

Forced Migration, Urbanization and Health: Exploring Social Determinants of Health Among
Refugee Women in Malaysia

by

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B.F.A., University of Victoria, 2006

M.A., University of East Anglia, 2010

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Supervisory Committee

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Abstract

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The susceptibility of individuals to illness and disease is greatly influenced by context specific social determinants of health (SDH), yet there is a dearth of literature pertaining to SDH among refugees, particularly those residing in urban areas. The purpose of this study was to identify and generate empirical evidence on SDH among female refugees in Malaysia. It focused specifically on Rohingya refugees, a stateless and persecuted Muslim minority from Myanmar.

Intersectionality formed the theoretical foundation of the study, which utilized a qualitative research design and employed an exploratory, applied research approach. Document review provided background and contextual information for primary data, which were collected using semi-structured interviews and analysed using thematic analysis. The study was undertaken in affiliation with the United Nations High Commission for Refugees (UNHCR) and had two primary outputs: it provided UNHCR with information and recommendations to inform context-specific program and policy development, and it generated rich empirical findings that contribute to the nascent evidence base on SDH in the context of forced migration. Results indicate that key factors affecting the health and wellbeing of Rohingya women include: their journey from Myanmar to Malaysia, income, employment, food security, transportation, the physical environment, UNHCR, security issues, education, religion, healthcare, and social capital/the social safety net. These interacted, overlapped and compounded each other, forming a ‘web of interrelated factors’ that affected participants’ health. Findings provide insight into the instrumental role of the sociopolitical context in structuring the lives of urban refugee women, and emphasize the importance of extending current discourse beyond refugee women’s needs and vulnerabilities to consider their resilience and agency in situations of significant hardship.

Keywords: Social determinants of health; refugee women; intersectionality; vulnerability; Rohingya

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List of Acronyms

AI	Amnesty International
CSDH	Commission on the Social Determinants of Health
EBO	Euro Burma Office
ERT	The Equal Rights Trust
EU	European Union
FA	Financial assistance
HRW	Human Rights Watch
IAD	Individual Assistance Department (UNHCR Malaysia)
IDP	Internally displaced person
INFR	International Federation for Human Rights
IOM	International Organization for Migration
MA	Medical assistance
MRGI	Minority Rights Group International
MSF	Médecins sans Frontières
NGO	Non-governmental organization
RA	Research assistant
SDH	Social determinants of health
SGBV	Sexual and gender based violence
TB	Tuberculosis
UN	United Nations
UNHCR	United Nations High Commission for Refugees
RELA	<i>Pasukan Sukarelawan Malaysia</i> /The People's Volunteer Corps

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Words cannot express my gratitude towards my family for their patience and unwavering support. Jen and Hal, thank you for teaching us about the things that matter – in doing so you gave us the courage to take chances and follow what we believe in.

Dedication

This is dedicated to the refugee women, men and children I met over the last three years. Despite having endured profound hardship and loss, they lived lives imbued with compassion, fortitude, and hope, and demonstrated time and again that “refugees present perhaps the maximum example of the human capacity to survive despite the greatest of losses and assaults on human identity and dignity” (Muecke, 1992, p.521).

Chapter 1: Introduction

Background

Violence, persecution, and egregious human rights violations: these are just some of the reasons why thousands of Rohingya – an ethnic minority from Myanmar – have been forced to flee their homes and seek asylum at a time when neighbouring countries are implementing increasingly restrictive immigration laws, refusing to process asylum claims, and returning asylum seekers to the countries from which they fled (Human Rights Watch [HRW], 2013; The Equal Rights Trust [ERT], 2012; Ullah, 2011).

This research focuses on the Rohingya, a Muslim group from Myanmar often cited as one of the most persecuted minorities in the world (Al Jazeera, 2012; Taylor & Wright, 2012). Following sectarian violence in Myanmar in 2012 and 2013 (HRW, 2013a), there has been a sharp rise in the number of Rohingya undertaking the arduous boat journey to Malaysia in search of refuge (Lefevre, 2013). This study involved Rohingya women who have joined the growing cadre of over 30,000 Rohingya refugees in Malaysia (United Nations High Commission for Refugees [UNHCR], 2013a), a country with a large population of urban refugee (Crisp, Obi, & Ulmas, 2012).¹ In an international context, these refugees are part of the globally urbanizing refugee population: while camps used to house the majority of refugees, today only a third of the estimated 10.5 million refugees in the world live in camps and over half live in urban areas (UNHCR, 2013a).

Many refugees endure harrowing journeys to reach Malaysia, only to find that “once they arrive, they are abused, exploited, arrested and locked up – in effect, treated like criminals”

¹ As of December 2013, 140,982 refugees and asylum seekers had been registered by UNHCR Malaysia (UNHCR, 2013c).

(Amnesty International [AI], 2010, p. 3). Malaysia has been ranked one of the worst countries in the world in which to be a refugee,² and for Rohingya women, rights violations, sexual and gender based violence (SGBV),³ dangerous living and working environments, food insecurity, difficulty accessing health and education services, and exposure to trauma and stress are some of the challenges they face (AI, 2010). None of these factors is, on its own, unique to Rohingya women, but the combination of these factors and the intersection of their refugee status, statelessness, and race/ethnicity is.⁴

The interaction between dimensions of refugees' identity and the socioeconomic and political context in which they live has a significant impact on health (Guruge & Khanlou, 2004) – as such, it is important to understand the lives of Rohingya women in Malaysia in order to inform context-specific health program and policy development. Yet such information is currently lacking: while there is substantial academic literature related to refugees in general (Carballo & Nerukar, 2001; Eastmond, 2007; Essed, Frerks, & Schrijvers, 2004; Harrell-Bond & Voutira, 2007), there is a dearth of academically sound, publicly available information pertaining to refugees in Malaysia.

Social Determinants of Health

Pressing health issues confronting urban refugees include infectious diseases (S.L.

² See the U.S. Committee for Refugees and Immigrants 2009 World Refugee Survey (ReliefWeb, 2013).

³ UNHCR defines SGBV as “any harmful act that is perpetrated against one person’s will and that is based on socially ascribed (gender) differences between males and females. It includes acts that inflict physical, mental, or sexual harm or suffering, threats of such acts, coercion and other deprivations of liberty, whether occurring in public or in private life” (UNHCR, 2011a, p. 6).

⁴ In the context of health inequities, race can be defined as both a biological construct (i.e. when a group’s shared genetic makeup renders them more susceptible to certain medical issues), and a social classification, whereby one’s genetic makeup denotes membership to a certain group, which results in differential exposure to SDH (Hebert, Sisk & Howell, 2008). Ethnicity is a social construct referring to shared features such as culture, language, history, traditions, and religion; in their article on race, ethnicity and health disparities, Hebert et al. argue that while ethnicity and race are distinct, the meaning of the two terms can overlap. As both terms are relevant when discussing Rohingya refugees, when applicable I employ the use of the joint term race/ethnicity.

Thomas, S.D. Thomas, & Komesaroff, 2008); workplace injuries and accidents (Carballo & Nerukar, 2001); SGBV (Horn, 2010); and psychological issues related to trauma (Khawaja, White, Schweitzer, & Greenslade, 2008). Although research has identified these health issues as being of particular concern to refugee populations, individual refugee's susceptibility to illness and disease is greatly influenced by context specific social determinants of health (SDH), which are the circumstances in which people "grow, live, work, and age, and the systems put in place to deal with illness" (Commission on the Social Determinants of Health [CSDH], 2008).⁵

While evidence shows that SDH have a profound influence on who becomes sick, and with what illnesses they become sick (Mikkonen & Raphael, 2010), the unique health profile of individual refugees is often obscured by the refugee label, which essentializes 'the' refugee experience and reduces individuals "to only one part of their identity, supposedly overshadowing ethnic, class, gender and other dimensions" (Essed et al., 2004, p. 8). Qualitative studies such as this provide a more nuanced understanding of the diverse lives, experiences, and response strategies of refugee women, and in doing so may help mitigate some of the issues above.

The overarching aim of this study is to address the lacuna in existing scholarship pertaining to the health determinants and unique needs of Rohingya women in Malaysia. Specifically, the qualitative research design generated rich empirical findings that contribute to the nascent evidence base (see Gifford, Bakopanos, Kaplan, & Correa-Velez, 2007; Roberts et al., 2009) on SDH in the context of populations experiencing forced migration. A further output of the research was the production of information and recommendations to support program and policy development at UNHCR.

⁵ The World Health Organization (WHO) is the principal health authority within the United Nations. The primary role of the CSDH – which was established and operated by WHO between 2005 and 2008 – was to review evidence pertaining to social determinants of health and catalyze action on issues surrounding health equity (CSDH, 2008).

Affiliation with UNHCR

I was affiliated with the Individual Assistance Department (IAD) at UNHCR Malaysia in various capacities between 2011 and 2014. During that time I assisted with the work of IAD, namely conducting vulnerability assessments by gathering information on refugees' medical and financial needs, and making recommendations regarding UNHCR assistance. The insight I gained in 2011 and 2012 provided both the impetus and foundation for the study. The analysis and interpretations I set out in this dissertation are strongly influenced by my experience working with refugees in Malaysia, my extensive involvement with IAD, and my immersion in the broader institutional setting in which the study was conducted.

SDH in the Context of Urban Refugees

UNHCR and scholars conducting research with refugees often categorize refugee populations by the settings in which they live: those who live in urban areas, and those who live in demarcated refugee camps (Campbell, 2006; Crisp, Morris, & Refstie, 2012; Marfleet, 2007). Urban refugees have been defined as those in “a built-up area that accommodates large numbers of people living in close proximity to each other, and where the majority of people sustain themselves by means of formal and informal employment and the provision of goods and services” (UNHCR, 2009, p. 2). Conversely, refugee camps are intentionally designed and constructed, usually by UNHCR, NGOs, and/or national governments, “to facilitate the provision of protection, solutions and assistance” (UNHCR, 2009, p. 13).

Certain conditions – such as overcrowding, poor sanitation, and inadequate nutrition – may be present in both urban areas and refugee camps, and thus illnesses that are caused or exacerbated by such conditions (i.e. nutrition related diseases, tuberculosis [TB] etc.) are of concern to refugees in both settings (Kouadio, Koffi, Attoh-Toure, Kamigaki, & Oshitani, 2009;

Riley, Ko, Unger, & Reis, 2007). However, refugees in camps are often provided with some essential goods and services such as food rations, medical care, and education (Benner, Muangsookjaroeun, Sondorp, & Townsend, 2008); this is not usually the case for urban refugees, most of whom are required to find their own methods of subsistence (UNHCR, 2009). Urban refugee populations are also more likely to be mobile, scattered within sprawling cities, and harder to monitor (Marfleet, 2007).

While there is a burgeoning scholarly evidence base on urban refugees around the world (Crisp, Morris, et al., 2012; Guterres & Spiegel, 2012; Pittaway, 2010; F. Thomas, Roberts, Luitel, Upadhaya, & Tol, 2011), to date most information on refugees in the Malaysian context is in the form of ‘grey’ literature authored by UNHCR and NGOs (AI, 2010; Crisp, Obi, & Ulmas, 2012; Smith, 2012; ERT, 2010). Moreover, while there is a robust, diverse range of academic literature on camp-based refugees (cf. Ahmed et al., 2012; Horn, 2010; Lischer, 2006; Turner, 2004), Malaysia does not have any refugee camps, and given fundamental differences between urban and camp-based settings, much of the existing evidence on refugees is not generalizable to the Malaysian context. With over half of the world’s refugees living in urban areas (UNHCR, 2013a) and the steady urbanization of the global refugee population (Spiegel, Checchi, Colombo, & Paik, 2010), it is increasingly important to understand how unique features of the urban environment affect the health of refugees (Spiegel & UNHCR, 2010). This field of inquiry is pertinent and timely in the Malaysian context, for the reasons outlined below.

Rohingya Refugees in Malaysia

The entrenched political situation in Myanmar has led millions of people to flee, drawing neighbouring countries, including Malaysia, into a protracted refugee situation (Cheung, 2012; Crabtree, 2010; Rahman, 2010). Documented persecution and denial of basic human rights of the

Rohingya in Myanmar (cf. Irish Centre for Human Rights, 2010; Kiragu, Rosi, & Morris, 2011; Lewa, 2009; Rogers, 2013) – including violence, lack of access to basic health and education services, restricted movement, forced labor, and land confiscation – have forced many Rohingya to seek refuge in Malaysia. Yet the ERT (2010) reports, “for the vast majority, their suffering has not ended upon reaching new shores. All too often, the Rohingya experience of life is a cycle of acute discrimination, escape, trafficking, poverty, detention, extortion and deportation” (p. 4).

Numerous challenges confronting refugees in cities stem from features of the urban environment itself: in Malaysia, for example, refugees have reported being too afraid (of arrest, assault, etc.) to travel across the city to the UNHCR office; they face language and financial barriers to accessing health care at government hospitals; and they are vulnerable to abuse and exploitation⁶ (Amnesty International, 2010). Refugees are distinguishable from other ‘vulnerable’ Malaysian sub-populations in that the government considers refugees to be in the country illegally,⁷ and thus they have limited legal recourse or protection, and are often unable or unwilling to approach authorities in order to report crimes (AI, 2011).

Since refugees in Malaysia live alongside Malaysian nationals, effort on the part of UNHCR to protect refugees from discrimination and persecution requires sound understanding of both the refugee population and the social, political, and cultural context in which they live. Yet there is a limited amount of detailed, scholarly information on the conditions in which refugees in Malaysia live, and little understanding of how these conditions – and the abuse and

⁶ In this context, examples of abuse include physical assault (e.g. corporal punishment in detention) and sexual assault (e.g. women assaulted by their employers); examples of exploitation include being paid very low wages and/or having wages withheld, having to pay money to avoid arrest/detention if stopped by law enforcement, etc. (AI, 2011; Nah, 2010).

⁷ In Malaysia, refugees are considered undocumented immigrants and thus are subject to detention, arrest, corporal punishment, etc. While the government of Malaysia considers UNHCR (and not the state) responsible for administering, protecting, and assisting refugees, there is no formal, binding covenant between Malaysian authorities and UNHCR (Crisp, Obi, & Ulmas, 2012b).

exploitation referenced above – affect the health and wellbeing of refugees. Such information is particularly important in light of the recent exodus of Rohingya asylum seekers fleeing Myanmar (Edwards, 2013), and the subsequent influx of new arrivals in Malaysia (Lefevre, 2013). While some refugees in Malaysia may consider voluntary repatriation to Myanmar in the coming years (IRIN, 2013), the escalating persecution of Rohingya people, as well as their statelessness, makes their repatriation far more difficult, and as such they are likely to remain a population of concern in Malaysia for the foreseeable future.

The Focus of This Dissertation

There are a myriad of ways to frame discussion surrounding the Rohingya people who flee Myanmar. It is at once a national, regional and global issue, one that can be considered from social, historical, political, legal, and human rights standpoints. As the purpose of this dissertation is to present empirical evidence on SDH among Rohingya refugees in Malaysia, primary consideration is given to social issues in the Malaysian setting; specifically, much of the evidence and recommendations are framed in the context of UNHCR, the agency tasked with refugee protection in Malaysia. While this limits the extent to which I am able to explore certain important issues (such as how regional politics affect the exodus of Rohingya people from Myanmar, the human trafficking syndicates they fall prey to, etc.), it allows me to consider, in detail, how the social and economic context in Malaysia affects the health and wellbeing of Rohingya refugee women. The specific research objectives and questions are described below.

Research Objectives and Questions

This study employed a qualitative research design and an exploratory, applied research

approach⁸ (Patton, 2002). The primary method used for data collection was semi-structured interviews (conducted with female Rohingya refugees), and a review of UNHCR documents (specifically, financial assistance assessments pertaining to Rohingya women) provided additional background/contextual information. Critical review of these documents provides unique insight into the challenges associated with using pre-determined categories to assess vulnerability among refugees in an urban context, and stands to make a particular contribution to the extant literature. Thematic analysis (Braun & Clarke, 2006; Saldaña, 2011) was used to identify themes from the semi-structured interviews and documents respectively, as well as those that crosscut the data corpus.

The objectives and research questions guiding this study were:

- 1) To create knowledge on the health of female Rohingya refugees in Malaysia and investigate their health needs and concerns.
 - What are Rohingya women’s main health concerns? Have these changed since they became refugees under the protection of UNHCR? How do they respond to these concerns? What barriers do they face in leading healthy lives in Malaysia? How willing/able are they to access services?
- 2) To identify and generate empirical evidence on social determinants of health among female Rohingya refugees in Malaysia.
 - According to Rohingya women, what are important determinants of health in the context of their lives in Malaysia? What social and environmental factors support their health and wellbeing? What factors put their health at risk?
- 3) To consider applications of the knowledge generated in this study in the context of programming related to Rohingya refugees’ health and access to health services in Malaysia.
 - How can information that provides a foundation for effective planning on issues related to refugee women’s health be created and communicated?
 - What strengths, assets, and existing response strategies within the Rohingya community can be used as the foundation for such efforts?

⁸ Applied research has been described as a flexible and versatile approach to research in which the primary focus is “the production of knowledge that is practical and has immediate application to pressing problems of concern to society” (Brodsky & Welsh, 2008, p. 17). It can be differentiated from other types of research (i.e. theoretical) in that the information generated is likely to support “actionable knowledge” and outcomes (Somekh, 2008, p. 4).

Dissertation Outline

In the following chapter (Chapter 2) I review pertinent literature on refugees and social determinants of health. In Chapter 3, I discuss historical and present-day issues pertaining to Myanmar, the Rohingya people, and the situation of refugees in Malaysia. In Chapter 4, I outline the theoretical basis of this study, as well as the methodology and methods employed, and in Chapter 5, I consider ethical issues in collecting, processing, and presenting data. Chapter 6 contains background and contextual information obtained from a review of UNHCR financial assistance documents, and the next two chapters contain empirical findings: in Chapter 7, I present case studies and demographic data of participants I interviewed; and in Chapter 8, I present findings from the semi-structured interviews. Lastly, in Chapter 9, I discuss my findings and situate them in the context of existing evidence. I conclude this dissertation, in Chapter 10, with summary remarks and suggestions for future areas of inquiry.

Chapter 2: Social Determinants of Health and Refugees

Introduction

In this chapter I provide an overview of literature pertaining to SDH and contemporary refugee populations. I begin by discussing the concept of health equity and the SDH conceptual framework developed by the CSDH (Solar & Irwin, 2010) (Appendix A). I use the CSDH model to introduce key concepts related to SDH, and then expand discussion to include benefits and challenges of the evidence base on SDH, policy implications of an SDH approach, and a recent push by proponents of an SDH approach to translate evidence into action.

The second half of the chapter focuses on contemporary refugee populations. I begin by providing a brief overview of UNHCR, the primary organization responsible for their protection. I then define and differentiate between various categories of forced migrants, and review key debates in the study of forced migration. In the last section of the chapter I consider literature on key health issues and social determinants of health affecting refugee populations. Given that I review two distinct subject areas in this chapter (SDH and refugees/forced migration), I have attempted to provide a concise overview of both, focusing particularly on the literature that exists at the nexus between them and – out of necessity – limiting discussion of outlying topics.

Inequality and Inequity

Given the central role of health equity in the theoretical and empirical basis of SDH, it is necessary to distinguish inequity from inequality, two concepts that are often confused and conflated in research related to the distribution of health and resources (Sen, 2002). Health inequality denotes measurable differences in the health of individuals and groups, whereas health inequity refers to “differences in health which are not only unnecessary and avoidable, but, in addition, are considered unfair and unjust” (Whitehead, 1992, p. 219). A more nuanced

definition would also proffer that health inequities are socially produced and systematically distributed across society (Solar & Irwin, 2010). By its definition then, health equity is a normative concept, which is grounded in social justice and embedded in the broader human rights framework (Bonney, Morgan, Kelly, Butt, & Bergman, 2007; Gostin & Powers, 2006; Solar & Irwin, 2010).

The CSDH Framework

Health equity is the ethical foundation (Solar & Irwin, 2010) of the CSDH metaframework, which synthesizes existing theoretical models and concepts and provides a systematic means for considering health inequities within communities, countries, and the world (Solar & Irwin, 2010). As the CSDH model informed the design and execution of this study, I have used it to frame the following literature review on SDH. I chose to use the CSDH model over others because it is the most current and comprehensive SDH model, and it provided the broad structure I needed to situate and compare a range of existing evidence related to SDH. While other seminal SDH models – such as Dahlgren & Whitehead's (1991) rainbow model – have informed the CSDH framework, I opted not to draw heavily upon Dahlgren & Whitehead's model because it does not reflect theoretical developments that have taken place with regards to SDH in the last two decades; furthermore, it is not as conducive to explicating links and pathways between SDH and policy development (Bonney et al., 2007).

There are also variations and discrepancies between the CSDH model and other SDH models, which range from linguistic (e.g. the use of the terms structural and intermediate over distal and proximal) to fundamental conceptual differences (e.g. the explicit inclusion of socioeconomic context) (Solar & Irwin, 2010). One of the challenges with the SDH evidence base has been the absence of clearly defined and consistently used terminology, and the lack of a

master framework to cohesively integrate all the elements of the SDH approach: the CSDH framework takes significant steps towards resolving both of these issues, and for the purpose of this dissertation it provides a constructive way to define SDH and consider the SDH evidence base. The CSDH framework has numerous key components, which will be described in detail: socioeconomic and political context; social determinants of health inequities (also known as structural determinants); social cohesion and social capital; and social determinants of health (also known as intermediate determinants of health).

Socioeconomic and Political Context

The framework defines socioeconomic and political context as the social and political mechanisms that produce and perpetuate social hierarchies (Solar & Irwin, 2010). One criticism of other SDH models (e.g. Dahlgren & Whitehead, 1991) is that they ignore the social and political factors that produce and maintain SDH (Williams, 2003), and thus fail to provide the information needed to form effective policies and interventions (Bonney et al., 2007).

The CSDH framework differs from other models in its emphasis on contextual and structural factors. Since context varies depending on time and place, the authors provide five reference points that can be used to map context, which are: governance; macroeconomic policies (e.g. fiscal, trade); social policies (e.g. labour, social welfare); public policies (e.g. health care, education); and culture and societal values (e.g. religion) (Solar & Irwin, 2010). The explicit identification of these elements is important, because they provide researchers with a consistent frame of reference for mapping diverse contexts.

One critique of the evidence base on SDH is that some of the evidence conflates the social determinants of health inequities and social determinants of health (Graham, 2004). The CSDH framework is heavily influenced by the work of Graham, who argues that the concept of

SDH has taken on a “dual meaning, referring both to the social factors promoting and undermining the health of individuals and populations and to the social processes underlying the unequal distribution of these factors between groups occupying unequal positions in society,” (p. 102). The importance of this distinction rests on the fact that overall improvements in health determinants (e.g. better living standards, governance) and health (e.g. longer life expectancy) may mask inequities in their distribution throughout the population (e.g. the health of people in higher socioeconomic positions might improve while those in lower socioeconomic positions remains the same or declines) (Bonney et al., 2007; Graham, 2004).

The CSDH model addresses this dual meaning by clearly delineating and adopting two key terms, discussed in detail below: structural determinants, the ‘upstream’ factors known as social determinants of health inequities, and intermediary determinants, ‘downstream’ factors, such as material circumstances. While some scholars refer to distal factors, the CSDH use the term structural “in order to capture and underscore the causal hierarchy of social determinants involved in producing health inequities,” (Solar & Irwin, 2010, p. 30).

Structural Determinants and Social Determinants of Health Inequities

In the CSDH model, structural determinants “are those that generate or reinforce stratification in the society and that define individual socioeconomic position” (Solar & Irwin, 2010, p. 34). Social stratification refers to the hierarchical system in which wealth, power, and status are unequally distributed to different categories of people (Asimakopoulos, 2008).

Socioeconomic position indicates one’s place in the social stratification system. In the CSDH framework it is measured using three key indicators: occupation (which may reflect standing in the social hierarchy, exposure to occupational risks, elements of control and power, etc.),

education (which may reflect knowledge and skills, etc.), and income (which may reflect material resources, ability to convert money into goods and services, etc.) (Solar & Irwin, 2010).

In addition to occupation, education, and income, three social stratifiers are considered important structural determinants: social class (a relational concept used to denote ownership/control of assets), race/ethnicity (two distinct but overlapping terms used in the framework to denote the social categorization of people with shared physical attributes, culture and heritage; it can influence discrimination, access to power and resources, etc.), and gender (a term used to denote the socially constructed roles ascribed to women and men; it can influence access to power and resources, discrimination, etc.) (Solar & Irwin, 2010). A significant body of research has explored links between these indicators/stratifiers and health inequities (Benoit & Shumka, 2009; Hebert, Sisk, & Howell, 2008; Williams, 2003), and while it is beyond the scope of this dissertation to explore this in detail, two salient points provide the necessary basis for understanding its role in the model.

First, the interaction between socioeconomic and political context, structural mechanisms, and socioeconomic position are together known as the social determinants of health inequities, or what other authors may refer to as the ‘root causes’ (Marmot, 2007), or ‘cause of causes’ (Phelan, Link, & Tehranifar, 2010). Second, the socioeconomic and political factors introduced above (e.g. public policies related to health, education, social protection, etc.) affect the lives of individuals through socioeconomic position (Solar & Irwin, 2010), and socioeconomic position in turn affects exposure to intermediary determinants (Graham, 2004).

Social Cohesion and Social Capital

The concepts of social cohesion and social capital are highly relevant to discussion of refugees, many of whom come from communities fractured by social unrest and displacement.

Social cohesion has been defined as “the willingness of members of a society to cooperate with each other in order to survive and prosper” (Stanley, 2003, p. 5). While the concept of social capital does not have one definitive, accepted definition, Kawachi, Kennedy, Lochner, & Prothrow-Stith (1997) assert that key tenants of social capital “consist of civic engagement and levels of mutual trust among community members” (p. 1492). In the CSDH model, social cohesion and social capital crosscut structural determinants and intermediary/social determinants of health, functioning as an important bridging mechanism. While it is beyond the scope of this chapter to explore these concepts in detail, it is nevertheless important to acknowledge the important role they occupy in the social determinants of health conceptual framework, and they are discussed in subsequent chapters of this dissertation.

Intermediary Determinants/Social Determinants

In the CSDH framework, structural determinants of health inequities act through intermediary determinants, also known as the social determinants of health, and the health system is considered a distinct and pivotal social determinant. The remaining determinants are organized under three broad categories: material circumstances; psychosocial or social-environmental circumstances (hereafter referred to as psychosocial); and behavioural and biological factors.

Material Circumstances. Material circumstances directly affect the health of individuals and groups through factors such as living conditions, working conditions, and access to food and water. For example, overcrowded and unsanitary housing can contribute to the spread of infectious diseases such as tuberculosis (TB) (Kouadio et al., 2009); unsafe workplaces can lead to accidents and injuries (Carballo & Nerukar, 2001); food insecurity can lead to nutrition related diseases; and unclean water can lead to parasitic diseases (Vlahov et al., 2007).

Psychosocial determinants. Psychosocial determinants include social exclusion related to low socioeconomic position, coping mechanisms, level of social support, and exposure to stressful circumstances. Stress has been associated with a range of poor health outcomes; for example, Lantz, House, Mero, & Williams (2005) analyzed data from Americans' Changing Lives, a longitudinal study in the United States with over 3,600 participants, and found that: "results support the hypothesis that differential exposure to stress and negative life events is one of many ways in which socioeconomic inequalities in health are produced in society" (p. 274).

Wilkinson & Pickett (2009) describe how chronic stress takes a physiological toll on the body, leading to decreased immunity and strain on the cardiovascular system that can result in a host of health issues. Wilkinson is a leading proponent of the psychosocial approach to understanding inequalities in health, the basic premise of which is that individuals are cognizant of inequality within their community and society, and they compare their material possessions, status, and circumstances with others, which is particularly detrimental to the psychosocial wellbeing of the underprivileged (it leads to stress, shame etc.), and can negatively impact health (Solar & Irwin, 2010).

Marmot & Wilkinson (2001) draw on a range of evidence to assert that health inequalities cannot be explained solely on the basis of material deprivation or absolute income (i.e. whereby health status is thought to depend on one's own income, considered in isolation) (Kawachi & Subramanian, 2002). Rather, they support the argument that relative disadvantage can act through psychosocial pathways to negatively impact health; in other words, health depends not only on one's own income, but what one's income is relative to others in society (Kawachi & Subramanian, 2002). Marmot & Wilkinson (2001) stress that: "social dominance, inequality, autonomy, and the quality of social relations have an impact on psychosocial wellbeing and are

among the most powerful explanations for the pattern of population health in rich countries” (p. 1233).

Behavioural and biological. The third category of social determinants includes behavioural factors (such as physical activity, substance use, and diet) and biological factors (such as genetics, age, and sex) (Solar & Irwin, 2010). While tobacco, diet, and physical activity – known as the “holy trinity of risk” (Raphael, 2006, p. 663) – are often the focus of public health and policy initiatives, a growing body of research is questioning the extent to which individual risk behaviour determines health status. For example, findings from the Americans’ Changing Lives study suggest that “behavioral risk factors of smoking, alcohol consumption, physical inactivity and overweight statistically account for only a small part of the increased risk of poor health status” (Lantz et al., 2001, p. 37).

