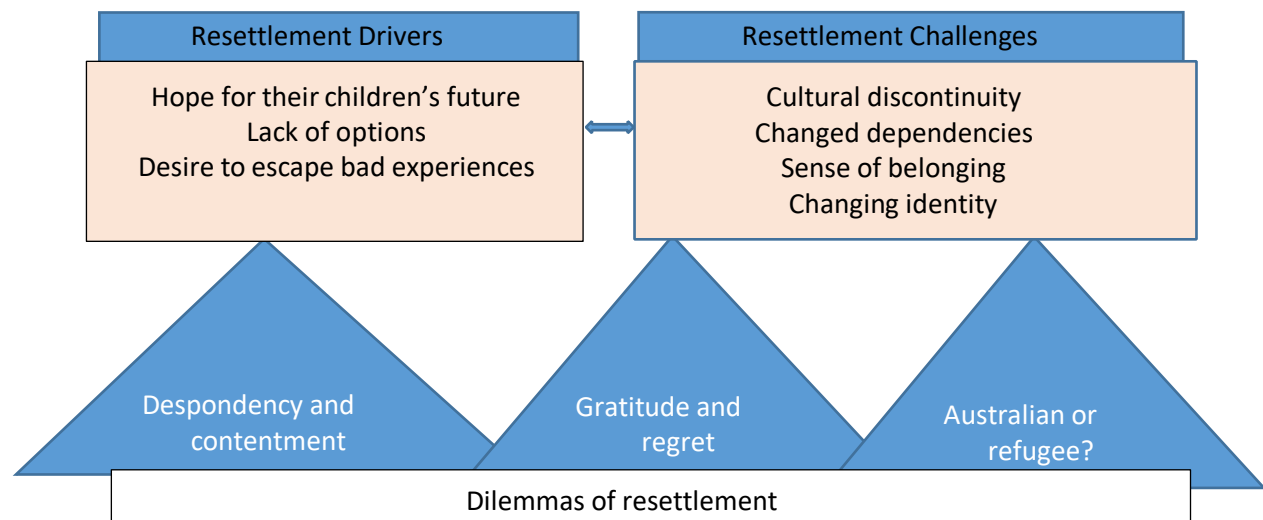
The findings from interviews are part of the PhD project of the primary author exploring the perceptions and experiences in accessing preventive health care services of 30 Bhutanese refugee women who had resettled in Melbourne Australia. The primary author is a Nepalese-Australian nurse, who shares the same culture and language of the Bhutanese refugee women

and likely to be considered an 'insider' by them, but also an 'outsider' as she is an educated Nepalese professional woman who is in Australia as a skilled migrant (Dwyer & Buckle 2009). Her interest in the health of Bhutanese refugee women began with her work with this population in refugee camps of Nepal during the 1990s. She continues in her role as a refugee health nurse in Australia.

Bhutanese refugee women aged 18 years and older were purposefully recruited through community networks. All 30 women were born in Bhutan, had lived in refugee camps in Nepal for at least 16 years and in Melbourne for at least four years. Most of them had never gone to school and were illiterate in their own Nepali language. All participants were married, and each had at least two children. While no study participant was personally known to the researchers, the primary author was known indirectly to some participants through her work with their community.

The interviews were conducted face-to-face in Nepali by the primary author in the homes of the study participants using a separate room with only the interviewer and interviewee present. A plain language statement in Nepali was provided and explained in detail prior to gaining consent. Participants chose a pseudonym, which confirmed their understanding that their words could be read by others. The interviews covered a broad range of questions relating to experiences accessing women's health services and included questions about perceived identity and follow-up question(s), for example, '(W)hat makes you feel/not feel Australian?' Poor literacy meant that the transcripts could not be returned to participants for checking, so

the issues raised in the interviews were summarised verbally at the end of each interview for confirmation.<sup>1</sup>



**Figure 1: Prominent themes from study findings- resettlement challenges and dilemmas**

## RESETTLEMENT DRIVERS

Women clearly expressed in the interviews that the process of resettlement was imposed upon them and that their choice would have been to return to their own country, which was denied to them. Their reluctant acceptance of the third-country resettlement options are explained as resettlement drivers.

The women's role as a mother was the most strongly expressed identity in the interviews and presented in terms of hopes for their children's future, which was the most powerful driver for their resettlement decision. This is consistent with a study of Iraqi refugees who resettled in the United States (Yako & Biswas 2014), where concern for their children was found to be the most

<sup>1</sup> Ethics approval was obtained from the University Human Ethics Committee (UHEC) at La Trobe University, Melbourne. Approval number 15-086

common motivator for their decisions about resettlement in third countries. Almost every woman in this study spoke about their children's future and the opportunities for them was the main reason for their decision to resettle. This was frequently expressed in terms of the advantages for their children from resettlement. 'We are here for our children' is one of the important themes to emerge from the interviews.

With few exceptions women in the study felt that their children would have bright futures in Australia and that any personal satisfaction would come largely from their own children's happiness and achievements in Australia. Most women had low expectations of personal happiness for themselves. Ganga expressed it this way:

I don't think I can enjoy life here in the fullest happiness, as we have problems with language, education and work. We had to leave our birth country and had to live in the camp for many years as we were forced to leave by the Bhutanese government. Now here [in Australia] we have our own house to live in and our children have a lot of opportunities (Ganga, 45–49 years).

The women saw many advantages for their children and linked their opportunities and future potential to their own and expectations of happiness.

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 must be happy in their happiness (Devi, 50–52 years).

Others, such as Phulmaya, compared her family's current life to life in the camps with particular appreciation for the opportunities their children had gained:

This is our country now, we are taking every advantage that the government has given to us. In the camp we didn't have anything, now we have everything, our children's future is good in this country (Phulmaya, 55–59 years).

Women raised the lack of other options in terms of places to live the rest of their life as a significant driver of resettlement. As repatriation to Bhutan was not possible, many women felt that third country resettlement gave them little choice. This issue was particularly apparent among older women. According to Saraswata the decision to resettle was essentially forced on her.

When there was a time to decide to come to Australia, it was such a hard decision to make. We didn't want to come. We spent our whole life in Bhutan and Nepal and we did not know what happened in Bidesh (abroad); we were not able to guess (Saraswata, 65–69 years).

The experiences in camps meant that resettlement was necessary for women like Aama, who talked about fleeing from Bhutan and living in camps with very scarce resources:

... though I am not happy for many things, I can't go back to Bhutan and I will die here.

We were forced to leave our country by bhote (the Monarch of Bhutan), we lived a miserable life in camps. We have a wonderful life here without any difficulties, for food and shelter. Now I want to be here, I will die in this country, nowhere else (Aama, 70–74 years).

The desire to escape from repeated bad experiences was another resettlement driver for Bhutanese refugee women. Sexual assault and threats of assault were common and others,

such as Devi, described the trauma of witnessing and experiencing violence. This was the reason she left her home, her village and her country. Living with memories of that time, especially of the violence against women, continues to haunt her. Fear of becoming a victim of sexual assault after witnessing the rape of her next-door neighbour was the main reason that she left Bhutan. She recalled that time:

In Bhutan, the army came to our house to look for the certificates [of citizenship], but my certificate was with my parents ... they burnt our house in front of us ... My husband was accused of belonging to the anti-government party. They used to come at night, they raped so many women. My husband was hiding from them, he was not at home, and I was so scared that I would be raped one day ... it was really hard for women to live in that situation (Devi, 50–54 years).

Experiences in the refugee camps were also miserable for many women as Saraswati reflected:

When we were in the camp, we did not have enough food. Everything was really not good to eat ... We never had good vegetables, we left all our belongings behind in Bhutan. We were a well-off family in Bhutan (Saraswata, 65–69 years).

The memory of scarcity, hunger, diseases and deaths were prominent when women recalled life in the camps. Leela recalled those days in camps and the inadequacy of basic needs such as, food, water supply, shelter, health care and lack of educational opportunities for children. The stresses of displacement continue to disturb her even after five years in Australia:

Twenty years was such a long time in the camp. It was too much pressure on many things including fulfilling the basic needs of food, shelter and health. Many people died

from diseases, lack of food, and lack of treatment. The tension and stress from that time is affecting me even now (Leela, 50–54 years).

## **RESETTLEMENT CHALLENGES**

Resettlement raises several challenges. Bhutanese refugees who resettled in New Zealand described difficulties when they first arrived. After living in camps for many years they did not know how to fulfil their basic daily needs, such as shopping, using public transport or even finding their way around their neighbourhood (Ferguson 2011).

The most common challenge for women in this study was cultural discontinuity, which was particularly associated with cultural and religious practices. The impact of cultural expectations was evident in their health seeking behaviours. In the refugee camps health care was directly associated with illness and the presence of symptoms. Remedies were initially sought through the family and traditional healers (Ferguson 2011). Women in this study reported similar feelings. Difficulties in fulfilling cultural and religious needs was expressed by almost all women. Prior to resettlement, the celebration of religious festivals was a shared community experience, but now the women felt confined to their households on these occasions. They recalled festive times in Bhutan and Nepal that were observed by everyone and affected the whole environment. This did not happen in Australia and many felt, like Chandrawati, that as the family festivals were not widely recognised, it was necessary to be mindful of neighbours even when celebrations occurred inside the home.

There is no similar culture, language or festival. If I am in Bhutan or Nepal when our main festival happens it sounds like all the world is having a festival, but here our



festival is not recognised. We are very reluctant to celebrate them publicly, it happens just inside the house. Nobody knows what's happening. We always need to be conscious of other people and think about how answer their questions. We can't make our minds and hearts very open during those times (Chandrawati, 40–44 years).

Breaking cultural continuity reinforced the sense of marginalisation and social segregation. This aspect of resettlement adversely affected some of the older Bhutanese women, and discouraged them from accessing health or social services or engaging with their community:

Because of our background and we don't know the culture and background of the people living next-door. We are reluctant to approach them because of fear of being different and so we don't celebrate our festivals freely (Bhima, 50–54 years).

The impact on motherhood that came with the changed dependency following resettlement was one of the strongest findings of this study. For many women, their role as mother was challenged, with women explicitly expressing concerns about changed dependencies resulting from their lack of language proficiency and consequent communication difficulties. The lack of English language and poor literacy meant greater dependency on their children for many women in this study. Such dependency affected the women's identity as a mother. It was the biggest challenge for women and affected their day-to-day life including how they accessed health services. Several studies have pointed to problems with the use of children as interpreters in health care (Gerrish et al. 2004; Hadziabdic et al. 2009), but we could find no other studies that identified reliance on children as interpreters raising questions about the role of motherhood.

Motherhood is profoundly important in the lives of Bhutanese refugee women and common to many women in patriarchal family structures (Ferguson 2011). The inversion of the roles of mother and child imposed a challenge to women's status. Dependency on children for routine daily living may create a loss of a family's internal and social authority structures, making women feel insecure and marginalised. For example, communication difficulties made Maya feel miserable as she was unable to express her feelings, her problems or her needs. Maya felt that her own voice had been suppressed as she was reluctant to rely on her children's support to communicate with others on an everyday basis. This was especially so when seeking health care. Maya believed that dependence on her children and unnecessarily exposing her private health issues to her children would create insecurity and threatened her capacity to sustain her role as 'mother'. Such feelings of inadequacy made women feel miserable.

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 with no 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).

The women associated their lack of language proficiency and their communication difficulties with their strong feelings of dependency.

I realise how powerful language is to communicate and to feel independent. (Maya, 50–

54 years).

I feel good but with the language barrier I am dependent for everything on my children  
(Monmaya, 55–59 years).

In every interview communication difficulty due to the lack of English language proficiency was repeatedly seen as the main reason for the women's dependency on their children and for not fully integrating into the community. Madhavi illustrated her feelings this way:

... well it's good that we don't need to worry about food now but how can I say I am happy while I can't speak what they speak. I am dependent on my children for everything. I think I am never going to be happy for many things (Madhavi, 55–59 years).

While illiteracy was unimportant to the women when they were in the refugee camps, in Australia their lack of English language has added to their increased dependency on their children and affected how the women saw themselves and unexpectedly increased their sense of vulnerability.

In the lives of the women, language difficulties touched every sphere of their efforts to integrate, especially where social inclusion and linguistic ability were strongly interconnected (Piller & Takahashi 2011). This was not a problem in Bhutan and in Nepal but for the women in the study, their lack of language skills meant that life was never going to be 'back to normal' (Strang & Ager 2010; Colic-Peisker & Tilbury 2003). The keys to social inclusion and a sense of belonging for women identified in other studies include language (Piller & Takahashi 2011), employment (Sapeha 2014), and recognition of their qualifications (Colic-Peisker 2009). The

importance of attachments to friends, relatives and communities is also common to non-refugee immigrants (Dobrowolsky 2011). Other studies have shown that opportunities for informal community classes, bilingual support and material targeted to their needs can be effective (Watkins et al. 2012; Hou & Beiser 2006).

A sense of not belonging was particularly evident when the women talked about their interactions with others. For example, the women felt that they could only use health services independently if they could communicate with health care providers without the involvement of others. While it was uncommon for these women to have access to health services in their own language, when they could it fostered a sense of belonging:

If there is no need to use an interpreter, I feel good, so to me if there is Nepali speaking health professional, that is where I go. Those times I feel that I am in Australia and that I belong in this country and I can use services without hesitation (Devi, 50–54 years).

Further, language limitation affected how the women felt about their inclusion in Australian society, and not being able to talk to neighbours was very significant for them. It raised daily awareness that they were different from their neighbours unlike in Bhutan and Nepal. Several women referred to their neighbours and neighborhood when asked about settling into their new country. Even 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. She described a simple scenario to show what was missing between neighbours and their relationships after resettlement.

We do not have that environment where we stay in the courtyard and yell out to our next-door neighbour demanding a cup of tea, which we could easily do back home. We need to be always mindful of what our next-door neighbours think of us and think about our behaviour. That hinders us to go and talk at the fence and ask for a cup of tea. This environment makes us feel that we are not in our country, but we will get used to these things as time passes. There is no intimacy here but a high level of formality, like saying hello or hi, but there isn't any feeling of connection. (Sita, 30–34 years).

Other studies have identified connection to communities as important for refugees after resettlement, but few have specifically focused on relationships with neighbours (McMichael et al. 2010; Gifford et al. 2007). Studies of refugees have pointed to difficulties in generating feelings of belonging after resettlement (Hathaway 2007) and the need for a social identity and social connectedness (Colic-Peisker & Walker 2003).

Devi compared the Bhutanese experience in Australia to other migrant populations in her local area. She felt that other ethnic groups showed no hesitation in displaying signboards in their language, or in talking and carrying out their religious or cultural performances in public, or even meeting in groups and talking in the shopping mall. Devi felt that embracing opportunities to be visible in the community was necessary to move forward, and that this was more important than regretting what was lost.

I feel this is not our country; this does not belong to us. I can see, Iraqi people have their signboard everywhere. If there is signboard written in Nepali, it makes me feel good. If we are living here with the feeling of not able to do anything due to language barriers, due to sickness or due to not having good skills and communication, I think we can't feel

Australian even though we receive Australian citizenship (Devi, 50–54 years).

A perception of changing identities also emerged in the interviews. When asked what would made you ‘feel Australian’, some replied that nothing could and that they would never feel Australian. Others were more positive. Being able to communicate with neighbours was the most common response; several women said that it would make them feel more connected and help them to feel that they belonged to the community.

When I will be able to talk to my next-door neighbour, when I am connected to the people around me or around my locality, then I feel I belong to this country (Kumari, 40–44 years).

Devi would like to see Nepali speaking health professionals in all health care services. It would make her feel proud and help her to use services independently. It would change how she views herself.

If we have Nepali speaking people in major areas like in the hospital, GP's clinic, in school that would make us feel that we are here in Australia and doing really good in this country, then maybe we feel more Australian (Devi, 50–54 years).

## **DILEMMAS OF RESETTLEMENT**

The concurrence of feelings of despondency and of contentment was apparent in the interviews, where the refugee women swapped continually between these feelings as they talked of their lived experiences. The terms *nirasha* [despondency] and *santusti* [contentment] were commonly used in the interviews.

Resettlement brought benefits but also brought losses, highlighting the complex nature of resettlement, particularly when it occurs without choice (Hauck et al. 2014). Such observations were not found elsewhere in the research literature, although individual components such as feelings of despondency do appear (Milner & Khawaja 2010; Danso 2002). A study of Somali and Ethiopian refugees resettled in Canada raised the issue of despondency (Danso 2002) and an Australian study, also of Somali refugees, reported similar feelings as a result of cultural discontinuity (Milner & Khawaja 2010).

One woman strongly associated her feeling of emptiness and the things that had happened to her, including becoming a refugee, living in the camps, coming to Australia and being sick, as due to her *karma* [result of actions in this or previous life]. Goma's passivity was expressed through submissiveness and acceptance of all life events, whether good or bad.

I am illiterate, I feel reluctant to go anywhere, I can't think anything, do not have any feelings. The hardship that we had was our own *karma*. But I am a bit worried about my health. What comes in your life you have to take whether it is happiness or sorrow. I think we are in a good country, but I still don't feel that I belong—maybe because of language and my own abilities to adapt (Goma, 45–49 years).

Illiteracy was a common cause of despondency. This limitation was not anticipated nor a problem in their own language in the camps where illiteracy was readily accommodated.

However, in Australia, not being able to read and write, even in their own language, made life difficult, particularly for older women, where there was no ability to acquire information or to learn how to navigate services without others.

It's good that we are in this country with all its facilities. We are receiving good health care and are getting lots of support. But we have our own issues with not being fully able to understand and take advantage of all the services. As I mentioned before it's the language. I can't read and write in my own language. What a dark life we have. I feel shocked without having children around. I realised how powerful it is, the language to communicate and to feel independent for our own benefits (Maya, 50–54 years).

However, there was also contentment in women's accounts. Concerns about food, water, healthcare and their children's education were no longer worries for these women, which made them content. Now their concerns had shifted to being able to live with dignity, to be able to speak and to go out independently.

Everything is good here, treatment, food, environment, education for children, but for us to live, to speak, to go around is much better in Nepal and Bhutan. With so many facilities I still do not feel that we belong to this country, but I do feel lucky that we are not deprived of basic needs for health, and food and water (Anie, 35–39 years).

Gratitude and regret were a commonly observed dilemma that was reinforced by relationships with close neighbours and language barriers. Sanu expressed her feelings in this way:

... yes, I am a citizen; I am very proud being a citizen of this beautiful country comparing our life in refugee camp, staying there with the refugee tag. But I do not feel I am Australian, as language becomes a barrier in every step. I can't go out and talk to my neighbour and tell her what I feel about her. This situation would not be there if I was in Nepal or Bhutan. From my heart, honestly speaking I do feel that I belong to Bhutan,



where we had our good life. And we also spent our very important significant life in the camp, I feel Nepali too (Sanu, 50–54 years).

For several of the women, resettlement had given them the opportunity to identify as citizens after being stateless for many years, however connections to Bhutan and Nepal, particularly in regard to cultural traditions, continued to be important in their lives. In contrast, the obstacles faced in Australian life, particularly in regard to celebrating religious festivals, seemed bittersweet. Ganga said that despite the many facilities available in Australia, her life was much better in Nepal and Bhutan because there she was able to speak to everyone and could get around independently.

Everything is good here, treatment, food, environment, education for children, but for us to live, to speak, to go around is much better in Nepal and Bhutan. With so many barriers I do not feel that we belong to this country but feel lucky that we are not deprived of basic needs for health, food, and water like in camps (Ganga, 45–49 years)

Bhagawati expressed self-pity but accepted the reality of her situation

I feel sorry for myself when I can't understand what other people say and when they can't understand what I say. But this is a reality. Everyone like me who is not educated has the same problem in this country (Bhagawati, 50–54 years).

The ability to speak English helped women to identify as Australians but illiteracy and communication difficulties were raised many times in various contexts. The quote below from Kumari elucidates her subjective feelings and the reasons for feeling 'like a Bhutanese refugee' despite receiving Australian citizenship.

... hard to get into everything here; we can't speak to our next-door neighbour. When we go shopping, we have to be careful. We have to buy things by just looking at them. I can't read the label, I can't ask or talk to people. When I take public transport, travelling from one to other place, I don't know where to go without having support from another person (Kumari, 40–44 years).

There was also confusion about whether to identify as an Australian or as a refugee or even as Bhutanese-Nepali. While many women in the study had gained Australian citizenship status, this seemed to be more symbolic and for security in a quest for social identity. Although formally Australian citizens, they did not feel that they were Australian. Feelings of citizenship are subjective and can take time to acquire (Krstic 2017), so it is important to recognise that these responses came from a small group of women who had lived in Australia for only five years. Others clearly embraced their new lives in Australia with little regret. Julie appreciated being a citizen after being stateless for a long time but found it hard to identify as an Australian.

I know I am Australian citizen, but if somebody asked me, I respond, 'I am Bhutanese', it comes automatically. But I am confused, we lived in Nepal for 18 years and we follow the same culture and speak same language, means I should say that I am Bhutanese-Nepali. But we were stateless for many years and now being citizen of this country is a great thing. But my identity comes first as a Bhutanese (Julie, 30–34 years).

One young educated woman expressed confusion about what she had gained and what she had lost with resettlement:

I know I am now an Australian citizen, very proud to be a citizen of this wonderful country. But still I feel I am Bhutanese as I follow the culture and we speak language, I feel I have a different identity as my thinking is different, my language is different, but I am trying to think that I am lucky to be here (Sita, 30–34 years).

In contrast Lusi found the whole experience of resettlement to be positive and interesting. Lusi embraced every opportunity and benefit available in Australia.

I am educated, I am working and I feel I can work anywhere in Australia. I have a normal life. No restrictions, I enjoy freedom, I earn and I spend, I can buy what I like, there is no feeling of deprivation. My child is having a very good education, we are driving, we have our own house, and we are travelling from one state to another, even overseas to see our relatives, we are able to spend money. All these things would not be happening or even come in a dream if we were still in the refugee camp. I am enjoying every moment here as I am receiving so much from this country (Lusi, 30–34 years).

A few women, often younger, saw many opportunities that would make their life easier in Australia than it had been before. These women generally had higher levels of language proficiency and could be a useful resource for the Australian Bhutanese community. Prior to resettlement younger women would not normally have the opportunity to be seen as community leaders. This is another example of changed roles due to resettlement. Women who had spent their childhood in refugee camps seemed to embrace resettlement more readily. For example, Kanchhi, who was just three years old when her parents came to the refugee camps, acknowledged that growing up thinking about an unknown future was quite scary. Coming to Australia and gaining citizenship had opened many opportunities for her and she was very

grateful.

Even though life is not easy here, I feel I am Australian as I can get more opportunities for myself and for my young family here. We are getting things here which would not be possible in the camp (Kanchhi, 25–29 years).

Sanu, who had become an Australian citizen could not explain what made her feel Australian even after seven years.

Nothing makes me feel like I did in Bhutan. I am missing everyone so badly or possibly I am taking this refugee journey differently. I do not feel like a refugee in the camp because we are really well settled here. We have our own house, my husband and children are working, but I still feel that I am Bhutanese, and that is where I belong (Sanu, 50–54 Years).

## **CONCLUSION**

The complexities of resettlement are evident in the dilemmas faced by the participants in this study, which exposed the intersections of multiple changing identities in the lives of Bhutanese refugee women and influences on their day to day lives. These women are mothers but dependent on their children in ways unfamiliar to them, which leads to questioning of their motherhood. Resettlement brought both gratitude and regret to these Bhutanese refugee women—for what they had gained and what they had lost. Feelings of despondency and contentment resulted from their experiences of having to leave Bhutan with no option of returning. Hopes for a better future for their children was critical in their thinking about settlement. Challenges arose from cultural discontinuity, particularly the impact of

communication difficulties and illiteracy and the absence of easy social connections with neighbours. Such challenges influenced individual behaviours, beliefs and decision making. Many women in the study still identified as refugees and sought services including health care from that perspective; that is they only sought medical help when symptoms could not be ignored.

Their reliance on children as interpreters exacerbated cultural discontinuity and disturbed mother–child relationships. Understanding the multifaceted nature of Bhutanese refugee women’s identities will facilitate improvements to their lives. These multiple identities are not only interlinked but also entangled, bringing both positive and negative resettlement experiences. A better understanding of how competing identities interact should lead to more effective strategies, including tailored programs and activities that can influence behaviour, provide support and address needs appropriately. For example, the importance of relationships with neighbours was a useful study finding, as it suggests an avenue that could be targeted to improve the transition and integration of refugees after resettlement. Active bi- or multi-cultural neighbourhoods are likely to enhance social inclusion and foster linguistic ability. The study also recognised that Bhutanese refugee women’s own identity was influenced by their gender as well as their lived experiences, ethnicity, education, social status and age.

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## Summary

In this chapter, I presented the research findings that briefly described characteristics of my research sample and findings that are specific to Bhutanese refugee women's perceived identities, their related challenges and dilemmas, and their behavioural response to the use of preventive health services in resettlements. I also discussed the communication difficulties due to illiteracy, language barriers and how this hinders women to feel satisfied about their own home and neighborhood. A few women were hopeful for a good life and trying to embrace every opportunity, but others are regretful for being very dependent on their children in everyday life. Resettlement made these women be highly dependent on children which has challenged their feeling of motherhood. As children's better future was the prime driver for resettlement, women in this study are happy to see their children to enjoy work, study and overall life. For some women, while their feeling of loss and not belonging within themselves hindered their grasping of opportunities such as health service access, the next chapter provides the overview of the barriers in relation to accessing cervical and breast cancer screening services in Melbourne.

## 7. BARRIERS TO SCREENINGS

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This chapter presents the findings related to perceived barriers to cervical and breast cancer screening services. It includes two publication manuscripts detailing the health seeking barriers of Bhutanese refugee women to the different cancer type's screenings.

The revised version of the first manuscript title 'Perceived barriers to cervical cancer screening among refugee women after resettlement: A qualitative study' has been submitted to the Contemporary Nurse Journal in September 2019 and the same version appears in this thesis.

The second manuscript title 'Access to breast cancer screening — perception, and perceived barriers among older Bhutanese refugee women resettled in Australia: a qualitative study' was published in the Australian Journal of Cancer Nursing in May 2019. This appears as the published paper in the thesis.

Both manuscripts have recognised the unique phenomena of symptoms-based health seeking among Bhutanese refugee women and other associated factors including health professional's behavior. These publications are intended for Nurses and health professionals working or interested in the area of refugee health.

## Submitted manuscript

**Citation:** Parajuli, J., Horey, D., & Avgoulas, M.-I. (2019). Perceived barriers to cervical cancer screening among refugee women after resettlement: A qualitative study.

*Contemporary Nurse*

Intended audience	Journal [2018 Impact Factor]	Publication status	Extent and nature of candidate's contributions	Extent and nature of co-authors contributions
Nurses and health professionals working in the area of refugee health	<i>Contemporary Nurse</i> The journal impact factor 2018:1.216	First submission was 29 <sup>th</sup> August 2018. Revised version submitted on 10 <sup>th</sup> of September 2019	Contribution of candidate: 80%.  This includes data collection, data analysis, drafting and revision of manuscript; submission to journal	Contribution of co-authors: 20%.  This includes discussion of ideas expressed in paper and critical review.

## **Perceived barriers to cervical cancer screening among refugee women after resettlement: A qualitative study**

### **Abstract:**

**Background:** Cervical cancer screening rates are low among refugee populations who have resettled in Australia, including among Bhutanese women who are at increased risk of cervical cancer. Understanding the barriers to accessing preventive health care is an important starting point to changing health behaviours.

**Objective:** To identify perceived barriers to accessing cervical cancer screening programs among Bhutanese refugee women in Australia.

**Method:** In-depth interviews with 30 Bhutanese refugee women resettled in Melbourne, Australia were analysed using an Interpretative Phenomenological Analysis (IPA) framework.

**Findings:** A strong overarching theme was evident; health-seeking behaviour among the Bhutanese refugee women was strongly associated with symptoms and can be described as ‘no symptoms- no check-up’. Three major contributors to health behaviour were: poor knowledge, cultural motivations and refugee experience. Poor knowledge was a consequence of low health literacy and lack of information. Cultural motivations included the notion of the sacred body and related stigmas, and strong faith in doctors.

A set of latent themes associated with health professional behaviour was also identified in the experiences women recounted: screening was not offered; opportunistic screening occurred without education; and the use of interpreters was inappropriate and involved a mix of failure to use publicly available trained interpreters and informal use of family members. A contrary theme was also evident among younger educated women: changing awareness.

**Conclusion:** Health professionals in the countries of resettlement need greater awareness of the barriers to health-seeking behaviours among refugee populations: cultural influences and norms; poor knowledge of health services and health systems; and poor practice by health professionals

**Key words:** Bhutanese refugee women, cervical screening, culture, health beliefs, barriers, service access

**Impact statement**

Using family members instead of professional interpreters and failing to explain procedures are barriers to cervical screening for refugee women.

## Background

As a signatory of the 1951 Refugee Convention, Australia is one of 26 countries participating in the resettlement program of the United Nations High Commission for Refugees (UNHCR) (Koser, 2015) and grants more than 13000 visas each year under this program (Australian Government, 2017 2018) . Among those who have resettled in Australia there are more than 6000 Bhutanese refugees, who fled their country in the early 1990s and lived in refugee camps for nearly two decades in Nepal (Commonwealth of Australia, 2007)

While resettlement offers opportunities for refugees, it can also create new challenges, including how to use health services, language difficulties, financial constraints and lack of familiarity have been identified as barriers (Lamb & Smith, 2002) Access to preventive care services, such as cervical cancer screening has particular relevance to Bhutanese women, as this cohort is at high risk of cervical cancer(Jemal et al., 2011) .

In Australia cervical cancer mortality rates have fallen significantly since the introduction of organised screening in 1991 (Aminisani, Armstrong, Egger, & Canfell, 2012; Anaman-Torgbor, King, & Correa-Velez, 2017). However, disparities persist with the incidence of cervical cancer and related mortality significantly higher among women born in developing countries (Lu et al., 2012; Menon, Szalacha, & Prabhughate, 2012; Rondet et al., 2014); which reflects lower rates of access to screening services for these groups (Weber et al., 2014). Similar patterns of screening behaviour are also displayed among South Asian born women in other high-income countries including the United States of America (Menon et al., 2012). Understanding the issues contributing to these lower screening rates among migrant women, particularly those refugees who are at increased risk, is important to determining ways to address the problem.

Qualitative methods are commonly used to gain understanding of human behaviours and experiences (Creswell, 2013; Holloway & Wheeler, 2013); and have particular value when the issues are potentially sensitive and vulnerable groups such as refugees are involved. The methodological framework of phenomenology, is frequently used in qualitative studies as a way of understanding the meaning of events and the subjective aspects of people's behaviours as phenomenology makes use of how people describe different phenomena as a consciously

experienced or 'lived' experience (Pascal, Johnson, Dore, & Trainor, 2011). Accordingly, in-depth interviews and phenomenology are commonly used to understand barriers to accessing health care (DiCicco-Bloom & Crabtree, 2006). At the same time, studies that attempt to capture women's life experience in a respectful manner infer a feminist framework. The combination of phenomenology within a feminist framework is a suitable approach to understanding barriers to cervical cancer screening.

Studies that involve minority groups add a further layer of complexity that needs to be taken into account, particularly in the analysis. Intersectionality theory allows exploration of multiple social identities among women through a multi-axial approach (Guruge & Khanlou, 2004). For example, a study of sex workers in Canada found that stigma attached to their occupation had added impact because of other factors including sexual orientation, aboriginality and socio-economic status (Hankivsky O et al., 2010). Similarly, the application of intersectionality can help to explain influences on the health-seeking behaviour of Bhutanese refugee women resulting from their multiple identities after resettlement.

This study aimed to explore specific barriers accessing cervical screening programs by Bhutanese refugee women who have resettled in Australia.

## **Methods**

### **Study design**

In-depth interviews were conducted face-to-face in Nepalese by the primary author (JP) between April 2016 and December 2016 in the homes of the study participants, in a separate room with only the interviewer and interviewee present. The interviewer, who is a Nepalese Australian works as a refugee health nurse and previously worked in refugee camps in Nepal. Concerns about poor uptake of preventative health care by refugee women prompted her current PhD studies. She has conducted many interviews and focus groups in her work and in her previous postgraduate studies.

An interview guide was developed based in the literature (Anaman, Correa-Velez, & King, 2016; Clark, Gilbert, Rao, & Kerr, 2014; Genoff et al., 2016; Lamb & Smith, 2002) with minor modifications after the first three interviews to incorporate additional information that had



recorded in field notes. The interviews covered a broad range of questions relating to experiences of accessing women's health services, particularly cervical cancer screening. Photo elicitation was used to facilitate data gathering; when women were unfamiliar with screening, photographs of screening activities were used as a tool to prompt their understanding (Clark-Ibáñez, 2004). Data collection continued until data saturation was reached. There were no repeat interviews. Interviews took 45-90 minutes and were recorded, transcribed and translated into English.

### **Study participants**

Bhutanese refugee women aged 18 years and older, who had resettled in Melbourne were purposively selected through information provided by Bhutanese community leaders. None of the study participants were personally known to the researcher, although she was known to some of the participants through her work with their community.

An information statement in the Nepali language was provided prior to the interview and read to those participants who were illiterate. Before commencing the interview, the researcher again explained the research project in Nepali before the women made their mark on the consent form. Participants were asked to provide their own pseudonym to confirm that they understood that others would read what they said. All women who were approached agreed to take part in the study.

### **Data analysis**

Transcripts were read and re-read. Interpretative Phenomenological Analysis (IPA) was undertaken with the assistance of Nvivo 11 (Edhlund & McDougall, 2017) for coding and data management. IPA involves a two-stage interpretation process. Participants are asked to clarify or explain and then researcher interprets how participants make meaning of their experience (Smith & Osborn, 2007). There are six steps in IPA to understanding a person's perspective of their experience: looking for themes; looking for connections, producing table of themes; continuing analysis with next case; creating master list of themes; writing up findings. Table 1 shows the section of the master list of themes related cervical screening derived from the data.

The primary researcher undertook the analysis as part of her PhD studies, with co-authors coding subsets of the data for checking.