The SDH approach does not negate the importance of individual behaviour on health. It does, however, emphasize that individual behaviour such as smoking, alcohol use, and physical inactivity are responses to stress and deprivation that manifest inequitably in the physical and social conditions in which people live (Solar & Irwin, 2010). In other words, the at the heart of SDH lies, “the task of identifying and ameliorating patterns of systematic disadvantage that undermine the well-being of people whose prospects for good health are so limited that their life choices are not even remotely like those of others” (Gostin & Powers, 2006, p. 1054).

The health system. The final social determinant of health discussed here is the health system. Solar & Irwin (2010) claim that some previous SDH models failed to explicate the importance of the health care system, and one feature that differentiates this framework from others is that the health system is considered a distinct determinant. Solar & Irwin (2010) argue that the health system is important because it can “directly address differences of exposure and

vulnerability not only by improving equitable access to care, but also in the promotion of intersectoral action to improve health status” (p. 40). In the context of refugee health, refugees’ increased risk of certain health issues (S. L. Thomas et al., 2008) is compounded by the formidable structural and psychosocial barriers they face in accessing health care (Asgary & Segar, 2011; McKeary & Newbold, 2010), an issue discussed later in this chapter.

Benefits and Challenges of the Evidence Base on SDH

The burgeoning evidence base on SDH is comprised of a diverse and interdisciplinary range of studies, theories, and perspectives (Solar & Irwin, 2010). To date, most literature has been produced by – and for the consumption of – academics and multinational organizations like WHO, and the complexity, jargon, and sheer length of many of the documents on SDH (see Bonnefoy et al., 2007; WHO, 2011a) may serve as barriers for those who might otherwise benefit from them, particularly people working on the ground or in non-health related policy fields.

Yet growing concern regarding how to translate evidence on SDH into action has prompted concerted effort by scholars and the WHO to make evidence on SDH more accessible to those who have the power to influence policy and practice. Rather than publishing results exclusively in peer-reviewed journals – a means of dissemination that may exclude academics and policy makers in low-income countries – knowledge sharing is increasingly taking place via more accessible methods. The foremost example of this is ‘Action: SDH’ (WHO, 2012), an internet resource that aims to serve as a clearinghouse through which WHO, academics and non-profit organizations can disseminate documents and explore issues related to SDH. Platforms such as this can serve as middle ground for academics, policy makers and civil society

organizations, and may prove to be an important way to bridge the persistent gap between evidence and action on SDH.

While there is widespread recognition of the need to translate evidence on SDH into policy (WHO, 2011b), numerous challenges with the evidence base serve as barriers to successfully accomplishing this. Some of the foremost barriers stem from the challenge of measuring inequity (as opposed to inequality) on both local and global levels, and to the lack of clarity regarding what is being measured (health? illness?). The proverbial elephant in the SDH evidence base is that most researchers are concerned with determinants of illness, not health. Bonnefoy et al. (2007) are among the few who address this: they discuss the importance of identifying the cause of causes in research on SDH, and argue that biological mechanisms cannot solely account for health variations; rather, “other processes are at work and they are amenable to causal analysis involving a pathway from the social to the biological. In this sense the concern is not inequities in health per se, but much more specifically the social determinants of inequities in illness” (p. 16). While this presents linguistic ambiguity, the tenets of the SDH approach support the study of both health and illness, and although the notion of a health continuum is contentious, conceptualizing health/illness as a continuum rather than distinct and oppositional categorizations (Antonovsky, 1996) is one way to resolve this discordance.

Consistent and Accurate Measurement of SDH

Numerous challenges regarding evidence on SDH pertain to issues of measurement. For instance, the latency period between cause and effect (i.e. exposure to SDH and morbidity and mortality) can make it challenging to delineate causal pathways, and to measure the impact of exposure to individual determinants of health. Coburn (2004) argues that, “disease and death are likely due to life-long cumulative influences rather than only to conditions in the immediate

environment” (p. 43), an argument that is aligned with the life course perspective, which suggests that health is affected by risks and benefits that accumulate throughout life, particularly during formative periods such as early childhood (Solar & Irwin, 2010).

The difficulty of establishing causal pathways in research on SDH is acknowledged by Bonnefoy et al. (2007), who state that while there is burgeoning literature on some facets of SDH, “the linkages back up the causal chain to the social determinants and down the chain to specific health indicators remain a considerable research and development task” (p. 209). It is beyond the scope of small-scale, qualitative studies such as this one to move this particular area of research forward, and I would argue that conceptualizing social dimensions of health more broadly – without explicating specific causal pathways – can still generate meaningful insight into SDH, an argument taken up in the discussion chapter of this dissertation.

Scale and units of analysis (individuals, communities, countries etc.) present another challenge for the evidence base; for example, while small scale studies such as this may be the best way to inform effective, context-specific policies, such studies may not be generalizable to regions and countries with different socioeconomic and political contexts. Conversely, researchers using large data sets or considering vast geographic regions in the study of SDH must be mindful of problems surrounding attribution (e.g. making inaccurate inferences based on aggregate data), and even if they produce relevant, valid and reliable data, they may lack the detail needed to develop programs and policies on the ground (Bonnefoy et al., 2007).

Studies that make inferences regarding inequity based on measures of inequality present another challenge to the evidence base. This challenge has acute implications for policy makers, because measures of inequality can significantly underestimate the extent of inequity (Reidpath & Allotey, 2007), and policy based on these measures may therefore be ineffective. Furthermore,

from a global perspective, much of the evidence on health equity fails to account for the fact that the impact of ill health is mitigated by good health and social services, which should be considered indicators of societal wealth (Reidpath & Allotey, 2007), particularly because such services are often inequitably distributed (i.e. they are better in wealthy regions like Scandinavia, and worse in poor regions with heavier disease burdens, like Southern Africa).

Assessing evidence on SDH on a global scale presents additional challenges. First, different systems are used to collect and analyze data in different parts of the world (Ompad, Galea, Caiaffa, & Vlahov, 2007), which can make accurate comparisons difficult. Second, indicators/stratifiers have different meanings in different contexts; as Bonnefoy et al. (2007) state, “concepts associated with the social determinants are not universal (for example, class, status and religion mean different things in different societies). Some caution is required, especially in using concepts originating in high income societies in low and middle income ones” (p. 19). This is particularly relevant when interpreting data from a global perspective, because indicators may have different relevance and health implications in various regions of the world. Challenges related to the context-specific meaning of some indicators (including income and education) among urban refugees manifested in this study, and are considered in the Chapter 9 of this dissertation.

Disciplines Brought Together Under the SDH Umbrella

A wide range of disciplines are associated with the SDH approach; some of these disciplines, and an example of what they may contribute to the SDH evidence base, include: philosophy (justice, equity) (Ruger, 2004; Sen, 2002); education and international development (human rights, capabilities, social reproduction) (Nash, 1990; Robeyns, 2006); sociology (structure and agency) (Williams, 2003); human geography (urban health) (Vlahov et al., 2007);

psychology (life course, psychosocial approaches) (Willson & Shuey, 2007) and more. A drawback of incorporating so many disciplines is that the evidence base is somewhat fragmented; it lacks a common set of definitions for key terms and concepts; and it can be challenging to find common ground amongst dichotomous approaches to data collection, analysis, and research in general. In the context of this study, however, one of the benefits of the multidisciplinary nature of an SDH approach is that it is well aligned with the study of forced migration (itself an interdisciplinary field of inquiry). Furthermore, it allows for the inclusion of a wide range of expertise and evidence; importantly, this includes evidence generated outside academia (such as ‘grey’ literature in the form of NGO reports), which is often the most current and informative information available in rapidly evolving humanitarian contexts.

Policy Implications of the SDH Approach

The SDH approach offers multiple points to intervene and effect change through policy, including: socioeconomic and political context (e.g. public policy that reduces or eliminates user fees in health and education); changes in structural determinants of health (e.g. equity and diversity sensitive hiring practices; equal pay for equal work); and alleviation of negative exposure to SDH (e.g. improved living standards and working conditions; improved food security; more equitable access to health services). Researchers concerned with SDH have differing opinions as to where to intervene; some favour improving immediate living conditions (i.e. social determinants of health) (Freudenberg, Galea, & Vlahov, 2005), while others argue that mitigating social determinants is not the solution, ultimately structural determinants must be addressed (Ompad et al., 2007). Burris & Anderson (2010) take a more equivocal stance: they recognize the importance of both structural and palliative interventions, and point out that deciding between “repairing the dam and saving the downstream victims of the flood” (p. 589) is

not always necessary. Farmer, Nizeye, Stulac, & Keshavjee (2006) echo this sentiment, stating: “distal and proximal interventions are complementary, not competing. International public health is rife with false debates along precisely these lines, and the list of impossible choices facing those who work among the destitute sick seems endless” (p. 1689).

While Farmer et al. (2006) acknowledge that it is not an either or choice, they ultimately recognize that the only way to address the root of the problem is to actualize social and economic rights and distribute resources more equitably. Although various researchers over the last two decades have made this general argument, there has been a palpable shift and progression in the last five years. It began with key figures such as Marmot (2007) acknowledging that while there are challenges with the evidence base (some of which I introduced above), and certain areas in particular require better evidence, we have enough knowledge on SDH to take decisive action. Two years later, the CSDH (2009) released their final report, which again stressed the need to address social injustice and inequalities that we know (and have evidence to prove) are killing people.

While this was a relatively bold position for WHO to take, some scholars criticized the report for being apolitical and issuing vague rhetoric that inequalities kill without acknowledging that, “it is not inequalities that kill, but those who benefit from the inequalities that kill” (Navarro, 2009, p. 440). While Navarro prefaces his assessment of the report with commendation for the important work and accomplishments of the CSDH, he produces an articulate (and acerbic) criticism of its shortcomings, stating:

We know about the killing, the process by which it occurs, and the agents responsible. And we, as public health workers, must denounce not only the process, but the forces that do the killing. The WHO will never do that. But as public health workers we can and must do so. It is not enough to define disease as the absence of health. Disease is a social and political category imposed on people

within an enormously repressive social and economic capitalist system, one that forces disease and death on the world's people. (p. 440)

This passage is indicative of a more widespread shift among proponents of SDH, who are moving beyond the argument that social factors determine health, and acknowledging that addressing SDH requires political action. In other words: social determinants of health are, at their very roots, political determinants of health (Krech, 2011). While advocates of the political economy of health approach have long been making this argument, it is increasingly (and more publicly) being taken up by civil society.⁹

Bolstering the evidence base on SDH; developing and implementing policies; and rigorously evaluating their impact are imperative, but these tasks cannot be accomplished without explicitly embedding the SDH approach in the broader political systems that generate and perpetuate inequities in power, wealth, and health. This is particularly important when considering SDH in the context of vulnerable populations such as refugees, and the remainder of this chapter considers key aspects of the global sociopolitical context as they relate to this research with refugees. I begin with an overview of the humanitarian organization tasked with protecting refugees (UNHCR); I then consider the meaning and implications of the term refugee as used to denote a social category of people, and lastly I consider key health issues affecting refugee populations.

UNHCR

According to the recent Global Appeal report (UNHCR, 2013b), UNHCR is:

An impartial organization, offering protection and assistance to refugees and others on the basis of their needs and irrespective of their race, religion, political

⁹ One poignant example of this is the 2011 WHO Global Conference on SDH in Brazil, where “more radical health campaigners rejected the official Rio Political Declaration on Social Determinants of Health, which had been carefully negotiated in advance in order not to upset sensitivities, and launched an alternative civil society Rio declaration” (Boseley, 2011).

opinion or gender...mandated by the United Nations to lead and coordinate international action for the worldwide protection of refugees.

UNHCR was founded in 1950, with a three-year mandate to assist Europeans displaced by the World War II (UNHCR, 2013e).¹⁰ In 1954 UNHCR won the Nobel Peace Prize and had its mandate extended, and over the next two decades it expanded its work to assist refugee populations in Africa, Asia and Latin America. UNHCR has continued to expand over the past sixty years, and while its primary focus remains refugees, the agency has additionally taken on a key role in assisting IDPs and stateless populations.

Relevant UNHCR Reports and Policy Documents

There is a plethora of guides, reports and policy documents authored by UNHCR: this section briefly highlights five that are relevant to this study.¹¹

The United Nations 1951 Convention Relating to the Status of Refugees and the 1967 Protocol. According to the United Nations, the 1951 Convention is “the key legal document in defining who is a refugee, their rights and the legal obligations of states. The 1967 Protocol removed geographical and temporal restrictions from the Convention” (UNHCR, 2010). A total of 147 states have acceded to the Convention and/or the 1967 Protocol (UNHCR, 2011b); accession among countries in South East Asia, however, is low: Malaysia, Thailand, Indonesia, Myanmar, Laos and Vietnam have not signed, and the only countries that have are Cambodia, the Philippines, and Timor-Leste. As Cheung (2011) states, South and South East Asia have “some of the least developed refugee legislation and asylum institutions in the world,” (p.6) and

¹⁰ This brief section covers basic historical facts about UNHCR, as stated on the UNHCR website. For an academic overview of the agency, see Hyndman's (2001) article, “Change and Challenge at UNHCR: A Retrospective of the Past Fifty Years.”

¹¹ Most of these documents, and a great deal of other information, are publicly available through a UNHCR website called RefWorld (UNHCR, 2013d).

given the prevalence of forced migration in the region, the aforementioned countries' refusal to sign the Convention has serious repercussions – namely that the Convention cannot be invoked to protect and/or advocate on behalf of many of the refugees and asylum seekers in the region.

UNHCR Policy on Refugee Protection and Solutions in Urban Areas (2009). This policy document replaced UNHCR's (1997) Policy on Urban Refugees, which was widely criticized for implying that urban areas were unsuitable for refugees, and suggesting that refugees who lived in urban areas relied too heavily on UNHCR for assistance (HRW, 2002; Pantuliano, Metcalfe, Haysom, & Davey, 2012). The 2009 policy adopts a much more constructive tone in that it acknowledges the steady urbanization of the global refugee population, and clearly establishes the two key objectives for UNHCR's policy regarding urban refugees, which are:

To ensure that cities are recognized as legitimate places for refugees to reside and exercise the rights to which they are entitled; and, to maximize the protection space available to urban refugees and the humanitarian organizations that support them. (p.5)

Overall, the document is a valuable reference for anyone concerned with refugees in urban areas, as it concisely sets out UNHCR's policy for implementing protection strategies on a global scale for refugees in urban areas (e.g. registration and data collection; security; promoting livelihoods and self-reliance, etc.).

Ensuring Access to Health Care: Operational Guidance on Refugee Protection and Solutions in Urban Areas (UNHCR, 2011b). In light of the fact that the health needs of refugees (and operational considerations of UNHCR) are different in urban areas and refugee camps, UNHCR issued this policy document which establishes guidelines for public health programming in urban settings. Specifically, the policy is based on a three-pronged approach

entailing advocacy, support, and monitoring & evaluation. A key principle of the policy is that UNHCR endeavours to ensure that refugees in urban areas can access a comparable range and quality of healthcare to the host population, at similar prices.

As the document is a public health policy (as opposed to a policy specifically focused on health care), it acknowledges the importance of addressing both immediate health needs *and* social determinants of health, priorities which UNHCR asserts to operationalize by assessing, monitoring, and evaluating “the health, nutritional, educational and economic status of refugees, ensuring needs are met in line with accepted standards and that quality services are available and accessible” (p.2).

UNHCR Global Report and Global Appeal (UNHCR, 2011d, 2013c). UNHCR issues a Global Report in June of each year.¹² The purpose of the report is to provide: a comprehensive overview of major trends and events in forced migration over the past year, statistics regarding forced migrant populations, and a summary of UNHCR’s operations (see UNHCR, 2011e for the section on Malaysia). The Global Appeal is another report published annually (and updates are sometimes issued bi-annually): it provides more detailed information on UNHCR’s operations in countries around the world, and projects budgetary and operational needs for the coming year. Both reports include data on multiple categories of forced migrants (i.e. IDPs, stateless people, and refugees) and provide extensive, up to date information on forced migration.

Contemporary Refugee Populations

The remainder of this chapter focuses on issues affecting refugees. I begin by clarifying the definition of various sub-populations of forced migrants; I then outline key debates in the

¹² Global Reports from 1999 – 2011, and Global Appeal documents from 2000 – 2013 can be accessed at <http://www.unhcr.org/pages/49c3646c4b8.html>

field of refugee studies, and end the chapter by considering relevant literature on health and SDH in the context of forced migration.

The Definition of a Refugee

One of the most challenging aspects of conducting (and reviewing) research on refugee health is the specific terminology used to define categories of displaced people, particularly because, “the question of who counts as ‘refugee’ in the enactment of international human rights is a contentious source of struggle between governments, state bureaucracies and critical movements,” (Essed & Wesenbeek, 2004, p. 53). Numerous classifications of people exist under the umbrella term ‘forced migrants,’ including asylum seekers (people who are forcibly displaced, have crossed an international border, and *claim* to be refugees but have not yet had their application adjudicated) (Asgary & Segar, 2011), and IDPs (people who are forced to migrate within the borders of their own country) (Roberts et al., 2009).

Refugees and asylum seekers may also be considered stateless (see Berkeley, 2009), defined in the statelessness convention as “a person who is not considered as a national by any State under the operation of its law” (UN, 1954).¹³ The definition of a refugee, according to the 1951 UN Convention on the Status of Refugees and the 1967 Protocol Relating to the Status of Refugees (UNHCR, 2010) (hereafter referred to as the Convention), is someone who fears persecution due to:

Reasons of race, religion, nationality, membership of a particular social group or political opinion, is outside the country of his nationality and is unable or, owing to such fear, is unwilling to avail himself of the protection of that country; or who, not having a nationality and being outside the country of his former habitual

¹³ While a distinction is sometimes made between de jure and de facto statelessness, there are no universally accepted/utilized definitions of these terms, and there can be considerable overlap between them. As a point of reference, de jure statelessness is usually used to describe people who are not legally citizens of any nation (such as Rohingya refugees in Malaysia), while de facto statelessness is generally used to describe those “who possess a nationality but where that nationality is ineffective” (UNHCR, 2011f, p.22).

residence as a result of such events, is unable or, owing to such fear, is unwilling to return to it. (p. 14)

In most countries, national governments control and administer the process by which asylum seekers are assessed to determine if they are genuine refugees (known as refugee status determination, RSD); in Malaysia, however, the government does not undertake RSD, and so UNHCR processes all asylum claims. The implications of this are significant, because while many governments have their own additional criteria to determine who can seek asylum and who qualifies as a refugee (Australia, for example, has refused to process asylum claims from Sri Lankans) (BBC, 2010), UNHCR assesses asylum claims against the Convention definition referenced above. Thus when discussing refugees in Malaysia, it is most appropriate to use this definition. It is, however, important to acknowledge the academic debate regarding the definition of a refugee; I discuss this in the following section, as well as other key debates in the study of forced migration.

Debates in the Study of Forced Migration

Numerous scholars have raised concern about the subjectivity and utility of the refugee label (cf. Buscher, 2011; Colson, 2007; Essed & Wesenbeek, 2004). In the introduction to their book on refugees, editors Essed et al. (2004) argue that the standard definition of a refugee fails to reflect the complex, interconnected reasons why people migrate, and they go as far as to state that, “none of the authors would deny the exceptional nature and dramatic impact of flight and of refuge in a situation of crisis, but few if any would label refuge as inherently different from other migratory experiences” (p.6).

This contradicts the seminal work of Stein (1981), who argued that “the refugee is not pulled out; he is pushed out. Given the choice, he [or she] would stay” (p.322). Fuglerud (2004) claims that Stein’s work is overly simplistic, because forced migration “often involves making

priorities and decisions similar to those found in other forms of migration and should be seen as one aspect of larger cultural and sociopolitical processes” (p. 43). While I agree that there may be common factors precipitating asylum seekers and migrants’ decisions to leave their country, there are also crucial differences, and the terminology utilized by S.L. Thomas et al., (2008) can be helpful in bridging Fuglerud and Stein’s respective arguments.

Rather than discussing push and pull factors,¹⁴ S.L. Thomas et al., (2008) distinguish between the root and proximate causes of displacement: they identify root causes of displacement as being situations such as war, other forms of persecution or armed conflict, and natural disasters, while proximate causes are those stemming from the root causes, including food insecurity/famine, outbreaks of disease, attacks targeting people of a specific ethnicity etc. Understanding root and proximate causes of displacement is imperative in the context of determining who refugees are, because refugee status is predicated on the circumstances underpinning migration. Yet there is a degree of subjectivity in interpreting which circumstances constitute valid refugee claims, and scholars have argued that asylum seekers are increasingly being met with restrictions and a culture of disbelief in the process to obtain what has become the ‘highly prized privilege’ of official refugee status (Colson, 2007; Eastmond, 2007; Zetter, 2007).

Eastmond (2007) writes cogently regarding the culture of distrust around asylum seekers, asserting that those who are lucky enough to have their cases heard are often met with scepticism and suspicion. She builds on the work of Fassin & D’Halluin (2005) to argue that as the refugee regime has shifted from political to humanitarian, a “crisis of asylum” is evident in the fact that

¹⁴ Circumstances in the country of origin that compel people to flee/migrate are sometimes referred to as ‘push’ factors, while factors in the destination country that are anticipated to offer improved quality of life are sometimes referred to as ‘pull’ factors (Gushulak & MacPherson, 2011).

“trauma and serious physical conditions have become the main social currency for admission...as the injured body has become the terrain of ‘truth’, medical certificates are replacing refugees’ own words,” (p.260). The increasing value of medical certificates and devaluation of refugees’ testimony during the RSD process is relevant to anyone doing research with refugees, and particularly those eliciting narratives.

More broadly, the culture of disbelief and devaluation of refugees’ testimony is indicative of measures increasingly being undertaken by states to restrict the number of asylum seekers and refugees; one recent example is Australia, which instituted off-shore processing to deter the arrival of ‘illegal’ refugees by boat (BBC, 2012). The Refugee Council of Australia (2013) issued information to combat myths about refugees and asylum seekers; the most pertinent in the context of this discussion is that while asylum seekers arriving by boat are often referred to as illegal immigrants, they are, in fact, neither ‘illegal’ nor ‘immigrants,’ because anyone has the right to seek asylum (Zetter, 2007). The use of the word illegal to describe some refugees and asylum seekers has contributed to a troubling discourse in which ‘genuine’ refugees are pitted against ‘fake’ or illegal ones (Essed et al., 2004): as Essed & Wesenbeek (2004) argue, “the construction of the category ‘illegal’ symbolizes the bankruptcy of the notion of ‘refugee’ in the Human Rights Declaration” (p.58).

Some activists, humanitarians, and (more recently) media conglomerates have rejected the use of the term illegal immigrants, claiming that illegal should be used to describe actions, not people (Keung, 2013). Bauder (2013) calls for increased usage of the term ‘illegalized’ to describe migrant populations, in order to “draw attention to the systematic process that renders people ‘illegal’ rather than blaming illegalized immigrants for the situation in which they are

placed” (p.5).¹⁵ The term illegalized is well aligned with an SDH approach and the ethos of this study, and is used throughout this dissertation.

Refugees as a Vulnerable Population

The debate surrounding refugees and vulnerability is highly relevant to this study. Refugees are often considered to be a ‘vulnerable population’ (McKeary & Newbold, 2010; Schwartz, 2011), a term used in health research to denote people who may have “increased susceptibility to adverse health outcomes as a result of inequitable access to the resources needed to handle risks to health,” (Alberta Health Services, 2011, p. 3) and who are at greater risk of being harmed during the research process because of their, “diminished competence, powerlessness, or disadvantaged status,” (Bond Sutton, Erlen, Glad, & Siminoff, 2003, p. 106). Luna (2009), however, is critical of the way in which vulnerability is applied as a label to entire subpopulations, because it fails to recognize diversity and differential vulnerability within heterogeneous groups of people; furthermore, she argues that “understanding vulnerability as a mere label does not help us to acknowledge, identify, and evaluate the life experiences of those deemed vulnerable” (p. 131). She proposes a relational concept of vulnerability – with marked similarities to intersectionality – in which ‘layers’ of vulnerability like poverty, gender, and illiteracy may overlap, compound, and shift depending on circumstances.

¹⁵ The overarching argument here is that *people* are not inherently illegal, though a person may undertake an action that is illegal or enter a country illegally (such as economic migrants who work without the proper permit). It is not illegal to seek asylum, though this point is often lost in the discourse on refugees and asylum seekers. The refugee Convention affirms the right to seek asylum (which was initially set out in the Universal Declaration of Human Rights); the Convention stipulates: “refugees should not be penalized for their illegal entry or stay. This recognizes that the seeking of asylum can require refugees to breach immigration rules. Prohibited penalties might include being charged with immigration or criminal offences relating to the seeking of asylum, or being arbitrarily detained purely on the basis of seeking asylum” (UNHCR, 2010, p. 3). In that sense, refugees and asylum seekers who are labeled illegal immigrants are ‘illegalized.’

In the context of refugees, this conceptualization of vulnerability can offer a more nuanced and accurate reflection of differential vulnerability. A nuanced approach to understanding vulnerability among refugees is particularly useful because distancing the refugee population from the vulnerability label entirely is not practical, as the label is deeply embedded in the public and academic discourse on refugees (Freedman, 2010). Moreover, rejecting the label completely is unnecessary, because refugee status is predicated on forced displacement and the risk of persecution, which means that all refugees are, by virtue of their refugee status, vulnerable to varying degrees (McKeary & Newbold, 2010).

Marfleet (2007) argues that “for governments eager to demonstrate their authority refugees present an attractive target: vulnerable and often ‘voiceless,’ they are a convenient focus for exemplary action against ‘illegals’ and ‘criminals’ – the same deviants who populate official discourses of the refugee in Europe and North America” (p.43) (an assertion that parallels the argument made by Bauder [2013] regarding the illegalization of immigrants and asylum-seekers). Conversely, the notion of refugees as a vulnerable population has, at times, been perpetuated by agencies and non-governmental organizations in order to raise awareness of humanitarian situations and support fundraising activities.¹⁶ As these examples illustrate, vulnerability is a complex and multidimensional label that has been applied to the refugee population for various reasons. For the purpose of this dissertation, issues pertaining to the use of the term are resolved by accepting the distinction used on the ground by UNHCR, that while all refugees are vulnerable, certain refugees have added vulnerabilities.¹⁷

¹⁶ See Freedman (2010) who highlights the use of photographs depicting women and children in fundraising campaigns.

¹⁷ Resettlement and assistance are examples of how the term vulnerability is operationalized within UNHCR, as refugees who are deemed particularly vulnerable may be prioritized for resettlement to a third country. The resettlement guidelines (UNHCR, 2011f) note that individuals belonging to the following

Refugees as Victims, Refugees as Resilient

The previous section considered the potential utility of the term ‘vulnerable’ as it is applied to refugees; this section considers the more insidious application of the victim stereotype. Rajaram (2002) provides acerbic critique of the way in which refugees are depicted by humanitarian agencies; she argues that refugees are represented as mute victims, framed in terms of helplessness and loss, the “pictorial representation of suffering and need,” (p. 251). Both Freedman (2010) and Harrell-Bond (1999) have examined the troubling representation of refugees as helpless recipients of aid; Freeman argues that not only are refugees represented as victims, they are often forced to adopt and perform the role of powerless victim in order to gain access to services and assistance.

Harrell-Bond is one of the most outspoken critics of the humanitarian aid system as it pertains to refugees (Harrell-Bond & Voutira, 2007; Harrell-Bond, 1999, 2000, 2002). In her nuanced analysis of refugee issues, she acknowledges the pervasiveness of the stereotype of refugees as helpless victims, yet argues that stereotypes of refugees are more complex, and there is in fact a dichotomous split between images of ‘good’ refugees who are “starving and helpless” and ‘bad’ refugees who are, “thankless, ungrateful, cheating, conniving, aggressive, demanding, manipulative, and even dangerous persons who are out to subvert the aid system” (2002, p.58). In subsequent work she names three pervasive stereotypes applied to refugees, stating: “today the term ‘refugee’ signals a burden, a victim, and a threat” (Harrell-Bond & Voutira, 2007, p. 295).

The notion of refugees as threatening is expanded upon by Marfleet (2007) who

sub-populations may be particularly vulnerable and in need of assistance and/or resettlement: women and girls (vulnerable to SGBV, trafficking etc.), children and adolescents (vulnerable to violence, disease, malnutrition etc.), older refugees (vulnerable to abuse, illness etc.), refugees with disabilities (vulnerable to abandonment, abuse, exploitation etc.), lesbian, gay, bisexual, transgender or intersex (vulnerable to hate crimes, criminal persecution, SGBV etc.), and refugees from minority or indigenous groups (vulnerable to discrimination, violent attacks based on their race/ethnicity etc.).

considers how, “on a global front refugees have come to be portrayed as calculating, aggressive, and undeserving—as opportunists who sought to exploit the credulity of Western publics” (p. 41). When one considers the divergent portrayals of ‘good’ and ‘bad’ refugees in tandem, it thus seems that while the global portrayal of ‘good’ refugees is one that incites sympathy, indignation, and financial support for humanitarian aid, when it comes to actually accepting refugees, many countries with the stability and resources to have secure borders have perpetuated the stereotype of refugees as bad, illegal, and threatening, and adopted an attitude of ‘not on our doorstep’ (BBC, 2010, 2012; Frelick & Adams, 2011).

Regardless of whether refugees are portrayed as ‘good’ or ‘bad,’ the stereotypes described above are simplistic and predominantly negative. Yet there is a growing cadre of academics and NGOs who espouse more holistic and multidimensional portrayals of refugees, a robust literature on refugees and resilience (cf. Montgomery, 2010; Munt, 2012; Pulvirenti & Mason, 2011; F. Thomas, Roberts, Luitel, Upadhaya, & Tol, 2011) and a necessary “shift from seeing beneficiaries of humanitarian aid as ‘victims’ to be pitied, to survivors of adversity—who often demonstrate unimaginable strength and dignity in the most adverse circumstance” (Harrell-Bond, 2002, p. 52).

In their article on the resilience of refugee women, Pulvirenti & Mason (2011) define resilience as “particularly successful or unpredicted adaptations to trauma, stress, risk and other negative life experiences” (p. 39). The authors conducted a qualitative study exploring resilience in the context of refugee women who experienced violence over the course of being resettled in Australia. They conducted semi-structured interviews with service providers who worked with women who had experienced violence during resettlement. They concluded that resilience is a valuable concept which can be utilized to understand the experiences of refugee women, though

they caution against a strictly individual application of the term resilience, as this negates the role of families, communities, and the social environment in fostering resilience. The authors advocate for extending beyond an individual conceptualization of resilience to a process-oriented, collective resilience that links individuals to their families, communities, and social environment.

Such a conceptualization of resilience is supported by other research findings. In their longitudinal study on child and adolescent resilience, for example, Sameroff & Rosenblum (2006) found that while indicators of child resilience (e.g. behavioural and emotional self-regulation) contributed to competence later in life, "the effects of such individual resilience did not overcome the effects of high environmental challenge, such as poor parenting, antisocial peers, low-resource communities, and economic hardship" (p.116). Almeida (2005) explored resilience and vulnerability to daily stressors, and his findings "highlight how people's age, gender, and education and the presence or absence of chronic stressors in their lives predict their exposure and reactivity to daily stressors" (p.64). Considered using an SDH approach, these findings provide insight into the role of broad structural determinants in fostering or weakening individual and community resilience.

When resilience is conceptualized in the manner outlined above, it becomes possible to extend discussion of resilience among refugees beyond academic literature to consider the ways in which refugees execute agency or 'resilience in action.' For example, one way in which refugees executed agency on a collective level took place in 2002, when Myanmar refugees in New Delhi gathered at the UNHCR office demanding more expedient processing of their applications, carrying placards that read, 'SOS' and 'Victims of UNHCR' (Marfleet, 2007, p. 42). Another interesting, if more subversive, example took place in Malaysia. Prior to 2009,

UNHCR Malaysia prioritized pregnant women for registration, which meant they did not have to endure the regular wait time. The wait time varies, but it can take many months to have an initial registration interview, which is only the first step in the long refugee status determination process. In 2009, UNHCR stopped prioritizing pregnant women, as many were able to access maternal care even without a UN document. There has also been speculation, however, that this change in policy was to address concerns that women were intentionally getting pregnant in order to obtain registration (Women's Refugee Commission & UNHCR, 2011).

While the later example is not a clear-cut example of collective agency, this interaction between action and policy exemplifies the power that refugees have to influence the structure within which they are embedded. It is particularly important for researchers to acknowledge the ways in which refugees execute agency, both individually and collectively, in order to problematize an issue that constituted the first half of this section: the ubiquitous assumption that refugees are powerless victims (Freedman, 2010).

Illness and Health Among Refugee Populations

Displacement poses a serious threat to the lives of many refugees: as S. L. Thomas et al., (2008) assert, “there is conclusive evidence that displaced populations are exposed to greatly increased health risks and suffer increased death rates” (p. 205). Specifically, refugees may be exposed to high levels of stress, trauma and violence, and have inadequate shelter, nutrition, and sanitation (AI, 2010; Lopes-Cardozo, Talley, Burton, & Crawford, 2004), conditions that put them at risk for a multitude of health concerns, some of the most prevalent of which are discussed below.

Infectious Disease

According to S. L. Thomas et al., (2008) “infectious diseases, such as malaria, parasitic infections, HIV, hepatitis A, B, and C, and tuberculosis, are among the main causes of disability and death of displaced persons,” (p. 202). Studies conducted in urban settings and camps around the world support the assertion that infectious diseases are a serious health concern for refugees; Chaves et al., (2009) for example, conducted a retrospective cohort study at an urban hospital in Australia, and found that refugee participants had “high rates of H. pylori infection (80%), latent TB infection (70%), vitamin D deficiency (37%), and strongyloidiasis (26%)” (p. 1770). Kouadio, Koffi, Attoh-Toure, Kamigaki, & Oshitani (2009) describe how measles and rubella – both of which are diseases for which there is a vaccine – broke out in refugee camps in Côte d’Ivoire, and they cite low vaccination rates, overcrowded living conditions, poor sanitation, and limited access to clean water as contributing to the spread of infectious disease within displaced populations.

Yet the health concerns affecting displaced populations cannot be considered in isolation from the context in which they lived prior to displacement. It is important to consider their pre-flight, flight, and post-flight circumstances and health issues because, as Carballo & Nerukar (2001) argue, “migrants moving because of poverty arrive with health profiles typical of those in their previous surroundings. Poverty breeds diseases of poverty no matter where or when it exists” (p. 559). Carballo & Nerukar's claim that displaced populations are at particular risk of contracting ‘diseases of poverty’ such as TB is echoed by S. L. Thomas et al. (2008), who refer to a disease *profile* of poverty among displaced populations, which is shaped by “persistent, emerging, and re-emerging infectious diseases, malnutrition, and war-related injuries” (p. 202). While the distinction between individual diseases of poverty and a disease profile of poverty may

appear inconsequential, it is important because it highlights the cyclical nature of poverty and interrelatedness of certain infectious and chronic diseases. The common thread connecting the above studies is that the authors (with the one exception of Chaves et al., 2009) acknowledge the importance of social and environmental conditions in contributing to the spread of disease among displaced populations.

Chronic Illness

While Harris & Zwar (2005) claim that rates of chronic illness (such as hypertension, heart disease and diabetes) among refugees may be comparable to non-refugees, displacement can greatly impact the severity and course of chronic conditions (S. L. Thomas et al., 2008). For example, the acute stress endured by some refugees may heighten conditions such as depression and cardiovascular disease (Cohen, Janicki-Deverts, & Miller, 2007); food insecurity can exacerbate nutrition related conditions such as diabetes; and refugees taking prescription medication may have their regimen interrupted or stopped altogether (e.g. while fleeing their country, if they are unable to afford medication, etc.). Refugees' access to medical treatment for chronic conditions generates a complex set of issues related to health equity (Leaning, Spiegel, & Crisp, 2011), and humanitarian agencies' limited resources make it a zero-sum equation in some settings, where refugees who are prioritized receive support for their treatment, and the remaining refugees do not (UNHCR, 2011e).

Sexual Health

Conflict and displacement can cause profound changes in social structure and gender roles (Horn, 2010); on a population level this can affect fertility rates and maternal health, while individual implications may include changes in family planning, unsafe abortions, and increased rates of sexually transmitted infections (STIs) (S. L. Thomas et al., 2008). SGBV is also a

concern for some refugees; in Malaysia, for example, “women refugees and asylum-seekers are often the targets of violence, including sexual or gender-based violence. They have little protection against such violence, with minimal access to lawyers, medical treatment, safe houses and other necessary support,” (Amnesty International, 2010). Al-Sharmani (2010) calls attention to the global scope of the problem, stating:

Refugee women and girls are exposed to multiple forms of violence. The displacement resulting from living in places of armed conflicts subjects women and girls to murder, rape, sexual slavery, enforced prostitution, trafficking, abject poverty and to a higher risk of violence inflicted by an intimate partner, family relatives or community members. (p. 1)

Yet while Al-Sharmani (2010) and other researchers acknowledge that SGBV is a serious health concern for refugees and displaced women (Buscher & Heller, 2010; Kerimova et al., 2003; Krause-Vilmar & Chaffin, 2011), the prevalence of SGBV varies greatly depending on geographic location and circumstances. For example, one survey found the prevalence of reported rape among female Kosovar-Albanian IDPs to be 4.3% (Hynes & Lopes-Cardozo, 2000), while a different study in Azerbaijan found that 21% of female IDPs interviewed reported that they had been raped within the last year (Kerimova et al., 2003).

Obtaining accurate data on prevalence of SGBV among refugees can be difficult, as SGBV survivors may not report incidents due to stigma, the re-victimization that can occur during the reporting process, or the inefficacy of the legal system in bringing perpetrators to justice (Hynes & Lopes-Cardozo, 2000). Lack of accurate data on SGBV is problematic for UNHCR and other aid organizations, because without a rough estimate of SGBV prevalence it is challenging to plan prevention strategies and offer treatment for potential health complications (e.g. unwanted pregnancy, injury, STIs, and a range of psychological issues) (Hynes & Lopes-Cardozo, 2000).

Psychological Health

Psychological issues – often stemming from circumstances involving trauma, stress, violence, detention, and loss – pose a serious health concern for refugees (Carballo & Nerukar, 2001; Khawaja et al., 2008; McKeary & Newbold, 2010; S. L. Thomas et al., 2008). While post-traumatic stress disorder, depression, somatization, and existential dilemmas are among the most common psychological issues associated with displacement (S. L. Thomas & S. D. Thomas, 2004), Carballo & Nerukar (2001) also point out that the trauma and exclusion experienced by immigrants may, “increase their risk of behaviors that, in turn, increases their susceptibility to all diseases” (p. 560).

One example of such behaviour is substance use; Streel & Schilperoord (2010) claim that for refugees, “the use of alcohol and psychoactive substances can be both an additional stressor and a consequence of stressors” (p. 268), the implications of which may include liver cirrhosis, accidental injuries, and risky sexual behaviour. It is difficult to know whether substance abuse affects refugees more or less than other sub-populations, as patterns of substance use among refugees are highly context dependent (i.e. there is variation depending on availability of substances, religious beliefs etc.). Substance use is highlighted here because it is one of many known issues that can be a health concern for individual refugees, and Streel & Schilperoord's description of substance use as both a stressor and consequence of stressors implies that it does not exist in isolation, but is part of a broader ‘web’ of issues affecting refugees, an issue discussed at length in Chapter 9 of this dissertation.

Health Care

The health-seeking behaviour of refugees is greatly influenced by their ability to access and pay for medical services, and the formidable barriers that prevent some refugees from doing

this mean that inability to receive treatment is itself a critical health concern (McKeary & Newbold, 2010; UNHCR, 2009). Limited services intended for refugees present one problem: in Malaysia, for example, UNHCR supports health services for refugees, but “lack of resources also prevented the expansion of health services beyond the existing two clinics, which serve 16,000 of the 90,000 persons of concern,” (UNHCR, 2011e, p. 270). Limited services are not the only issue, however, because refugees in Malaysia (and many other countries) are technically allowed to access national health services.

Asgary & Segar (2011) explored barriers to health care experienced by asylum seekers in the United States, and found the main barriers were perceived discrimination, linguistic issues, and difficulty accessing non-emergency care; they also noted that asylum seekers were very concerned with their health-care bills and worried they would be arrested or deported if they were unable to pay. For some refugees, accessing medical treatment is thus a risky, expensive, challenging endeavour and, “as long as basic needs such as food security, shelter, and employment remain unmet, asylum seekers may not see health care as an immediate priority. In other words, considering cost-benefit ratios, they view the expense of care with low perceived benefit,” (Asgary & Segar, 2011, p. 517). In the case of infectious diseases, delaying or being unable to access medical treatment may have serious health implications, not only for the refugee who is ill, but also for the broader refugee community and host population.

Injuries and Violence

According to WHO, “Injuries – resulting from traffic collisions, drowning, poisoning, falls or burns - and violence - from assault, self-inflicted violence or acts of war – kill more than five million people worldwide annually and cause harm to millions more” (WHO, 2014).

Compared to high-income countries, low and middle income countries have disproportionately

high rates of injury-related deaths (Hofman, Primack, Keusch, & Hrynkow, 2005), and as Hyder, Ghaffar, Masud, Bachani, & Nasir (2009) assert, injuries “have an even greater impact on loss of life in vulnerable populations” (p. 888).

Workplace related injuries are a particular risk for refugees, because in some countries, refugees have no legal right to work (Amnesty International, 2010), and even in the countries where refugees are legally entitled to work (e.g. South Africa) (Landau, 2006), high rates of violent crime and xenophobia can make joining the formal labour market difficult and dangerous (Krause-Vilmar & Chaffin, 2011). Regardless of whether they are legally entitled to work, many urban refugees join the informal labour market (UNHCR, 2009) in order to support themselves; for example, (Amnesty International, 2010) found that many refugees in Malaysia, “were working for meagre wages, experienced ill-treatment at the hands of their employers, had wages withheld arbitrarily or worked in conditions that were dirty, degrading and dangerous” (p. 16). Inadequate training and safety protocols can increase refugees’ risk of being injured at work (Carballo & Nerukar, 2001), and if they are injured while working illegally their employer may not provide compensation. This may impede their ability to afford medical treatment and leave refugees struggling to manage their immediate injuries and concomitant, long-term consequences.

Refugee Health and SDH

Although scholars have identified the health issues outlined above as being of concern to refugee populations, the susceptibility of individual refugees to illness and disease is greatly influenced by context specific SDH. That said, I was able to identify only one published academic study that specifically focuses on SDH among a displaced population. Roberts et al., (2009) conducted 21 qualitative interviews with IDPs in Uganda, and identified key social

determinants of health affecting their study population as being: traumatic events (which led to ‘over thinking’ and madness), overcrowding, poverty, and losing their land (whereby inadequate income and food led to physical health problems, and worry stemming from these issues led to psychological problems). While the study by Roberts et al. is highly relevant to the research I conducted, there are key differences, most notably that it involved camp-based IDPs in Africa (as opposed to urban refugees in Asia).

These differences are crucial, because while it is important to be cognizant of the health issues affecting refugee populations on a global scale, the SDH approach is predicated on the fact that socioeconomic and political context largely defines how structural determinants of health inequities and social determinants of health affect people in various settings. This is particularly true given the heterogeneity of camp-based and urban refugee populations, and as urbanization is itself a determinant of health (Global Research Network on Urban Health Equity, 2010; Vlahov et al., 2007), the urbanization of the global refugee population is an important factor to consider. As such, a primary consideration when designing and undertaking health research with refugees needs to be the specific geographic, socioeconomic and political context in which it is conducted.

Conclusion

This chapter used the CSDH model as the basis for defining the SDH approach and evaluating the strengths and limitations of the current evidence base on SDH from a global perspective. I briefly discussed the distinct policy implications of the SDH approach, and noted the increasing extent to which proponents of the SDH approach are calling for evidence-based action to address health inequities. I then highlighted key debates taking place in the study of forced migration, and reviewed relevant literature pertaining to health and social determinants of health among forced migrants. In doing so I identified a lacuna of academically sound, publicly

available information on the subject with which this research is concerned (SDH among urban refugees in general, and in particular in Malaysia). The research I undertook, which serves as the basis for this dissertation, addresses this specific gap and, more generally, contributes to the nascent evidence base on SDH in the context of populations experiencing forced migration (Gifford et al., 2007; Roberts et al., 2009). The following chapter provides information regarding the participant population (Rohingya refugees), and the Myanmar and Malaysian contexts in which they live.

Chapter 3: The Rohingya, Myanmar and Malaysia: Historical and Present-day Context

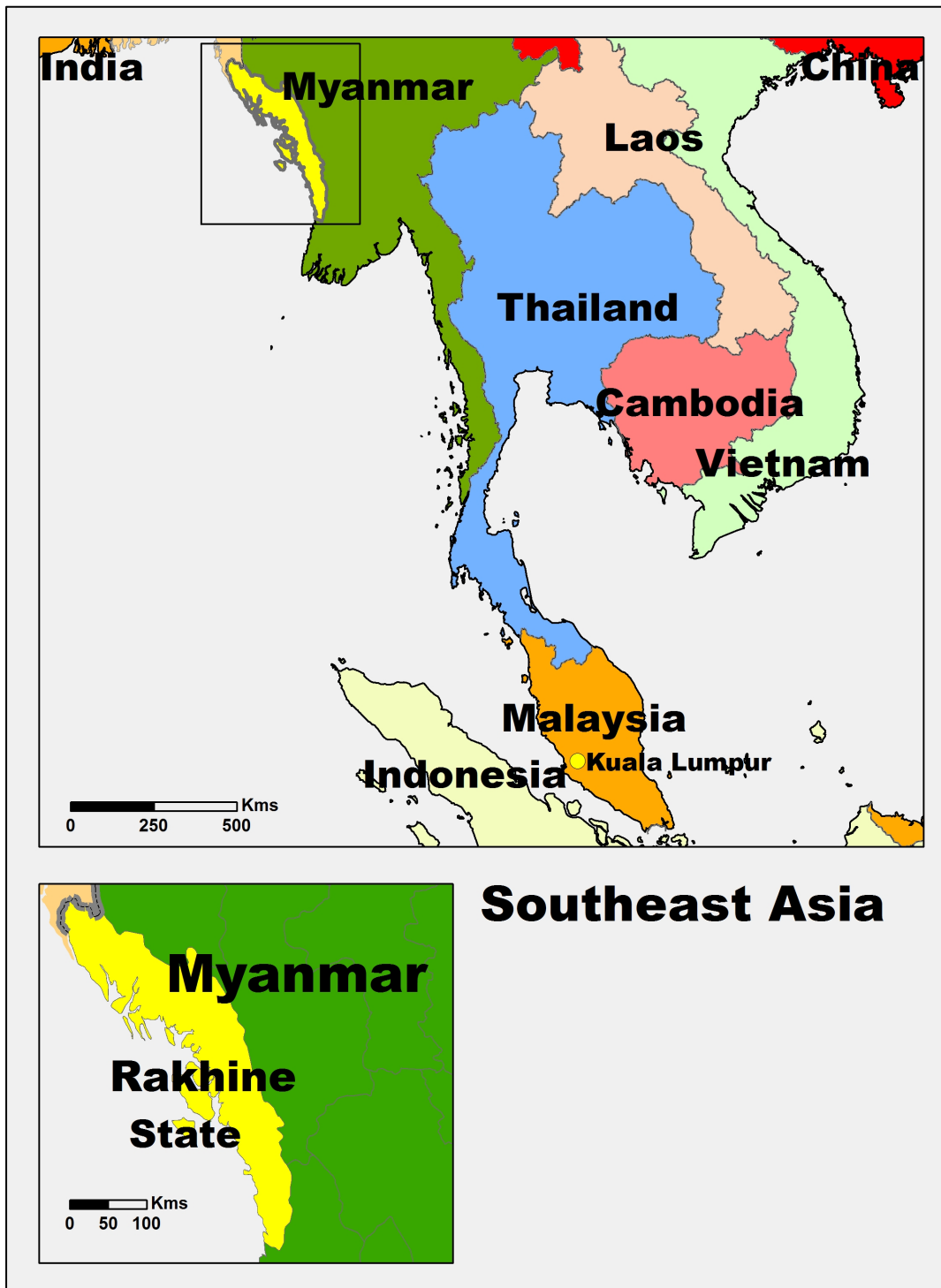
Introduction

This chapter provides an overview of the historical and present-day situation in Myanmar, and the context surrounding those who flee to Malaysia. I begin with a brief caveat regarding the limited scope and depth of the following section, as the sensitive and complex nature of issues surrounding the history of the Rohingya people – compounded by a prohibitive lack of impartial, accessible information – presented numerous challenges in constructing a well-informed, balanced review of the literature. Specifically, one major challenge stemmed from the discourse surrounding the historical and present-day status of the Rohingya people, which is discordant and, in some instances, vitriolic in nature (Smith, 1995). As the specific focus of this study is the lives and health of Rohingya women in Malaysia, I have therefore limited this section to a concise overview of the key debates surrounding the historical and present-day situation in Myanmar.

I begin by presenting basic information on the country of Myanmar, and an overview of key events in Myanmar's recent history. I then discuss the history of Rakhine State and explore the historical and present-day situation of the Rohingya people. I briefly review the current state of affairs in Myanmar – focusing particularly on tension between the country's democratization and the ongoing persecution of the Rohingya people – and end the chapter with a brief overview of the context surrounding asylum seekers who flee to Malaysia.

Geography & Demographics

Figure 1: Map of South East Asia



(Brendle-Moczuk, 2013)

Myanmar: Location, Language, and Religion

Located in South East Asia, the Republic of the Union of Myanmar borders the Bay of Bengal, the Andaman Sea, and the countries of Bangladesh, India, China, Laos and Thailand (CIA, 2013). Myanmar's population is estimated to be 55 million (CIA, 2013; Rogers, 2013) and is made up of eight recognized 'national races': the Burman majority (an estimated 68% of the population) (CIA, 2013), and the Chin, Kachin, Karen, Karenni, Mon, Rakhine and Shan (HRW, 2013a; Ullah, 2011). Most of the population (89%) is Buddhist and speaks Burmese, the official language of Myanmar, though hundreds of languages and dialects are spoken among ethnic minority groups, and nearly 10% of the population adhere to religions other than Buddhism (an estimated 4% are Christian, 4% are Muslim, and 1% are animist) (CIA, 2013; Ullah, 2011).

Natural Resources, Trade, and Development

Once known as the 'rice bowl' of Asia for its strong economy and food production (Rogers, 2013), Myanmar is now considered amongst the least developed countries in the world. Over 32% of the population is estimated to be living below the poverty line (CIA, 2013), and in 2012, Myanmar ranked 149th (of 187 countries) on the human development index (UNDP, 2013).¹⁸ That such pervasive and widespread poverty exists despite the country's abundance of natural resources (such as petroleum, timber, tin, lead, coal, and hydropower) (CIA, 2013) can largely be attributed to the fact that extractive resources, "are concentrated in a few hands...the exploitation of natural resources does not benefit the population at large" (CIA, 2013).

Since 1988, international resource extraction, trade, and investment in Myanmar have been limited by sanctions imposed by the U.S. and other governments, with the intent of inciting

¹⁸ The human development index is a way of assessing the development of countries around the world; the ranking is based on three key dimensions (health, education, and living conditions) measured by four indicators (life expectancy at birth; mean years of schooling; expected years of schooling; and gross national income per capita).

reform within the military junta and expressing, “disapproval of the regime’s objectionable behavior, [and] giving moral support to the democratic opposition” (Martin & Mix, 2011; Seekins, 2005, p. 440). However following the introduction of a parliamentary government in 2011 (discussed in detail later in this chapter) (CIA, 2013) and a subsequent series of democratic reforms (including the release of political prisoners, ceasefire talks with ethnic minorities, etc.) (Rogers, 2013), relations between Myanmar and other countries have improved significantly, and in 2012-2013 dozens of states and regional bodies (including the U.S., European Union [EU], and Canada) lifted sanctions against Myanmar (BBC, 2013a; The White House, 2012).

Yet human rights organizations have voiced concern over the potential consequences of lifting sanctions when the democratization and stabilization of Myanmar is still nascent (Ward, 2013): these concerns have a strong basis in a number of reports and news pieces documenting ongoing issues in Myanmar, including: human rights violations, environmental degradation due to rapid development and resource extraction, blocking of humanitarian assistance, and continued violence and “mass atrocities” in Rakhine State (Al-Mahmood, 2012; Brinham, 2012; HRW, 2013a; International Federation for Human Rights [INFR], 2013).

A Note on Terminology

While lack of census data makes it difficult to know the exact number of Rohingya people, a recent estimate suggests that the diaspora of Rohingya in Bangladesh, Malaysia, Pakistan, the Arab states of the Persian Gulf, and Thailand far exceed the estimated one million Rohingya who are believed to remain in Myanmar (Kiragu et al., 2011). Approximately 700,000 of the Rohingya people living in Myanmar live in Rakhine State (Kiragu et al., 2011; ERT, 2010), which is located along the coast of western Myanmar and is one of the poorest regions of the country (HRW, 2013a).

Formerly known as Arakan State, it was renamed Rakhine State by the military junta in 1989 and the ethnic majority became referred to as Rakhine people; some citizens in Myanmar, as well as organizations such as Human Rights Watch, have not accepted this name change and continue to refer to the state as Arakan, and the state's officially designated majority (Ullah, 2011) as Buddhist Arakan. In accordance with my decision to adopt the terminology used by the United Nations, in this document I refer to the state as Rakhine State and the Buddhist majority as Rakhine. In 1989, the military government also changed the name of the country from Burma to the Union of Myanmar, and in March 2011 it became Republic of the Union of Myanmar (widely referred to as Myanmar) (UN 2013). While some people and states have also chosen to contest this name change because it was instituted by an illegitimate military junta, the United Nations officially utilizes the name Myanmar, and it is increasingly being adopted by other institutions and states in international discourse (Banyon, 2013).

Considering the Rohingya in the Broader Context of Myanmar

Persecution of the Rohingya has been (and continues to be) embedded in the broader civil conflict that has plagued Myanmar for decades. While in depth discussion of this is beyond the scope of this dissertation (cf. Murphy, 2013; Rogers, 2013; Walton, 2008), it is important to acknowledge that the Rohingya are not the only ethnic group who face persecution in Myanmar: for decades, ethnic groups such as the Chin, Kachin, Karen, and Shan have been subjected to violence and persecution such as forced labor and relocation, systematic rape, and arbitrary killings at the hands of the military regime¹⁹ (Cheng Guan, 2007; Rogers, 2013). The situation in

¹⁹ There are various factions that make up Myanmar's extended military. Among the most significant are the Myanmar Armed Forces, known as the Tatmadaw, which Macdonald (2013) describes as "the central political actor in Myanmar for the last half-century" (p.21), and Nay-Sat Kut-kwey Ye (known as Nasaka), the "interagency border guard force comprising military, police, immigration, and customs" (HRW,

Myanmar remains dire for some ethnic minority groups,²⁰ and hundreds of thousands of people from various ethnic minorities have fled to neighbouring countries. While scholars and historians have identified some root causes of the persecution faced by ethnic minority groups in Myanmar,²¹ each group has its own unique history, and the trajectory of their engagement with the military regime varies significantly (Cheng Guan, 2007; Rogers, 2013).

The Rakhine people who have been engaged in the recent conflict with the Rohingya are also an ethnic minority, and according to Rogers (2013) they too are “suffering at the hands of the regime...they have common cause with the Rohingyas, and share a common goal to remove the regime and restore democracy,” (last page, Chapter 6). Yet there are key factors differentiating the situation of the Rohingya from other ethnic minorities, the most significant being that all of the ethnic groups cited above (Rakhine, Chin, Kachin, Karen, Mon, and Shan) are officially recognized as belonging to Myanmar’s 135 ethnic groups and are thus entitled to citizenship, whereas the Rohingya are not a recognized ethnic group and are not granted citizenship, rendering them stateless (HRW, 2012a, 2013a; Mathieson, 2009).

Other factors differentiate the situation of the Rohingya from other ethnic minorities: not only have “successive military governments harbored a uniquely vicious aversion to the Rohingya,” (Mathieson, 2009, p. 88) but this is compounded by the fact that Burman and Myanmar minority groups also vilify the Rohingya (HRW, 2012a). Additionally, while the

2013a, p.28) which plays an instrumental role in enforcing policies pertaining to IDPs and those attempting to flee the country.

²⁰ See the article by Milbrandt (2012), which presents evidence to support the argument that the forced displacement of the Karen ethnic group amounts to genocide; and Sollom et al., (2011) which documents deleterious health conditions and human rights violations in Chin State.

²¹ One such cause dates back to the Japanese invasion of Burma during World War II: while ethnic minorities including the Karen, Karenni, Chin, Kachin and Rohingya fought alongside the British and Americans, the Burman initially aligned themselves with the Japanese and, as Rogers (2013) argues, “some of the seeds of today’s tensions between the Burman and non-Burman ethnic groups were sown during this period” (Chapter 1, para. 9).

government has not substantively addressed the root and proximate causes of the Rohingya situation (i.e. issues surrounding citizenship, religious freedom, etc.) (HRW, 2012a), other ethnic minorities have engaged in dialogue with the government, in some instances resulting in successfully implemented ceasefire agreements (Banki, 2009; Cheng Guan, 2007; Murphy, 2013).

Human Rights Watch (2013) also notes that the abuses against the Rohingya have historically been ‘different in character’ than those committed against other minority groups. Some of the armed ethnic groups, such as the Karen, had formidable armies, whereas in the case of the Rohingya, armed groups formed in the 1980’s (e.g. the Rohingya Solidarity Organization and the Arakan Rohingya Islamic Front), “never posed a serious threat to the Burmese military state, their principal target, nor to Burmese society” (HRW, 2013a, p. 140). The small number of armed insurgencies in Rakhine State over the past few decades, particularly those led by the Rohingya, have been limited in both size and effect (HRW, 2012a). Armed insurgencies have never garnered much support from the Muslim groups in Rakhine State, and thus the arguments the government and other groups who oppose the Rohingya employ to promulgate their views and policies on the Rohingya are rarely related to counterinsurgency (HRW, 2013a). The following sections expand upon the brief overview provided here to consider the historical and present-day circumstances of the Rohingya people in Myanmar.