**Table 1: Master list of themes: Perceived barriers to cervical screening**

<b>Main theme: Symptoms based health-seeking ‘no symptoms- no check-up’</b>	
<b>Contributing themes</b>	<b>Sub-themes</b>
<b>Poor knowledge and ignorance</b>	<ul style="list-style-type: none"> <li>• Low health literacy</li> <li>• Lack of knowledge/understanding about screening leading low service utilisation</li> <li>• Not followed up on a regular basis</li> <li>• Lack of information leading low understanding of cervical screening and the service availability</li> <li>• Not informed/explained/discussed by doctor/nurse during health appointments</li> </ul>
<b>Cultural motivation</b>	<ul style="list-style-type: none"> <li>• Perceived cultural perception, norms, health beliefs</li> <li>• Sacred body</li> <li>• Stigma, shyness, and embarrassment</li> <li>• Strong faith in doctor/nurse</li> <li>• Hard to change cultural beliefs and behaviour</li> <li>• Influence of attitude and behaviour</li> <li>• Literacy/communication/language</li> </ul>
<b>Refugee experience</b>	<ul style="list-style-type: none"> <li>• Questioned value of preventative screening</li> <li>• Prior health care experiences</li> </ul>
<b>Health professional behaviour</b>	<ul style="list-style-type: none"> <li>• Responsibility lies with doctor/nurse</li> <li>• Screening not offered</li> <li>• Interpreter not used</li> <li>• Use of family members as interpreter</li> </ul>

## **Trustworthiness**

To ensure trustworthiness an interview guide was used, which was pilot tested and modified from field notes. All interviews were recorded. The interviewer was not personally known to the study participants, although some knew of her through her role as a refugee nurse. A random sample of the transcribed interviews [10%] were independently translated by a second native speaker of Nepalese who is also a PhD student at another institution. As the transcripts could not be checked by the participants due to their low literacy, the themes were informally verified with community members. Broad identified themes were discussed informally with other community members (leader was given name by researcher) who's view was same as the findings of this study. Participants chose their own pseudonym which clarified that their understanding that their words would be read by others. Age ranges were used in the quotes to protect anonymity.

## **Ethics**

Prior to each interview, the study information sheet in Nepalese describing the study, and including information about confidentiality was given to participants and explained in detail to them. Ethics approval was obtained from the University Human Ethics Committee (UHEC), the La Trobe University, Melbourne Australia (Approval Number 15-086).

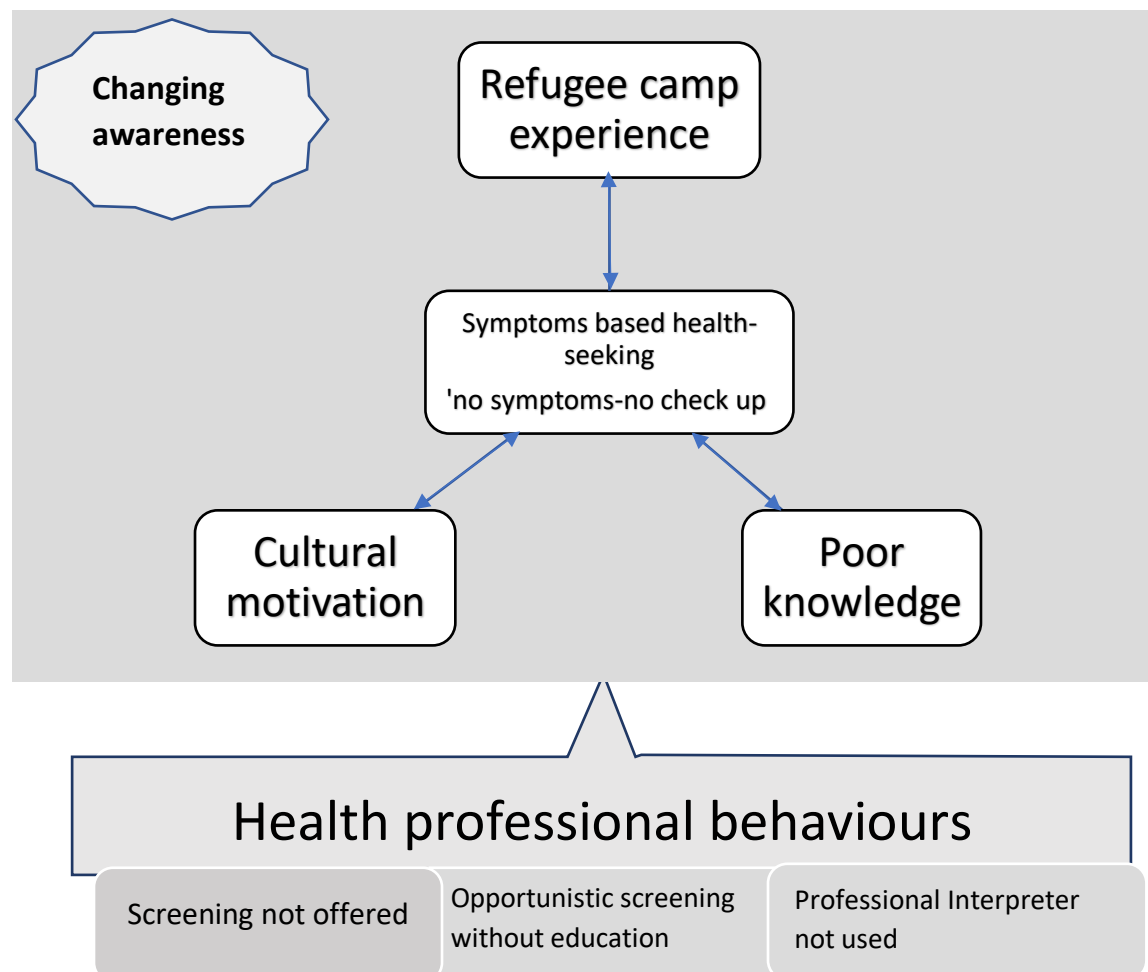
## **Study findings**

Thirty women aged 26- 70 years, who had lived in Melbourne for at least four years took part in the study (range 4-7 years). All 30 were born in Bhutan and had lived refugee camps in Nepal for an average of 20 years (range 18-23 years). Most had never gone to school and were illiterate in their own language. Photo-elicitation was required for seven women. All participants were married and had at least two children.

A strong overarching theme was evident (see Figure 1); health-seeking behaviour among the refugee women was strongly associated with symptoms. In the words of several women in the study this theme can be described as 'no symptoms- no check-up'. Three major manifest themes contributed to this behaviour: poor knowledge, cultural motivations and refugee camp experiences.

In addition to the factors associated with cervical cancer screening behaviours, a second set of latent themes associated with health professional behaviours were identified as the women recounted their experiences in their interviews. These included: screening not offered; opportunistic screening without education; and failure to use professional interpreters. A contrary theme was also evident among younger educated women: changing awareness.

**Figure 1: Barriers to Cervical Cancer Screening among Bhutanese women in Australia**



### **‘No symptoms- no check-up’**

Symptoms-based health-seeking behaviour was a common feature in almost all interviews and was summed up in the refrain ‘no symptoms- no check-up’. Women firmly believed that symptoms prompted health-seeking, and the large majority reported that they presented to health care only after being sick. For these women, if no visible signs or symptoms meant good health and that health services were not needed.

No symptoms-no check-up was integrated into the three major contributing themes in several ways and used to justify why preventative cervical screening had not been pursued.

Women, such as Bhagawati, related the lack of symptoms to lack of knowledge of preventive care services:

I don’t have any problem; no pain, no bad experience, no discharge, there is no need to do anything. We don’t go for a check-up without having a problem. (Bhagawati 55-59 years)

Lack of symptoms reinforced by cultural motivations were apparent in several interviews. For example, for Rathi, the absence of symptoms, reinforced by not needing to expose her body, meant that she did seek preventive care:

Not feeling any importance about doing this test as there is no pain, no discharge and no indication of any disease. I was thinking, why do I need to show my body to anyone? (Rathi 60-64 years)

Bhima pointed to her experience in the refugee camp, the lack of knowledge about the test and cultural influences, and the lack of symptoms as the reasons for not using the cancer screening services:

These services were not in the camp and not in Nepal. We never heard about it. Other women in the community do not understand about it as this does not come as a sickness, means no sign and symptoms, no pain, no discharge etc. then people think there is no problem. The importance of it is not known. Other things could be those who understand, but do not do it due to shyness. It is not talked freely about this with

the doctor or by the doctor and with family, I have used this service but not in regular basis as I do not realise how important this is to do it in every two years. (Bhima 50-54 years)

### **Poor knowledge**

Poor knowledge of cervical cancer screening was a major contributing theme throughout the study, irrespective of participants age or education level. Thirteen of the 30 women in the study had never heard of cervical cancer screening and only 15 women had actually undergone screening at least once, an average of 5 years after arrival. Most women in this study were illiterate; 21 of the 30 women were not literate in their own language. Health literacy was very low among the women, who readily admitted to their ignorance, stating 'I didn't know', 'nobody told me' or 'I never heard', 'we didn't have this service in the camp'. Women also said that services were not discussed with them in an understandable way. Here, Kamala clearly showed that, as she was not informed effectively. she failed to present for cervical screening after resettlement rather but waited for 5 years.

...lack of information in our community about it, means that nobody knows about it. If somebody told me 5 years ago, I would have done it then. We can feel shy, but we need to be given information in the right way and told that a female GP can be available to do this. (Kamala 30-34)

Several women reported that they did not know about screening services or its importance. Among those who had been screened, only two had been followed up. Women expected health professionals to tell them if a test was important.

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

There is no knowledge about this test within our community. Everybody should know that this test is for the prevention of cervical cancer not the treatment of pain or discharge. There is no concept of doing any test if there is no perception of the problem. (Sita 30-34)

## **Cultural motivations**

The behaviour of almost all women in the study was strongly motivated by cultural issues, particularly taboos attached to exposing their 'private parts', which are perceived as 'sacred' in Bhutanese culture where shyness is valued. Embarrassment from the related stigma attached to exposing the female body was a strong deterrent in terms of health-seeking, including follow-up after screening. In contrast, there was strong cultural faith in doctors.

### **The sacred body and related stigmas**

Few women in the study had ever exposed their private parts to anyone else before; most had delivered their babies alone in their homes in Bhutan or the refugee camps. The screening test was very confronting to them. For some like Saraswata, the idea of cervical cancer screening challenged how she had lived her life:

I have given birth of my all children alone at home when my husband was away. I had nine children one after another, nobody saw me, and I didn't show to anyone. My health down there is good. I have no discharge, now at this age, I am not going to do this, even thinking about this is extremely hard for me. (Saraswata 65-69 years)

Even when symptoms were present, women were reluctant to seek help.

Although I used to have lower abdominal pain and pain around vulvae and vagina and vaginal discharge, I was very shy to talk about this... I thought, how am I able to hide this until it gets severe? I will keep hiding it. (Madhavi 55-60 years)

Even talking about cervical cancer screening was confronting and offensive to some women.

For example, Phulmaya declared that she would never participate in it:

I have not done it because I was very shy and, 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. (Phulmaya 55=59 years)

The difficulties in talking about health issues and checks generated discomfort and offence.

Madhavi described it this way:

There are so many women hiding this problem and not saying anything due to discomfort to talk about our own issue in our society. There are so many women who can't talk even in front of their husband. Huge stigma around in women's health issue.  
(Madhavi- 55-59 years)

### **Strong faith in doctors**

Despite the reluctance to talk about personal issues, the Bhutanese women in this study demonstrated strong faith in doctors, which was manifest in their willingness to comply with doctor requests or recommendations for screening.

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

### **Refugee camp experiences**

The third main contributing theme to women's health-seeking behaviour can be attributed to their previous experiences in the camps. Almost all women questioned why cervical cancer screening was needed, as it had never been offered in their refugee camps.

Only basic health services were available in the refugee camps in Nepal, and the women in this study were used to doing what health professionals asked them to do. The habits developed during this period, of seeking health care when clearly needed or when told by health professionals including continued with these Bhutanese women after resettlement, as echoed by this woman:

... Though I think, I need to be responsible for my body, I have not done this test after being here for seven years, because I didn't know about it. Nobody told me to do it. We did not have this service in the camps. (Chandrawati 40-44)

The experiences of refugee camps where scarcity, hunger, disease and deaths were common, meant that women such as Leela, were not concerned about preventative health services such as cervical screening. Memories of life in the refugee camps after resettlement was still



affecting her, making access to preventative health services such as cervical screening seem unimportant:

Twenty years was such a long time in the camp. There was too much pressure on many things including fulfilling the basic needs of food, shelter and health care. Many people died from diseases, and lack of food, and lack of treatment. The tension and stress from that time is affecting me even now (Leela-50-54 years).

### **Health professionals' behaviour**

A set of latent themes identified through women's reports of their experiences were related to health professionals: screening not offered; opportunistic screening without education; and failure to use professional interpreters.

#### **Screening not offered**

All women had sought primary health services many times since their resettlement, but few had been offered cervical cancer screening. Constant refrains throughout the interviews were, 'Why didn't my doctor tell me?' or 'If it was important, my doctor should have told me'. Because the option of screening tests had not been raised by doctors or other health professionals, women doubted the value of such tests.

I have not done this, many times I went to the doctor and my doctor didn't tell me to do it. I think, if the doctor didn't tell me, it means that it's not very important for me to do. (Madhavi 55-59 years)

...I regularly go to GP and have blood tests, but the GP has never talked about this test. (Mayadevi 40 -44)

#### **Opportunistic tests without education**

At least 15 women had undergone the cervical screening, but many of these still did not know why it was done. Screening was opportunistic and not planned. It occurred during an appointment with the doctor for another purpose.

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)

Health professionals did not provide information on cervical cancer or screening practices.

I have done this test only one time. Nobody told me to do it on a regular basis. I think I do not need it as I do not have any symptoms. (Narayani 60-64 years)

Many women were curious about the reasons for the test, even after having it.

I felt why I need to do it, I have never heard about it before; it was not there in the camp. the doctor didn't explain more about it but I was still curious about it and he asked me to come back for the report in two weeks. (Kanchhi -25-29 years)

Kamala had the test in her postnatal check-up, but the procedure wasn't explained well, and she found it confronting. Her doctor just said, 'I want to see down there', but never explained why, or what was involved. She felt that as her doctor had asked, she had to agree.

I thought this is for my life, if something is wrong, I will get treatment. But my doctor didn't explain me well about the procedure, it was a bit confronting, when the test is done by exposing women's private parts and using some equipment but what I all felt that as my doctor was doing it this would be for my own benefit. (Kamala-30-34 years)

### **Failure to use professional interpreters**

In their accounts, women reported that on many occasions, the doctor did not use a professional interpreter, but instead used a family member to interpret for them. Everyone said that this made it hard to talk about sensitive issues.

.... 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)

Language barriers, the failure to use professional interpreters or using a family member as an interpreter, meant that the purpose of the cervical cancer screening test was not explained to the women. When performed without explanation, the procedure made the women more anxious and increased discomfort.

I didn't know why they needed this test. Maybe the doctor told my son who was with me, but he didn't tell me anything, I didn't know about it. After a few weeks the doctor informed that the result was normal. (Aama 50-54 years)

### **Changing awareness**

Changing awareness was an important, contrary theme that only appeared among young and educated women in the study.

.... I feel like, if I myself as an educated woman do not bother doing this, then who will do it. But as we are talking, I feel I will do it [cervical cancer screening] in the future. If I, and others like me, don't do it, how can we expect our mothers to do it? (Annie 35-39 years)

Annie also made the connection between symptoms and behaviour change.

I think only when health problems arise that our behaviours change. For example, I had sugar problems in my second pregnancy, and then I started to be conscious of my dietary intake. (Annie 35-39 years)

Younger women also saw that education, particularly from health professionals was key to changing health behaviours.

It takes a lot of time and this thing [encouraging screening] must come from the doctor or nurse. Women need to be encouraged to make them do it otherwise it will be not easy. (Kalie 35-39 years)

### **Discussion**

The barriers to accessing preventative health care services, including cervical cancer screening, experienced by Bhutanese refugee women in this study after their resettlement in Australia were based on: their own lack of knowledge, their expectations of care, and the behaviours of health professionals.

Symptoms-based health-seeking, reflected in the 'no symptoms-no check-up' theme in this study, was common behaviour among this group of refugee women, and can be explained with the Health Belief Model (HBM)(Irwin M. Rosenstock, 1974), where health behaviours occur in

response to perceptions of personal threat of a disease. Such perceptions are influenced by general health values, specific health beliefs and understanding of the possible consequences of specific health problems (Masoudiyekta et al., 2018). Among the women in this study, health knowledge was poor; there were cultural factors that discouraged women from asking about their bodies, and expectations about health services that reinforced by their experiences in refugee camps, where health care focused on acute needs.

Other studies have found poor health literacy and poor understanding of health care systems to be prime obstacles to health-seeking among refugees after resettlement in Australia and other high-income countries (Cheng, Vasi, Wahidi, & Russell, 2015; Riggs et al., 2012). However, the refugee women in this study did attend health services, yet cervical cancer screening was rarely offered or explained to them. Due to the women's lack of knowledge of preventive health care, they didn't know to ask, and health professionals didn't tell them or offer the service to them. Important cues to action, or signals to engage in health behaviour among this population were missing. Health professionals either failed to prompt the women or did not explain its importance. Screening was not offered; and when opportunistic screening did occur, there was no education; and poor practices with interpreters. There was also evidence of growing awareness of the needs of this service in the community among younger, educated refugee women.

As in many other studies, lack of suitable information for the women was evident. The large majority of women in this group were illiterate, but even for those who were educated, lack of explanation about screening during clinic visits led to lack of knowledge and awareness. This problem was exacerbated when health professionals did not use professional interpreters but instead used family members. Other studies have found similar practices undermine the provision of culturally appropriate health care (Clark et al., 2014; Kenny & Lockwood-Kenny, 2011). Like other studies illiteracy, even in women's own language, added to the complexity of cervical screening education among this group (Bellamy, Ostini, Martini, & Kairuz, 2017; Clark et al., 2014). Such situations diminish perceptions of the seriousness of such actions, which in the HBM creates barriers to taking effective action (Masoudiyekta et al., 2018; Sundstrom, Brandt, Gray, & Young Pierce, 2018).