Key Events in the History of Myanmar

Myanmar was a British colony from 1824 until the country gained independence in 1948 (Walton, 2008). Following independence, the country faced ongoing ethnic conflicts and political instability under the leadership of Prime Minister U Nu, and in 1962 Ne Win successfully executed a coup which brought the Burmese Socialist Party into power and marked

the start of military rule that would last decades (Ullah, 2011). Whereas Aung San – the former leader of the Burma Nationalist Army and, “the hero of the Burmese independence movement,” (Walton, 2008, p. 889; Murphy, 2013) – had been conciliatory with ethnic minorities and was committed to including them in the reformation of a newly independent Myanmar, Ne Win’s rule was characterized by his xenophobic stance on foreigners and ethnic minorities (M. Smith, 2013). As a result of his governance, Myanmar became isolated, its economy faltered, and the rights of minorities were increasingly violated (Cheng Guan, 2007; M. Smith, 2013).

Ne Win’s devastating economic policies and undemocratic, repressive rule led to disunity within the country, which came to a head in a series of violent events in 1988 (Cheng Guan, 2007; Smith, 2013). In March 1988, a fight between students in Yangon served as a catalyst for a series of mass pro-democracy demonstrations that garnered the participation of students, monks and members of all echelons of society (Watcher, 1989). According to Steinberg (1989), the root causes of the crisis that ensued were, “poor policies; mismanagement; arbitrary, capricious, and authoritarian rule; insensitivity to internal needs; violence; political arrogance; and deceit” (p. 185).

It was during the political turmoil of 1988 that Aung San Suu Kyi, daughter of General Aung San, began to emerge as Myanmar’s iconic pro-democracy leader, but both the Ne Win government and successive governments reacted strongly to Suu Kyi, restricting her freedom and participation in politics and confining her to house arrest for much of the next two decades (Cheng Guan, 2007; Rogers, 2013). Aung San Suu Kyi was released in 2010, the year that Myanmar held its first general election in 20 years (M. Smith, 2013). The 2010 election marked a turning point in the history of the country, transforming “Myanmar’s political landscape from a

military junta of exclusive jurisdiction within a closed system to that of a presidential republic with a parliamentary system characterized by multi-party elections” (Macdonald, 2013, p. 21).

Following the elections, power was transferred to a nominally civilian government led by Thein Sein, and under his leadership, the government has made notable advances towards democratization by allowing Aung San Suu Kyi to adopt an increasingly visible and influential political role, legalizing trade unions, releasing political prisoners, and holding successful bi-elections (Macdonald, 2013).²² There is, however, significant discordance between the purported democratization and demilitarization of the country and the ongoing violence in Rakhine State, some of which has allegedly been perpetrated by military personnel (HRW, 2012b), an issue which is taken up at the end of the chapter.

Historical Context: Rakhine State

The history of Rakhine State – and the Rohingya people who populate it – is largely contested, but historians and scholars have generally accepted a few key events. One is that Arakan was an independent state until it was invaded by Burman King Bowdawpaya in 1784 A.D. and annexed to the Burman kingdom (Euro Burma Office [EBO], 2009; HRW, 2012a; Smith, 1995; Yin, 2005). According to Smith, following this annexation over 20,000 ‘Arakanese nationalists’ fled to “British-controlled Bengal to ask for help and protection - and it was continuing fighting along the Naaf River border, which finally brought the British into Burma in the first Anglo-Burman War of 1824-25,” (p.3).

A second point widely accepted by scholars and historians is that Muslims inhabited Rakhine State hundreds (if not thousands) of years prior to Independence (EBO 2009; Yin, 2005; Yunus, 1994). Yin, for example, traces the presence of Arab Muslims as far back to 712 A.D.,

²² See Macdonald (2013) for an overview of Myanmar’s political situation following the 2010 elections.

while Yunus claims that between 1430 and 1638 nearly all rulers of Arakan were descendants of King Solaiman Shah, a converted Muslim. The Burmese often refer indiscriminately to Muslims in Myanmar as ‘Bengali’ (HRW, 2013a; Yin, 2005), yet there are a number of distinct Muslim groups in Myanmar, each with different ethnic and historical backgrounds (Minority Rights Group International [MRGI] 2008; Yin, 2005; Yunus, 1994).

In Rakhine State, there are two distinct Muslim groups. One is the Kaman (also sometimes called Arakanese Muslims or Myanmar Muslims), who speak Rakhine or Burmese language and share common customs with the Buddhist population; their lineage in Rakhine State has been traced back to 15th century, and a major distinguishing feature between the Kaman and other Muslim groups is that the Kaman are recognized and granted citizenship by the government of Myanmar (MRGI, 2008; Yunus, 1994). There is no agreement, however, surrounding the historical roots of the present-day Muslims who identify themselves as Rohingya, an issue discussed below.

The Rohingya People

“The Rohingyas. Bengali Muslims or Arakan Rohingyas?”

This heading is the title of a 2009 Briefing Paper prepared by the Euro Burma Office (EBO). While it could, on the surface, refer to questions surrounding the linguistic terminology used to identify the Rohingya, an in-depth reading of the question elicits more complex and contentious issues regarding the history of the Rohingya people, their genealogy, and their claim to citizenship in Myanmar. There are varying accounts of the origin of the term ‘Rohingya’: according to the EBO, “in the 1950’s, the name, ‘Rohingya’ began to be used by Arakan Muslims to denote Bengalis who had settled in Arakan before independence, in an effort to qualify for citizenship” (p.2).

The authors of the report also trace political use of the term ‘Rohingya’ to this time, claiming that it was used by key figures (including Prime Ministers U Nu and U Ba Swe) in reference to the Bengali population in Arakan. A. Chan (2005) concurs that the term ‘Rohingya’ was first introduced in the 1950’s. He claims it was first used by educated Bengalis living in Arakan, and by an MP in a newspaper article published in August 1951; however, he takes care to point out that the term “cannot be found in any historical source in any language before then” (p. 397).²³ This is contradicted by Buchanan (1799), who published an article that described some of the languages spoken in Burma; he wrote:

I shall now add three dialects, spoken in the Burma Empire, but evidently derived from the language of the Hindu nation. The first is that spoken by the Mohammedans [Muslims], who have long settled in Arakan, and who call themselves Rooinga, or natives of Arakan. (p.56)

Yin (2005) also claims the inception of the word Rohingya took place before the 20th century, and various articles and international non-governmental organization (NGO) reports include information supporting the long history of the Rohingya people in Rakhine State (HRW, 2012a; Ullah, 2011; Yin, 2005). Rohingya people themselves continue to state their historical claim in various forums; the following excerpt, for example, was taken from the website of the Arakan Rohingya National Organization (2011):

The Rohingya with bona fide historical roots in the region have evolved with distinct ethnic characteristics in Arakan from peoples of different ethnical backgrounds over the past several centuries. Genealogically Rohingya are Indo-Aryan descendants. Genetically they are an ethnic mix of Bengalis, Indians, Moghuls, Pathans, Arabs, Persians, Turks, Moors and central Asians, and have developed a separate culture and a mixed language. (para.19)

²³ It should be noted that A. Chan, a Rakhine professor based at Kanda University in Japan, is a staunchly anti-Rohingya scholar (see Eleven Myanmar, 2013); according to Al Jazeera (2013), he “is at the forefront of a body of quasi-academic material that denies the existence of the Rohingya race, claiming they are ‘a fabricated people.’”

Yin stresses that the Rohingya, “refute many Rakhines’ contention that they are the British era settlers and product of the British colonial expansion into contemporary Burmese territory. They consider themselves to be the natives of the Arakan” (p. 164-165).

According to Rogers (2013), however, many Myanmar citizens maintain that Rohingya people began arriving illegally from Bangladesh in the 19th century. Many people in Myanmar refuse to use the term Rohingya and deny that Rohingya people are a distinct ethnicity (referring to them instead as ‘Bengali’ or by the derogatory term ‘Kalar’), let alone their claim to be natives of Arakan (HRW, 2012a). As only certain ethnicities are entitled to Myanmar citizenship, denying the very existence of the Rohingya ethnicity is, arguably, an antecedent obstruction to the stateless Rohingya obtaining citizenship.

Issues of citizenship and identity are complicated by the fact that during the 1800’s, the British – who at that point oversaw Burma as a province of India – met their labor needs by moving people between East Bengal and Burma (Ullah, 2011). This – compounded by the fact that Muslims and Buddhists have lived on both sides of the Naaf river (which forms part of the border between Myanmar and Bangladesh) for over a thousand years – resulted in intermixing of people from the two regions, and as such, “the present cultural and ethnic distinctions - between Buddhists and Muslims or Rakhines and Rohingyas - were not always so clear’ (Smith, 1995, p. 3).

In recent years, as Aung San Suu Kyi has adopted an increasingly powerful and legitimate role in Myanmar politics, human rights activists and the Rohingya people hoped that she would emerge as a much needed advocate for Rohingya rights and protection. Suu Kyi has not, however, embraced such a role. Instead she has largely abstained from engaging in

discussion surrounding the Rohingya. In her few statements about the issue she has been cautious and conciliatory, but has not expressed support for the Rohingya, and in a rare published statement on the Rohingya made during an interview with The GlobalPost (2013), her spokesman Nyan Win is quoted as saying:

For example, in the Rakhine case, she [Aung San Suu Kyi] very rarely says anything about this. She says she was forced to speak about the Rohingya group...She believes, in Burma, there is no Rohingya ethnic group. It is a made-up name of the Bengali. So she can't say anything about Rohingya. But there is international pressure for her to speak about Rohingya. It's a problem. (para.10)

While Suu Kyi's failure to advocate on behalf of the Rohingyas is at variance with her longstanding role as Myanmar's leading human and minority rights advocate, some have posited that her silence is politically motivated, as to speak on behalf of the Rohingyas would cause enmity with her political allies and the large proportion of the Myanmar population who dislike the Rohingya people (Taylor & Wright, 2012).

Often cited as one of the most persecuted minorities in the world (Al Jazeera, 2012; Taylor & Wright, 2012), the Rohingya have been referred to as vulnerable (ERT, 2010), oppressed (Lewa, 2009), "virtually friendless" (Kiragu et al., 2011, p. 7), and forgotten (Refugees International, 2008). Yet Mathieson (2009) contests the use of the word forgotten, arguing, "the Rohingya are not a 'forgotten people,' as many headlines described them. They are more a foresworn people. No one wants them, even though the world is well aware of their predicament" (p. 90). Suu Kyi's silence is therefore not an isolated occurrence – rather, it is indicative of the more widespread failure of politicians and the international community at large to advocate on behalf of the Rohingya people. The following sections briefly explore key historical events in Myanmar and how they have shaped the present-day conflict that has caused so many Rohingya people to seek refuge in neighbouring countries.

Historical Causes of Tension Between the Rakhine and Rohingya People

The displacement and persecution of the Rohingya people in Myanmar is not a recent occurrence. Cycles of displacement can be traced back hundreds of years (Cheung, 2011), with major ‘waves’ of international displacement occurring as far back as 1784, when many Rohingya left for Bangladesh after Arakan was conquered and assimilated into Burma (Ullah, 2011).

Tension and conflict between the Arakan and Rohingya can be traced back at least as far as the 1940’s: the Arakan fought alongside the Japanese, who invaded Burma during World War II; the Rohingya, however, supported the British, and when the British retreated in 1942 many Rohingya fled to Bangladesh (HRW, 2013a; Ullah, 2011). Then, in 1947, a Mujahid rebellion demanded autonomy for Rohingya people, and while it failed to garner widespread support it generated pervasive distrust among some Rakhine people, who feared the development of a separate Muslim state (EBO, 2009; Mathieson, 2009).

Mathieson (2009) claims that while it is hard to pinpoint historical sources of the widespread contempt for the Rohingya, issues stemming from racism, the belief that Rohingya are ‘illegal’ migrants, and claims around national security form part of the context. Kyaw-Nyein & Prager-Nyein (2013) offer a differing opinion: they identify key points of tension amongst non-Rohingya in Myanmar as being the perceived proliferation of Islam in the country (as seen in an increasing number of mosques, amongst other things), coupled with declining effort amongst Muslim people to integrate into the country. Kyaw-Nyein & Prager-Nyein’s strongly articulated argument offers a more balanced perspective than most contributions to the polarized discourse surrounding the Rohingya in Myanmar. They claim that by oversimplifying the issues surrounding the Rohingya, and adopting, “a uniform conflict narrative that stigmatized and stereotyped the conflicting parties,” the international media, NGOs, and activists have:

Failed to pay attention to underlying causes and the social, economic, historical and political contexts, and have instead relied on the snapshot impressions of advocates and activists. By doing so, it has become nearly impossible for the international public to understand the conflicts as anything other than an expression of primordial hatred or a clash of cultures. (para.13)

Their argument has parallels with the harsh criticism that has been levied at the humanitarian and media response to the Rwandan genocide (which, scholars have argued, portrayed a reductionist, depoliticized scenario of ethnic hatred and tribal warfare taking place in a far-flung ‘failed state’) (Melvern, 2001; Schimmel, 2011). Roots of the Rwandan genocide can, in part, be traced to the disruption and reconfiguration of social order that took place during and after colonialism (Hintjens, 1999), an argument that is also pertinent to the current situation in Myanmar. Murphy (2013) cites the legacy of colonialism as a root cause of present-day conflict and displacement in Myanmar. He notes that the British forcibly divided Burma along ethnic and religious lines, whereas before social identity had been predicated more on, “position in mandala-hierarchies, class and place of residence” (p.68), and he references “the incubation of strong xenophobia under British rule, which likely served the function of providing alternative foci for anti-colonial sentiments,” (Murphy, 2013, p. 68).

Following the 1962 coup in which Ne Win and the Burmese Socialist Party came to power (Ullah, 2011), Rohingya people in Myanmar were “systematically denied their civil, political, economic, and social human rights” (Rahman, p. 234), and in 1978 the government initiated a violent pre-census registration campaign known as ‘Naga Min (Dragon King)’ to identify and expel ‘illegal foreigners’ in the country, as a result of which over 200,000 Rohingya fled to Bangladesh (Cheung, 2011; HRW, 2012a; Rahman, 2010; Ullah, 2011). The huge influx of Rohingya from Myanmar into Bangladesh caused tension between the two countries, and the vast majority of the Rohingya were repatriated – sometimes forcibly – to Myanmar (Cheung,

2011; Rahman, 2010).²⁴ An amended Myanmar Citizenship Law was instituted in 1982, and it marked a decisive moment for the Rohingya, as they were excluded from the list of recognized national ethnic groups, and therefore rendered stateless (Cheung, 2011; ERT 2012; Rahman, 2010; Ullah, 2011). The repercussions of the 1982 law were long-lasting, as it “formed the legal basis for arbitrary and discriminatory treatment against the Rohingya” (Brinham, 2012, p.40) which continues today.

Persecution of Rohingya in Present-day Rakhine State

The longstanding persecution and denial of basic human rights of the Rohingya in Myanmar have been well documented by international NGOs, scholars, and the media (cf. Al Jazeera, 2012; Irish Centre for Human Rights, 2010; Kiragu et al., 2011; Lewa, 2009; Rogers, 2013). While Rohingya people in Rakhine State have faced restrictions and persecution for decades, the situation worsened after conflict between the Rakhine and Rohingya flared up in May, 2012, when Rohingya men allegedly raped and murdered a Rakhine woman (HRW, 2012a, 2013). Six days later, Rakhine villagers stopped a bus in Toungop town and killed ten Muslims on board; tensions quickly escalated between the two groups, prompting widespread rioting, looting, arson and the internal displacement of over 125,000 Rohingya and other Muslim people (HRW, 2013a).

When conflicts escalated again in October 2012, both the media and international NGOs reported that rather than the spontaneous attacks that had occurred previously, the violence appeared to be, “a coordinated campaign to forcibly relocate or remove the state’s Muslims”

²⁴ A similar occurrence happened in 1991/1992, when over 250,000 Rohingya people fled to Bangladesh; again, the vast majority were repatriated, though it is estimated that about 29,000 of those who arrived in 1991/1992 remain in Bangladesh (ERT, 2012). In addition, over 200,000 undocumented Rohingya in Bangladesh are considered people of concern by UNHCR. The situation for Rohingya refugees in Bangladesh is protracted, complex, and dire; amongst other hardships, they have limited protection, rights, freedoms, access to humanitarian aid, or durable solutions (Kiragu et al., 2011).

(HRW, 2013a, p. 158; Szep & Marshall, 2012). It was reported that in the worst attack, more than 70 Rohingya were massacred in Mrauk-U Township, where there were, “28 children who were hacked to death, including 13 under age 5” (HRW, 2013, p.10). Violence was perpetrated by both Rakhine and Rohingya people, and members of both groups were injured, killed, and displaced (HRW, 2012a). Yet while the majority of those killed and displaced were Rohingya, it has been noted that the Rakhine received more government assistance; one example of this is Mrauk-U township, where Human Rights Watch interviewed, “displaced Arakanese Buddhists, who had adequate shelter, food, water, sanitation, and freedom of movement, and nearby displaced Rohingya, who had very little food, inadequate shelter, and inadequate medical care” (HRW, 2013a).

In March of 2013, nearly one year after the initial incident, it is estimated that over 100 Muslims were wounded and killed in another incident in Meiktila after an alleged disagreement between a Muslim shop owner and Buddhist patron; this was the first major attack to occur outside Rakhine State, and it came in the wake of, “weeks of incitement through anti-Muslim sermons by members of the Buddhist monkhood,” (HRW, 2013a, p. 17; Integrated Regional Information Networks, 2013). The violence that occurred in 2012-2013 is set against a backdrop of longstanding human rights violations committed against the Rohingya people in Rakhine State. These include, but are not limited to, “restrictions on freedom of movement, marriage, education, employment and economic livelihood, land and property ownership, freedom of religion, and other basic facets of everyday life” (HRW, 2013a, p.77), which are briefly described below.

Restricted movement. The movement of Rohingya people in and around Rakhine State is highly restricted, and in many cases Rohingya people are prevented from travelling outside

their villages (HRW, 2012a, 2013). Since the conflict in 2012-2013, tens of thousands of Rohingya people have been confined to IDP camps, and while foreign media and humanitarian access to the camps is limited, a journalist writing for a Canadian newspaper gained access in May 2013 and described one camp as: “a sprawling, guarded prison,” where “conditions range from rudimentary to deplorable. Unable to leave, few people can work. Nearly every camp reeks of overflowing latrines” (Otis, 2013).

The restricted movement of Rohingya people in Rakhine State, “severely impedes their already limited access to employment, education, health and trade. Rohingya who leave Myanmar are denied the right to return; their names are struck off family lists and they face long-term imprisonment if captured upon re-entry,” (ERT, 2012, p.8). Inability to move freely thus compounds the multitude of other rights violations affecting the Rohingya in Rakhine State, and the situation following the 2012-2013 conflicts is particularly dire; as Brinhamm (2012) asserts, “cut off from their livelihoods and sources of income, unable to access markets, hospitals and schools, and without access to relief aid, hundreds of thousands of Rohingya are facing disaster” (p.40).

Restrictions on marriage and children. A local order in Rakhine State stipulates that Muslims must apply for a permit before marrying – obtaining one requires payment (in the form of a fee and sometimes additional bribes) and patience, as it can take a few years for a permit to be granted. According to Lewa (2009) a local order also prohibits unmarried couples from living together or having sexual contact, acts which are “punishable by up to 10 years imprisonment” (p. 32). In 2013, the government in Rakhine State announced renewed implementation of a decades-old regulation that restricts the number of children married Rohingya couples can have to two (HRW, 2013b); one of the few anti-Rohingya policies to elicit a comment from Aung San

Suu Kyi, who reportedly said that “it is not good to have such discrimination. And it is not in line with human rights either,” (BBC, 2013b). To phrase it more strongly, it is essentially a measure to control the Rohingya population growth, one that can have serious health implications for Rohingya women (e.g. unsafe abortions, hiding or giving children away, etc.) (HRW, 2013b).

Restricted education and health care. Rohingya children in Rakhine State have had their right to education, “systematically violated” for years, and access to education worsened considerably after the violence in 2012-2013 (HRW, 2013a, p.81). The reasons for this include inability of the government and/or schools to ensure the safety and security of Rohingya students; school closures; policies against hiring Rohingya teachers; and failure to provide education in the Rohingya language (HRW, 2013a; Lewa, 2009).

Similar restrictions affect access to health care: Rohingya people need travel permits even in medical emergencies, which limits their access to treatment facilities; there is a lack of Rohingya medical personnel; and since the violence in 2012, Rohingya people have had limited access to government hospitals (HRW, 2013a; Lewa, 2009). Compounding these issues are the limitations and challenges facing international NGOs attempting to provide medical care to people in Rakhine State; even Médecins sans Frontières/Doctors Without Borders (MSF) – an international NGO renowned for providing medical services in insecure and conflict prone regions in the world – was forced to drastically cut back their services in Rakhine State due to threats and intimidation made by Rakhine people, stemming from what they perceived to be a pro-Rohingya bias among international NGOs (MSF 2012, 2013).

Genocide, crimes against humanity and ethnic cleansing. The quantity of media coverage surrounding the Rohingya has increased as the recent conflict escalated, and the

discourse – particularly among media and international humanitarian organizations – notably extended beyond descriptions of ‘communal violence’ to include more inculpatory terms. Of particular note is a (2013) investigative documentary by Al Jazeera called, ‘The Hidden Genocide,’ which outlines persecution of the Rohingya in Rakhine State, and a Human Rights Watch (2013a) report entitled, “‘All You Can Do is Pray’ Crimes Against Humanity and Ethnic Cleansing of Rohingya Muslims in Burma’s Arakan State.’ While there are serious legal and political implications to using the term genocide, William Schabas, former President of the International Association of Genocide Scholars, said in an interview:

In the case of the Rohingya that we’re moving into a zone where the word can be used. When you see measures preventing births, trying to deny the identity of the people, um, hoping to see that they really are eventually, that they no longer exist, denying their history, denying the legitimacy of the right to live where they live, these are all warning signs that mean that it’s not frivolous to envisage the use of the term genocide. (Al Jazeera, 2013, 45 minutes 56 seconds)

Members of the current Myanmar government object to the use of such terminology. One MP in Rakhine State, Aung Mya Kyaw, rejected the claims made in a recent Human Rights Watch (2013a) report, stating, “the violence did not occur racially or religiously. It happened between those who want to seize the territory and those who want to defend that territory. Ethnic cleansing is not the matter of that issue,” and a spokesperson for the Office of the President dismissed the same report as groundless and one-sided (The Nation, 2013). It is not surprising that the government opposes the use of terms such as genocide and ethnic cleansing, as they increasingly draw international attention to the situation of the Rohingya, and threaten to undermine international perception of the government’s reformation.

Myanmar's Reformation and Present-day Political Situation

In response to the democratization process taking place in Myanmar, Western countries and regional bodies such as the U.S., Canada and EU are increasingly investing in the country and engaging in dialogue with the President and Aung San Suu Kyi (BBC, 2013a; The White House, 2012; Ward, 2013). Yet the ongoing conflict in Rakhine State is in stark contrast to the country's purported stabilization and democratization, and NGOs have accused the international community of prioritizing trade and investment rather than attempting to address the ongoing civil conflict (IFHR, 2013); as Brinham (2012) argues, the "failure of the international community to use their leverage over the Burmese state to ensure protection and recognise the rights of Rohingya and other vulnerable populations in Burma could have dire consequences for both democracy and stability in Burma" (p. 6).

The discordance between Myanmar's reformation and the formidable issues that continue to plague the country is exemplified in the statement made by current President Thein Sein shortly after the 2012 conflict in Rakhine State began, in which he claimed the only way to resolve the 'Rohingya issue' would be to expel the Rohingya from the country, sending them to third countries or UNHCR controlled camps (Al-Mahmood, 2012); UNHCR High Commissioner Antonio Guterres quickly rebuffed the suggestion, stating: "as a refugee agency we do not usually participate in creating refugees" (HRW, 2012a, p. 7). Recent public dialogue such as this between key political and humanitarian leaders is indicative of the uncertainty surrounding the future of the Rohingya. What is clear is that despite the commendable progress towards democratization made over the past two years, Myanmar has failed to take tangible steps towards finding a long-term solution for the Rohingya people. The consequences of this are significant,

as unless the situation improves for Rohingya people in Myanmar they will continue to put their lives at risk on perilous boat journeys to neighbouring countries in search of safety.

Fleeing Myanmar

The longstanding and escalating persecution of Rohingya people in Myanmar has led hundreds of thousands of Rohingya to seek refuge in neighbouring countries (Ullah, 2011), and they continue to do so in record numbers: UNHCR estimated that between June 2012 and May 2013 over 27,000 people left the Bay of Bengal (most from Rakhine State) on boats bound for various countries in Asia (Edwards, 2013). Yet many Rohingya people fleeing persecution in Myanmar face ongoing and formidable risks in their search for refuge, including detention, human trafficking, deportation, and severe poverty (ERT, 2010); the following section provides an overview of the conditions facing those who seek asylum in Malaysia.

The Malaysian Refugee Context

Rohingya Refugees in Malaysia

In the Malaysian context, the Rohingya are numerically significant in terms of the ethnic makeup of the refugee and asylum seeker population. Of the 131,387 refugees and asylum seekers from Myanmar registered with UNHCR as of December 2013, approximately 52,152 were Chin; 32,611 were Rohingya; 11,713 Myanmar Muslim; 7,940 Rakhine; 3,647 Burmese & Bamar; 5,374 Mon; 5,437 Kachin and other ethnicities from Myanmar) (UNHCR, 2013b). While women make up the minority of refugees in Malaysia (30%) (UNHCR, 2013b), an increasing number of women and children have reportedly joined the recent boat exodus of Rohingya from Myanmar (Corben, 2013). There is limited published analysis on the unequal gender distribution of refugees in Malaysia; however, during interviews I conducted with male Rohingya refugees for UNHCR, some of them explained that their family had only been able to afford to smuggle

one person to Malaysia, so they came first with the intention of earning money to send to their family in Myanmar (a claim echoed in a 2010 report on Rohingya refugees in Malaysia) (ERT, 2010) and/or of finding employment and then bringing their family over when they could afford.

While this may partially explain the disproportionate number of male refugees in Malaysia, it is clearly part of a complex set of push and pull factors influencing migratory patterns. For example, Ullah (2011) found that push factors influencing the Rohingya to flee Myanmar – many of which were discussed earlier in the chapter – included, “killing, forced labor, rape or sexual abuse, denial of citizenship, and physical abuse,” (p.148). Pull factors have, more generally, been recognized to include improved living conditions, greater economic opportunity, and better access to services such as education and medical care etc. (Gushulak & MacPherson, 2011) (though it could be argued that for the Rohingya, their lack of access to these in the first place is a push factor). Yet asylum seekers fleeing Myanmar increasingly find themselves detained in inhumane conditions and embroiled in human trafficking syndicates in Thailand (Marshall, Szep & Mohammed, 2013; Reuters, 2013), and for many of those who reach Malaysia, the combination of factors that drew them there are incongruent with the harsh realities they face upon arrival, for the reasons outlined below.

Overview of the Malaysian Context

Malaysia has a population of nearly 30 million (Department of Statistics Malaysia, 2013), and in addition to refugees registered with UNHCR, there are an estimated 2.2 million regular migrant workers and 2.2 million irregular migrant workers²⁵ (AI, 2010). The Malaysian

²⁵ Irregular migrant workers are those who enter the country illegally and work, those who work without a work permit, or those who violate the terms of their work permit (e.g. people who overstay their work visa, etc.) (International Labour Organization, 2013).

government has no legal framework for coping with refugees, asylum seekers, or stateless people, nor does it make the distinction between forced and economic migrants (ERT, 2010).

Few academic articles focus specifically on refugees and asylum seekers in Malaysia (cf. Alexander, 2008; Buscher & Heller, 2010; Nah, 2010), and as such the most current, comprehensive, publicly-available information on the situation of refugees in Malaysia comes from reports authored by NGOs. Two reports are of note: an Amnesty International (2010) report that outlines the human rights violations refugees and asylum seekers in Malaysia are subjected to, and a report by the International Rescue Committee (A. Smith, 2012), which details results from a large study on the issues facing Myanmar refugees living in Kuala Lumpur.²⁶ There is considerable overlap in the content of these two reports, and a summary of the key issues covered in the reports is provided below.

Challenges and Rights Violations

Refugees in Malaysia are subjected to serious violations of their human rights (Amnesty International, 2010), and because of Malaysia's failure to ratify important international agreements (most notably the refugee Convention and its 1967 Protocol) (UNHCR, 2010), they often have little or no recourse (A. Smith, 2012). Among the most pressing concerns are arbitrary detention and issues surrounding employment, housing, education, and healthcare.