Cultural beliefs and stigma were prominent barriers to accessing women's health services in this study, and similar findings have been found in other Australian studies (Shawyer, Enticott, Block, I-Hao, & Meadows, 2017). Such findings reinforce the need for health care professionals to recognise the importance of cultural norms for women from particular ethnic groups; for Bhutanese women, the concept of the 'sacred body' holds particular value.

Another important cultural aspect of health care revealed in this study was the high respect afforded to health professionals, both doctors and nurses, who were perceived as the most authentic health professionals. For some, doctors in particular, had the utmost authority and their advice would always be followed, despite other cultural taboos. These findings offer an important opportunity for doctors, and the nurses working with them. They can play a central role in motivating Bhutanese refugee women to undertake cervical cancer screening. The clearly expressed views of women in this study was that if their doctor did not raise a health issue, it meant it was not important. This finding shows that important factors in health behaviour, recognised in the HBM, were missing. The women did not understand the importance of cervical cancer screening nor the benefits of taking action.

At least one other study (Colucci, Minas, Szwarc, Guerra, & Paxton, 2015) has found that lack of knowledge and lack of cultural sensitivity among Australian health professionals created barriers to accessing appropriate services for refugees. More worrying perhaps, was how frequently women in this study reported the failure to use professional interpreters during their health visits, despite their availability at no cost in Australia (Clark et al., 2014). Ideally, health services should make use of the resources available and provide opportunities to educate about health issues and appropriate health service utilisation (Gifford, Bakopanos, Kaplan, & Correa-Velez, 2007). Specialised health services that focus specifically on the needs of refugees and provide culturally sensitive care may be an effective response ;(Correa-Velez & Ryan, 2012; Davidson N et al., 2004). Unfortunately, the reality for refugee women in this study, the behaviours of health professionals added to the barriers they faced in using and understanding preventive health care.

Health professionals are critical to changing understanding about the value of preventive care for this group and improving their knowledge of cervical cancer screening. The experiences of

the Bhutanese refugee women reported in this study, show that there were lost opportunities to take action towards cervical cancer prevention and to educate women about their care.

### **Study limitations**

The major limitation of this qualitative study was that it involved a specific Bhutanese refugee group of women. Several of the barriers to health service access identified were attached to the Bhutanese cultural context and beliefs. Findings may not be generalisable to other refugee cohorts, although similar themes may be evident in other groups. The study took place in Australia, which has a universal health system and free interpreter services, conditions that do not necessarily apply in other high-income countries.

### **Impact statement**

Better understanding of the issues that motivate the health-seeking behaviours of refugee women may help to overcome barriers to cervical cancer screening. Bhutanese refugee women were not motivated to seek preventive cervical screening as they believed in the phenomena of 'no symptoms-no check-up'. Health professionals have important roles in initiating screening procedures for this population and educating women about them. Screening should include explanation of the procedures and reinforce the importance follow-up over time. This is particularly important when literacy is poor and when women have strong faith in health professionals to guide their care.

### **Conclusion**

This qualitative study of Bhutanese refugee women resettled in Australia highlighted the phenomenon of 'no symptoms-no check-up' as a central barrier to accessing preventive services, specifically, cervical cancer screening. This behaviour was influenced by various factors such as poor knowledge on the importance of preventive care, expectations of health care built on extended experiences in refugee camps, cultural issues and beliefs, and the behaviour of health professionals. Screening was commonly not offered, and when offered done without explanation. Family members were often used in place of professional interpreters, creating a significant barrier to raising sensitive issues.

Health professionals in the countries of resettlement need greater awareness of the role they play in creating barriers to health-seeking among refugee populations. Improving cultural competency in the health workforce will improve the health care provided to refugees.

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## Published article

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# 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 decades<sup>1</sup>. 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 Australia<sup>2</sup>. 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 effective<sup>1</sup>. 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 cent<sup>3</sup>. However, the service access and utilisation rate in Australia among migrant and refugee women is significantly lower compared to rates in the host population<sup>3,4</sup>.

Breast cancer is the most common cancer diagnosed in women and accounts for approximately 28% of all cancers in Australian women<sup>5</sup>. 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 populations<sup>6</sup>.

Australia has resettled more than 6000 Bhutanese refugees under the United Nations' humanitarian program as part of a coordinated international strategy<sup>7</sup>. 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 group<sup>8-10</sup>.

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<sup>6,11</sup>. 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 behaviour<sup>12</sup>. Intersectionality allows exploration of multiple social identities among women through a multi-axial approach by taking account of their different roles<sup>12</sup>. 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 understanding<sup>13</sup>. 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 11<sup>14</sup> 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 findings<sup>15</sup>. In the two-part interpretation process participants were asked to clarify or explain and the researcher interpreted how participants made meaning of their experience<sup>16</sup>. 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." (Aamma<sup>2</sup>)*

*"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 Aama<sup>1</sup> 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." (Aamma)*

### 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)*

Aama<sup>2</sup> 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." (Aama<sup>2</sup>)*

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<sup>11,17,18</sup>. 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 present<sup>8</sup> and that preventative health care is an unfamiliar concept<sup>19,20</sup>. 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<sup>21,22</sup>, 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 studies<sup>23</sup>, and that knowledge of the link between breast cancer and screening can motivate women to undergo breast-screening<sup>6</sup>. 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 needs<sup>24</sup>. 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 services<sup>22</sup>, 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<sup>18,25</sup>.

## 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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## **Summary**

In this chapter, through two publication manuscripts, I discovered perceived barriers to accessing cervical and breast cancer screening services for Bhutanese refugee women. The findings showed that 50% of women had never been screened and were not aware of the fact that that screening services were available for their needs. It was very surprising to learn that although these women have attended a GP practice many times, the cervical and breast cancer screening was not discussed with them and screening was not offered. When offered it was without education, resulting in the women not attending follow up appointments. I also found the women themselves were very much influenced by symptoms-based health seeking with cultural beliefs and stigmas around screenings and lack of knowledge in preventive health care. It was critical to note that both the women and health professionals were equally responsible for creating these barriers. In the next chapter I will discuss the women's own ideas and suggestions for a best practice model to improve their access to these services.

## **8. BEST PRACTICE MODELS**

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This chapter looks at the suggested solutions by the refugee women to increase their participation in cervical and breast cancer screening services. The revised version of manuscript title 'Best practice models recommended by Bhutanese refugee women for cervical and breast cancer screening in Australia: A qualitative study' has been submitted to the Health Promotion Journal of Australia in August 2019 and the manuscript appears in the same way in this chapter. The manuscript is intended for a broader audience including policymakers and service providers.

**Citation:** Parajuli, J., Horey, D., & Avgoulas, M.-I. (2019). Best practice models recommended by Bhutanese refugee women for cervical and breast cancer screening in Australia: A qualitative study *Health Promotion Journal of Australia*

Intended audience	Journal [2018 Impact Factor]	Publication status	Extent and nature of candidate's contributions	Extent and nature of co-authors contributions
Broader audience including policy maker and service providers.	<i>Health Promotion Journal of Australia</i>  The journal impact factor 2018:1.333	First submission was in 12 <sup>th</sup> of March 2019.  The Revised version submitted to the journal on 27 <sup>th</sup> Aug 2019.	Contribution of candidate: 80%. This includes data collection, data analysis, drafting and revision of manuscript; submission to journal	Contribution of co-authors: 20%. This includes discussion of ideas expressed in paper and critical review.

## **Submitted manuscript**

### **Best practice models recommended by Bhutanese refugee women for cervical and breast cancer screening in Australia: A qualitative study**

#### **Abstract**

**Purpose:** The purpose of this paper was to explore what a refugee women's health screening program would look like if the views of Bhutanese refugee women were incorporated into service design and the approaches to targeting access to cervical and breast cancer screening.

**Methods:** Qualitative study, used in-depth interviews with 30 Bhutanese refugee women resettled in Melbourne, Australia.

**Results:** Two practice models were identified by refugee women: a doctor-initiated model involving opportunistic screening during consultations for other purposes; and a group screening model. Participants emphasized the need for a supportive environment with culturally appropriate services, community education and peer networks to encourage and facilitate their participation in cervical and breast cancer screening services. General practitioners can provide guidance, opportunistic screening that includes education, and advice about follow-up. The need for the routine uses of professional interpreter services was reinforced.

**Conclusion:** Available cervical and breast cancers screening services are not attuned to refugee women's views where this study focuses attention on the roles and practices of doctors in preventive health care for refugee women. Merging their perspectives with those of providers and policymaker's can fill the existing gaps and support to formulate the new interventions that will improve women's access to such preventative services.

**Keywords:** Refugee, women, model of care, cervical screening, breast screening, recommendation

# **1 INTRODUCTION**

Cervical and breast cancers are major health burdens in Australia and a critical public health problem, due to their high rate of morbidity and mortality (1). However, despite the free universal access to health care women from low income and ethnic minority groups are less likely to use sexual and reproductive cancer screening services compared to other women in Australia(2, 3). The problem is exacerbated among refugee women resettled in Australia, where the screening participation rate is lower in migrant and refugee women compared with the host population (4). Several researchers have documented a multitude of barriers to the use of breast and cervical cancer screening among refugee populations in Australia (3, 5-7).

This problem is not unique to refugees resettled in Australia, similar patterns of sub-optimal screening behaviour are also found in other refugee and migrant women, particularly from South Asian populations, in other high-income countries. Poor knowledge, cultural norms, practices and beliefs inhibit the uptake of cancer screening(8)

Such barriers include issues related to the refugees themselves (e.g. personal characteristics, sociocultural issues, and the impact of previous experiences), issues related to health services (e.g. practice issues and practitioner knowledge), and the context of resettlement (e.g. policy issues)(9) Few studies have explored the appropriateness of existing screening models, which tend to be based on policymakers' recommendations and studies in high-income western populations (10, 11), and there appear to be no published evaluations of screening programs based on participatory approaches, that is programs that incorporates recommendations from refugee women themselves. Such approaches, also referred to as community participation, community engagement, and patient-centred are highlighted in various studies exploring the delivery of needs-based cancer screening services (10, 12).

## **1.1 Cancer screening in Australia**

Australia runs a national organised screening program for cervical and breast cancer screening, both free of charge to all eligible women(13, 14). Over the 20 years since the full implementation of the screening program, it has been estimated that this program has reduced breast cancer mortality by between 21 to 28 percent (15), and cervical cancer incidence and mortality by half (13).

The most recent cervical cancer screening guidelines recommends cervical screening every three years for women aged 25 to 74 years. These screening tests are performed by GPs ( General Practitioners) or accredited registered nurses across a range of primary healthcare settings including doctors' clinics, family planning clinics, community health centres, sexual health clinics and Aboriginal medical services (16). The Australian national breast cancer screening guideline recommends biennial mammograms for all women aged 50-74 years by invitation from Breast Screen Australia and for those women 40-49 years on the recommendation of their general practitioners (GPs) (15).

This paper is part of a larger study that explores the experiences and perceptions of Bhutanese refugee women in accessing and using cervical and breast cancer screening services after resettlement in Australia. The study asked participants for their suggestions on ways to improve cancer screening for Bhutanese women. This paper addresses the following questions:

- What do Bhutanese refugee women suggest would improve their access to cervical and breast cancer screening services in Australia?

## **2 METHODS**

### **2.1 Research approach**

In-depth interviews underpinned by phenomenological and feminist methodological frameworks were used to explore women's experiences and their meanings. Phenomenological theory attempts to understand the meaning of events, interactions, and the subjective aspects of people's behaviour, and to provide a description of these phenomena as they are consciously experienced (17), while a feminist framework captures women's life experiences in a respectful manner (18) that is beneficial to them (19). Since women are central to this research, this approach puts women's lived experience at the centre (18, 20).

The interviewer, who is a Nepalese Australian, works as a refugee health nurse and previously worked in refugee camps in Nepal. Concerns about the poor uptake of preventative health care by refugee women prompted her current PhD studies. She has conducted many interviews and focus groups in her work and in her previous postgraduate studies.

### **2.2 Study participants**

Thirty Bhutanese refugee women aged 26-70 years, who had lived in Melbourne for at least four years (range 4-7 years), took part in the study. All 30 were born in Bhutan and had lived in refugee camps in Nepal for an average of 20 years (range 16-23 years). Most of the women had never been to school and were illiterate in their own language (21/30, 70%). All participants were married and had at least two children.

Participants were recruited purposefully based on pre-set criteria through local Bhutanese community leaders who widely disseminated brief information about the study in the Nepali language and English throughout the Bhutanese community. None of the study participants were personally known to the primary researcher (JP), although she was known to some participants through her work in their community. No one who was approached refused to take part in the study. Recruitment and interviews continued until confirmation of data saturation occurred.

### **2.3 Study design**

The interviews were conducted face-to-face in Nepali by the primary author (JP) between April 2016 and December 2016 in the homes of the study participants and took place in a separate room with only the interviewer and interviewee present.

An interview guide developed based on the literature had minor modifications after the first three interviews to incorporate additional information recorded in field notes. The interviews covered a broad range of questions relating to experiences of accessing women's health services, particularly cervical and breast cancer screening. During the interviews, women were also encouraged to talk about their suggestions on ways to improve cancer screening for Bhutanese women, which is the focus of this paper. Photo elicitation was used to facilitate data gathering. This occurred for seven women who were unfamiliar with screening, when photographs of screening activities were used as a tool to prompt their understanding (21). There were no repeat interviews.

### **2.4 Data analysis**

Interviews took 45-90 minutes and were recorded, transcribed and translated into English. A sample of the interviews (10%) were independently translated by a second Nepalese PhD student enrolled at another institution. There were no discrepancies between the translations identified.

Transcripts were read and re-read and analysed using guided content analysis to answer the specific research question (22, 23) with the assistance of Nvivo 11 (24) for coding and data management. Due to the poor literacy of the study population transcripts were not returned to participants for verification, but the themes raised in the interviews were confirmed with informed community leaders.

## **2.5 Rigour and Trustworthiness**

Rigour and trustworthiness were ensured through the use of an interview guide was used. Prior to each interview, a study information sheet was given to the research participant with a full verbal explanation in the Nepali language of the research process, including how confidentiality would be ensured. Interviews were only conducted after informed consent was obtained. Participants chose their own pseudonym which clarified their understanding that their words would be read by others.

## **2.6 Ethical consideration**

Ethics approval was obtained from the University Human Ethics Committee (UHEC), La Trobe University, Melbourne, Australia.

# **3. FINDINGS**

## **3.1 Participation in screening programs**

All women in the study saw their GP regularly. However, only 15 of the 30 women in the study had experienced cervical cancer screening, and only one woman was regularly participating in the screening program. The other 14 women who had been screened for cervical cancer at least once, had not been followed up. Nine women had undergone a breast cancer screening mammogram; none had been followed up after two years.

General practitioners (GPs) initiated most screening tests, and on average, the first screening, for either cancer, occurred five years after a woman's arrival in Melbourne. Few women attended the GP service specifically for a screening test. For most women, who had been screened, the screening occurred in appointments made for other reasons.



## **3.2 Improving cervical and breast cancer screening services in Australia**

Three main suggestions were evident in the refugee women's response to questions about how screening services could be improved, but critical to these was the need for a supportive environment. The suggestions included: the role of GPs; a group screening model; and ongoing education.

### **3.2.1 A supportive environment**

Provision of a supportive environment was paramount in women's suggestions to feeling comfortable using screening services. A supportive environment was described in terms of specific supportive factors, the involvement of settlement workers, and effective service coordination.

Supportive factors identified by the women included: community awareness campaigns; assistance in making medical appointments; the use of trained interpreters during health consultations; the provision of appropriate information from GPs; and effective reminder systems.

More information, assistance in accessing services, appointments etc. No children should be used as an interpreter. (Maya 50-54 years)

If we talk more about this with our friends and family then everybody may know about it. (Dayadidi 55-59 years)

If someone does not know about it, they need to be informed. The doctor has never told me. My GP never uses an interpreter... It's very hard to talk about these things if your son is used as the interpreter. (Ganga 45-49 years).

The invitation letter from BreastScreen Victoria was seen as supportive as it encouraged women to go for a breast screening mammogram. Many of the women in the study could not read the letter themselves, but as the older women lived with their extended family, educated family members check their letters and facilitate attendance.

The letter came to the house, that was the reason that Ganga [daughter-in-law] took me. (Saraswata 65-69 years)

However, participation in screening, even when it does occur, does not mean that the purpose is well understood.

When we came here, the community guide took us to the GP. In the GP's practice, the GP did all the tests, like blood tests, but didn't do this test [screening]. In the beginning, I didn't know about it, but after two years the letter came, and I went to do it, then I know that it is for a cancer check. Since then I have been doing it every two years. But I do not understand more about it. I am doing it because they asked me to do it. (Pabi 45-49 years)

### **3.2.2 Settlement workers**

Government-funded settlement workers who support refugees resettle in their new country, were highly praised and respected by some women. Such workers were seen to: disseminate important information about necessary health checks; help refugee women access services for the first time; and connected Bhutanese refugee women with each other.

As knowledge about health screening is very low among the refugee population, some women like Kumari have only had cervical cancer screening after prompting and encouragement by a settlement worker. However, the lack of any follow-up, has led her to believe that she does not have any women's health problems.

When we had just come here, we were asked to go somewhere to do this and there were other Bhutanese women as well. Other sisters talked about it. I felt good. (Kumari 40-44 years)

The high degree of support provided at the start of their resettlement had positive associations for many of the refugee women.

### **3.2.3 Effective service coordination**

A common theme in women's suggestions for improving care was effective coordination. For example, the women wanted someone to connect them to different health services. One suggestion was that this could happen through community meetings to discuss cervical screening and breast screening. Alternatively, women suggested that a local community contact (many suggested that the primary researcher conducting the interview) could actively connect them to local services. For example, Kalie said to the researcher:

Another thing you can do is to conduct a community meeting and talk about these services openly. Also, connect women to local authorities and continue holding a meeting every month until they all do it. Give your contact number to women so that they can ask you any questions they have. I think you can do it as a small program on a regular basis to raise the awareness. Our didibahini [sisters] need individual encouragement to make them understand. Women in our community are still feeling very low. We need to work together to uplift them. (Kalie 35-39 years)

Opportunities to network with similar people who have had screening, was seen to be one way to encourage other women to be screened, as Kumari said:

We need to be linked to the person who knows the services and who can speak for us. We need someone who can show us the path to take. (Kumari 40-44 years)

When we came here, everything was new; new language, new system, new education. At this our age we are facing a lot of challenges in our lives just to settle. We need more practical support. (Annie-35-39 years)

### **3.3 The role of GPs**

There was broad and consistent support for GPs to play a role in improving the experiences of cervical and breast cancer screening among the women in the study. They saw GPs as an authoritative source on health issues and the means for opportunistic screening and education.

#### **3.3.1 GP as authoritative sources**

GPs have a strong influence on the lives and health of women in this study and many saw their authority as critical to encouraging themselves and other refugee women to undergo cancer screening tests. The most common recommendation from women about improving the uptake of screening was for GPs to more actively promote and encourage cancer screening tests to refugee women. Many women in this study wanted their doctor to tell them what screening tests were required and when; they were surprised that their doctors had not raised these tests during their regular contact with them. The high status of doctors in the Bhutanese community was apparent in the interviews and women were adamant that they would listen to, and accept, their doctors' suggestions or requests, despite cultural barriers and taboos, even if they were not themselves

convinced of the benefits of cancer screening.

In the following examples, women clearly expressed the influence of their doctor in decisions to undertake screening tests. The women were keen to follow their GP's instructions,

My GP told me to do it and I thought it must be necessary and so I did it. If my GP didn't tell me I would not know about it and would not do it. (Daya 55-59 years).

...but if my GP asked me to do it, I would think there must be a good reason for it. I think, there are so many women who are seeing a GP, if their GP initiates doing this, everybody will do it. (Monmaya 55-59 years)

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

My GP asked me to do it and because it was the GP's suggestion, I made my decision.  
(Madhavi 57)

I think if their GP tells everyone, they would do it. Because our women believe so much in the GP. (Chandrawati 41-44 years)

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

We don't see what's happening in our body. If the doctor says to do something; this must be a very important one. (Daya 55-59 years)

My GP told me that this test is for a woman to prevent cervical cancer. It needs to be done every two years. I have done it once after I had my daughter. (Annie 35-39 years)

About one year after I came to Australia, my GP told me to do and I have done this test since then. I get a letter every two years, and I go and do it every two years. (Lusi 31-34 years)

### **3.3.2 GPs as a means for opportunistic screening**

The possibility of opportunistic screening during GP consultations was a common suggestion made by the women in this study, which they saw as highly feasible as they all attend their GP regularly for other health reasons.

Pregnancy care was suggested as suitable time for such screening to occur. Kanchhi had had a cervical cancer screening test when she presented for a postnatal check-up after childbirth. However, the GP did not explain the test or why she needed. Despite this, Kanchhi thinks this is this approach is a way to make women have the test.

I was called by the GP at Dianella Community Health to come in for a postnatal check-up. Along with other tests the GP did this test but did not explain much about it and I could not understand her very well. I do not know much the test, but I did it anyway. Having the GP initiate it is a good way to make women do it, as I did. (Kanchhi 25-29years)

For many years I didn't know about it, but later as part of my postnatal check-up my GP told me to do it, then I knew about it and did the test. As I know about the test, I tell my friends, my mother, and my sister, so that everybody would be aware of it. (Kamala 30-34 years)

### **3.3.3 GPs as potential educators**

One-to-one education from their GP was suggested as an effective way to improve participation in screening programs. The majority of the women who had a screening test, had done so because their GP had initiated it is. However, the other half of the women in the study who had been screened, had been told about it, despite seeing their GP as frequently. Women in the study wanted information from their doctor, who they saw as authoritative and knowledgeable about their health needs and the health system, as shown in the following quotes:

We need to raise public awareness in this area. Every woman needs good information about it. Maybe they don't know the system of doing it, maybe they don't know who provides the service, maybe they are too shy to talk about it. I think the GP is the best and most authentic person to tell us about this. We all are dependent on GPs for our health. (Devi 51-55 years)

I think information from GPs and other health workers on a constant basis will help women to understand the services and encourage them to use them. (Kanchi 25-29 years)

Sita also agreed that GPs play a very important role to educate women and to promote cervical and breast screening tests. However, she also emphasised that GPs should use professional

interpreters to enable understanding and education for the women and to ensure that the women can raise their concerns as well.

If GPs give the information, it would be good. They [GPs] will listen but if there is no interpreter, they cannot get a complete picture of any health problem and motivate them [women] to do these screening tests. (Sita 30-34 years)

### **3.4 Group Screening Model**

At the start their resettlement two women in this study (Bhima and Kumari) had experience with a nurse-led group cervical screening program. Both those who attended this service described it as a great experience, particularly as it had started with the nurse talking about the test. The nurse explained why the test was needed, what it involved, how she was going to do it and what to expect during the procedure.

One participant, Bhima, thought that this group program would be good for all women. She found that having the test in the group made it feel special. It was a motivating experience for the women involved and the way that it was done meant that they gained useful knowledge and understanding.

The settlement worker organised a program to do this test, and I did it in a group. I also helped other women to interpret. At that time two women were identified with cervical cancer and had to go through surgery. I found doing it in a group for the first time to be very supportive. (Bhima 50-54 years)

Similarly, Kumari felt very secure and relaxed when the test was undertaken as a member of the group. It helped her to have the settlement worker conduct the screening and to have a friend in the room. She reported that the nurse explained the test to her very nicely and made it clear that there were no males present. Kumari liked that she could speak her own language with a female interpreter present. She found that having a group of women present all for the same purpose made having the test easier.

In my 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 no male present and I could speak my language. (Kumari 40-44 years)

### **3.5 Ongoing education**

The need for education in a range of forms was a common thread across the interviews. The women had a number of suggestions as to how education could occur, including: through their GP (which is addressed above); through peer networks; and through community education programs.

#### **3.5.1 One to one approach**

Kamala thinks that outreach services, like doing a home visit and educating women individually can also be effective.

If a person like you [researcher] could go to the individual houses and talk about this test that would be more effective. (Kamala 30-34 years)

#### **3.5.2 Peer education**

Many women in this study suggested the need to develop a system of peer education, which was described as getting women from the community who understand about cancer screening to actively help others decide to attend cancer screening services. The following quotes evoked this idea:

I really want to work so women take the path of empowerment, but they need more counselling, and individual meetings and indirect and direct reinforcements. (Kalie 35-39 years)

Communication from friend to friend, and peer group meetings would be good to motivate women to do screening. (Kamala 30-34 years)

Several women reported that sharing information about cervical cancer screening within their family is helpful and supportive. For Sanu, it was her sister-in-law who told her about screening and who took her to the doctor. The thought of cancer made Sanu feel afraid.

I have done this just about 9 months ago, I have been here [in Australia] for 7 years, and no one told me to do it until my sister-in-law told me. I was scared when I did it thinking

of the result and the word cancer, but the result was good. (Sanu 50-54 years)

Other women also described learning about screening from family members or friends, rather than from an outside person, and said that this made them feel more comfortable which helped to convince them to have the screening done.

I knew about this from a family member, and then I decided to do this test. (Bhima 50-54 years)

The encouragement and support from younger women to their mothers or mothers-in-law also helped older women access services.

I always tell our women to do this test, if you are feeling shy choose a female GP. The family members who know about the test need to encourage their mothers or mothers-in-law. They can write on a piece of paper for their mothers or mothers-in-law to show to their doctors to make them do the test (Pabi 45- 49 years)

Engaging in conversations with friends was another way that women found the confidence to seek screening services, as shown in Chandrakant's comment:

.... then my other friend told me that we must ask ourselves to do it. Then I went to the GP and I asked myself to do it. (Chandrawati 40-45 years)

Family and friends who have had cervical screening were suggested to become '**role models**' to other women and actively share their experiences, to motivate other women to be screened.

I think I will tell all the women who I meet and who I know. I think it's very important that we should organise some program. (Chandrawati 40-45 years)

### **3.6 Community education**

The third way that women suggested that education about the importance of cervical and breast cancer screening and how to access these services to provided was through community health education initiatives. Strategies, preferably in the Nepali language, clearly communicating the importance of adhering to recommended screening schedules. Some women suggested that such



messages should emphasise the potential adverse health outcomes when screening is missed. Sita expressed it this way:

.... However, they will understand if we make them understand by saying that this is very important. If we do not do it there is a high chance of having cancer (Sita 30-34 years)

Lusi, who is educated, talked about evidence-based education. She had many suggestions for group education for these women:

We need to talk about the data, refer to their friends who have done the screening and ask them how they felt about it. This is an easy way for them to know more about it.

....Relate the information to their life benefits .... educate women not to feel shy, this is related to your life. If information come from different people with the same message, the information that will work. Information and reinforcement from GPs to clients and relatives makes it convincing. ....Information sessions from language schools via the teacher about this. [We need to ] spread the information, maybe from ethnic radio and put in the local Nepali paper to raise awareness. (Lusi 30-34 years)

Integral to the community education strategy that women outlined was education and encouragement from people known to the community and by someone who knew their culture and their circumstances. The women felt that these factors would mean that others would be more likely to use screening services. Kumari expressed it in this way

...the people like you [the interviewer/researcher] who know us from the camp can play a big role in providing good service and education. I can ask you any question. (Kumari 40-44 years)

.... I feel happy to meet you [the interviewer/researcher] because you know our journey. You know where we came from and what was our situation from the beginning to the day we left camp. I think we need more information from the people like you about this and other services that we require as women. (Kumari 40- 44 years)

Women voiced the benefits of education and awareness-raising programs from someone who can speak their language and who is known to them.

Some women didn't do it as they didn't know, we didn't have this service before. We don't know anything about it. We need to be educated regarding cervical and breast cancer tests. It is different when an English-speaking person comes to tell us and when you [the interviewer/researcher] come and tell us. It has a different value. You need to take the lead, to tell all women. You need to talk to the GP practices where Bhutanese women go. (Lusi 30-34 years)

Bhima suggested that encouragement and constant reinforcement from women who speak their language, and from someone working in the health sector, would be the right person to talk to about the benefits of screening and motivate women to attend screening services.

If you [primary researcher] as a person who knows the community and speaks the language go house to house and tell them about the services, it will work. Sometimes, you could talk to a group or organise appointments for them individually. (Bhima 50-52 years)

I think people who know the community and culture need to go to women to meet them and talk to them about this to make them understand. They need to tell them about the services and its importance. Raise awareness about the services. (Kalie 35-39 years)

It's good that you [primary researcher] are coming to our community. You must do something about it. You need to talk to all women to initiate this. Please do it within a month. (Madhavi 55-59 years)

Although not all younger women in the study had been screened, Sita identified the need for a strategy that specifically addressed older women.

I think there is no problem for me or the women of my age, but our mothers are aged women and are very reluctant to do this test until, and unless, it is requested by a doctor or they have problems related to this. They are very shy, and they have a deeply rooted concept that this part [of their body] is not to be seen by anyone except their husband. Even when there is women doctors, they feel that it would be shameful if they expose their private part to them. However, they will understand if we make them understood by

saying that this is very important if we do not do it as there is a high chance of having cancer. (Sita 30-34 years)

#### **4. DISCUSSION**

This paper describes the types of services that Bhutanese refugee women suggest improving their access to cervical and breast cancer screening services in Australia. Two practice models were strongly suggested: opportunistic screening by GPs and group-based screening. Critical to both models was the need for a supportive environment, where women felt supported and could speak and hear their own language. The women also supported ongoing education, either from their GP, from peer networks or through community education programs. These suggestions align with the Ottawa Charter for health promotion by creating supportive environments (25)

Despite preventative screening measures for cervical and breast cancer operating widely in Australia (2), like many other refugee and immigrant groups, the Bhutanese refugee women in this study were unaware of the existence or importance of these services. This study offers suggestions from the targeted consumer population, that is resettled refugees in Australia, on the types of screening services they want. Incorporating consumer views into the design of screening programs has been shown to be an effective way to improve uptake, in contrast to services designed by policy-makers (10, 12).

The suggestions by the Bhutanese refugee women to actively involve GPs in the initiation and education of cancer screening demonstrates clearly the high status of doctors in that community, which may be intensified by their years in refugee camps and related health conditions from that period (26). The women clearly indicated their willingness to follow their doctor's instructions, even if they had no understanding about the reasons behind them. In Australia, most cervical screening is performed in GP practices (13), yet it seems that the doctors involved in the care of the Bhutanese refugee women in this study are apparently unaware of their power to influence this group, as many had not taken the opportunity to advise or motivate the women to undergo cervical and/or breast cancer screening. The situation in Australia is not unique as studies in other countries have also reported the influence of other primary health care workers in initiating preventative health care measures (11, 27).

There were other suggestions for improving the uptake of screening services that involve GPs, including making better use of existing language services and improving service coordination are other ways to enhance. Bhutanese refugee women are unable to raise concerns about their health if it means that they need to involve their children as interpreters with their doctors. These sorts of practices are outside the control of the refugee women seeking care. Kagotho and Pandey (2010) found that cultural practices and the health care system in the country of origin influence the health-seeking behaviours of individuals, when in a new country (28). Health services need to consider the needs of those seeking care, including ethnic-specific needs, which have been shown to contribute to inequality in cervical and breast cancer screening programs (29, 30). Bhutanese refugees, who have spent long periods in refugee camps with limited healthcare provision, have no knowledge of cervical and breast cancers screenings services, and so need additional support from those providing their health care, including explanations about the need for follow-up.

The group screening model that was suggested in interviews originated from experiences in the early resettlement period, where the strategy was probably used by a resettlement worker to manage large groups of refugees resettling at the same time. The advantages that the refugee women gained who were involved in that process, may not have occurred to those who organised it. The women found that the process to be reassuring and an opportunity as a group to share knowledge and support. Common experiences of discomfort and stigma often identified as barriers to seeking and accessing cervical screening programs could be overcome through the sense of supportive environment. Similar results have been found in group antenatal care (31).

Alongside the models of care, women spoke clearly that their need for ongoing education to address their lack of knowledge about the importance of attending screening services and the potential adverse effects of failing to diagnose cancer early. Other studies have also shown the importance of specific education, including the need to highlight relevant clear health messages including the 'quality of life' and 'life or death' implications associated with screening, which could be crucial to maintain follow-up (32). Our findings, like other studies, further demonstrate that women prefer to be actively taught, not merely told about services. Education is more likely to motivate take up and involvement in regular follow-up screening (33, 34).

Community-based education and peer networks are likely to be effective, and there appears to be an important role for younger, educated refugee women, to help in the education of their community and the encouragement of older women to seek cancer screening tests. A common-sense approach would involve people familiar with the culture and language in health education strategy. This strategy has been shown to promising in terms of increasing awareness and willingness to take up cancer screening in South Asian populations in Canada, where lay health educators were embedded in four care practices (35)

Peer networks involving friends and family (12) can be a successful way to enhance women's knowledge and engagement in cancer screening programs, and also addresses the issue of illiteracy that is common among the study population. A continuing relationship with someone who acts as a peer educator would enable understanding of the need for services and how to access them and could contribute to women achieving control over their own health needs. This approach would help women to clarify their health beliefs and identify taboos in relation to screening tests.

This study has limitations. It was conducted with only 30 women in Melbourne, Australia, and the findings may not be applicable to other refugee groups or to similar groups in other settings. However, the findings do offer possibilities for other studies, including evaluations of different models of care and targeted education strategies. Several findings were consistent throughout the sample population, such as the authoritative role of doctors. The study population was largely illiterate, and this was likely to influence their knowledge and understanding of preventive health care, but there appeared to have been a lack of understanding of the implications of their illiteracy among those providing their care.

## **5. CONCLUSION**

Low rates of cervical and breast cancer screening are common among South Asian refugee and migrant populations and strategies to include these women in the design of health services is likely to benefit both refugees and other new arrivals to a country. Bringing the ideas of refugee women into discussions about improving cervical and breast cancer screening could possibly lead to changes in how GPs practice, in how care is offered and how education is delivered to

this vulnerable group. Making use of the authoritative position of GPs to both initiate screening and to more actively educate refugee women about the need for follow up will require better use of professional interpreter services to build more supportive environments. Doctors need to be more aware of their influence among this population if they are to achieve better health outcomes for them.

The development of a group screening model, that is supported by community education and peer networks, will enhance culturally appropriate services, and promote refugee women's motivation and interest in initiating and managing their own care. Future interventions need to be properly evaluated for their effectiveness and acceptability among this group.

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## Summary

In this chapter I explored the refugee women's own ideas to promote their participation in cervical and breast cancer screening program. Almost all women in the study highlighted the fact that if their doctor asked them to do these screening tests, they would do them despite the cultural barriers. It appeared that the doctors involved in the care of the Bhutanese refugee women in this study were apparently unaware of their power to influence this group, as many had not taken the opportunity to advise or motivate the women to undergo cervical and/or breast cancer screening. Women suggested the doctor-initiated intervention and Group screening intervention along with supportive environment and education would encourage them to undergo screenings. I believe merging women's perspectives with those of health professionals and policymakers can fill the existing gaps and help support the formulation of new interventions that will improve women's access to such preventive services. In the next chapter I will briefly discuss and contextualise the findings in the border perspective of other studies.