Detention. According to Amnesty International (2010), in Malaysia: "Refugees and asylum-seekers are subject to criminal penalties, harassment, ill-treatment, extortion,

²⁶ I cite the Smith (2012) study frequently in this chapter, simply because it is one of the few recent, published study I was able to find that provides information on the health and lives of Myanmar refugees in Kuala Lumpur. The study included a survey of over 1000 randomly selected households of Myanmar refugees living in Kuala Lumpur, 10 qualitative focus groups, and 9 key informant interviews with staff from UNHCR and NGOs.

unnecessary and prolonged detention, and are placed at risk of refoulement”²⁷ (p.7). Other reports corroborate the frequent detention of refugees: Cheung (2011) asserts that nearly half of all refugees in Malaysia have, “experienced arrest and multiple deportations, as well as a significant number reporting being whipped,” (p.12) while 42% of the Myanmar refugees in Kuala Lumpur who participated in the recent study by A. Smith (2012, p.58) reported that at least one member of their household had been arrested in the last year. The participants in Smith’s study who had been detained reported spending between one day and one year in detention, and “almost all respondents described the conditions and treatment in detention as bad or very bad. About 60% said they received regular meals, 40% said they got water for bathing, and almost 20% said they got nothing,” (p.60). Members of the Malaysian Government have stated that authorities do not detain refugees and asylum seekers with UNHCR cards, but numerous sources report instances where UNHCR cardholders are detained for long periods and in some cases deported to Thailand (Amnesty International, 2010; Dateline, 2011).

Employment, housing and education. Many refugees in Malaysia do not have the resources to rent adequate housing, and therefore live in makeshift, run down, and/or overcrowded accommodation²⁸ (Nah, 2010). Refugee children are not permitted to attend Malaysian schools, and while many of them attend learning centres supported by UNHCR, community groups, and NGOs, an estimated 60% of school-age children registered with UNHCR do not receive any form of education (UNHCR, 2013f). The study by A. Smith (2012, p.) found that 10% of the children (under 18) within the households sampled worked: 72% were

²⁷ As set out in Article 33 of the 1951 Convention, refoulement is the expulsion or return of a refugee “to the frontiers of territories where his life or freedom would be threatened on account of his race, religion, nationality, membership,” (UNHCR, 2010, p. 30).

²⁸ More than half (57%) of the sample from the A. Smith (2012, p.52) study reported sharing accommodation with five to ten people; 31% reported sharing with more than 11 people, and 5 respondents said they lived with over 30 people.

between 12-18 years-old, and 28% were age 11 or younger. Since it is illegal for refugees to be employed, refugee children and adults often undertake work that leaves them vulnerable to exploitation, low wages, and “dirty, degrading and dangerous” conditions (AI, 2010, p. 16; Buscher & Heller, 2010). Of participants in the Smith study, about 30% (311 respondents) reported experiencing employment problems; of these 311 respondents:

80% reported not receiving wages for work completed or only receiving partial wages. The second most frequently reported problem was verbal abuse (42%), followed by on-the-job injury (15%) and dismissal without reason (15%), and physical abuse (6%). Most of the reported abuse was committed by the employer. (p. 45)

Despite the challenges outlined above, there is limited support available for refugees in Malaysia: A. Smith asserts that there are, “numerous gaps in service provision and unmet needs within the refugee communities,” as illustrated by the fact that “when respondents were asked whether they or a member of their household received humanitarian aid or services during the past year, 92% indicated that they did not receive anything” (p.61).

Health and healthcare. While the challenging conditions confronting refugees in Malaysia render them vulnerable to a range of health problems (AI, 2010), for many refugees the cost of treatment at government hospitals can be prohibitive. UNHCR therefore supports NGO clinics that provide primary health services (i.e. diagnosis and treatment of basic health conditions, referrals etc.) at little or no cost. A. Smith (2012) reports that the most prevalent health issues among those visiting one of these NGO clinics are upper respiratory tract infections, “followed by rheumatic complaints, hypertension, gastritis, and diabetes” (p.47). Thirty-nine percent of participants in the A. Smith (2012, p.47) study said that since arriving in Kuala Lumpur they had had a serious medical issue that necessitated treatment; of those, 94% sought treatment, while those who did not cited financial difficulties and lack of documentation

as the reasons why. The validity of these concerns is illustrated by the example cited in the study, in which a Chin man without UNHCR documents or money for treatment was admitted to a government hospital with a broken leg that required external fixation;²⁹ he is quoted as saying:

‘They fixed my leg, but when they learned I didn’t have documents and couldn’t pay for the services, they removed all the pins they had put in my leg. When they took everything out, I was left worse off than before I came in’ (p. 48).

Barriers to healthcare, including financial difficulties and lack of documentation, were a recurrent theme in the qualitative interviews conducted for this study, and are discussed at length in the results chapters of this dissertation. The discussion above illustrates that while UNHCR Malaysia makes a significant investment in refugee health (UNHCR, 2011e), the health-related needs of refugees in Malaysia exceed the resources UNHCR has to address them, especially given the high cost of secondary health care. In light of this, research on SDH among refugees is important, because understanding the context-specific factors contributing to their health and illness is a key step towards making cost-effective investments that extend beyond the narrow scope of basic health care and effectively target a broader range of health determinants.

Conclusion

I began this chapter by providing detailed information regarding the historical and present-day situation of Rohingya people in Myanmar, including the current conflict that has led thousands of Rohingya asylum seekers to flee to neighbouring countries such as Malaysia. While the primary focus of this study is the health and wellbeing of Rohingya refugees in Malaysia, it is necessary to consider the conditions from which these refugees fled because, as S.L. Thomas et al. (2008) argue, people who are forced to flee their countries:

²⁹ External fixation is surgical treatment that uses screws to stabilize and align fractured bones (MedlinePlus, 2013).

Are more often than not the poorest, most marginalized members of society, as a result of which prior to displacement they invariably had preexisting unmet health needs. Many have lived in conditions of poverty with inadequate nutrition and housing and limited access to education and health services...Such factors need to be taken into account when considering the potential impact on the health-care services of the country or region of destination and the design and management of subsequent health and social interventions. (p.201)

In light of Thomas et al.'s argument, the overview presented in this chapter is pertinent because the circumstances in which Rohingya women live before they flee have a lasting effect on their health and wellbeing, and – consequentially – on the health and social interventions intended to improve their lives in Malaysia (issues that are considered in Chapters 7 - 9). While this section focused primarily on the challenges and rights violations experienced by refugees in Malaysia, later chapters of this dissertation also expand on this discussion to consider how female Rohingya refugees respond to these challenges and function within the Malaysian context.

Chapter 4: Methods

Introduction

In this chapter I discuss the planning and execution of this study, focusing primarily on methodology and logistical elements of data collection. I begin by outlining the theoretical basis of the study, and then review the sampling and recruitment strategy (including my decision to focus specifically on Rohingya women). Following this, I explain the qualitative research design and methods, and consider the logistics of data collection, including issues pertaining to research assistants (RAs) and translation. Lastly, I provide a summary of the steps through which I undertook thematic analysis of the interview data, and I end the chapter by outlining limitations of the study.

Theoretical Basis of the Study

Two decades ago, scholar Marjorie Muecke (1992) identified the main paradigms that dominated the field of refugee health as being “the objectification of refugees as a political class of excess people, and the reduction of refugee health to disease or pathology.” She went on to call for two alternative paradigms: “one to take the polyvocality of refugees into account, and one to construe refugees as prototypes of resilience despite major losses and stressors” (p.515). These two ‘alternative paradigms’ are well aligned with the intersectionality framework, discussed below, which formed the theoretical underpinnings of my research.

Muecke’s comments remain pertinent today. Countries are taking extreme measures to prevent people from seeking asylum (such as Australia, which instituted off-shore processing) (BBC, 2012), and the field of refugee health remains dominated by biomedical research in which individual and group pathology undermine critical analysis of the social, environmental, and political contexts that give rise to many health issues (Brough, Gorman, Ramirez, & Westoby,

2003). A growing number of scholars are, however, recognizing the limitations of a narrow biomedical approach to research with refugees and calling for new modes of inquiry, one of which is intersectionality (Guruge & Khanlou, 2004).

Intersectionality is a paradigm built on the work of Crenshaw (1991), predicated on the notion that “various dimensions of social stratification—including SES [socioeconomic status], sex, gender, ethnicity, race, age and others—can add up, or cumulate, to great disadvantage for some groups of people” (Hankivsky et al., 2010, p. 8). A tenet of intersectionality is that while dimensions of social identity may have differential value and health impact, they are intrinsically linked and cannot be considered in isolation (McGibbon & McPherson, 2011). Parallels can be drawn between intersectionality and other long-established approaches (including holism and the web of causation, etc.) (cf. Morse and Chung, 2008; N. Krieger, 1994), and this has led some to question the novelty or unique utility of intersectionality. Yet while there are key areas of overlap (namely, all of these approaches are underpinned by a broad focus on the interconnected and holistic nature of social phenomenon), intersectionality is an explicitly feminist approach that confronts issues of power, privilege and oppression by critically considering the interconnected nature of aspects of identity (Herk, Smith, & Andrew, 2011).³⁰

Intersectionality can provide a useful framework through which to consider linkages between structural determinants of health inequities (e.g. gender, race/ethnicity) and SDH (e.g. living conditions, psychosocial factors); as McGibbon & McPherson (2011) argue, intersectionality is “a natural theoretical underpinning for informing policy to address inequities in the SDH as they pertain to women and other vulnerable populations” (p. 61). Intersectionality

³⁰ Intersectionality also as far reaching practical and legal implications; see, for example, discussion of decisions made by the Supreme Court of Canada regarding the intersecting nature of grounds of discrimination (Ontario Human Rights Commission, 2014).

can also be used to problematize aspects of the SDH framework. For example, Hankivsky & Christoffersen (2008) argue that “gender underscores a myriad of limitations with the current approaches to health determinants and how such dominant approaches may contribute to maintaining the status quo and re-entrenching a range of social, political, and economic hierarchies that influence health” (p.274). They use gender to illustrate shortcomings in current SDH approaches, namely that gender is not always recognized as a key health determinant, and when it is acknowledged it is often considered in isolation from other health determinants and from public policy that generates and reinforces gendered health inequities.

Adopting an intersectionality approach can thus create opportunities to refine our understanding of SDH, and challenge the reductionist tendency to define and measure health determinants in definitive categories rather than conceptualizing them as complex and interconnected. Furthermore, an intersectionality approach highlights significant parallels between the limitations of conceptualizing health determinants in distinct categories, and the potential harm of categorizing refugees based on features of identity or perceived categories of vulnerability, an issue discussed later in this dissertation (see Chapter 9).

An intersectionality approach is helpful in framing the theoretical questions that underpin this study: how does the intersection of various aspects of social identity affect Rohingya women’s experience of health, illness, and its determinants in their present day lives in Malaysia? Do Rohingya women situate themselves as active agents with control and autonomy over their lives and health, and do they speak about their health as determined and constrained by aspects of their identity (such as refugee status, race/ethnicity) and the broader structural context in which they are embedded? What features of identity and the social environmental context render some women more likely to adopt resilient strategies?

The overarching focus on resilience in this study stems from strong ethical and conceptual justification for adopting a framework that explicitly considers the agency of refugees rather than only their deficits and vulnerabilities (Muecke, 1992). Focusing on the strengths of Rohingya women by identifying the ways in which they responded to illness and strove to be healthy provided an alternative to research on refugees that is reductionist and ‘pathological’; as Muecke (1992) aptly points out, “absent is the study of refugee health or of healthy refugees” (p.521).

While finding techniques for analyzing intersecting aspects of identity can be challenging for researchers (Hankivsky et al., 2010), a growing body of evidence is being developed to explicate and address such challenges (Ludvig, 2006; McGibbon & McPherson, 2011). My study thus makes a contribution to this emergent theory by increasing our understanding of intersectionality and SDH in the context of refugee women.

Focusing on Refugee Women

Benoit & Shumka (2009) have contributed to our understanding of gender and sex as key determinants of health – gender being “a social construct regarding culture-bound conventions, roles, and behaviors” for men and women, and sex being “a biological construct premised upon biological characteristics enabling sexual reproduction” (N. Krieger, 2003, p. 653). While males and females have many health issues in common (e.g. certain types of cancer; infectious diseases like TB, etc.), they also face unique health concerns (e.g. those related to reproductive health) and have differential exposure to SDH (Solar & Irwin, 2010).³¹ Forced migration can amplify such differences, as it fundamentally disrupts traditional gender roles (Rajasingham-Senanayake,

³¹ This may be particularly true for Islamic women observing *purdah*. *Purdah* is a practice pertaining to the seclusion of women from men, and often involves women staying in the home (Palmer, 2011); a report by WHO (2011b) on SDH notes that *purdah*-related restrictions are likely to influence health seeking behaviour.

2004; Turner, 2004) and the resultant recalibration of masculinity and femininity can have serious implications for the health of refugees (Horn, 2010; Jaji, 2009).

A large body of feminist literature informs our current understanding of refugee women (cf. Freedman, 2010; Ghorashi, 2008; Merry, Gagnon, Hemlin, Clarke, & Hickey, 2011; Pavlish, 2005; Pittaway & Bartolomei, 2001; Pittaway, 2010). Research has illustrated that many female refugees have limited self-determination and are at significant risk of SGBV (Freedman, 2010; Manchanda, 2004; Pavlish, 2005), yet there is tension between recognizing the unique vulnerabilities confronting female refugees, and branding refugee women as victims by framing them solely in terms of their vulnerabilities (Freedman, 2010); as Manchanda (2004) argues, human rights “flow from being recognized as a citizen. The woman refugee/IDP represents the epitome of the marginalization and the disenfranchisement of the dislocated. Her identity and her individuality are collapsed into the homogeneous category of ‘victim’” (p. 4179). Applying a victim/vulnerability label to all female refugees fails to acknowledge their heterogeneous experiences and perspectives, and negates the resilience and agency executed by many (Ghorashi, 2005).

A primary criticism of gender related policies on female refugees is that they fail to integrate the perspectives of the refugee women they are meant to protect (Freedman, 2010). While it is clearly important for humanitarian agencies such as UNHCR to incorporate the perspectives of the populations they serve, the reality is that such agencies do not always have the capacity to seek extensive input or undertake studies to gain a nuanced understanding of variation within and between subsets of the populations they serve (such as people of different age groups, genders etc.), even though these might enhance the efficacy of their programming. As present, there is a dearth of information on the health and response strategies of Rohingya

women in Malaysia; accordingly, the research topic and participant population for this study were chosen in order to address this gap.

Methodology

The research design for this study was qualitative, and I used an exploratory, applied research approach. Numerous researchers support the use of a qualitative approach to research on refugees and SDH: Khawaja, White, Schweitzer, & Greenslade (2008), for example, note that researchers are increasingly adopting inductive, qualitative approaches in order to make sense of refugees' varied and complex experiences. Roberts et al., (2009) undertook research on SDH among IDPs in Uganda, and they argue that qualitative methods are appropriate for such research, in part because they “explore relationships between social determinants of health [and] help generate research questions which can then be investigated through quantitative methods” (p.3). Qualitative research has been used by a wide array of other researchers in the study of health determinants (Jinks, Ong, & O'Neill, 2010; J. Krieger et al., 2002; McKague & Verhoef, 2003), and has been extensively employed to identify and assess the health needs of refugees (Asgary & Segar, 2011; Benner et al., 2010; Horn, 2010; Hugman, Bartolomei, & Pittaway, 2011; Krause-Vilmar & Chaffin, 2011; Pavlish, 2005).

Methods and Recruitment

The primary research method I employed in this study was semi-structured interviews. In addition, I reviewed UNHCR financial assistance (FA) documents. Rather than framing the FA documents as academic data and conducting in depth analysis, I primarily drew on the FA documents to support the interview and case study data. The contextual and background information provided by the FA documents was particularly relevant given challenges that

emerged during the iterative interview process (i.e. limitations regarding follow up interviews), and it helped offset the relatively small interview sample size.

One strength of including multiple sources of data/information is that it enables triangulation, which has been defined as a method employed by researchers “to check and establish validity in their studies by analyzing a research question from multiple perspectives” (Guion, Diehl, & McDonald, 2011, p. 1; Leech & Onwuegbuzie, 2007). The use of semi-structured interviews and document review meant that the diverse perspectives of Rohingya refugee women and humanitarian workers at UNHCR, as well as my own, are reflected in the data.

The Document Review Process

Before I reviewed the documents, administrative staff at UNHCR anonymized them by removing identifiable information (including the refugee’s name, UN number, telephone number and the caseworker’s name). In order to protect the anonymity of the refugees and caseworkers, I do not summarize individual cases in their entirety; rather, I present a general overview of the information contained in the documents, and use segments of individual documents to demonstrate key points.

I began by reading through all of the documents, and based on this first reading I determined inclusion/exclusion criteria. For example, I came across a few documents that were extremely short or incomplete, and as I would not have been able to extract meaningful information from these documents, incompleteness/insufficient information became a criterion for excluding documents. I used a combination of deductive and inductive techniques to identify categories of information and themes. The review was deductive in that FA documents are written in a standard format, and they contain different sections for specified information (e.g.

the FA form has separate sections for information such as date of birth, ethnicity, address, added vulnerabilities, and the caseworker's assessment and recommendation). During the first read through, I identified deductive categories of information in the structured sections of the FA documents that would be relevant to the review.

At the same time, the review was inductive in that I identified additional categories/themes from the unstructured section of the documents (i.e. the section that contained the caseworker's assessment, including information pertaining to occupation, wage, housing, rent, etc.). After creating a tentative list of categories/themes, I read through the documents a second time, excerpting information into categories and refining the categories as I went. I then carefully reviewed all of the excerpts, identified broader themes (discussed below), and calculated basic demographic figures pertaining to age, marital status, etc. Once I had conducted the preliminary review, I completed the process by revisiting the excerpted information one final time, confirming interpretations, and identifying crosscutting themes.

Semi-structured Interviews

After reviewing existing literature on qualitative methods and interviewing (Gubrium, Holstein, Marvasti, & McKinney, 2012; Halabi, 2005; Hansen, 2006; Patton, 2002), I selected semi-structured interviews as the primary method of data collection for this study, largely because interviews were a powerful method with which to elicit in-depth, narrative responses from participants. A semi-structured interview approach involves asking participants a series of "predetermined but open-ended questions" (Ayres, 2008, p. 810), and employing this approach enabled me to obtain the information required to address the research objectives, while at the same time giving participants an opportunity to discuss issues that were important to them.

Despite the overall suitability of semi-structured interviews, in the context of this study certain issues required careful consideration. For example, most refugees in Malaysia have undergone mandatory, structured interviews as part of the refugee status determination process,³² and there are potential problems associated with interviewing refugees who have undergone stressful interviews in the past (e.g. they may give curt answers, or feel uncomfortable bringing up topics about which they are not directly asked, etc.). I attempted to mitigate these issues by using a guided-yet-flexible interview approach as opposed to a highly structured one; in this way, participants had freedom and agency throughout the interview. I also confirmed that participants knew their responses would not be linked to their UNHCR files and would not have an impact on their status with UNHCR. Furthermore, I was able to build additional rapport/trust with some refugees by conducting follow-up interviews.

Numerous other factors made semi-structured interviews an effective method of data collection. Foremost, conducting semi-structured interviews enabled me to obtain information that directly addressed the research questions (i.e. the data provide insight into Rohingya refugees' main health concerns, response strategies, and what they believe to be important determinants of health – information that can be used to inform program and policy development). The interviews generated in depth, individuated data that offer an alternative to the pervasive stereotypes about refugees within public and academic discourse (see Harrell-Bond, 1999). Eastmond (2007) asserts that refugee narratives “can promote a greater appreciation of the diversity of experience involved in forced migration, against universalizing and stereotypical descriptions of what it means to be a ‘refugee,’” (p. 253) a sentiment which is

³² These interviews usually involve a standard set of questions, and the burden of proof lies with the asylum seeker (i.e. their testimony must illustrate that they meet the criteria for becoming a refugee) (Harrell-Bond & Voutira, 2007).

both aligned with the theoretical basis of this study and reflected in the diverse narratives generated through the interviews.

Recruitment Criteria

I undertook purposeful sampling (Patton, 2002), using three criteria as the basis for recruitment: participants needed to be Rohingya women, 18 years or older, who had been recognized as refugees by UNHCR Malaysia.³³ My rationale for focusing on Rohingya women was to delineate differential female experiences as refugees, as outlined in more detail above, and since this study focused on Rohingya women (not children or youth) I limited participation to those 18 years of age and older. My rationale for including recognized refugees (and excluding asylum seekers) was predicated on the fact that the services and assistance available to these distinct groups varies significantly and, barring exceptional circumstances, UNHCR assistance programs in Malaysia are currently only available to recognized refugees.

Participant Recruitment

Participants were recruited from the hundreds of refugees who come to the UNHCR office in Kuala Lumpur each day. The RA and I predominantly recruited from the registration waiting area,³⁴ as all refugees are required to attend appointments with the registration department periodically to renew their UNHCR cards. One advantage of recruiting from this

³³ While most Rohingya refugees in Malaysia were themselves forced to flee Myanmar, there are also some refugees born in Malaysia to *parents* who fled Myanmar, and these women were eligible to participate as long as they met the three recruitment criteria described above.

³⁴ On occasion, we recruited women who were at the office for non-registration related purposes. For example, in instances where there were no recognized female Rohingya refugees in the registration waiting area, the RA and I recruited from the resettlement (RST) and outreach/protection (OPI) waiting areas. On a few occasions, we recruited women who were at the office to see RST or IAD but were mistakenly seated in the registration waiting area. Recruiting from these different waiting areas did not have a significant impact on the sample; that is, women in the different waiting areas had comparable experiences.

group was that it could include almost any female adult Rohingya refugee recognized by UNHCR Malaysia. This facilitated the recruitment of a diverse sample.

During recruitment, the RA and I would approach a female refugee and ascertain if she met the selection criteria; if she did, the RA gave a short explanation about the study and then asked the woman if she was interested in participating. In most instances, the potential participant then discussed the issue with whoever had accompanied her to the office (usually her family members) before conveying her interest in participating. Between 5 and 10 of the women we approached said they could not or did not want to participate; some gave no reason, others said it was because they had to look after their children, and some were worried they would miss their appointment. One woman initially agreed, but when we had gone to the interview room and read through the verbal consent script she decided not to participate. This indicated that the consent process was effective in conveying the information women needed to make an informed decision about whether to participate (or not), and also that this participant was comfortable exercising her right not to participate (i.e. she did not feel coerced or pressured to participate).

Data Collection

Interviews took place between the end of April and June 2013. I undertook one trial interview, which was not recorded or included in the analysis, in order to determine whether the recruitment strategy and interview guide (see Appendix B) were effective in practice. They were, and based on the trial interview I made slight adjustments to the interview guide and then used the revised guide to structure all subsequent interviews.

In total, 34 women were interviewed for this study. Of those interviewed, one participant was excluded because the interview had been interrupted part way through, and as I had asked fewer than half of the questions the interview did not provide sufficient data to be included. I

conducted one initial interview with each participant at UNHCR (the duration of which was between 15 and 65 minutes). I initially intended to ask participants if they would be interested in doing a second, follow up interview, but it became evident during data collection that many of the women lived very far away from the UNHCR office (see Chapter 7 for details about participants' geographic location), and this limited the number of participants with whom I could conduct in-person follow-up interviews. In response to this, approximately halfway through data collection I adapted the strategy for follow-up interviews and conducted some (4) by telephone.³⁵

While there is a longstanding tradition of employing telephone interviews as an effective method of data collection in quantitative research (e.g. large-scale surveys), telephone interviews have generally been viewed as auxiliary, and sometimes inferior, sources of data collection in qualitative studies (Lechuga, 2012; Sturges & Hanrahan, 2004). Trier-Bieniek (2012) notes that qualitative researchers conducting telephone interviews must “battle the stereotype that telephone interviews are hygienic, an act of convenience, and that they foster less of a rapport between researcher and participant” (p. 641). Yet Trier-Bieniek herself rejects this notion, asserting that qualitative telephone interviews are an effective method of data collection that can generate rich and detailed findings. She highlights the advantages of semi-structured interviews – undertaken using a participant-centered, feminist approach – and argues that they can be a particularly effective method for exploring sensitive topics. She bases this assertion on her own study, in which she noted that “participants felt at ease sharing sensitive information over the phone, possibly because they were somewhat anonymous and stayed in settings that were comfortable for them” (Trier-Bieniek, 2012, p.635).

³⁵ As all of the women I asked to participate in follow-up interviews indicated that they had a phone, inability to access a telephone did not cause potential participants to be excluded. One woman did, however, decline to participate in a telephone interview because she said her house was too busy; I suspect meant that she may not have had the space/opportunity to speak on the phone in private.

Sturges & Hanrahan (2004) have also contributed to the literature on telephone interviews. They initially set out to undertake face-to-face interviews, but circumstances required them to conduct some interviews over the telephone. They compared the interview transcripts of both types of interviews, and found no substantive differences, leading them to conclude that telephone interviews are a viable method of data collection. Sturges & Hanrahan also note that the lack of nonverbal communication may be a drawback in conducting telephone interviews, and in the context of this study that was indeed a drawback. This drawback was, however, outweighed by the benefits of telephone interviews. Refugee participants did not have to endure the security risks and financial/time cost of travel to the UN office; they did not have to find childcare; and in one case I obtained a greater quality and quantity of data during a telephone interview than when I conducted an in-person interview with the participant at her home (see Rashida's case study, Chapter 7, for further discussion). Telephone interviews enabled the refugees to participate from the comfort of their homes, settings in which they were likely more comfortable and that negated stress potentially caused by the physical presentation of themselves required by in-person encounters at UNHCR (similar advantages were also noted by Trier-Bieniek, 2012). The most basic advantage of the telephone interviews, however, was that they enabled me to conduct follow-up interviews that would otherwise have been difficult due to geographic distance.

Scholars have suggested numerous benefits to conducting multiple interviews, including that it can build familiarity and trust between the interviewer and interviewee, which may lead to greater detail and depth; it can provide opportunities to clarify and explore aspects of the previous interview; and the break between interviews can provide a chance to rest and reflect (Gubrium et al., 2012; Saldaña, 2011). The follow up interviews I conducted manifested all of

these benefits, and data resulting from further exploration of topics that had been discussed in the initial interviews was particularly fruitful. The interviews (including those conducted in person and over the phone) were audio recorded³⁶ for transcription, analysis, and consent purposes.³⁷

In total, I interviewed 28 of the participants once: the location of these initial interviews was a private interview room at UNHCR. I interviewed 4 participants twice (i.e. I interviewed 3 participants once at UNHCR and once on the telephone; and I interviewed one participant once at UNHCR and once at her home). I interviewed one participant on three separate occasions (once at UNHCR, once at her home, and once on the telephone). All of these interviews were included in the analysis (33 initial interviews, 6 follow up interviews). I stopped collecting data when, after conducting upwards of 40 interviews, I assessed there to be a sufficient level of data saturation (i.e. information, themes and patterns were emerging consistently and no new issues were arising) (Onwuegbuzie, Dickenson, Leech, & Zoran, 2009; Sim, 1998). I made notes after each interview in a reflective journal, and these notes proved helpful during data analysis; in particular, they provide insight into the context and circumstances surrounding individual interviews that were not captured on the audio recordings.

³⁶ In one instance there was a problem with the audio recorder and it did not record the interview properly, but as I had made detailed notes during the interview I was able to include it in analysis.

³⁷ The exchange in which the participant gave verbal consent to participate was recorded, and consent is discussed in detail in Chapter 5. It is possible that participants may have been less inclined to speak freely because they were being recorded, but no one overtly expressed that concern. Recording the interviews meant that verbatim transcriptions could be generated, and these allowed for more reliable and detailed analysis than would have been possible if the interviews had not been recorded.

Research Assistants, Language, and Translation

Translation was a necessary part of this study, as I do not speak Rohingya language and none of the participants spoke English.³⁸ Rohingya is a distinct, mixed language, and there are differing opinions on the languages from which it emerged: according to Yin (2005) it contains elements of Arabic, Urdu, Persian, and Dutch, whereas others categorize it as a unique dialect of Bengali similar to that spoken in Chittagong, Bangladesh (HRW, 2012a; Minority Rights Group International, 2008). In addition to their native tongue, some Rohingya people also speak Burmese language (HRW, 2012a), a small number of refugees in Malaysia speak English, and many learn Malay language.³⁹

I conducted this research with the help of two female RAs who spoke English, Rohingya, and Malay. The participants indicated their preferred interview language (30 preferred Rohingya, 2 Burmese, and 1 Malay),⁴⁰ and the interviews were conducted in that language. The RAs were women employed as interpreters at UNHCR, and one potential concern with using them as RAs was that their status as UNHCR interpreters might influence potential participants' decisions to join the study. I took numerous steps to mitigate this concern (e.g. clearly explaining to participants that this study was not linked to their UN file, and that neither the RA or I had the ability to make decisions about their case, etc.), steps which are described in greater detail in Chapter 5.