## 9. DISCUSSION

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In this thesis, I have explored Bhutanese refugee women's experiences and perceived barriers to accessing cervical and breast cancer screening services. I discuss the research findings presented in earlier chapters by first revisiting my research questions to address specific issues that the study raised. I explore these issues in the context of relevant literature and the theoretical concept of intersectionality, which was outlined in Chapter four.

My first question relates directly to the perceptions and experiences of Bhutanese refugee women and the second question focusses on barriers to accessing screening services. The final question looks for women's ideas about the model of care that they thought would improve their use of cervical and breast cancer screening services.

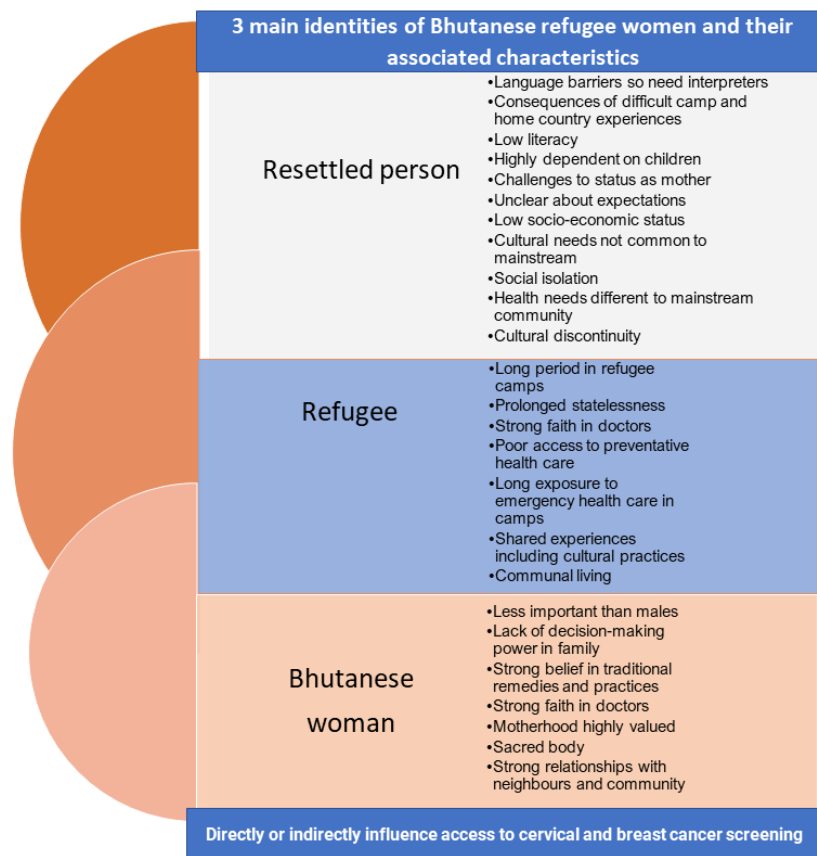
Chapters six, seven, and eight discussed these issues in detail in the form of manuscripts; however, the issues briefly covered in my discussion include: the impact of Bhutanese refugee women's different identities, and their associated characteristics on health seeking behaviours; the issue of symptom-based health seeking; the health professionals issues leading to mismatched expectations. This chapter also discusses the women's own ideas for addressing low uptake of cancer screening. Next, the chapter summarises the strengths and limitations of the study followed by the implications and recommendations for practice and future research. The chapter concludes with my personal reflection.

### **Perceived identities, perception and behaviour**

Three perceived identities of the Bhutanese refugee women were evident in influencing their perceptions of the value of cervical and breast cancer screening services and whether such services were used. These identities were the women's roles as resettled persons, as refugees, and as Bhutanese women themselves. Each of the recognised identities was associated with particular characteristics (see Figure 1), some of which appeared to be influential in terms of health-seeking behaviours. There were clearly intersections between these three identities and an interplay between different characteristics which emerged most clearly as the dilemmas

described in Chapter 6. In terms of health seeking behaviours, the women, as resettled people, were grateful for the health services available to them, and regularly attended local GP clinics. As refugees, the women were unfamiliar with preventive health services and unfamiliar with the Australian healthcare system. As Bhutanese women, they have a higher risk of both cervical and breast cancer (Menon, Szalacha, & Prabhugate, 2012; World Health Organization, 2014), and have been poorly educated, were ignorant of the need for screening, and reluctant to raise concerns about their 'sacred' body. The women were reliant on healthcare professionals to advise them about the need for cancer screening and to facilitate their access. Other ways that different identities affected health seeking behaviours are discussed below.

**Figure 1: Bhutanese refugee women perceived identities and it's intersections**



### Identity as a resettled person

Characteristics associated with a Bhutanese refugee woman's identity as a resettled person, included language barriers that required interpreters. The women's lack of literacy in their own language, which was not a problem in the refugee camps, but became significant following

resettlement and had a strong influence on their knowledge and perceptions of the value of preventive cancer screening, with no opportunity for these to change. Unlike the mainstream population, as resettled people, the Bhutanese refugee women were unfamiliar with the concept of preventive health and lacked knowledge of the Australian health care system and how to use health services that were recommended and readily available to them. (see Chapters 6 and 7). Other Australian studies with resettled refugee populations have also noted poor health literacy in regard to the importance of preventive services and poor understanding and familiarity of healthcare systems (Cheng, Vasi, Wahidi, & Russell, 2015; Jiwrajka, Mahmoud, & Uppal, 2017; Riggs et al., 2012).

The Bhutanese women's identity as a resettled person in a new country, reinforced by compounded communication difficulties on many occasions leading to higher dependency on their children. Most of the women in the study were illiterate in their own language, (21 of the 30 women interviewed could not read or write in their native language) and one woman described the impact of illiteracy as 'not being able to read and write is like putting a black tape on your eyes' (see Chapter 6). For those that were literate, the absence of written material or signs in their language, increased their sense of not belonging (see Chapter 6). Lack of literacy increased access barriers as there was no easy way to educate these women about cervical and breast cancer screening services and why these were needed. Another Australian study identified communication as a barrier to educating African refugees about the quality use of medicines (Bellamy, Ostini, Martini, & Kairuz, 2017). In that study there was a similar lack of awareness, or use, of the national Translating and Interpreting Service (TIS) as in this study [see Chapters 6 & 7], but the issue of refugee literacy in their own language was not raised, although several studies have pointed to the need for special measures for health education, where this may be common among migrant and refugee groups (Colucci, Minas, Szwarc, Guerra, & Paxton, 2015; Jiwrajka et al., 2017; Lawrence & Kearns, 2005; Riggs et al., 2012).

The health education measures to improve health literacy in cancer screening as women suggested in this study was, 'word of mouth' in the form of peer and community education and community network by the person they know (see Chapter 8). This is consistent with other studies where, social supports and education, capacity and confidence building programs,

establishing community networks sought to be enhancing the level of awareness in individual promoting health service utilisation (Cheng I. H, Drillich, & Schattner, 2015; Szajna & Ward, 2015)

Unfortunately reports by the Bhutanese women in this study that health professionals failed to use professional interpreters is consistent with other studies (Davidson et al., 2004; Hoffman & Robertson, 2016; Sheikh-Mohammed, Macintyre, Wood, Leask, & Isaacs, 2006; Shishehgar, Gholizadeh, DiGiacomo, & Davidson, 2015). This study found this practice was a barrier to preventive healthcare rather than a barrier to accessing primary healthcare services as all the women in the study regularly used primary care services (see Chapters 7 & 8).

### **Identity as a refugee**

Two characteristics associated with a Bhutanese refugee woman's identity as a refugee appear to be important to their perceptions of preventive health care: their prolonged period living in refugee camps; and their strong faith in doctors.

The refugee journey for the Bhutanese women in this study, which is described in Chapter 2, included a prolonged period in refugee camps in Nepal where immunisations were the only form of preventive healthcare and where medical care was only sought in the case of emergencies. These experiences appear to have been important to building the perceptions of the Bhutanese women who could see no purpose in seeking healthcare when there were no symptoms, especially when their doctor had not asked them to do so (see Chapter 7).

The overview of nine systematic reviews that were published between 2010 and 2017 to look for common barriers to healthcare services following resettlement conducted as part of this thesis and reported in Chapter 3, found unfamiliarity to be important, but none of the included reviews referred to the refugee experience affecting perceptions of preventive healthcare (Parajuli & Horey, 2019a, 2019b). This could be because of the different refugee population groups involved or their length of time in refugee camps or the country of resettlement, as these factors may also affect perceptions of preventive healthcare.

However, also reported in Chapter 3, is a systematic narrative review of qualitative studies involving refugee populations resettled in Australia, which included 12 primary studies. Again there was no mention of the potential impact of the refugee experience on the perceptions of preventive health care, although like in this study the review does point to the high expectations that refugees had for doctors and the cultural mismatch in terms of preventive and mental health care, which largely related to differences in the understanding of diseases and culture (Parajuli & Horey, 2019a, 2019b).

### **Identity as a Bhutanese woman**

Several characteristics associated with being a Bhutanese woman influenced their health behaviours including whether they accessed cervical and breast cancer screening services after resettlement. These characteristics were common across the women in the study and included: a deep-rooted concept of the sacred body, creating taboo around exposing private body parts, the status of motherhood, and the traditional female role in a patriatriarchal culture (see Chapters 6 and 7).

The cultural notion of a 'sacred body' was very strong among the women, some of whom acknowledged that their experiences of the processes involved in cervical and breast cancer screening were confronting and this posed a large barrier to screening, especially where the women had no understanding of its importance. While previous Australian studies have emphasized the special need to strengthen doctor-patient relationships for refugees (Cheng et al., 2015), and other aspects of cultural beliefs in relation to health-seeking (Cheng et al., 2015; Clark, Gilbert, Rao, & Kerr, 2014; Colucci et al., 2015; Omeri, Lennings, & Raymond, 2006; Riggs et al., 2012), the term 'sacred body' was not found elsewhere. This is important because the notion of sacredness conveys the very deep feelings that the Bhutanese women attached to exposing their bodies.

The Bhutanese women's status as mothers was highly valued by the study participants, who saw it as giving them a significant place in their community. However, resettlement in Australia had unexpectedly led the women to be highly dependent on their children. This included how and when they could access health services (see Chapters 6 and 7). Such dependency arose

through their lack of language and literacy, and through their inability to navigate transport and services, including the Australian healthcare system. This reversal of roles of mother and child was threatening to the women's sense of motherhood. The situation left women feeling insecure, vulnerable and marginalised in a new way. The issue was critical to how the women saw themselves, especially when their children were used as interpreters in their healthcare, which made discussion of sensitive topics harder and the women more reluctant to put themselves in that situation. Several women reported that they would not seek screening for themselves because of these reasons. Several studies have pointed to problems with using children as interpreters in healthcare settings (Gerrish, Chau, Sobowale, & Birks, 2004; Hadziabdic, Heikkilä, Albin, & Hjelm, 2009) (See Chapters 6 & 7), but the dilemma of motherhood that such practice leads to has not been reported elsewhere.

Although women in this study talked a lot about the impact of the reversal of mother-child roles in accessing health services, the specific issue of gender roles in accessing health care was not raised in the interviews. This may have been because other issues such as their lack of literacy, other language barriers and unfamiliarity with the health system had higher impact for these women, or it may have been because they accepted their roles in their community. However, the women in this study had been in Australia for only an average of five years, and it could be expected that awareness of gender inequality will increase with greater exposure to such issues in Australian society. This is likely to occur with increasing education, personal independence and as the women consider the opportunities for their female children (Daniely & Lederman, 2019).

## **Perceived barriers to accessing cervical and breast screening**

The most significant features influencing the health-seeking behaviour of the women identified in this study were presence of symptoms-based health seeking and issues with health professionals that resulted in an apparent mismatch of the expectations of the women and the health professionals providing their care.

## **Symptoms based health seeking**

Symptom-based health seeking was established as normal behaviour among this group of refugee women and appeared to be reinforced by the common belief that can be summed as 'if it was an important health issue, our doctor should have told us'. There was little understanding of screening or preventive healthcare among most women in the study, which, although can be explained by their lack of education and refugee-camp histories, this has not been previously reported in the research literature. This explicit behaviour of symptoms-based health seeking can have particular negative impact when it comes to accessing cervical and breast cancer screening services, which are designed to check up for the asymptomatic person to enhance early diagnosis and treatment to prevent cancer incidence and deaths. (Australian Institute of Health and Welfare, 2018; BreastScreen Australia, 2018) . Periodic screening tests has huge impact in preventing cervical and breast cancer. The evidence explained that since the implementation of organised cervical and breast cancer screening in Australia the cervical and breast cancer incidence and mortality has significantly fallen (Aminisani, Armstrong, Egger, & Canfell, 2012; BreastScreen Australia, 2018; Weber et al., 2014).

The presence of symptoms-based health seeking behaviour was strongly supported by women's lack of knowledge about the importance of cervical and breast cancer screening. In this study the behaviours of women closely linked up to their perceived characteristics as explained earlier such as low or no literacy, language barriers, their cultural beliefs and stigmas which collectively hindered to access appropriate information and communication and negatively contributed to accessing cervical and breast cancer screening services. Some of these findings are consistent with other studies, such as the study done in Somali women in Norway displayed emotional barriers such as fear and embarrassments, language, culture and religious concerns related to sexuality and trust (Addawe, Brux Mburu, & Madar, 2018). Cultural factors were also very strong among Iranian women. The comparative study among African refugee and non-refugee in Australia showed that overall, knowledge level about cervical cancer is limited among refugee than non-refugee women. (Addawe, Brux Mburu, & Madar, 2018; Adegboyega, 2017; Anaman, Correa-Velez, & King, 2016; Khazaee-pool et al., 2014).(see Chapter 7)



## Health professional issues

The Bhutanese women raised two main issues in relation to health professionals, that appeared to be important influences on the behaviour of the women in terms of their use of preventive health services: poor cultural understanding and poor practices in regard to interpreters.

Both issues were identified in the overview of systematic reviews and the narrative review of Australian studies to identify barriers and facilitators to health service utilisation by refugees in resettlement countries reported in Chapter 3 (Parajuli & Horey, 2019a, 2019b) This study added further insight into the impact of these issues.

A high regard for their doctors was apparent in the interviews with the Bhutanese refugee women with several claiming that they would do whatever their doctor asked them (see Chapter 7) and stated repeatedly that if screening were important that their doctor would have told them about it. This aspect of Bhutanese culture, where doctors and other health professionals are held in such high esteem, is likely to be poorly understood by Australian doctors and others, and possibly unlikely to fall within health professionals' interpretation of what comprises 'culturally appropriate care'. Unfortunately, it was outside the scope of this study to confirm whether doctors and other health professionals understood this influence and, if they did, how this changed their practice, if at all.

Although this study only considered the viewpoints of the Bhutanese refugee women, many of the women reported in the interviews that screening had been not offered to them. There also appeared to be little opportunistic screening, and when it did occur, did so without any education about the purpose of the procedure or for the need for follow-up. The failure to adequately explain screening procedures to the refugee women could be due, as the narrative review also found, to inconsistencies in the use of interpreter services, which was largely due to not knowing that a refugee would be attending and consultation times that were too short to organise an interpreting service(Parajuli & Horey, 2019a).

This study provides some insight into the impact—and potential impact of these health professional issues. Failure to understand the high regard of health professionals meant that opportunities to initiate screening were missed. This highlights the significant barrier to

appropriate cancer screening from a mismatch in expectations that has arisen for this population: the women didn't know to ask, and their GPs didn't tell them or offer screening to them. A common refrain in the interviews was 'If it was important to do, our GP should tell us about it'. This provides a very clear example of the relationship between poor health outcomes and poor cultural understanding. It also suggests that cultural competency strategies that include components directed at both health professionals and consumers could be more effective at increasing involvement in care (Horvat, Horey, Romios, & Kis-Rigo, 2011). A key finding of the narrative review reported in Chapter 3 was that newly resettled refugees in Australia have high expectations of their doctors, including the belief that they will be familiar with their experiences and cultural beliefs (Parajuli & Horey 2019b). Apart from poor health outcomes, expectation mismatches have been linked to trust with health professionals (Correa-Velez, Spaaij, & Upham, 2012; Jiwrajka et al., 2017; Lamb & Smith, 2002; Lawrence & Kearns, 2005).

Another significant barrier to screening arising from poor practices relates to the impact of using children as interpreters on the mother-child relationship specifically. This was discussed earlier and was a cause of concern for several women who did not want to be so dependent on their children. As the women were reluctant to raise issues with their doctor that sensitive to them in front of their children, they indicated that they would not seek this type of health care.

## **Refugee women's desired models of care**

Two important insights from the women emerged when asked what sort of cancer screening services that refugee women would be likely to use. The two suggestions, GP-initiated screening and group screening (see Chapter 8) are simple solutions for a complex problem and were both underpinned by the stated needs of community-based or peer education and supportive environments.

The importance of social networks for Bhutanese refugee women may be a consequence of their extended period of communal living in refugee camps but also because of their lack of literacy, where communication with others only ever occurs orally.

One finding in this study, not directly related to the research questions, was the importance that the Bhutanese refugee women placed on their neighbours. Connection with their neighbours was something that had greatly missed following their resettlement. Despite the difficulties of the camps, the women shared many things with their camp neighbours, including festivals, rituals and religious activities. As one woman said ‘there is no similar culture, language or festival here. If I am in Bhutan or Nepal when our main festival happens it sounds like all the world is having a festival’. While several studies have identified the significant need for refugees to connect to communities after resettlement, (Gifford, Bakopanos, Kaplan, & Correa-Velez, 2007; McMichael, Gifford, & Correa-Velez, 2010), I could find no study that reflected the high importance of neighbours that was evident in my interviews.