³⁸ There is significant discussion regarding translation and the use of interpreters in qualitative research (cf. Filep, 2009; Irvine et al., 2007; Wong & Poon, 2010), some of which relates specifically to research with refugees (Jacobsen & Landau, 2003). See also Lai & Mulayim (2010), who review an innovative program in Australia that trains refugees to become interpreters for other refugees.

³⁹ Malay language, also known as *Bahasa Melayu*, is the official language of Malaysia (The Government of Malaysia, 2013).

⁴⁰ On the two occasions participants asked that the interviews be conducted in Burmese language, I conducted those interviews with the assistance of female UNHCR interpreters who were fluent in Burmese.

The decision to use UNHCR interpreters as RAs for this study had clear advantages: the interpreters had extensive translation experience and knowledge related to the lives and health of Rohingya women, and I had established good working rapport with them prior to starting my research. Furthermore, from a logistical standpoint, it would have been very difficult to find female RAs who spoke Rohingya and were not refugees and/or UNHCR employees, as Rohingya language is not generally taught outside of Myanmar.

I briefed the RAs regarding the purpose and execution of this study, as well as their roles, responsibilities, and ethical conduct (e.g. confidentiality). When I was preparing the RAs for this study, I asked them to try to translate exactly what the participant was saying and avoid summarizing or omitting dialogue.⁴¹ They both informed me that it was difficult to translate between English and Rohingya verbatim (due to lexical and grammatical differences between the languages),⁴² and that certain concepts (such as ‘community support’) would have to be explained to participants, as there is no direct equivalent in Rohingya language. After we started conducting interviews it became apparent that for some participants, the directly translated questions were not sufficient, and these participants needed a more detailed explanation of some questions in order to understand and feel confident answering them. The RAs understood the essence and intention of the questions in the interview guide, and they were therefore able to explain the questions to participants in greater detail when necessary. More than simply translating, the RAs thus had a “cultural brokering” role in the interviews (Temple & Young, 2004, p. 173), and the data generated in this study was affected by their interpretations of concepts and statements.

⁴¹ During the interviews, the actual translation process began when I made a statement or asked a question in English, and the RA translated my words for the participant. The RA then translated the participant’s response into English, and the dialogue continued in this format.

⁴² See Suh, Kagan, & Strumpf (2009) for discussion of this and related translation issues.

In response to this, I took numerous steps in order to determine the accuracy of the RAs' translations and explicate the ways in which they may have influenced the interview data. For example, to ascertain the accuracy of the translations, I undertook a review of 50% of the interviews (once I had transcribed the interviews, I had a UNHCR translator who had not been involved with the interview listen to the audio recording and concurrently read the transcription, making note of any translation and transcription errors).

I kept a detailed record of every translation error identified. The first interview we conducted (the only one conducted in Malay language) had the most errors, and so I asked an additional interpreter and a Malaysian colleague to review it: they noted that the participant spoke at length before the RA translated, in addition to which the participant was not fully fluent in Malay and made grammatical errors which might have caused the RA to misunderstand what she was trying to say. I too had noticed during this interview that the interpreter was not translating frequently enough, and I asked her to translate more frequently in subsequent interviews. The rest of the transcripts had only minor corrections (e.g. a few words had been omitted or mistranslated) but nothing that significantly changed the essence of what was said, which indicates that the accuracy of translation during the semi-structured interviews was relatively high.

The RAs' vocabulary also provides insight into their translations. The RAs used a diverse range of words to describe participants' feelings and states of being (e.g. shy, peaceful, happy, patient, helpless, afraid, lucky, sad, uncomfortable, disappointed, persecuted, satisfied, suffering, hardship, worry, stress, freedom, miserable, regretful, etc.). Their translations demonstrated the breadth of their English vocabulary, and were nuanced enough for me to elucidate connections between participants' emotions and physical states of being. For example, rather than using only

basic/rote words such as mad, happy, etc. they differentiated between subtle differences in emotions and experience, which allowed me to gain insight into the occurrence of things such as psychosomatic illness.

I sought the input and feedback from the RAs on various aspects of data collection, including the interview guide and interviewing process. Soliciting the RAs' insight into the research process was an informal way in which to, "acknowledge the cultural brokering role that translators and interpreters play by carrying out the research with them as key informants" (Temple & Young, 2004, p. 173). While I did not involve the RAs as key informants in a formal sense, I did adjust my interview questions in response to their feedback, and I debriefed with them informally after each interview and formally after data collection was complete. Their thoughts and feedback on issues such as how willing/able participants were to answer certain questions, factors that may have influenced participants' answers, and steps that could be taken to improve the health and wellbeing of Rohingya women were particularly insightful.

Analysis

An Inductive Approach to Qualitative Analysis

According to Bryman & Burgess (1994), "qualitative data analysis is essentially about detection, and the tasks of defining, categorizing, theorizing, explaining, exploring and mapping are fundamental to the analyst's role" (p.176). To analyze the qualitative interview data in this study, I undertook a largely inductive process of thematic analysis (Patton, 2002), the overarching aim of which was to generate "a detailed and systematic recording of the themes and issues addressed in the interviews and to link the themes and interviews together under a reasonably exhaustive category system," (Burnard, 1991, p. 461). The rationale for undertaking an inductive form of analysis stemmed largely from the fact that while many determinants cited

in the CSDH framework (Solar & Irwin, 2010) are relevant to refugee health, others of particular relevance to refugee populations are not included.⁴³ As such, rather than undertaking deductive data analysis based on an existing SDH framework, an inductive approach in which themes and sub-themes emerged directly from the interview data seemed most appropriate.

An inductive approach has proved effective for other researchers conducting qualitative research with refugees (Halabi, 2005; Khawaja et al., 2008; Pavlish, 2005), and it has been fruitful in research on SDH. For example, in their study exploring SDH from the perspective of clients at a health centre, McKague & Verhoef (2003) found an inductive approach was most appropriate, because “it was apparent that client participants were not identifying clear categories of health determinants but, rather, were speaking in detail about their personal experiences with factors influencing their health” (p.706). This was also the case in this study (i.e. most participants gave personal accounts of events and situations that affected their lives, rather than directly identifying categories of health determinants), and an inductive approach enabled me to identify the unique patterns and themes that emerged from their narratives.

Thematic Analysis

Strengths and limitations. I undertook thematic analysis of the interview data. Fereday & Muir-Cochrane (2008) describe thematic analysis as “a form of pattern recognition within the data, where emerging themes become the categories for analysis” (p.4), while Vaismoradi, Turunen, & Bondas (2013) draw on the work of Sparker (2005) to define it as a process through which scholars examine “narrative materials from life stories by breaking the text into relatively small units of content and submitting them to descriptive treatment” (p. 400). While there is

⁴³ E.g. Migration status is one determinant that is relevant to refugees but not explicitly recognized in the CSDH. Benoit & Shumka (2009) note the serious effects migration can have on health, and include migration status in their own SDH framework because they argue that it is a key health determinant that intersects with other determinants such as race/ethnicity.

limited published literature pertaining specifically to thematic analysis (Vaismoradi et al., 2013), Braun & Clarke (2006) provide a thorough assessment of its purpose, strengths and limitations. They assert that it can “provide a rich and detailed, yet complex, account of data,” (p. 78) and that it is an effective way to identify and analyze themes across a data set.

Thematic analysis has, however, been criticized for being a rudimentary method of analysis, and more specifically for failing to incorporate peer-checking⁴⁴ as a standard way of ensuring reliability (Vaismoradi et al., 2013).⁴⁵ Yet Vaismoradi et al. note that “because of the pure qualitative nature of thematic analysis, peer checking of intercoder reliability is not always possible since there is scepticism about the value of such testing,” (p. 403).⁴⁶ The scepticism they refer to includes the argument that peer checking does not necessarily mean that the codes are objective, only that “two people can apply the same subjective perspective to the text” (p.403). Ultimately, Vaismoradi et al. (2013) argue that both thematic and content analysis “benefit from transparent structures that, with a defined sequence of analytical stages, provide researchers with clear and user-friendly methods for analyzing data” and are “robust enough to be used for conducting an introductory study on a novel phenomenon” (p.403).

The process of thematic analysis. Braun & Clarke (2006) describe six steps to thematic analysis – becoming familiar with the data, generating codes, looking for themes, reviewing themes, naming and defining themes, and writing the final document – which I used to guide my interview analysis. The first step was to transcribe all of the interviews, and I chose to do this

⁴⁴ Peer checking is an approach used to increase reliability and validity in qualitative research (Vaismoradi et al., 2013); it involves a person with training in qualitative methods checking the findings of peer researchers for intercoder reliability.

⁴⁵ Reliability has been defined as an “epistemic criterion thought to be necessary but not sufficient for establishing the truth of an account or interpretation of a social phenomenon. An account is judged to be reliable if it is capable of being replicated by another inquirer” (Schwandt, 2007, 'Reliability').

⁴⁶ According to Vaismoradi et al. (2013), intercoder reliability “refers to the extent to which more than one coder independently classifies material in the same way as peer researchers” (p.403).

myself in order to become familiar with the data. After transcribing the interviews, I uploaded them into Dedoose,⁴⁷ then read through the transcriptions, and began generating both semantic (explicit) and latent (interpretive) codes (Braun & Clarke, 2006). Once all of the interviews had been coded I reviewed the list of codes and began organizing them into broader themes. This step involved combining, renaming, and ordering codes into subthemes and themes. I continued to review and refine the themes, and then began writing the results and discussion chapters of this dissertation.

My own perspective shaped the analysis process and findings, as the themes I identified were, to a certain degree, influenced by my perceptions of (and experience with) Rohingya women in Malaysia. In response to this, I incorporated self-reflection into the data collection and analysis processes. I made reflective notes after each interview in order to explicate and keep a record of my perspective, and some of these notes are presented in conjunction with the case studies in Chapter 7. One of the most relevant notes pertained to a shift in my perspective that took place early in data collection, when I realized that I was slowly uncovering some of the unconscious layers of expectations, assumptions, and opinions I had about Rohingya women. In the first few interviews I conducted, I realized that the women's fortitude, candour and strength (of opinion, of conviction, and of character) had surprised me, as it was incongruent with certain assumptions I had about the struggles and response strategies of Rohingya women.

For example, I realized that I had underestimated Rohingya women's ability to work and support themselves in the urban context. In this instance, my changing perceptions were likely due to the fact that prior to conducting this research I interacted only with highly vulnerable

⁴⁷ Dedoose is the qualitative data analysis software I used to store, organize, and manually code data; for more information see Dedoose, 2012.

refugees who depended on UNHCR for medical and financial assistance, whereas in this study I interviewed a broad sample of Rohingya women who were more self-sufficient. Critical reflection (Mezirow, 1998) during and after data collection helped me to identify my own perceptions and assumptions and be mindful of how these affected – and evolved over the course of – the study.

Lastly, thematic analysis is well aligned with (and in this instance shaped by) a constructionist approach. Since an underlying tenet of the constructionist paradigm is that “meaning and experience are socially produced,” (Braun & Clarke, 2006, p. 85) my analysis extends beyond a surface reading or linguistic analysis of refugees’ interview transcripts to consider “the sociocultural contexts, and structural conditions, that enable the individual accounts that are provided” (p.85). For example, in later chapters of this dissertation I consider some of the psychosocial, monetary and logistical elements of the Malaysian context that underpin the poor healthcare seeking behaviour described by some refugees. As Eastmond (2007) argues, the narratives provided by refugees during interviews are not straightforward accounts of reality; rather, “we must relate them to the social and political contexts that have shaped and continue shaping the circumstances of their lives and which engage their commitments. Organizing themes and metaphors of such stories serve as important guides for analysis” (p. 252). In the results chapters of this dissertation I discuss themes that emerged from the interviews, themes from the document review, as well as themes that crosscut the data corpus (Braun & Clarke, 2006).

Rigor and Validity

A significant body of literature explores issues related to assessing rigor, validity, and credibility in qualitative research (cf. Cutcliffe & McKenna, 1999; Guion et al., 2011; Kitto,

Chesters, & Grbich, 2008; Leech & Onwuegbuzie, 2007; Whitemore, Chase, & Mandle, 2001). To frame these issues in the context of my own research I draw on the work of Whitemore et al. (2001), who provide a relevant synthesis of the extant literature on assessing validity in qualitative studies. Whitemore et al. (2001) present a critical overview of issues surrounding validity, and identify key challenges as being: the tension between creativity and rigor in the research process, the inappropriateness of evaluating qualitative research against quantitative standards, and the need for explicit criteria and techniques to assess validity in qualitative research.

While there is no single, gold standard means of assessing rigor and validity in qualitative research, various techniques can be employed depending on the parameters of the study in question (Miller, 2008). Whitemore et al. (2001) provide a list of 29 techniques commonly used by researchers to demonstrate and/or assess validity in qualitative research (examples include articulating data analysis decisions, providing verbatim transcriptions, demonstrating prolonged engagement, reflexive journaling, providing an audit trail, etc.). While Whitemore et al.'s list is not exhaustive, it provides a comprehensive and efficient way to consider issues surrounding validity, and I have therefore used it to assess issues of validity in the context of this study (specifically, I describe if/how each of the 29 techniques suggested by Whitemore et al. manifested in this study; see Appendix C).

Limitations

Executing the study exactly as it was designed proved difficult, because half of the study participants lived too far away from the office to conduct in-person follow up interviews, and thus the number of in-person follow up interviews I was able to conduct was limited. While I mitigated this problem somewhat by conducting interviews via telephone, a drawback of

conducting interviews over the phone is that it prohibited me from directly observing participants' homes and neighbourhoods. A second limitation stemmed from the fact that I did not speak Rohingya language, which meant I was unable to engage in the natural and nuanced dialogue that results when people converse in the same language. This limitation was unavoidable, however (as it was not feasible for me to learn Rohingya language within the timeframe of this study) and I undertook the steps outlined earlier in this chapter to resolve issues related to language and ensure accurate translation.

While there was strong rationale for focusing specifically on Rohingya women, the decision not to interview men limited the breadth of perspectives and information I was able to gather, and thus findings are relevant but not generalizable to the Rohingya population more broadly. Similarly, the information generated from this exploratory study is specific to the context of female Rohingya refugees in Malaysia, and it is therefore not generalizable to other populations of refugees. That said, the findings provide insight into features of the urban refugee experience (such as urban living conditions, barriers to healthcare, primary health concerns, and response strategies) that may have significant parallels and relevance to other refugee populations.

Conclusion

I began this chapter by outlining the methodology and theoretical basis of this study. I then explained the methods employed in this study, and described the actual process of data collection and analysis, including the number of interviews and interview locations, the involvement of RAs and the translation process, and a step-by-step account of the thematic analysis I undertook. In the following chapter, I describe and examine decisions I made during

the planning and execution of this research to consider how key ethical issues manifested in the context of this study.

Chapter 5: Ethical Considerations in Collecting and Presenting Data

Introduction

This study received ethical approval from the Human Research Ethics Board at the University of Victoria, and was undertaken in accordance with university regulations, policies and procedures governing the ethical conduct for research involving human participants. This chapter provides a brief overview of ethical issues that are relevant in the context of this study, focusing primarily on consent and issues surrounding my role as a doctoral student conducting research in affiliation with a humanitarian agency.

Consent

One of the cornerstones of ethical conduct in research with human subjects is informed consent. Informed consent is predicated on the notion that participants should be fully informed of the “purpose, methods, demands, risks, inconveniences, discomforts, and possible outcomes of the research, including whether and how the research results might be disseminated,” (Israel & Hay, 2008, p. 431) and then freely decide whether or not to participate. Yet the process of ensuring truly informed consent is complex and rife with ethical challenges (Sultana, 2007), particularly in research with refugees (Harrell-Bond & Voutira, 2007; Hugman et al., 2011; Mackenzie, McDowell, & Pittaway, 2007). One challenge relates to the very premise of informed consent, which implies that it is possible to accurately predict what will occur during the research process and the impact it will have on participants (Hugman et al., 2011). Another significant challenge is that the consent process stipulated by academic institutions may be incongruent –inappropriate, even – in the context of specific research sites and participant populations (Mackenzie et al., 2007).

In the context of this study, my university allowed me to obtain verbal consent from participants, which was more suitable than written consent forms because some participants were illiterate,⁴⁸ and there is no standard written Rohingya language. Before each interview began, the RA read the verbal consent script (see Appendix D) aloud to each participant (in Rohingya/Burmese/Malay), which ensured that information about the study was clearly and consistently presented to participants in a way that allowed them to make an informed decision regarding their participation.

Yet while the verbal consent process was preferable to written consent, it too presented challenges. Most challenges stemmed from the fact that in order for the consent script to be accepted by the university ethics board it had to provide information on a comprehensive range of issues, including, for example, how electronic data would be stored (in this case I was using Dedoose analysis software, which stored the data on servers located in the U.S.). This made the information sheet very long, and meant I was discussing electronic data stored on servers in the U.S. with participants, many of whom were illiterate, had never used a computer, and did not know what electronic data or servers were. As I outline in the Chapters 8 and 9 of this dissertation, most refugees in Malaysia hope to be resettled to the U.S., and therefore a brief mention of the U.S. during the consent process was more likely to raise confusion and false hope than provide meaningful information regarding consent.

In addition, for many of the UNHCR interviews I have witnessed and conducted with refugees (e.g. to assess financial and medical needs) their consent was implied, and it may have

⁴⁸ While it is hard to ascertain (and find publicly available) accurate figures, one estimate suggests that 80% of Rohingya in Myanmar are illiterate (Lewa, 2009); this figure is not surprising, given that the Rohingya language has no orthography and the Rohingya people in Myanmar have limited educational opportunities (HRW, 2013a).

been perplexing to the refugees who participated in this study that they had to go through a longwinded process and give their formal verbal consent to participate in this study, when they had participated in multiple interviews in the past that may have covered far more sensitive topics, yet had no formal consent process. The purpose of this discussion is not to question the utility of informed consent in studies like this, but simply to highlight that the ways in which refugee participants perceive the consent process may, in some cases, be incongruent with the way researchers and university ethics boards conceptualize consent.

In response to issues surrounding consent in research with refugees, Hugman et al. (2011) developed a participatory action research model to address how refugees give consent to participate in research, which entails involving refugees as partners, not simply participants; conducting participatory research involving two or more cycles; engaging refugee partners in an ongoing, relational consent process as opposed to one-time consent, etc. While their model addresses many of the challenges highlighted above, and does, in many ways, seem more appropriate than traditional consent processes, it necessitates a long-term, community based approach that is simply not feasible given the constraints of most graduate research (financial, time, scope, etc.). Moreover, Hugman et al. developed their model in a high-income, Western country (Australia), and it would therefore need to be adapted in order to be functional in low-income, non-Western contexts, particularly those in which refugees are illegalized.

The fact that this research was conducted outside Canada adds another dimension to the issue of consent, as obtaining informed consent to conduct research with a vulnerable population in a foreign country is a complicated process, often marked by a dichotomous split between what satisfies ethical requirements at universities and what constitutes ethical behaviour in the field (Sultana, 2007). For example: the fact that I had ethical approval from my university would have

been largely irrelevant to participants if they themselves had no realistic channels through which to file a grievance with the university or contact me once I had left the country.⁴⁹ Based on my experience with the refugee population in Malaysia, a small minority of refugees can speak, read and write in multiple languages (including English), while other refugees have told me that due to having no education they are illiterate, innumerate, and have difficulty explaining their experiences using formal measures of time;⁵⁰ for the latter refugees, writing and faxing a letter of complaint would present numerous challenges.

In general, consent processes may therefore be less effective at providing protection for refugees than at providing protection for institutions and researchers (Hugman et al., 2011), as consent often:

Assumes knowledge, confidence and other personal and social resources to understand and to be able to claim redress should the need arise...in practical terms, it is very hard to envisage how refugees living in a camp or in an urban community in a global Southern country can obtain tangible redress from an ethics committee of a university. (p. 659; 663)

Framing the issue of informed consent is the need to contextualize research ethics in both time and place, and while in international research this argument is perhaps best teased out in the broader debate around ethical universalism vs. moral relativism (Shaw, 2008), such discussion is beyond the scope of this chapter. Therefore, the modest claim established here is that consent procedures must be contextualized in the time and place in which the research is conducted (Shaw, 2008), and in the context of this study, what was considered ethical practice in research

⁴⁹ These challenges were largely mitigated by my affiliation with UNHCR, an argument that I develop later in the chapter.

⁵⁰ For example, some refugees I interviewed struggled to convey how many days/weeks their journey to Malaysia took; others cannot recognize, write, or recite their own UNHCR number, which consists of one letter and numbers and is a crucial way for refugees to identify themselves not only to UNHCR but also if they are not carrying their UN card when they are detained, admitted to hospital, etc.

with urban refugees in Malaysia, may not be considered ethical in research with camp-based refugees in Somalia, or with non-refugee participants.

Hugman et al., (2011) suggest that one way to mitigate some of the issues raised above is by conducting research in affiliation with an organization, and they go on to cite the example of UNHCR, as channels of communication between refugees and UNHCR will remain long after studies have ended. This can increase the opportunity for participants to air grievances and seek redress should they need. My affiliation with UNHCR was an integral part of the study design and execution, and it mitigated a significant number of potential ethical concerns, as discussed in the following section.

Conducting Research in Affiliation with UNHCR

From the outset, this study was designed in consultation with staff at UNHCR Malaysia – they provided useful input into ethical and logistical aspects of the study, and gave their approval for it to be carried out. Conducting research in affiliation with UNHCR generated a unique set of challenges and benefits, briefly outlined below.

Managing Risks and Benefits When Conducting Research With Refugees

Harrell-Bond & Voutira (2007), explore the political, physical, and bureaucratic barriers facing researchers conducting research with refugees, and though they argue for a participatory approach to research with refugees, they claim that researchers may need to, “convince them [refugees] that the research is in their own best interest either because it addresses urgent conditions of survival or because it acknowledges their presence and historicity or both” (p.290). The notion of trying to ‘convince’ refugees that participating in research is in their own best interest raises numerous issues, the most pressing of which is how to ensure that research

actually is in their best interest and does benefit them. Minimizing the risks and maximizing benefits for the refugees who participated in this study is something I was mindful of while designing and undertaking it, yet while risks and benefits could be tentatively assessed prior to starting the study, it was only during and after data collection that the full range of risks and benefits became evident.

For example, I could only begin to understand how refugee women found the experience of participating in interviews after I started data collection. As the purpose of this research was to gain insight into the health, living conditions and response strategies of refugees, a fundamental ethical consideration was that participants might discuss sensitive topics or events. While the research was designed in such a way that participants were never pressured to discuss topics that caused them distress, some participants did express strong emotions. In fact, two participants began to cry before or during their response to the first question, which suggests that it was not necessarily the interview process that upset them, but that they had been under stress prior to the starting interview, and during the interview they expressed what was on their mind.⁵¹ When a participant became sad or upset during the interview, I reminded her that she could pause or stop the interview at any point, but all of the women chose to continue the interview.⁵²

In response to the fact that some participants became emotional during the interviews, I began asking participants at the end of the interviews how they had found the experience. This enabled me to assess risks and benefits based on participants' feedback, and mitigate the possibility that participating in the interviews was causing participants undue stress. When I

⁵¹ The case study of Amina in Chapter 7 of this dissertation provides an example of a participant who became upset, as well as her later reflection on her emotions and how the interview affected her.

⁵² One advantage of being affiliated with UNHCR was that if a refugee had become very distressed or had indicated a desire for counselling, I would have been able to refer them to a partner NGO for professional counselling, but in the end neither of these scenarios occurred.

asked for their feedback on how they found the interview, participants offered a range of responses: 7 said they found answering the questions easy, and 3 said it made them feel happy. One participant said she was a bit nervous because she had never done an interview like this before and did not usually leave her home. Another participant said she found certain questions hard to answer because she had not known what to say, and because she was ashamed to answer (though she did not elaborate on what she was ashamed of). Four women said that they were glad to share their experiences with someone because talking had relieved their burdens,⁵³ and during a follow-up interview one of these participants articulated:

I feel happy to answer your questions because before this I cannot, I cannot tell my feeling to anybody, I have nobody to listen. So I can tell you my, my feeling I will share, I can share the story with you, I feel very happy to talk with you... Like the local people, the local people see our Rohingya people all of them is uneducated, so ah I will make, I will keep it confidentially because I didn't tell anyone about this, so the day after I tell the officer what has I pray, I express my feelings to the officer, so I feel really happy. (11)

While this participant had a positive experience, the range of feedback summarized above suggests that the women had differing perceptions of what it was like to participate in this study, and whether or not they found the experience beneficial was subjective.

One tangible benefit of participating in this study was that each participant received compensation in the form of a small food parcel (containing rice, milk powder, and nutrient-enriched biscuits). The parcel was sized to adequately compensate participants, but was not so large as to induce someone who was not already interested in participating in the study. I decided

⁵³ This finding is aligned with research by K. Dyregrov, A. Dyregrov, & Raundalen (2000), who studied refugee families' experience of participating in qualitative research, and found that the opportunity to tell their story was beneficial for some participants.

to give food because it was likely to be beneficial for participants,⁵⁴ and it mitigated some of the issues associated with cash honoraria.⁵⁵

Around the time I started data collection, IAD received a large number of donated food parcels to distribute to vulnerable refugees, and due to this fortuitous turn of events I was able to provide larger food parcels to some of the most needy refugees who participated in this study.⁵⁶ Prior to the start of data collection I would never have considered doing this, primarily because I assumed that providing participants with differing levels of compensation would be unethical. I came to believe, however, that as long as I provided the standard, pre-determined amount of compensation to all participants, distributing additional food items to participants who suffered from food insecurity and/or serious material deprivation, while unequal, was more equitable. For example, some participants were in good health, had stable jobs, and expressed no major problems in their life; other participants had serious or chronic illnesses, were dealing with immediate risks of eviction and food insecurity, and were in desperate financial situations. Having the option to provide the later participants with extra food helped to alleviate their immediate suffering, and was one way to ensure that participants were compensated in a way that was responsive to their significant discrepancies in need.

While the food parcels were the most tangible and anticipated benefit for participants in this study, a few interviews generated more significant, unexpected benefits. For example, one

⁵⁴ This assessment was made based on previous data, which suggested high rates of malnutrition among refugee children in Malaysia (International Organization for Migration [IOM] 2011), and consistent mention of food insecurity during prior interviews I had conducted with vulnerable refugees in Malaysia.

⁵⁵ Cash may have been seen as coercive given the financial needs of the population and thus created bias in the sample; it is also not in line with UNHCR procedures to pay refugee participants, and it may have set a precedent for future studies conducted at UNHCR.

⁵⁶ On the occasions when I did this, it was only after the interview had been completed, and I made a clear distinction between the small food packet that was provided for participating in the study and the larger food packet that was not from me or part of the study, but was provided by UNHCR to assist vulnerable refugees.

woman showed me her medical note during the interview: she had misunderstood what it said, as she thought it was a note the doctor gave her in case she had an emergency and needed to go to hospital, while in actuality it was a referral letter to the cardiology ward of a major hospital; the doctor had written, “Kindly see this patient for further assessment and your urgent opinion,” to rule out a serious heart condition that could lead to heart failure or heart attack. While the woman had not come to UNHCR that day to seek medical assistance, her participation in the study resulted in her learning what the note said and the importance of seeking further medical attention.

Reflections on My Roles as a Researcher and Aid Worker

I confronted numerous ethical dilemmas related to my standing as a researcher and former UNHCR caseworker. At the outset of the study I clearly articulated to participants that taking part in this study would not result in preferential treatment during standard UNHCR processes; it was important to make this explicit, because I did not want participants to alter their responses based on a mistaken belief that it would influence processes like resettlement. At the end of each interview I invited the participant to ask any questions, and when appropriate I provided them with basic information about UNHCR programs and processes; this was information that was publicly available but was difficult for many participants to access and understand. For example, I provided many participants with contact details and a map to NGO health clinics; I informed numerous women (who expressed interest in providing education for their children) of the location of the schools/learning centres nearest to their homes; I gave some participants the contact number for the Rohingya community organization; and I informed one woman that her husband – who was being exploited by his employer – could report this to a specific unit at UNHCR.

While providing such information was ethical and highly beneficial for some participants, it did not completely mitigate the challenges of my role as both researcher and UNHCR affiliate. One of the main challenges stemmed from the fact that a few participants repeatedly asked for assistance or resettlement during their interviews, despite my initial explanation that I was not in a position to offer such assistance. While some refugee women consistently expressed their desire for assistance and/or resettlement, others refrained completely, and one of the more perplexing aspects of this issue was that it became clear during the interviews that the extent of a participant's needs did not necessarily correspond with the frequency and urgency with which she requested assistance.⁵⁷

My experience as a caseworker meant that I was able to identify a few refugee women amongst my research participants who were in need of assistance (despite the fact that they did not always explicitly ask for it), and this raised lingering questions – for example, to what extent was I responsible for ensuring that these women were able to access/receive attention from IAD? What if I knew that they both needed and would qualify for assistance, but that their case may be overlooked amidst the hundreds of other refugees seeking assistance? These are just two examples of issues that became even more complicated when they involved units outside IAD, and while I still grapple with some of these questions, as data collection progressed I developed what I believe was an appropriate way of responding to the needs of participants in my role as researcher. In short, I shared general information about UNHCR procedures with participants, and when necessary and appropriate I referred participants' cases directly to IAD or the relevant

⁵⁷ For example, one older woman was at immediate risk of eviction and had defaulted on medical treatment because she could not afford it; she was clearly in need and was aware UNHCR could provide assistance, but she did not ask for it. Other women had greater access to financial resources and were in less need of assistance, but asked for it multiple times during the interview.

UNHCR unit. Any information I provided or referrals took place at the end of the interview, so as to minimize the effect this could potentially have had on data.

One critical aspect of the study design was that participants' responses were not linked with their existing UNHCR files; in fact, in order to ensure an increased level of anonymity and confidentiality I did not ask for participants' full names, UNHCR numbers, or other identifying information.⁵⁸ While the decision not to link participants' responses with their UNHCR files meant that I had no access to relevant data contained in their files (such as complete basic biodata, level of education, etc.), I ultimately decided that in the context of this study clear separation was necessary, primarily due to ethical issues associated with linking the participants' data (e.g. how could a refugee give informed consent to release her file when she was not allowed to access her own file, and did not know what information was contained in it?). Furthermore, this approach generated a greater sense of trust and openness so that participants need not be concerned that information they provided during the interview would jeopardize their standing with UNHCR.

The issues above stemmed largely from my roles as a researcher and UNHCR affiliate, and at times during data collection I felt a degree of tension surrounding these roles and the responsibilities associated with them. Broadly speaking, this tension surrounded my responsibility to protect participants' UNHCR information and interview data, and at the same time assist participants by helping them access the information and services they needed. Had I only been at the field location long enough to conduct my research, I would not have been aware of when, how, or to whom to refer vulnerable refugees, and ultimately my affiliation with the

⁵⁸ While a few participants' provided me with their UNHCR numbers in order for me to facilitate the aforementioned referrals, I destroyed this information as soon as the referral had been made.

research site (UNHCR), my knowledge of the refugee population, and my experience conducting vulnerability assessments with IAD is what enabled me to navigate the ethical dilemmas above and gather data in a way that was both aligned with my university's requirements and responsive to the needs of participants.

Conclusion

The examples in this chapter illustrate some of the complex ethical issues surrounding research with refugee participants, and how they manifested in the context of this study. As a researcher I was responsible for embodying ethics on an individual level, both by designing a study that complied with ethical standards on paper, and ensuring that these standards translated into ethical conduct in the specific field site and context in which the research was conducted. While I drew upon on university ethics guidelines to ensure the study design and parameters met ethical standards, I relied largely on the experience I gained at the research site prior to data collection to translate these ethical principles and navigate context-specific dilemmas in the field. For example, I drew upon my experience at the research site and with the participant population to navigate issues of consent, as there is a paucity of published literature on obtaining informed, context-appropriate consent when conducting short-term, non-participatory research with refugees.

Consent is just one of the key ethical issues pertaining to research involving refugees, and additional ethical issues emerge when researchers conduct studies in affiliation with NGOs and humanitarian aid organizations. Refugee organizations like UNHCR, and the researchers who work in affiliation with them, possess a wealth of institutional and tacit knowledge regarding conducting ethical research with refugees, and based on my experience conducting this study I believe that both UNHCR and researchers would benefit greatly if this information were distilled

into a set of guidelines for conducting ethical research with refugees. Such guidelines would address the significant lacuna in existing scholarship on how researchers working in affiliation with humanitarian agencies can conduct ethical research with refugees and other vulnerable populations; it might also bridge some of the incongruences between university ethical requirements and realities ‘in the field,’ while ensuring that participants’ rights and best interests are protected.

Beyond protecting the basic rights of refugees, I would argue that conducting ethical research with illegalized refugee participants means accepting a degree of advocacy as an ethical imperative. Mackenzie et al. (2007) claim that just as it is essential to identify both causes and cures in biomedical research, it is not enough to simply identify issues in social science research - one must address them when possible. Turton (1996), is even more explicit in his commentary on forced migration in Africa, stating: “I cannot see any justification for conducting research into situations of extreme human suffering if one does not have the alleviation of suffering as an explicit objective to one’s research” (p.96). At the heart of this study is an ethical responsibility to not only gather and analyze data in an ethical manner, but to ensure that the results are disseminated among key stakeholders to inform programs and policies that address SDH and ultimately improve the quality of life for refugees in Malaysia.

Chapter 6: Document Review

Introduction

The Individual Assistance Department (IAD) at UNHCR Malaysia receives thousands of requests for financial assistance (FA) and/or medical assistance (MA) from refugees each year.⁵⁹ These requests – which come in the form of faxes, letters, emails, medical memos, phone calls, and walk-ins – are reviewed by UNHCR officers and then prioritized for assessment. Cases that are prioritized are then assessed by a UNHCR caseworker: normally, an interview is conducted with the refugee and a brief document will be written. Caseworkers use information gathered during the interview to write documents which usually outline: the reason assistance is required; pertinent facts about the refugee's life; whether or not they are considered to have an added vulnerability;⁶⁰ and recommendations regarding assistance.

I was affiliated with IAD in various capacities between 2011 and 2014. Prior to starting data collection for this study, I had conducted over 100 financial and medical assistance assessments for IAD. A few of the financial assistance assessments I conducted in 2012 were with Rohingya women, and thus the resultant documents were included in my review. While the information I present in this chapter is taken from FA documents, my analysis and interpretations are strongly influenced by my personal experience and, in that sense, reflect my roles as both a researcher and humanitarian aid worker.

⁵⁹ As IAD does not have the capacity to assess each request, requests for assistance are prioritized (based on vulnerabilities, urgency, etc.). It was not possible to ascertain what percentage of Rohingya refugee women who requested assistance in 2012 were prioritized for assessment.

⁶⁰ A list of the categories of added vulnerabilities relevant to the refugees in these documents is presented in Table 1.

For this chapter, I reviewed FA documents that were conducted with Rohingya women in the 2012 calendar year.⁶¹ These documents contain a range of information related to social support, family composition, employment, housing/living conditions, security issues, health and more. Given the limited amount of published, publicly available data on refugees in Malaysia, this information is helpful in that it generates insight into the context surrounding refugees in Malaysia, as well as the UNHCR processes in place to assist vulnerable refugees. The specific aim of the review is to provide context/background for my own research findings, with particular emphasis on identifying and explicating factors that affect the health of Rohingya women in the Malaysian context.

Chapter Outline

I begin this chapter by providing a brief explanation of the documents, and limitations of the review; I then present an overview of the information contained in the documents, and conclude by considering the institutional context in which the documents were written.

Inclusion and Exclusion Criteria

Financial Assistance (FA) and Medical Assistance (MA) are two distinct types of assistance: MA is almost always issued on medical grounds (i.e. assistance is issued to refugees with serious medical conditions), whereas FA is issued to refugees with needs stemming from a broader range of added vulnerabilities (such as disabled refugees, SGBV survivors, single parents, etc.). While I reviewed all MA and FA documents from 2012, I focus this discussion solely on FA documents, because they provide greater insight into the diverse range of issues affecting vulnerable Rohingya women in Malaysia, as well as pertinent background information that contextualizes the research findings generated by this study.

⁶¹ I received approval from UNHCR to use these documents anonymously for the purpose of this study.

I reviewed all of the 2012 FA assessments conducted with Rohingya women that were available in the primary assessment folders. Nevertheless, a small proportion of the documents may have been saved elsewhere, and it was not possible to include these in the review. In total, I reviewed 52 FA cases from 2012, and four of these were excluded (three because they were incomplete or contained insufficient information; one because it contained conflicting information about the refugee's ethnicity and I could not ascertain if the refugee was in fact Rohingya). As a result, a total of 48 cases form the basis of the information in this chapter.

Parameters and Limitation of the Document Review

The information is based on refugees who had been identified as having an added vulnerability and prioritized for assessment, and as such, findings are biased towards more vulnerable refugees. This means that the information presented neither represents nor reflects the experiences of most female Rohingya refugees in Malaysia (i.e. these cases are likely to be more extreme). That said, that the women on whom these documents are based are known to have added vulnerabilities provides an interesting point of comparison with the women who participated in the semi-structured interviews (as added vulnerability status was not a criterion in the latter's selection).

One constraint of this document review is that the documents contained variable information, which limited comparability between them; for example, while most of the documents stated the woman's age, marital status, number of children, etc., some documents omitted this information. The variable information contained in the documents is, in part, due to

differences in the type of cases being assessed, as well as differences between the caseworkers.⁶² Despite the fact that standard information was not included in every document, the purpose of reviewing the documents was to provide a broad overview rather than a statistical representation of the population, and as such it was still possible to generate relevant findings that provide context for the rest of this study.

Information from the Financial Assistance Document Review

In order to present information in this section in a clear and organized manner, themes and categories that emerged during the FA document review have been grouped under the following sub-headings: age and added vulnerabilities; children and extended family; security; health; housing and rent; employment; support; and assistance.

Age and Added Vulnerabilities

All 48 documents included the age of the Rohingya women being interviewed, which ranged from 16 to 76 years (average age = 37 years). Forty-four of the refugees were assessed to have one or more added vulnerability, the most common of which were being a single parent, elderly,⁶³ or having a family member (usually the husband/sole provider) in detention.

⁶² These differences include interview technique, years of experience, gender, and nationality of the caseworkers. All of the documents were written in English, and the caseworkers had varying levels of competency in written English, which is another factor that contributed to differences between the documents. These issues are discussed further at the end of this chapter.

⁶³ There is no universally accepted age at which people are considered old/elderly. The agreed age at which the UN identifies people as being old is 60 years and above, though exceptions may be made on a case-by-case basis depending on mitigating circumstances (WHO, 2013).

Table 1

Age

Age (years)	Number of women
Between 16-19	2
20-30	21
31-40	10
41-50	3
51-60	7
61-70	3
71-80	2

Added Vulnerabilities

Added vulnerability	Number of women
Single parent	13
Elderly	11
Detention	10
SGBV	4
Other	4
HIV	3
SGBV & Single parent	1
Minor & Single parent	1
Serious medical condition	1

Children and Extended Family

Three documents did not specify whether the women had children; according to the rest of the documents, 43 women had children, and only 2 did not. The number of children the women had ranged from 1 to 6 (average = 2.9), and 34 women indicated they were living with children who were minors (i.e. under 18).⁶⁴ Two women had adopted children, and one woman – pregnant with her second child at the time of the interview – said she wanted to give her baby up for adoption. Nearly one-third of the women said they had extended family in Malaysia (e.g. siblings, in-laws, nieces/nephews, grandchildren etc.), while 7 said they had no extended family.

Security

Most of the information in the documents regarding refugees' safety and security pertained to risk factors, although two protective factors were noted. One protective factor,

⁶⁴The information in the documents provides a good indication of the number of children Rohingya women have; it is not, however, a precise measure of their total number of children, because the women may have had children they did not mention (i.e. adult children; children who are in Myanmar or another country, etc.).

identified by 4 women who had been detained, was that they were released upon showing their UNHCR card and/or direct intervention by UNHCR staff. The second protective factor, articulated by 2 women, was that they felt safer in Malaysia because they were able to speak Malay language. Factors that put refugees' safety and security at risk were mentioned more frequently in the documents, and can be roughly grouped into two categories: SGBV and arrest/detention for immigration issues or illicit activity.

SGBV

Four of the assessments were conducted with women who were survivors of SGBV. All of these women had suffered multiple instances of domestic violence perpetrated by their husbands, although the scope and severity of the incidents varied. In some documents, information about the specific violence women had been subjected to was quite vague: one document stated that the woman had suffered 'abuse' from her husband on many occasions prior to their divorce, another said the woman faced 'maltreatment' from her husband and in-laws. The other two documents provided more detailed depictions of the violence: one stated that the woman's husband had assaulted her and broken her hand; the other stated a pregnant woman's claim that her husband was a drug user who had assaulted her so severely that she required stitches.

Arrest/detention

Nine of the documents noted that the women's husbands had been either arrested or detained for reasons related to immigration offences and/or criminal activity. In one instance, not only was the husband detained, but the woman and her father had also been detained by social welfare officers during an immigration raid, and were only released when UNHCR intervened. Another document noted that UNHCR helped secure the release of a woman and her 4-month-

old child, who were detained by the Welfare Department along with others accused of begging. Refugees' fear of being arrested in raids was apparent in the documents, and it influenced life choices such as methods of subsistence. For example, fear of arrest was cited as the reason why a diabetic woman worked odd jobs as the sole provider for her adult children: the family believed that UNHCR cards offered protection from arrest/detention, and while the mother had a UNHCR card, her children did not.

Four documents cited incidents related to forced deportation and/or human trafficking – in one case, an elderly woman's husband used to beg on the street, but he was detained twice for begging and sold to a human trafficker. Another woman claimed to have recently found three of her children who had gone missing in Thailand months prior. She said an agent told her she would need to pay him to bring her children to Malaysia, but she could not because she was already struggling to support herself and her other children.

The documents also contained information about entire families being arrested/detained. One family had been arrested by the authorities a total of three times. The first time, the whole family was deported to Thailand, but they quickly managed to return to Malaysia; the other two times, they were released when they showed their UNHCR cards. Another family was also arrested three times. The first two times, the whole family was deported to the border and managed to come back to Malaysia within a few days; the third time, they were released after showing their UNHCR cards. The woman from this family stated that aside from these three incidents, they experienced no threats from the authorities and they felt fairly safe in Malaysia.

The cases cited above highlight a few relevant points, including the fact that human trafficking and arbitrary arrest/detention are security issues that crosscut the experience of refugee populations in Malaysia, affecting women, men, adults, children and entire families. The

documents also indicate that UNHCR cards do offer refugees protection from arrest and detention; unfortunately, the documents do not contain enough information to make more definitive statements on this issue (i.e. it is unclear how many of the women/their husbands showed the authorities their UNHCR cards yet were detained anyway, or how many had to show their UNHCR cards *and* pay a bribe, etc.).

Four documents specified that the women's husbands were arrested on criminal charges (drug possession, possession of stolen property, theft, and fraud). The distinction between the refugees who had been detained on immigration infractions and those who had been formally arrested and criminally charged is an important one. While the former are likely to be held for a number of weeks or months in detention before UNHCR can facilitate their release, refugees charged with committing crimes are liable to face long and potentially harsh sentences (e.g. imprisonment, caning, whipping, fines etc.), and UNHCR does not necessarily intervene in such cases.

Health

Health conditions. Half of the women interviewed said they suffered from a health condition, the most frequent of which was hypertension (which affected 6 women). Other common conditions included diabetes and gastric problems. These findings (i.e. high prevalence of self-reported hypertension among a vulnerable population) are aligned with a well-established body of literature that links low socioeconomic status (SES) with increased risk of conditions such as hypertension and diabetes (Gorman & Sivaganesan, 2007; Marmot, 2007). Pickering (2006) asserts, "the possible pathways by which SES affects cardiovascular disease include effects of chronic stress mediated by the brain, differences in lifestyles and behavior patterns, and access to health care" (p.262). These findings are also aligned with recent studies in the field

of refugee health, which found high rates of hypertension and diabetes among other refugee populations: 22% of Iraqi refugees in Jordan had hypertension and 11% had diabetes (Mateen et al., 2012, p.444), and among one sample of refugees undergoing outpatient psychiatric treatment in the U.S. the prevalence was even higher (42% had hypertension and 15.5% had diabetes) (Kinzie et al., 2008, p. 108).

Serious health conditions. Some documents noted that the women suffered from very serious health conditions: 5 women had heart problems, 3 women had HIV, 2 had vision problems, one woman had a serious spinal problem, and one woman had a health condition (affecting her legs) that required surgical intervention. Some women with chronic conditions that required medication and regular follow-up at hospitals or clinics, which contributed to a cycle in which the costs associated with medication and medical care contributed to their financial difficulties, and financial difficulties impeded their ability to access medical care. Six women explicitly stated that they had abstained from seeking medical care (or defaulted on suggested treatment) because they could not afford it. Of these 6 women, only one had mild symptoms (she reported difficulty breathing when she felt depressed); the other 5 women had more serious conditions that could have potentially fatal complications if not treated.

For example, one woman with diabetes, heart disease, and hypertension reported going on and off her medication because she could not always afford it, while the woman who required leg surgery did not have the operation because she could not pay for it. One woman had pulmonary TB and was required to visit a clinic daily to take her medication: her doctor advised her to have a chest x-ray done, but she was unable to pay for the x-ray and transport to/from the hospital. Lastly, 2 women stated that they did not take their children (who had flu-like symptoms) to see a doctor because they could not afford the costs.

Of the 3 women with HIV, all were on highly active antiretroviral therapy (HAART). HIV infected refugees under the protection of UNHCR Malaysia have access to HAART and the medical care they need to manage the illness; they also have access to refugee community health workers who monitor their health and wellbeing. Despite this support, the HIV patients faced serious challenges related to both subsistence and health. One of the HIV positive women had defaulted on HAART treatment. Another said that because of her illness she was unable to work and support her three children (her husband was also unable to work, as he had been injured in an accident). The third woman with HIV resorted to begging in order to support her four young children, and the caseworker noted that her newborn baby appeared malnourished.

Nutrition. Four documents noted issues related to nutrition. One stated that the woman interviewed was anaemic, and two documents referred to nutritional issues with children: in one case the husband was detained, and the wife (allegedly a drug user) and children ate one meal a day. Another woman, a single mother and SGBV survivor, claimed that her child frequently fell ill with flu and fever, which the caseworker noted might be due to poor nutrition. Unlike some refugees, however, this woman and her child often accessed the free medical care available to them at a refugee health clinic. Nutrition related issues were also noted in the case of a young woman, 8-months pregnant at the time of the interview, who allegedly had no money, had not been getting enough to eat, and had no way to pay for her delivery or baby supplies.

Family members suffering from health conditions. Fourteen of the documents noted that the women's family members – most often their children or husbands – suffered from an illness, medical condition or accident-related injury. For example, one woman said her husband had hypertension, diabetes, and schizophrenia, while two other women claimed their husbands had been injured in accidents; in all instances the women said their husbands were unable to

work due to their conditions. Two of the women had children with asthma. One was a baby who had needed to be hospitalized due to her asthma. The other was a child who required medication and hospital check-ups, which the single mother estimated cost RM150/month (\$50)⁶⁵; this was a significant amount considering the family's rent was RM200/month (\$67).

The health problems outlined in the FA documents are less severe than those cited in the MA. This is to be expected, because while assessments for financial assistance may be undertaken due to any number of vulnerabilities (e.g. SGBV, detention etc.), medical assessments are only done with refugees who require treatment for serious medical conditions. Nevertheless, it is evident from the FA documents that there was a high rate of reported morbidity among female Rohingya refugees, and that their health conditions were linked to and affected by the circumstances in which they lived.

Housing and Rent

The majority of documents (35 of 48) included a monetary figure pertaining to the cost of accommodation. It is challenging to compare and derive meaning from this data, however, because the type and detail of information provided in each document varied so much.⁶⁶ While some documents simply stated the monetary rental cost with little description of the accommodation, other documents stated whether the cost was born by the woman herself or community members; who the woman lived with and how much her family's share of rent was; the number of rooms she rented, condition of the accommodation, etc.

⁶⁵ Malaysian currency is the *ringgit* [RM], and the exchange rate at the midpoint of data collection was 1.0 Canadian dollar [signified here with the dollar sign \$] to 3.0 Malaysian *ringgit*; this is the exchange rate used to calculate monetary figures throughout this dissertation (Fx Currency Exchange, 2013).

⁶⁶ The variable information is, in part, due to the fact that most of the interviews were conducted over the telephone, others in person at UNHCR, and a few were conducted by an officer who visited the refugees' homes.

The women who paid rent spent between RM150 (\$50) and RM700 (\$233) each month. The most frequently paid (mode) rental fee was RM250 (\$83), and the following examples describe the varying types and quality of accommodation inhabited by the women who paid this amount. One woman, who had four young children and was HIV positive, lived in a dilapidated one-story house with three bedrooms; she and her family stayed in one room, while other tenants occupied the other two rooms. Another woman, struggling to support her two young children while her husband was in detention, was supposed to pay RM250 (\$83) to her friend; for this amount she and her children were allowed stay in the hall of her friend's home, but as she could not afford to pay she was at risk of homelessness. Another woman (whose husband was also in detention) stayed with her two young children in a room she rented from a friend, an arrangement that could continue until her husband was released from detention (no further details were given about the physical space they occupied, who else lived in the home, etc.).

The highest rental fee (RM700/\$233) was paid by a refugee woman and her husband who lived with 11 other family members. According to the home visit document, they stayed in a large semi-detached house that had two upstairs bedrooms, a living room, a large dining room and spacious kitchen, as well as amenities such as a TV and satellite dish, gas stove, fridge, and washing machine. In contrast, the woman with the lowest rent paid nothing at all, as she and her three young children occupied a wooden shack that had been built illegally and was soon to be demolished. A few documents described cramped, sparse, and in some cases unhygienic living conditions: one document used the adjectives dirty, damp, untidy, and musty to describe a refugee's living conditions, while another document stated that the refugee's accommodation was an unhygienic, two room shack in which the kitchen also served as a bedroom.

One issue mentioned consistently in the documents was the number of women who were behind in rent and/or at risk of eviction. It is notable that all of the women who said they had been evicted or were at risk of eviction had one of three added vulnerabilities: their husbands were detained, they were SGBV survivors, or they were single parents. Thirteen women stated that they were between 2 and 6 months behind in rent, and some were also behind in utilities (e.g. one woman, who lived with her five minor children, had already had the electricity cut off, and was at risk of having the water cut off as she had not paid the bill in 2 years).

For some of these women, the kindness and discretion of their landlord mitigated the potentially devastating consequences of their rent-debt. This was the case for one single parent, whose landlord took pity on her and waived 2 months rent; the woman was 5 months behind in rent and struggling to subsist, because her husband had gone missing 3 years prior. She was also suffering from pulmonary TB, which prevented her from working, and her only support came from her sister and 94-year-old father who worked a few days a week. For women whose landlords were not so kind, their inability to pay rent often resulted in precarious housing, and in total, 6 women had either been evicted or were at risk of eviction (e.g. 2 of these women specified that they were at risk of eviction if they did not pay rent by the end of the month, one said she had been evicted while her husband was in detention).

In the latter case, community support mitigated the consequences of her eviction, as someone from the Rohingya community intervened and provided the woman and her baby with accommodation. Community members provided accommodation for 3 other women who had been evicted, but they had been warned they could only stay temporarily. One of these women, whose husband was in detention, was at real risk of homelessness. She was moving with her

three minor children every few days to stay with different community members, as no one could (or would) allow her to stay any longer than that.

The fact that community support was neither unconditional nor indefinite was evident in the case of a young SGBV survivor: she was 8-months pregnant and had been abandoned by her abusive husband. While a community member had provided her with accommodation, she was allegedly at risk of homelessness, as the woman would not let her stay after the baby was born. Nearly all of the women at risk of eviction were unemployed, which made it hard for them to secure and pay for adequate accommodation.

Employment

Thirty-two of the forty-eight women (67%) had no formal or informal employment: 13 of these women had between 1 and 5 children (all of whom were minors, ranging from infants to youth) and some were pregnant at the time of the interview, which made it difficult for them to work. Nine documents cited poor physical health as a reason why the women were not working. An additional five documents cited age as a factor inhibiting women's ability to work (i.e. one document said the woman was a minor who claimed she could not get hired because of her young age; the other 4 women were older and suffered from various medical problems).

Sixteen of the women (33%) undertook formal or informal work: 3 worked as housecleaners, 3 went out begging, 3 worked in restaurants, 3 sold tissues or flowers on the street, 2 worked at a factory, one sorted food items, and one worked odd jobs. It is hard to compare the remuneration the women received for these jobs, as the documents reported the information in various different ways (i.e. some cited wages by day, some by month, and few noted the number of hours or days the women worked). While it is therefore difficult to

determine the women's average wage, the information is nevertheless indicative of the spectrum of wages they earned.

Rohingya women working in restaurants and as housecleaners appeared to earn the most – between RM500-650 (\$166-217) per month.⁶⁷ The only indication as to how many hours/days they worked to earn this wage is from one document, which said the woman worked 26 days a month and earned between RM500-600 (\$166-200), which on average equates to a scant RM21 (\$7) per day. A woman who worked in a factory said she worked 10 hours a day, 5 days a week for RM450 (\$150) per month; she also sold clothes on the side for RM50-100 (\$17-33) per month. Some documents cited earnings per day as opposed to per month: begging at mosques earned RM30-40 (\$10-13) per day, dishwashing RM15 (\$5) per day, and housecleaning RM20-30 (\$7-10) per day.

For women who managed to find work but did not have family to look after their children, the cost of childcare consumed a large portion of their meagre earnings. For example, 3 women said they paid a friend or community member between RM200-300 (\$67-100) per month to look after their children while they worked, which was between one-third and one-half of their monthly earnings. For school-aged children, a viable alternative to childcare was attending an educational institution such as a religious school or UNHCR supported learning centre.⁶⁸ The woman who had been taking her children to work with her at the factory realized this, and she asked the UNHCR officer assessing her case to help her find education for her children; the

⁶⁷ These findings can be considered alongside results from the 2012 International Rescue Committee study (Smith, 2012, p.45), which reported that 74% of Myanmar refugee and asylum-seeker respondents in Malaysia earned between RM500-1000/month (\$167-333). This figure does not include the Mon ethnic group (who earned more on average). The author also notes the need for further information on variation in earnings between households, the type of jobs available to refugees based on geographic location, etc.

⁶⁸ Discussion of education here is limited, because although it was mentioned in some of the documents, it was not discussed in detail. Please refer to the Chapters 8 and 9 of this dissertation for more in depth exploration of issues surrounding refugee education in Malaysia.

officer made a referral to accommodate this request, and noted that placing the children in school would save the refugee up to RM300 (\$100) per month in childcare costs.

Yet there are also costs associated with many of the educational opportunities available to refugee children in Malaysia. For example, one woman said she paid RM350 (\$117) per month to send her children to a religious school, despite the fact that she was in debt. For women who sent their children to UNHCR supported learning centres, the school fees they paid varied (e.g. one woman paid nothing, while another paid RM100 [\$33] per month). For some women, the cost of education was prohibitive, and a few women said their children had never attended school, as they could not afford the costs associated with it.

Some children did not go to childcare or school, and 5 women said that they took their minor children to work with them. In one case, the woman used to occasionally take her minor children to work alongside her at her job, which was sorting food items. She worked 6 days a week and earned approximately RM250 (\$83) a month, RM8-9 (\$3) per day when she went on her own, and RM12 (\$4) per day when she took her children, which meant the children cumulatively earned the equivalent of \$1 for a day's work. This was the only case in which a woman took her children to work at her formal place of employment; more common were the women who took their children to beg in the street.

One woman used to take her three young children to beg, and would use the RM40-50 (\$13-17) per day they earned to buy food, but she claims to have stopped begging after she and the children were nearly arrested. Since it is illegal for refugees to beg or sell goods such as tissues and flowers in the street, those caught doing these activities are at risk of being detained

by RELA,⁶⁹ police, immigration officials or social services. In one incident, social services intervened in the case of a young Rohingya woman who had taken her three children to sell flowers on the street. Social services contacted UNHCR about the incident, which prompted IAD to undertake the FA assessment that was included in this review. Another woman took her five minor children out to sell tissues over the weekend; she said she was able to earn RM20-30 (\$7-10) per day, which she used to buy food, milk powder and diapers for the children. She noted that the weather impeded her ability to work, and she could no longer earn much because it was the rainy season.

Most of the women assessed for financial assistance – inclusive of those with formal jobs, those who went begging, and those who were not employed – struggled to support themselves and their families, and many relied heavily on the support of family, friends and community members.

Support

According to the documents, 10 (21%) of the women said they were not receiving support from family, friends, community etc., while 34 (71%) of the women were. While this support sometimes took the form of small cash donations, it was often ‘in-kind’ support related to basic subsistence (e.g. food, accommodation, etc.). Of the women who indicated they were receiving support, 10 specified they were receiving support from family members (including their husband, grandchildren, parents, in-laws, nieces, and siblings), 7 said support came from community members and neighbours, and 7 said they were receiving support from friends.

⁶⁹ RELA stands for *Pasukan Sukarelawan Malaysia*/The People’s Volunteer Corps; it is a volunteer civilian force operating in Malaysia with the mandate and authority to seek out “Illegal Immigrants” (Ministry of Home Affairs Malaysia, 2013) and report them to police and/or immigration authorities.

The women were resourceful in soliciting other support to meet their needs. For example, one woman managed to acquire food from the local grocery shop by promising to pay when her husband was released from detention; one elderly lady found support from friends and neighbours who allowed her to live/eat with them (they even provided her with money for medical care); and one woman received food parcels from a local NGO. Lastly, one young woman in her late teens had divorced her husband after the birth of their first child: she was being supported by a Rohingya family who had taken her in because they felt sorry for her, and she was also receiving a small amount of money for subsistence costs from a male friend.