The weakening of communal, cultural and religious practices due to a lack of social connectedness, may increase refugee women’s sense of marginalisation and social segregation and subsequently affect their capacity to engage in effective health seeking behaviours. Many women in this study felt isolated and that for them, life was never going to be ‘back to normal’ (Colic-Peisker & Tilbury, 2003; Strang & Ager, 2010).

While the influence of primary healthcare workers in initiating preventive healthcare measures has been documented elsewhere (Coulter & Ellins, 2007; Esteban-Vasallo, Aerny-Perreten, García-Riolobos, López Rubio, & Domínguez-Berjón, 2017) the option of group screening does not appear to have been evaluated as an ongoing strategy to engage certain groups of women in cancer screening. Women in this study thought that group screening could mean that knowledge and experiences could be shared, which would help to reduce discomfort and the stigma of seeking this type of care.

## **Strengths and limitations**

This study had several strengths and limitations, to which my insider outsider roles contributed. My insider role gave me access to this population, both through my reputation as a refugee nurse and as someone who shares a common language and understanding of their cultures. As a qualitative study several strategies were employed to enable study of a sensitive

topic within a vulnerable population. Use of in-depth interviews, made it easier to explore various influencing factors and aspects of health seeking behaviours both broadly and at a more detailed level. My role as a nurse meant that I could raise sensitive health issues. Being an outsider meant that the women felt safe when they talked about things that they were uncomfortable to share with their families and neighbours. An important strength of this study is that it gives voice to women otherwise not heard.

Another strength of this thesis was the opportunity it provided to publish manuscripts across a range of peer-reviewed journals in various discipline areas, including anthropology and cancer nursing.

As with all studies, limitations exist in this study as well. This study was conducted with Bhutanese refugee women and the findings may not be generalisable to other refugee cohorts. The participants were all female, so issues may not apply to men although some are likely to be common, such as dependence on children in accessing services. This study did not include health professionals, so their perspectives on some of the issues raised were not explored or confirmed, such as the women's reports of interpreters not being used.

The need to conduct interviews in Nepali was both a strength and limitation. It gave access to a vulnerable group of women but meant that interviews were conducted and transcribed by a single person. To address this, a second translator was used to double translate ten percent of the interviews for verification.

The lack of literacy among many of the participants meant that transcripts could not be validated so all interviews were summarised by the interviewer at the end of the interview and a summary of findings confirmed with community leaders.

## **Implications for practice and policy**

The findings from this thesis have potential implications for strategic directions in the development of interventions and practices to address the health access issues among refugees in Australia, particularly refugee women, and in doing so to reduce the health inequalities faced by these groups. Related to these are several policy implications.

While the nature of this research was exploratory, the findings show that the experience of protracted time in refugee camps coupled with high levels of poor literacy has led to lack of knowledge of cancer screening. This is likely to also apply to other preventive health strategies. The consequences of these conditions included symptoms-based health seeking and mismatched expectations between refugees and the health professionals providing care to them. Refugee women interviewed for this thesis expressed a high faith in doctors and expectations that their doctors would recommend cancer screening if it was important to their health. Even when this happened, there was no associated education about the purpose of the test or the need for follow-up. This thesis did not explore the expectations of doctors or their reasons for not using professional interpreters, but these practices were significant barriers to screening. When mismatches such as this occur, there is potential for the high regard that refugees have for health professionals to transform into mistrust (Parajuli & Horey, 2019a). The practice implications from this are that health professionals need to be aware of their authority and influence on refugee groups and the need to develop approaches that empower these people to be involved in decisions about their health care.

To do this effectively healthcare workers will need greater understanding of their personal cultural values, as this will help them may gain greater insight into how these values may impact the care given to refugee groups and may contribute to mismatched expectations between health professionals and refugees. In practice this could be addressed by health professionals scrutinising their own assumptions, and by asking questions to establish the context in which refugee groups live and what is important to them. For example, despite their lack of literacy, women in this study were given written information in Nepalese that they could not read, or ask their children to read to them.

Bhutanese refugees who spent more than 18 years in refugee camps will have little exposure to cancer screening and other preventive health services and will need to be taught the value and purpose of these if they are to participate regularly in screening programs. Understanding the specific needs of refugee groups in health education is critical if it is to be effective. This includes how such education is planned and delivered. The women in this study wanted peer and community education, which are strategies that meet their cultural and literacy needs.

Building ongoing social services will also build capacity and confidence among refugees. State and local government groups in Australia should work to establish community networks, or support existing networks, to raise awareness of health issues and promote preventive and other health service utilisation among refugee groups. There are likely to be cost-benefits from early diagnosis and treatment through these education channels that other formats cannot reach.

This study identified models of care suggested by the women that could improve their active participation in cervical and breast cancer screening services. Processes need to be developed to gather the views of refugees about the services available to them and how they can be improved or changed to better meet their needs. For example, the development of specialised health services that focus specifically on refugees could improve accessibility and the delivery of culturally sensitive care.

Evidence of poor literacy, poor health literacy and poor understanding of health care in this study highlighted their need for direct 'verbal communication' either one-to-one or in the group to be informed about health issues. Understanding of this need by health professionals may encourage greater efforts in opportunistic health education during consultations.

## **Recommendations for practice**

- Cultural competency training should be embedded into the health professional curricula and in ongoing professional development, including the periodic use of cultural competency self-evaluation tools.
- Referral processes and appointment systems need to be streamlined to facilitate easy access by refugees.
- Drop in and outreach services for refugees need to be established in areas of high need where accessibility by public transport is difficult or costly.
- Strategies to make access to interpreters easier for health professionals are needed.
- Greater use of opportunistic health education and screening is required.
- Cultural competency and the use of professional interpreters should be included as criteria in the accreditation of GP practices

- Bi-lingual staff should be appointed to health care services where there is a high proportion of refugee clients.
- Refugee support services need to help connect refugees with their neighbours and other social groups in their area.
- Consult with relevant ethno-cultural groups in the design of programs that target them.

## **Recommendations for future research**

- Evaluation of a group screening model to determine whether this approach is cost-effective and culturally appropriate. Evaluation measures should include the impact of the strategy on the women, including their sense of empowerment and decision-making.
- A longitudinal study of refugees following resettlement to identify whether barriers to accessing health services persist and/or change over time and to assess the impact of different education strategies on health outcomes.
- Qualitative studies to explore strategies to empower refugee women in ways that are culturally sensitive and meet Australian cultural expectations of gender equity. These studies could include exploration of the impact of reversals of mother-child relationships and community leadership by younger rather than older women and how these changes can be managed successfully.
- Action research on ways to promote health and other literacy in illiterate populations.
- Analysis of the existing patterns of the use of professional interpreters by GPs, and exploration of the reasons that interpreters are not used and barriers to their use.

## **Personal reflection**

As a Nepali woman and researcher, the opportunity to study a topic that was sensitive with a group of women who were vulnerable was both rewarding and challenging. Although I am not from the same community, my cultural background as a Nepali woman and shared language with the research participants, enhanced both my research and my research experiences. Our common language and culture made the women more comfortable and more open with me

during the interviews than they otherwise would have been, particularly as I was not part of their social networks.

Many women told me that they had never before talked about their own health and wellbeing, especially anything related to women's health. Some women became quite emotional during the interview as they never experienced anyone showing care or concern about their very private health issues that some women had suffered for many years. Women shared health problems that they had never disclosed to anyone before. They also shared their feelings of being dependant on their children in every step of their daily life now that they were in Melbourne. I found that by introducing myself in terms of my previous work in the refugee camps back in Nepal helped to build trust and increased the women's confidence to talk to me freely about their issues. However, there was variation among the women interviewed. Women who were younger, educated and in employment shared their experiences more easily those who were older and uneducated.

I hope that this thesis will be a tool to advocate for refugee women's issues and to advance refugee health care in the Australian resettlement context.

## **Conclusion**

This thesis offers an overview of the barriers to accessing cervical and breast cancer screening services among Bhutanese refugee women after resettlement in Melbourne, Australia. This study revealed the significant phenomenon of 'no symptoms-no check-up' as a major barrier to accessing preventive services, specifically, cervical and breast cancer screening, and offers different ways to break this chain of behaviour.

Following resettlement, the identities of the Bhutanese refugee women in this study as a resettled person, as a refugee and as a Bhutanese woman were found to intersect and interplay to reinforce the challenges the women faced. Such interactions were underpinned by the women's lack of literacy, lack of knowledge of preventive health care and poor cultural awareness among the health professionals providing care to them. Doctors, in particular, need to be more aware of their influence on this population if they are to achieve better health outcomes for them.



This research also highlights the refugee women's own ideas to improve their participation in cervical and breast cancer screening. Linking these ideas to healthcare provision strategies would be useful to improve health care delivery system to refugee community. More needs to be done to increase cultural competency and understanding for both refugees and healthcare providers. Better cultural understanding, more effective communication and more community connections are likely to establish ongoing trust and build a greater sense of belonging among refugees after their resettlement.

Overall, the evidence of this research study asks health care practitioners to recognise the complexities of the circumstances out of which refugees come, and of the challenges they faced in every step of their journey and that continue with resettlement. These issues need to be recognised and appreciated to achieve effective service provision.

This thesis contributes to the research in this area and should inform refugee health care practice and associated systems and policy.

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## **Appendix**

1. Ethics Approval
2. Participant information statements- English-Nepali
3. Participant statement of informed consent- English-Nepali
4. Withdrawal of consent form – English-Nepali
5. Invitation to participate in research project – English – Nepali
6. Interview guide
7. Publication licence- CSIRO
8. Publication acceptance confirmation – TAJA
9. Poster presentation- Poster



RESEARCH OFFICE

MEMORANDUM

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**To:** Dr Melissa Monfries, School of Psychology and Public Health, College of SHE  
Jamuna Parajuli, School of Psychology and Public Health, College of SHE

**From:** Senior Human Ethics Officer, La Trobe University Human Ethics Committee

**Subject:** Review of Human Ethics Committee Application No. 15-086

**Title:** Access to cervical and breast cancer screening: Perceptions, experiences and perceived barriers among Bhutanese refugee women living in Melbourne

**Date:** 6 November 2015

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Thank you for your recent correspondence in relation to the research project referred to above. The project has been assessed as complying with the *National Statement on Ethical Conduct in Human Research*. I am pleased to advise that your project has been granted ethics approval and you may commence the study now.

**The project has been approved from the date of this letter until 31 December 2018.**

*Please note that your application has been reviewed by a sub-committee of the University Human Ethics Committee (UHEC) to facilitate a decision before the next Committee meeting. This decision will require ratification by the UHEC and it reserves the right to alter conditions of approval or withdraw approval at that time. You will be notified if the approval status of your project changes. The UHEC is a fully constituted ethics committee in accordance with the National Statement under Section 5.1.29.*

The following standard conditions apply to your project:

- **Limit of Approval.** Approval is limited strictly to the research proposal as submitted in your application while taking into account any additional conditions advised by the UHEC.
- **Variation to Project.** Any subsequent variations or modifications you wish to make to your project must be formally notified to the UHEC for approval in advance of these modifications being introduced into the project. This can be done using the appropriate

form: *Modification to Project – Human Ethics* which is available on the Human Ethics website at <http://www.latrobe.edu.au/researchers/ethics/human-ethics> If the UHEC considers that the proposed changes are significant, you may be required to submit a new application form for approval of the revised project.

- **Adverse Events.** If any unforeseen or adverse events occur, including adverse effects on participants, during the course of the project which may affect the ethical acceptability of the project, the Chief Investigator must immediately notify the Senior Human Ethics Officer. An *Adverse Event Form – Human Ethics* is available at the Research Office website (see above address). Any complaints about the project received by the researchers must also be referred immediately to the Senior Human Ethics Officer.
- **Withdrawal of Project.** If you decide to discontinue your research before its planned completion, you must advise the UHEC and clarify the circumstances.
- **Monitoring.** All projects are subject to monitoring at any time by the University Human Ethics Committee.
- **Annual Progress Reports.** If your project continues for more than 12 months, you are required to submit a Progress Report annually, **on or just prior to 12 February**. The form is available on the Research Office website (see above address). Failure to submit a Progress Report will mean approval for this project will lapse.
- **Auditing.** An audit of the project may be conducted by members of the UHEC.
- **Final Report.** A Final Report (see above address) is required within six months of the completion of the project or by **30 June 2019**.

If you have any queries on the information above or require further clarification please email: [humanethics@latrobe.edu.au](mailto:humanethics@latrobe.edu.au) or contact me by phone.

On behalf of the University Human Ethics Committee, best wishes with your research!

Kind regards,

Ms Sara Paradowski  
Senior Human Ethics Officer  
Executive Officer – University Human Ethics Committee  
Ethics and Integrity / Research Office  
La Trobe University Bundoora, Victoria 3086  
P: (03) 9479 – 1443 / F: (03) 9479 - 1464  
<http://www.latrobe.edu.au/researchers/ethics/human-ethics>

7<sup>th</sup> February 2016

## PARTICIPANT INFORMATION STATEMENT

**PROJECT:** Access to cervical and breast cancer screening: Perceptions, experiences and perceived barriers among Bhutanese refugee women living in Melbourne

**PhD student:** Jamuna Parajuli

**Principal supervisor:** Dr Dell Horey

**Co-supervisor:** Professor Pranee Liamputtong

**Ref no:** 15-086

This study is being conducted by Jamuna Parajuli, PhD student from the Department of Public Health, School of Psychology and Public Health, under the supervision of Dr Dell Horey. The study has received approval from La Trobe University Human Ethics Committee.

The purpose of this research is to achieve a holistic understanding of the Bhutanese refugee women's views of accessing cervical and breast cancer screening programs, specifically their perceptions, experiences, and perceived barriers and facilitators to use these services. This research involves taking part in a one-on-one interview with the researcher (Jamuna Parajuli), and it will take approximately one hour.

By taking part in this research you are helping to advance our understanding about how Bhutanese women can be best supported to access these services which are an important part of women's health. Your experiences will provide a valuable contribution to women's health research and help improve the services as per the needs of the newly emerged Bhutanese community.

There are no expected risks associated with this project. However, if during the interview you experience some discomfort you can choose to end the interview and withdraw from participating in the research.

Participating in this research is voluntary and you are free to withdraw at anytime. All data is confidential and pseudonyms (fictitious names) will be used to ensure that you will not be able to be identified. Data will be used in Jamuna Parajuli's PhD thesis; may also appear in subsequent publications, reports or conference presentations. After five years, in line with La Trobe University guidelines, all data will be destroyed. During this time no persons, other than the researcher will have access to this data. You are welcome to have access to your personal data and the results from the study at any time throughout the project.

If you would like to participate in this research please indicate by signing the accompanying consent form and calling Jamuna Parajuli to arrange an interview time. If you have any questions or concerns please do not hesitate to contact Jamuna on the contact details below;

Jamuna Parajuli

La Trobe University, Bundoora, 3086

0452424800

17985075 @students.latrobe.edu.au



*If you have any complaints or concerns about your participation in the study that the researcher has not been able to answer to your satisfaction, you may contact the Senior Human Ethics Officer, Ethics and Integrity, Research Office, La Trobe University, Victoria, 3086 (P: 03 9479 1443, E: [humanethics@latrobe.edu.au](mailto:humanethics@latrobe.edu.au)) . Please quote the application reference number **15-086**\_\_\_\_\_.*

**We hope you can help us with this project and look forward to your valuable contribution.**

Jamuna Parajuli

Dr Dell Horey

7<sup>th</sup> February 2016

**Invitation to participate in a research project**

If you are Bhutanese, married, and have been recommended to have a “Pap smear test” and /or “mammogram” since you have arrived in Australia. We would appreciate hearing about your experiences

**I WOULD LOVE TO HEAR YOUR EXPERIENCE**

I invite you to participate in the research project ***Access to cervical and breast cancer screening: Perceptions, experiences and perceived barriers among Bhutanese refugee women living in Melbourne.***

This is a PhD research project that I am undertaking at La Trobe University. The aim of the project is to learn about your experience, perceptions and barriers to accessing cervical (pap smears) and breast cancer screening (mammograms) programs.

Your participation in this project will help improve the services for Bhutanese refugee women in accessing cervical and breast screening programs in the community. Hence, your participation in this research project would be highly valued but is completely voluntary.

Please contact me if you are interested in participating in this project

My name: Jamuna Parajuli

My phone number: 0452 424 800

If you have any queries about the project or wish to discuss this invitation further, please feel free to contact me.

Thank you for considering the request

Yours sincerely,

Jamuna Parajuli

PhD student, La Trobe University

**PARTICIPANT STATEMENT OF INFORMED CONSENT**

**PROJECT TITLE:** Access to cervical and breast cancer screening: Perceptions, experiences and perceived barriers among Bhutanese refugee women living in Melbourne

**PhD student:** Jamuna Parajuli, **Principal-supervisor:** Dr Dell Horey

I..... have read and understand the participant information statement and consent form, and any questions I have asked have been answered to my satisfaction. I agree to participate in the research, knowing that I may withdraw at anytime. I agree that the research data provided by me during the research may be included in a thesis, presented at a conference and published in journals on the condition that neither my name nor any other identifying information is used.

I CONSENT TO BEING AUDIO RECORDED (please circle): yes / no

NAME OF PARTICIPANT:.....

SIGNATURE:.....DATE:.....

NAME OF RESEARCHER:.....

SIGNATURE:.....DATE:.....

**WITHDRAWAL OF CONSENT FORM**

**PROJECT TITLE:** Access to cervical and breast cancer screening: Perceptions, experiences and perceived barriers among Bhutanese refugee women living in Melbourne

PhD student: Jamuna Parajuli Principal-supervisor: Dr Dell Horey

I would like to withdraw my data from the study on the condition that all data I have provided will be destroyed. Also, I understand that there will be no negative consequences or disadvantages for me, or the education provided by La Trobe University. With adherence to UHEC guidelines, completed withdrawal of consent forms will be retained, however personal data will be immediately destroyed.

NAME OF PARTICIPANT:

SIGNATURE:.....DATE:.....

## In-depth Interview guide

### **PROJECT TITLE: Access to cervical and breast cancer screening: Perceptions, experiences and perceived barriers among Bhutanese refugee women living in Melbourne**

#### **BACKGROUND**

*[Before we start the interview I would like to ask a few questions about you. None of this information will be used to identify you in any way but will help to better describe the women taking part in this study in any future publications.]*

1. Where were you born?
2. How old are you?
3. How many children do you have?
4. How long have you been married?
5. How much time, if any, did you spend in refugee camps before coming to Australia?
6. How many years have you now lived in Australia?
7. What level of education have you attained?
8. Have you done any training or updated your education since being in Australia? If so, what have you done?
9. Are you an Australian citizen?
10. What is your current occupation? [How long have you had your current job?]
11. Have any of your family members died with breast or cervical cancer? Can you tell me about that please?

#### **Part A: Cervical Cancer Screening**

1. Tell me what you understand by Pap smear test (cervical cancer screening)?
2. Can you describe your first experience of having a pap's smear test that you have in Australia?
3. Could you tell me how you became aware of the service and what factors helped you to use this service?
4. Have there been any barriers for you in accessing services that conduct pap smears? If so could you share these experiences with me??
5. If you have not used this service; could you tell me why?
6. Can you tell me what influences your decision to use or not to use cervical screening services?
7. Can you tell me what you believe a pap smear involves?
8. Do you have any suggestions that would improve Bhutanese women's experiences of accessing and having a pap smear?

**Part B: Breast cancer screening**

1. Can you please tell me what you understand by Breast cancer screening or a screening mammogram?
2. Can you describe your first experience of having a mammogram in Australia?
3. Could you tell me how you found out about the service of providing a mammogram? If so could you share these experiences with me?
4. Have there been any barriers for you in accessing a mammogram?? Could you share some with me?
5. If you have not used this service; could you tell me why?
6. Can you tell me what influenced your decision to use or not to use breast screening services?
7. Can you tell me what you believe is involved in having a mammogram?
8. Do you have any suggestion that would improve Bhutanese women's experiences of accessing and scheduling a mammogram?

Thank you for accepting to taking part in this research project

## सहभागीका लागि जानकारी विवरण

**परियोजना:** “गर्भाशयको द्वार (सर्भिकल) तथा स्तन क्यान्सरको जाँचमाथिको पहुँच: मेलबर्न निवासी भूतानी शरणार्थी महिलाको बुझाइ, अनुभव तथा देखिएका व्यवधान”

**पीएचडी विद्यार्थी:** जमुना पराजुली, **प्रमुख-सुपरीवेक्षक:** प्रोफेसर प्रनी लायमपुटङ्, **सह-सुपरीवेक्षक:** डा मेलिसा मनफ्राइज

संकेत नं.:

यस अध्ययन जन स्वास्थ्य विभाग, मनोविज्ञान तथा जनस्वास्थ्य स्कुलमा प्रोफेसर प्रनी लायमपुटङ् र डा मेलिसा मनफ्राइजको सुपरीवेक्षणमा पीएचडी विद्यार्थी, जमुना पराजुलीबाट भइरहेको छ। यो अध्ययनले ला ट्रोव विश्वविद्यालयको मानव आचारसंहिता समितिबाट अनुमति प्राप्त गरेको छ।

यस शोधकार्यको उद्देश्य गर्भाशयको द्वार तथा स्तन क्यान्सरको जाँच गर्ने कार्यक्रममाथिको पहुँचमा भूतानी शरणार्थी महिलाहरूको विचारको समग्र बुझाइ हासिल गर्नु हो, विशेषगरी यी सेवाहरू प्रयोगका सम्बन्धमा उनीहरूको बुझाइ, अनुभव, तथा देखिएका व्यवधान र सहजकर्ताका विषयमा। यस शोधकार्यले शोधकर्ता (जमुना पराजुली) सँग एक-एक जनाको हिसाबमा भाग लिन लगाउँछ र यसले लगभग एक घन्टा समय लिनेछ।

यस शोधकार्यमा भाग लिएर महिला स्वास्थ्यको महत्वपूर्ण अंशको रूपमा रहेका ती सेवाहरूको पहुँचका लागि भूतानी महिलाहरूलाई कसरी उत्तम सहायता प्रदान गर्न सकिन्छ भन्नेबारे हाम्रो बुझाइलाई तपाईंले सुद्ध गर्न सहयोग गर्दै हुनुहुन्छ। तपाईंको अनुभवले महिलाको स्वास्थ्य अनुसन्धानमा महत्वपूर्ण योगदान प्रदान गर्नेछ र नव आगन्तुक भूतानी समुदायको आवश्यकताअनुरूपका सेवाहरूलाई सुधार गर्न सहयोग गर्छ।

यस परियोजनासँग जोडिएका कुनै अपेक्षित जोखिमहरू छैनन्। तथापि, यदि अन्तर्वार्ताको समयमा तपाईंले कुनै असजिलो महसुस गर्नभयो भने तपाईंले अन्तर्वार्ताको अन्त्य रोज्न सक्नुहुन्छ र शोधकार्यको सहभागिताबाट अलगिन सक्नुहुन्छ।

यस शोधकार्यमा सहभागिता हुनु स्वेच्छिक कार्य हो र तपाईं कुनै पनि बेलामा यसबाट अलगिनका लागि स्वतन्त्र हुनुहुन्छ। सबै तथ्यांकहरू गोप्य हुन्छन् र तपाईंलाई नचिनियोस् भन्ने कुरा निश्चित गर्न परिवर्तित (काल्पनिक) नाम प्रयोग गरिनेछ। तथ्यांकलाई जमुना पराजुलीको पीएचडी थिसिसका लागि प्रयोग गरिनेछ; यो भविष्यका अरु प्रकाशन, प्रतिवेदन वा सम्मेलनका प्रस्तुतीकरणहरूमा पनि देखा पर्नेछ। पाँच वर्षपछि, ला ट्रोव विश्वविद्यालयको निर्देशिकाअनुसार, सम्पूर्ण तथ्यांकलाई नष्ट गरिनेछ। हालको समयमा शोधकर्ताबाहेक अन्य कसैसँग पनि तथ्यांकमाथि पहुँच हुने छैन। परियोजना अवधिभर कुनै पनि समयमा अध्ययनबाट तपाईंलाई आफ्नो व्यक्तिगत तथ्यांक तथा नतिजामाथिको पहुँच चाहिएमा तपाईंलाई स्वागत छ।

यदि तपाईंले यस शोधकार्यमा सहभागी हुन चाहेमा कृपया यससँगै प्राप्त सहमतिपत्र फाराममा हस्ताक्षर गरेर र अन्तर्वार्ताको समयको चाँजोपाँजो मिलाउन जमुना पराजुलीलाई फोन गरेर सो कुराको संकेत गर्नुहोस्। यदि तपाईंसँग कुनै प्रश्न वा अवधारणा भए कृपया विनाहिचकिचाहट जमुनालाई तल दिइएको विवरणमा सम्पर्क गर्नुहोस्;

जमुना पराजुली

ला ट्रोब विश्वविद्यालय, बुन्दूरा, ३०८६

0452424800

17985075 @students.latrobe.edu.au

यदि तपाईंसँग अध्ययनमा तपाईंको सहभागिताको विषयमा शोधकर्ताले सन्तोषप्रद उत्तर दिन असमर्थ रहेको कुनै गुनासो वा चासो छ भने तपाईंले वरिष्ठ मानव आचारसंहिता अधिकारी, आचारसंहिता तथा निष्ठा, शोध कार्यालय, ला ट्रोब विश्वविद्यालय, भिक्टोरिया, ३०८६ (*Senior Human Ethics Officer, Ethics and Integrity, Research Office, La Trobe University, Victoria, 3086*) फोन नं. 03 9479 1443, ईमेल: [humanethics@latrobe.edu.au](mailto:humanethics@latrobe.edu.au) मा सम्पर्क राख्नुहोस्। कृपया आवेदन संकेत नम्बर \_\_\_\_\_ उद्यत गर्नुहोला।

हामी आशा गर्छौं तपाईंले हामीलाई यस परियोजनामा सहयोग गर्न सक्नुहुन्छ र तपाईंको मूल्यवान योगदानको अपेक्षा गर्दछौं।

जमुना पराजुली, प्रोफेसर लायमपुटङ् र डा मेलिसा मनफ्रायज



## शोध परियोजनामा सहभागी हुन आमन्त्रण

अष्ट्रेलिया आइपुगेपश्चात के तपाईले गर्भाशय द्वारको क्यान्सर जाँच (cervical cancer screening) (Pap's smear test) र स्तन क्यान्सर जाँच (mammogram) गराउनु भएको छ?

### मलाई यहाँको अनुभव सुन्ने मन छ

यो “गर्भाशयको द्वार (सर्भिकल) तथा स्तन क्यान्सरको जाँचमाथिको पहुँच: मेलबर्न निवासी भूटानी शरणार्थी महिलाको बुझाइ, अनुभव तथा देखिएका व्यवधान” (“Access to Cervical and Breast Cancer Screening: Perceptions, experiences and perceived barriers among Bhutanese refugee women living in Melbourne”) नामक शोध परियोजनामा सहभागी हुनका लागि आमन्त्रण गर्नका लागि हो। यो पीएचडी शोध परियोजना हो जसलाई म ल्याट्रोब विश्वविद्यालयमा पूरा गरिरहेको छु। यस परियोजनाको उद्देश्य गर्भाशयको द्वार (cervical) तथा स्तन क्यान्सरको जाँच गर्ने कार्यक्रमका बारे तपाईको अनुभव, बुझाइ तथा पहुँचमाथिको व्यवधानका बारेमा जान्नु हो।

यस परियोजनामा तपाईको सहभागिताले समुदायमा cervical तथा स्तनको क्यान्सर जाँच गर्ने कार्यक्रममाथि भूटानी शरणार्थी महिलाहरूको पहुँचको आवश्यकतालाई पूरा गर्न सेवाहरूलाई सुधार गर्न सघाउ गर्नेछ। यसर्थ, यस शोध परियोजनामा तपाईको सहभागितालाई उच्च मूल्यांन गरिनेछ तर यो पूर्णरूपमा स्वेच्छिक हो।

यदि तपाई यस परियोजनामा सहभागी हुन चाहनुहुन्छ भने कृपया मलाई सम्पर्क गर्नुहोस्।

मेरो नाम: जमुना पराजुली

मेरो फोन नम्बर: 0452 424 800

परियोजनाका बारेमा तपाईसँग कुनै प्रश्न भए वा यस आमन्त्रणबारे छलफल गर्न चाहनुहुन्छ भने कृपया निर्धक्क मलाई सम्पर्क गर्नुहोला।

अनुरोधलाई मनन गरिदिनुभएकोमा धन्यवाद।

भवदीय,

जमुना पराजुली

पीएचडी विद्यार्थी, ल्याट्रोब विश्वविद्यालय

## सहभागीको सूचित अनुमति विवरण

**परियोजना:** “गर्भाशयको द्वार (सर्भिकल) तथा स्तन क्यान्सरको जाँचमाथिको पहुँच: मेलबर्न निवासी भूटानी शरणार्थी महिलाको बुझाइ, अनुभव तथा देखिएका व्यवधान” (“Access to Cervical and Breast Cancer Screening: Perceptions, experiences and perceived barriers among Bhutanese refugee women living in Melbourne”)

**पीएचडी विद्यार्थी:** जमुना पराजुली, **प्रमुख-सुपरीवेक्षक:** प्रोफेसर प्रनी लायमपुटङ्, **सह-सुपरीवेक्षक:** डा मेलिसा मनफ्राइज

म ..... ले सहभागीका लागि जानकारी विवरण तथा अनुमति फारामको अध्ययन गरेको छु र बुझ्दछु, र मैले सोधेका सबै प्रश्नको चित्तबुझ्दो जवाफ प्राप्त गरेको छु। म शोधकार्यमा सहभागी हुन मञ्जुर छु, कुनै पनि बेलामा यसबाट अलगिन सकिने पनि थाहा छ। मैले उपलब्ध गराएका शोध तथ्यांकहरूलाई मेरो नाम वा कुनै पहिचान खुल्ने सूचना प्रयोग गरिनेछैन भन्ने शर्तमा शोधकार्यको समयमा थिसिसमा समावेश गरिन्छ, सम्मेलनमा प्रस्तुत गरिन्छ र जर्नलमा प्रकाशित गरिन्छ।

मेरो भनाइलाई रेकर्ड गरिनेमा सहमति जनाउँछु (कृपया गोलो लगाउनुस्): हो/होइन

सहभागीको नाम:.....

हस्ताक्षर:.....मिति:.....

शोधकर्ताको नाम:.....

हस्ताक्षर:.....मिति:.....

## अनुमति फिर्ता लिने फाराम

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**परियोजनाको शीर्षक:** “गर्भाशयको द्वार (सर्भिकल) तथा स्तन क्यान्सरको जाँचमाथिको पहुँच: मेलबर्न निवासी भूटानी शरणार्थी महिलाको बुझाइ, अनुभव तथा देखिएका व्यवधान” (“Access to Cervical and Breast Cancer Screening: Perceptions, experiences and perceived barriers among Bhutanese refugee women living in Melbourne”)

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मैले उपलब्ध गराएका सम्पूर्ण तथ्यांकहरू नष्ट गरिनेछन् भन्ने शर्तमा म यस अध्ययनबाट आफ्नो तथ्यांक फिर्ता लिन चाहन्छु। र, म यो पनि बुझ्दछु कि यसबाट मैले तथा वा ला ट्रोब विश्वविद्यालयबाट प्रदान गरिने शिक्षामा कुनै पनि किसिमको नकारात्मक परिणाम वा उपेक्षा हुने छैन। युएचईसी निर्देशिका अनुसार, भरिएका अनुमति फिर्ता लिने फारामलाई राखिनेछ, तथापि व्यक्तिगत तथ्यांकलाई तुरुन्त नष्ट गरिनेछ।

सहभागिको नाम:

हस्ताक्षर:.....मिति:.....

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Best wishes,  
Janelle

**Janelle Heald**

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24th October 2019

Dear Jamuna,

This letter is to confirm that your article *Resettlement challenges and dilemmas: An in-depth case study of Bhutanese refugee women in Australia*, co-authored with Dell Horey and Maria-Irini Avgoulas, has been accepted for publication in the next issue of TAJA (30:3). This is due to be published in December 2019.

Please do let me know if you have any questions.

All the very best,



Kathleen

Dr. Kathleen Openshaw

Managing Editor TAJA





# Access to cervical and breast cancer screening: Experiences of Bhutanese refugee women living in Melbourne

## Background and objective

Preventative health care measures, like pap smear tests and screening mammograms are unfamiliar to Bhutanese refugee women. In the Bhutanese-Nepalese cultural context, women's health issues are often hidden and not widely discussed. This study explored the perceptions and experiences of Bhutanese refugee women who had lived in Australia for about five years, in regard to accessing cervical and breast cancer screening programs.

## Methodology

An exploratory phenomenological qualitative study using in-depth interviews with photo-elicitation to facilitate data collection.

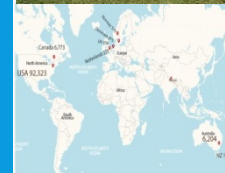
## Results

Many women lacked knowledge of breast and cervical screening tests, and didn't know about the services available to them. Those women who did know felt screening tests were not needed as they perceived themselves to be very healthy.

Language barriers, cultural beliefs, and lack of knowledge about preventive screening tests were common reasons for not accessing services. Those who did use screening services failed to maintain regular follow-up. Screening was considered secondary to other health conditions although uptake was higher among younger women.

## Conclusions

Accepting, accessing and maintaining regular cervical and breast screening seemed culturally unfamiliar behaviour for Bhutanese refugee women, who had a strong cultural identity as refugees, particularly among older women. Preventive health care was not viewed as necessary. However, young women with greater exposure to Australian society were more inclined to use regular screening programs, which may show a shift in identity from refugee to citizen.



*"I think I am okay. My health down there is good. I have no discharge from there. While I was pregnant, I never have any problems, no morning sickness, I gave birth to my all children alone at home when my husband was away."*

*"If I was a sufferer of cancer with the symptoms of bleeding, leaking, discharge, pain, water leaking, I would have gone for this test. I may ask a GP. But I have no problems, I am okay. I am shy of showing my lower body, which I never shown to anyone."*

*"I could not do these tests because I did not know about them. I think our didibahini (sisters) are not doing them because they do not know about the services. I found out today, nobody told us before."*

*"As we came here, everything was new—new language, new system, new education, new ways to buy things—at this age we are facing lot of challenges in our life to be settled."*

*"We had to struggle a bit in the beginning due to language, and as other family members, our parents, are not able to speak the language, we had lot of responsibilities. We were not aware of the systems here. It was bit scary, but we never have problems now with food and accommodation like we had in the refugee camp."*

*"I can't read and write in my own language, at my age I am going to school. I did not learn much for the first year of schooling. My mind was not working. I feel sad not being able to read. I only go to the GP when I am sick, when I need tablets. I didn't know about these tests before. Next time I will ask my GP to do them for me."*