Six women mentioned being supported by their children – in some cases their children were adults, in other cases they were still minors. One was a recently widowed woman who received no support from extended family or community members, so she depended on her eldest son (who worked as a dishwasher for RM500/\$167 per month) to support her and her three minor children. Women who were entirely or partially dependent on others for support were vulnerable (to food insecurity, eviction, etc.) when their support was interrupted or stopped altogether. For example, one elderly couple tried to earn money begging at a mosque, and they were also assisted by Malaysian neighbours who occasionally provided them with food, but the precariousness of their situation was evident in the fact that if they did not receive donations and could not afford food, they would not eat. This level of insecurity was also experienced by one woman in her early twenties: she had been abandoned by her husband when she was pregnant, and was left supporting their four small children on her own; the caseworker noted that she had been subsisting on one meal a day and seeking donations from anyone who was willing to help.

Assistance

Nearly every document included a recommendation, made by the caseworker, regarding whether the woman should receive assistance from UNHCR (and if so, the amount and duration of assistance).⁷⁰ Monthly financial assistance was recommended for 30 of the 48 women (63%), emergency financial assistance was recommended for 2 of the 48 (4%), and both emergency and monthly assistance was recommended for another 2 of the 48 (4%). Food parcels were recommended for two women (one of whom also received monthly assistance). Two guarantee letters were issued (one for milk powder, the other for hospital costs for a woman who also received emergency financial assistance).⁷¹ The issue of assistance – namely the women’s perceived need for it and difficulty obtaining it – was a recurrent theme in the interviews I conducted, and this issue is discussed further in Chapters 8 and 9.

The first half of this chapter has provided an overview of the FA assessments conducted with Rohingya women in 2012. UNHCR is a key structural determinant of health for refugees in Malaysia,⁷² and it is therefore important to consider not only the needs and concerns of Rohingya refugees, but also how UNHCR assesses and responds to those needs. The following section therefore considers the institutional context in which these documents were written, and factors that may have contributed to differences in their content.

⁷⁰ Multiple, distinct forms of assistance exist. Cash assistance can take the form of monthly financial assistance (when cash is delivered to vulnerable refugees one time each month for a set number of months) or emergency financial assistance (when cash assistance is issued to vulnerable refugees on an immediate, one-time basis).

⁷¹ Food parcels are another form of assistance that may be provided (the contents of these vary, but they generally include fortified milk powder and staple foods such as oil, pulses and grains). A guarantee letter is an official document, issued to hospitals and medical centres, through which UNHCR agrees to pay a specified financial sum towards the cost of a refugee’s medical treatment.

⁷² See Chapters 8 and 9 for examples and arguments supporting this assertion.

Considering the Context: Assistance Documents and Their Authors

The variable range, depth and quality of information included in the documents presented numerous challenges for this review. In particular, I encountered challenges comparing the documents and calculating basic statistics from the data, as some of the documents lacked key pieces of information. While it is important to acknowledge inconsistencies between the documents and consider their potential effects on the review (see the limitations section), rather than perceiving these limitations as flaws, I argue that they provide a point of departure from which to consider why the documents contained such a variable range and depth of information.

This is particularly important because the documents were not written for academic purposes, they were written in order to determine who – amongst refugees identified as highly vulnerably – was most in need of assistance. Most of the documents contained recommendations that had a profound, sometimes life changing impact on the lives of refugees, and explicating the context in which they were written is a valuable way to increase our understanding of the people and processes that govern refugee assistance. An overview of factors influencing the range, depth and type of information in the documents is therefore provided below.

Method of Interviewing

The method of interviewing (over the telephone, in person at UNHCR, or at a refugee's home) influences the type and accuracy of information gathered during assessments. For example, while conducting interviews over the telephone using an interpreter is often the most feasible/economic method of undertaking assessments, limitations inherent in this method include inability to see refugees and their body language, facial expressions, and physical state (e.g. whether they are frail, thin, immobile, etc.). When interviews are conducted in person at the UNHCR office, a caseworker has the advantage of seeing the refugee, yet the assessment is still

limited because – as with telephone interviews – the officer cannot see or verify the refugee’s living conditions, meet their caretaker or family, etc. As such, home visit assessments tend to contain more information regarding the refugee’s living situation, and this, in part, accounts for some of the variation in the FA documents.

Education and Experience

Caseworkers have different levels of education (ranging from high school diplomas to masters degrees); they have worked with IAD for various lengths of time (from a few months to years); and for most of them English is their second language, factors which are likely to affect both the style and content of the documents. It is important to note from the outset that there is no gold-standard formula for determining which refugees are the most vulnerable and what assistance they need; rather, there are sets of procedures, guidelines, forms, and an institutional culture which inform and shape what are, to a certain extent, subjective judgments.

The way in which caseworkers make these judgments is likely affected by a variety of factors, including their level of formal education (as this may influence their capacity for logical reasoning and critical thinking), and the extent of their tacit knowledge (i.e. their level of experience as a caseworker could influence everything from the cases they are assigned to their final recommendations). A caseworker’s level of involvement in a case is also likely to affect the way they assess it and the level of detail they include in each document. For example, a caseworker might be more thorough the first time they assess a refugee for assistance, and less thorough if they have been involved with the case for months/years and have already written multiple documents pertaining to a particular refugee.

Circumstances in Which Assessments are Conducted

Each document could have been shaped – to varying degrees – by the circumstances in which it was written. For example, sometimes caseworkers write documents in stressful circumstances, such as when a refugee in urgent need of assistance arrives at UNHCR late in the afternoon. In such instances, the caseworker must rush to complete the administrative steps required to issue emergency assistance by the end of office hours (this includes conducting an interview assessment, writing the document, and multiple administrative steps to obtain and issue assistance). Other examples of circumstances that could influence the quality and depth of documents are when a caseworker is writing a document/recommendations so that they can issue a guarantee letter for a refugee who is being rushed to surgery; or when they are writing a series of documents in the afternoon, after spending the morning undertaking vulnerability assessments with dozens of refugees – a task which can be both intellectually and emotionally taxing.

These examples of how situations can affect the quality and content of the documents reviewed in this chapter are not meant to imply that variation between documents always stems from stressful circumstances or time limitations, as much of the time caseworkers have the resources, time, and support they need to do thorough assessments. When thinking about differences between documents, other important considerations may therefore revolve around emotion and impartiality.

Emotion and Impartiality

In my experience, I have found professionalism, compassion, impartiality, and equitable decision-making to be competencies many caseworkers strive to embody when conducting assessments and making recommendations; yet emotion – which may, in some instances, impinge on these competencies – is also a key component of casework. It is evident from even

the brief discussion above that the type of cases assessed often involve, among other things, women living in situations of abject poverty; women who have been physically and sexually abused; women suffering from serious, sometimes terminal medical conditions; and women who have been subjected to a host of other injustices and indignities. These cases are bound to invoke an emotional reaction, and the distinct ways in which caseworkers process emotion and ‘make sense of’ their cases likely accounts for some of the variation in the content and style of the documents. This does not mean that caseworkers are only influenced by emotions associated with ‘helping,’ (such as empathy, compassion or guilt); indeed, a caseworker may feel anger, frustration, apathy, or a myriad of other emotions. My point is that emotions may influence what, if anything, a caseworker decides to recommend in terms of assistance, as well as the information they chose to include or exclude from the document in order to justify their recommendations.

Discussion

The 48 financial assistance documents reviewed in this chapter provide insight into the lives of vulnerable Rohingya women in Malaysia, in particular, the context in which they live, their needs, and response strategies to the challenges they face. Some of the key challenges they confront stem from difficulty finding and maintaining employment, arrest and/or detention, food insecurity, medical issues which are compounded by limited access to health care, inadequate and unstable housing, and SGBV.

There are evident interconnections between some of these challenges: for example, one 30-year-old woman was a single parent with four minor children. She could not afford to send her children to school, which meant she had to look after them. As such, it was not possible for her to undertake formal employment, and in the past she had resorted to collecting garbage for

RM5-10 (\$1.67-3.33) per day. Her daughter suffered from asthma, and needed medication, which cost approximately RM150 (\$50) per month. Due to her expenditures and lack of income, this refugee was 3 months behind in rent and was at risk of eviction. While she had siblings in Malaysia, they were not able to assist her because they too were struggling to support their families.

While it is clear that this refugee faced formidable, interconnected challenges, by virtue of being a female single parent, she also had access to community and institutional support that was not available to couples or families. For example, if she was evicted, she and her children could have sought help at a women's shelter, at least temporarily. It is much more difficult for two parent families to access shelter services, however, and while families in crisis might be eligible to receive emergency or monthly cash assistance from UNHCR, a family at risk of homelessness would ultimately need to draw on NGO or community support to locate new housing.

This was the case for one woman, her husband, and their six children whose house had burned down in the month prior to the assessment. The family lost all their belongings including their clothes, household and personal items in the fire. The husband, who supported the family, lost his job because his employer had provided their house and needed time to recover his loss. Since they had nowhere else to go, the woman and her family had taken shelter in the place where her sister (a single mother of four) stayed, but all three rooms in the dwelling were occupied so the family was staying in the cramped hallway. The adults supported the 10 children by collecting scrap metal to sell, and borrowing money from parents and siblings.

In the Malaysian context, I employ the term community support broadly, to encompass material (and sometimes psychosocial) support refugees receive from family, friends, NGOs, and

other members of the refugee community. Had I been assessing the aforementioned case, I would have concluded that this family had community support, as the woman's sister provided them with shelter, and they were able to borrow money from other family members. It was clear from the documents, however, that caseworkers had different understandings of the term community support. For example, in one document the caseworker noted that the refugee's shelter and basic subsistence needs were provided by her friends, yet the caseworker also stated that the refugee was not receiving any community support.

Varying interpretations of concepts such as community support may have affected the recommendations, as many caseworkers factor the level of community support a refugee is receiving into their assessments. Another issue that affected assistance recommendations was the degree to which caseworkers believed the refugees. While there is no formal place in the assessment template to indicate the perceived validity of the refugee's claims, in one document the caseworker explicitly doubted whether the refugee was telling the truth about where she was living, with whom, her level of community support, etc. Statements in that document are prefaced with 'the refugee claims' and the caseworker did not recommend assistance, as ultimately he/she did not believe the refugee's story. Another document also noted that the refugee lied about her employment: she claimed to have stopped working because of ill health, but her daughter, who spoke to the caseworker separately, said that her mother was still employed at a factory.

The information reviewed in this chapter should therefore be considered with the understanding that refugees who were interviewed may have withheld information or misled the caseworker in order to obtain assistance. I do not intend to imply that refugees plot or scheme in order to capitalize on assistance; based on my experience conducting assessments, I think it is

more likely that dire circumstances compel some refugees to lie in order to obtain resources they desperately need. In other words, refugees may say things they think will help them get assistance, and given that most assessments are conducted over the phone, the validity of any given claim can be difficult to decipher.

Issues surrounding the validity of claims made by refugees underscore the chasm between the academic and humanitarian value of these documents. The concerns of a humanitarian caseworker who doubts the claims made by a refugee are likely to be immediate and quite practical. For example, are lies told by one refugee indicative of a common tactic employed by refugees to get assistance? Do caseworkers need to be more discerning in their assessments? Should lying disqualify refugees – who may still be vulnerable and in need – from receiving assistance?

The questions of an academic who learns of such a scenario might be quite different. What features of their past and present circumstances compel some refugees to lie? Are refugees who lie simply embodying their assigned role in a system of asylum that systematically questions (and, increasingly, casts doubt on) their past and present life circumstances (Eastmond, 2007; Fassin & D'Halluin, 2005; Finch, 2005)? All of these questions are relevant, particularly in this chapter, in which individual documents written for a humanitarian agency were reviewed for academic purposes. While it is beyond the scope of this dissertation to answer all of the questions raised above, issues surrounding the validity of claims made by refugees emerged at multiple points during this study (including during primarily data collection and analysis) and they are revisited in the Chapter 9.

Conclusion

In this chapter I reviewed financial assistance documents pertaining to Rohingya refugee women that were written by UNHCR caseworkers in 2012. The purpose of reviewing these documents was to sensitize readers to the context in which female Rohingya refugees live and seek assistance in Malaysia – not only the social and environmental context, but also the context in which UNHCR caseworkers assess and respond to the needs of refugees.

Key points of discussion pertained to how refugees are assessed for financial assistance, and factors that influence the assessment process and recommendations (such as caseworkers, added vulnerabilities, etc.). The value of such information is that it provides insight into the perspectives of humanitarian aid workers at UNHCR, and enables us to tease out key theoretical debates in the field of refugee studies (i.e. the notion that some refugees as lie in order to obtain status or assistance; the use of pre-determined categories to identify/assess vulnerable refugees). In doing so, this chapter lays the groundwork for discussion of related themes that emerged – from the perspective of refugee participants – in the semi-structured interviews, namely those pertaining to UNHCR, assistance, and vulnerability (see Chapter 9).

There were limitations to reviewing these documents, including lack of depth/detail and limited comparability amongst documents. Additionally, the sample was not representative of female Rohingya refugees; it was a subset of biased towards the most vulnerable, as the sample was made up of women who had requested financial assistance (and been prioritized for assessment). There were also strengths to reviewing these documents, namely that they were recently written, the sample was the target population for this study, and they provide insight into SDH among Rohingya refugee women in Malaysia. Information presented in this chapter complements the qualitative interview results discussed in the following three chapters of this

dissertation in that it provides an appropriate foundation from which to consider more nuanced, in depth data on the life experiences of Rohingya women, including the key factors that affect their health, and how they respond to the challenges they face. In the following chapter I expand on the information provided thus far by presenting three case studies and basic demographic data on the Rohingya women who participated in the qualitative interviews.

Chapter 7: Demographic Information and Case Studies

Introduction

I begin this chapter by presenting demographic information about the Rohingya refugees who participated in the qualitative interviews. I then present case studies of 3 participants, as well as my brief reflections on the process of interviewing those participants. The case studies are intended to sensitize readers to the lived realities of female Rohingya refugees in Malaysia, and to provide insight into how multiple, interacting themes – all of which are discussed in detail in the following results chapter – manifested in the lives of individual participants.

Participants

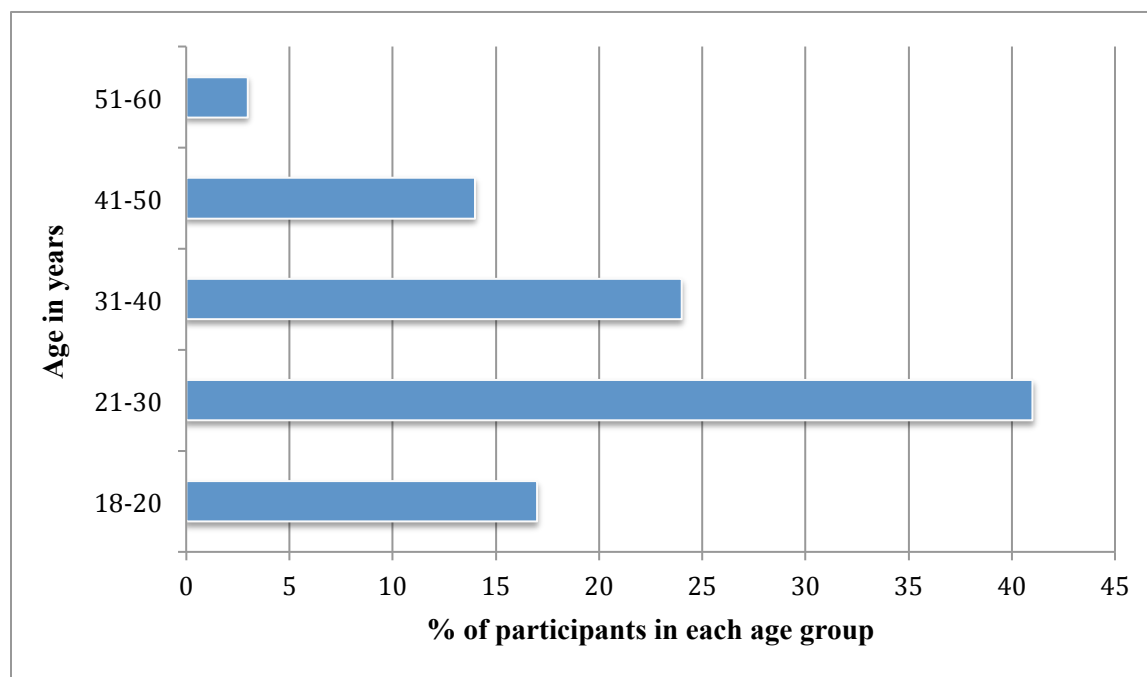
The interviews I conducted were qualitative and semi-structured, and as such I did not systematically gather information from participants regarding their level of education, their income, the resources they had access to in Myanmar and Malaysia etc. I did try to get very basic information from each participant (which I have included below)⁷³ including: her age and marital status, the number of children she had, her place of origin in Myanmar, her Malay language proficiency, the length of time she had been in Malaysia, and her place of residence in Malaysia.

⁷³ As I do not have complete data for every category of information (e.g. I know the age of 30 participants, but not the remaining 3), I have indicated this by putting the total number of participants included in each count in parenthesis in the heading.

Demographic Information

Table 2

Age of participants (30 participants)



Marital status (all 33 participants). Twenty-nine participants were married, and the remaining 4 participants were widows.

Number of children (all 33 participants). Only one participant did not have a child, and she was pregnant with her first. All of the other women had between one and eight children (with an average of three),⁷⁴ and 3 participants were pregnant at the time of the interview.

Place of origin in Myanmar (30 participants). Eleven participants said they came from a city in Myanmar, while 19 came from a rural village.

⁷⁴ One woman had children but I did not find out how many – she is therefore not included in this average.

Language (all 33 participants). Two-thirds of participants (23) spoke some Malay language, 10 did not.

Table 3

Length of time participants had been in Malaysia (32 participants)

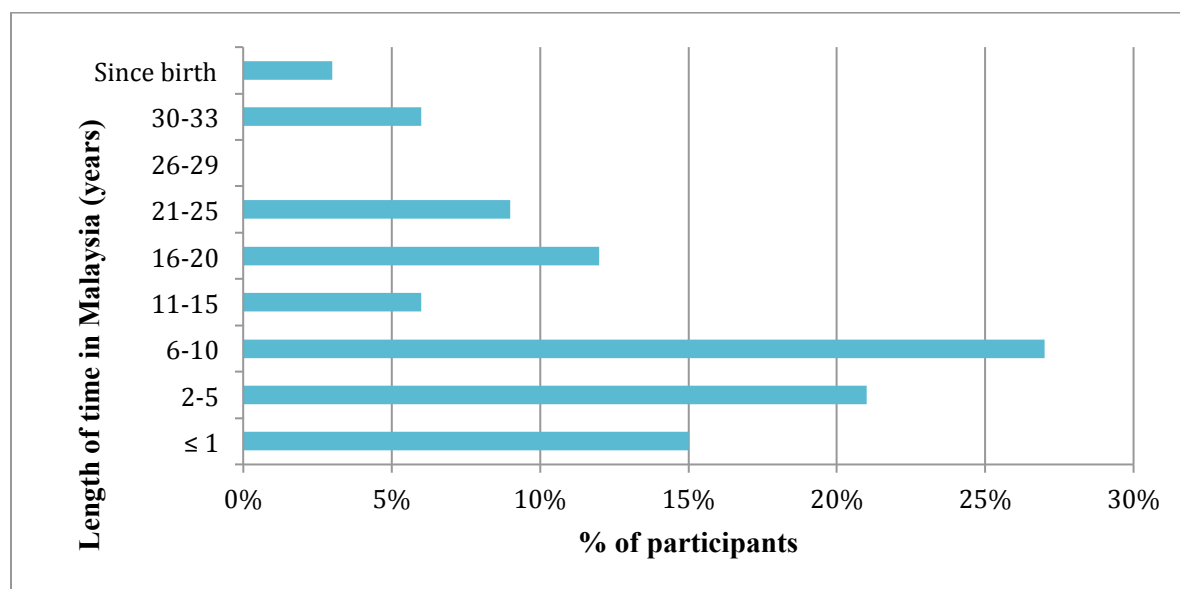
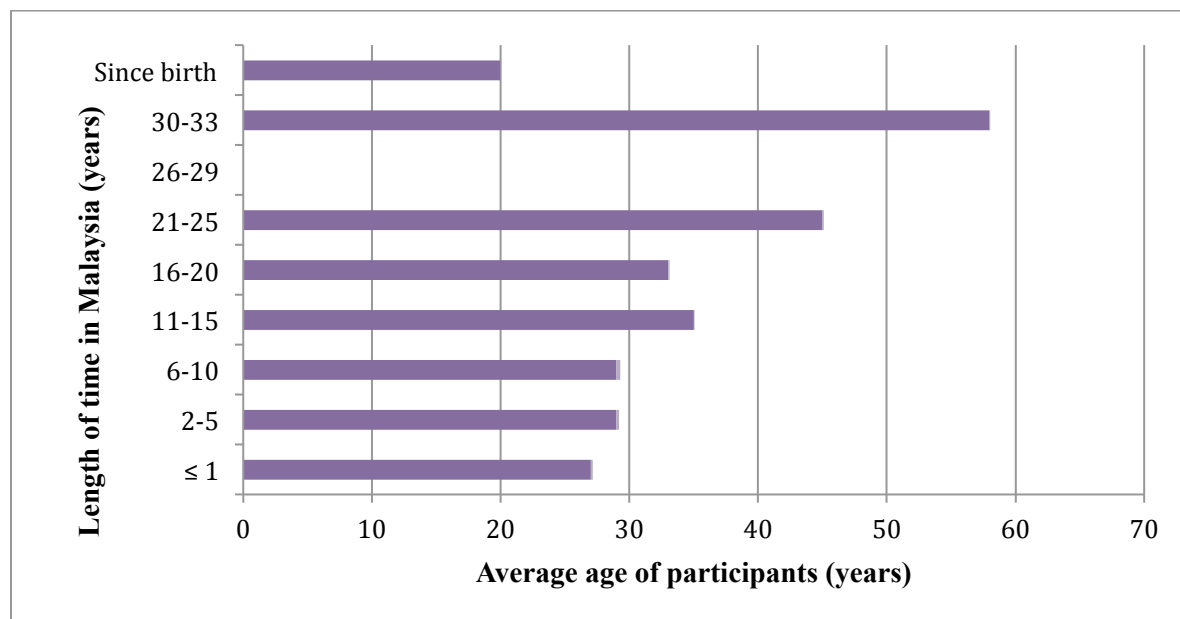


Table 4

Age profile of participants based on their number of years in Malaysia



Area of residence in Malaysia (31 participants). Fifteen participants lived in and around Kuala Lumpur (6 lived in Ampang; 3 in Selayang, 2 in Klang, 1 in Sungai Serai, 1 in Puchong, and 1 in Sri Gombak). One participant lived in Seremban (in the neighbouring state of Negeri Sembilan, approximately 67km from the UNHCR office in Kuala Lumpur).⁷⁵

Sixteen participants lived in states which are located further away from the UNHCR office: 8 lived in the northwest coastal state of Penang (approximately 331km from UNHCR), 4 lived in the southern state of Johor (approximately 273km from UNHCR), 2 in the western coastal state of Kedah (in Alor Setar, approximately 434km from UNHCR), 1 lived in Perak (in Ipoh, approximately 203km from UNHCR), and 1 in the southern state of Melaka (approximately 135km from UNHCR).

Case Studies

I selected the participants described below to be featured as case studies for two main reasons. First, these participants provide insight into the diversity of the sample: for example, Amina had been in Malaysia less than 1 year, Azu 3 years, and Rashida 21 years;⁷⁶ Rashida had one child, Azu had two, and Amina three; they lived in different parts of Malaysia (Kuala Lumpur, Penang, and Johor), Rashida had received assistance from UNHCR while the other two had not, etc. Secondly, their interviews provide insight into key themes that emerged from this study: for example, their narratives provide information on the boat journey from Myanmar to Malaysia, the role of UNHCR, and the ways in which structural determinants of health inequities (such as gender and un/employment) affect intermediate determinants of health (such as material

⁷⁵ All of the approximate distances cited here were calculated using Google Maps (2013), with the precise address of the UNHCR office in Kuala Lumpur as the starting point, and the general state as the destination.

⁷⁶ Pseudonyms are used to protect the identity of case study participants.

conditions) and access to health care. These themes are explored in the following results and discussion chapters, as are all three of the case studies presented below.

Case 1: Amina

When I interviewed 30-year-old Amina, she was 5-months pregnant and still traumatized from her journey to Malaysia. She and her three children had only been in Malaysia 8 months, having fled the violence in Rakhine State and survived an arduous journey to join her husband, who had been living in Malaysia for nearly a decade. Amina had not seen him since he had come to Malaysia to work, but he had regularly sent some of his earnings to her in Myanmar, which she had lived off of until the previous year, when he became sick and was no longer able to work or send money. The timing of this coincided with the violent uprisings in Rakhine State, and both factors compelled her to flee with her children; she said:

The money that my husband giving us is not enough for us, we cannot buy the house, we cannot buy the land, we cannot do our business because of the situation in Myanmar we got very very worse, we cannot do any work, so I decided to take a boat and come to Malaysia.

In late 2012, Amina boarded a boat that she hoped would take her to Malaysia, but the boat became lost at sea, and after 10 days the passengers disembarked in India. While on the boat, the 83 passengers (70 men, 7 women and 6 children) were given insufficient food and water and were forced to stay in a squatting position, conditions that affected Amina's health: she experienced dizziness, chest pain, and nausea, and by the time the boat reached India she had limited muscle movement in her legs and was unable to walk or stand. She was admitted to hospital, and says that a kind Indian policeman paid for her treatment and assisted her and the other passengers by buying them food and other necessities so they could continue their journey to Malaysia.

The boat spent another 6 days at sea before being stopped by the Thai navy.

According to Amina, members of the Thai navy sold her and the other passengers to agents, who paid for them on the spot and then took them to a hiding place in the jungle.⁷⁷ The men, women and children from the boat were kept locked inside a bamboo hut, not allowed to move or speak freely. Amina described the case of one girl who was taken outside and sexually harassed, and said she often witnessed people being subjected to humiliating punishment and then beaten.

After 7 days in Thailand, agents took Amina and her children to Malaysia, where they were hidden in various houses for nearly 10 days. The agent demanded RM10,000 (\$3,333) from Amina's husband for her release, but as her husband did not have that much money the agent threatened to sell Amina to another man, and return the children to her husband so they could beg for him. Amina repeatedly called her husband crying and eventually the agent released her and the children when her husband borrowed RM4,000 (\$1,333) and promised to pay the agent the remaining money later.

After fleeing violence in Myanmar, being lost at sea, hospitalized in India, sold by the navy in Thailand, and held captive in Malaysia, Amina began her new life in Malaysia. Amina's husband was a recognized refugee with a UN card and they had applied to UNHCR for her and the children to get derivative status. This process can take some time, but Amina was fortunate in that her wait was under 6 months, and on the day I interviewed her she was going to be granted refugee status and issued her UN card. This was important, because despite being 5-months

⁷⁷ This corroborates widespread claims of human trafficking of Rohingya asylum seekers in Thailand (Channel 4 News, 2013; HRW, 2013c; Sparks, 2013). Reuters news agency recently conducted an investigation that exposed Thai immigration officials allegedly selling Rohingya asylum seekers to human trafficking rings, which prompted both the UN and the U.S. to call for further investigations (Marshall et al., 2013).

pregnant, financial barriers and lack of identity documents had prevented Amina from seeking medical care; she said:

I don't have a [refugee] card so I didn't been there [the clinic], because they said if you don't have a card they will not entertain you. So when I got the letter that showed that I am a status of refugee, then I went there to register my baby.

Amina's husband was sick and unable to work, and while he had seen a doctor he did not know exactly what his illness was or how to treat it. The family was in debt because of the money they had paid the agent, and the friends they had borrowed from were asking for their money. Amina, her husband, and their three children stayed in one rented room, and while rent was relatively low at RM150 (\$50) per month, the family could not afford it and were 2 months behind. The family was fortunate, however, in that they stayed in the home of a community member, so they were not at imminent risk of eviction. Amina said that after she delivered the baby she planned to find a job so she could support her family, but with no one to support the family in the meantime, and both her and her husband needing medical care, the family faced formidable difficulties; in describing their situation, she said:

We try to manage, but we don't know how to manage anymore. Even today we came here [UNHCR] we don't have the transport money, we didn't pay the rent as well, we borrow from some friend to come here because we was thinking, if we got the [refugee] card here today it would be good for us and my children. And I was planning to ask my children to collect the rubbish to sell it back because I don't know, I don't know what is the way anymore...

My reflections on interviewing Amina:

Of the interviews I conducted, I found Amina's to be one of the most emotional. Amina appeared distressed - not in a hysterical way, but in a resigned, somewhat despondent way. Her tone of voice, body language, and facial expressions gave indications of the trauma she had endured, yet she was not reticent to answer any of the questions, and she offered long answers, often without prompting.

When she began to cry at one point during the interview I reminded her that she could pause or stop the interview at any point, to which she replied, "There is no people asking for us about these thing...I'm not upset whatever you ask me, it's just that it's like a mother asking the

daughter. When I was sitting there you suddenly call me here asking about the journey, asking about my feeling, so suddenly I feel sad for my parents, because my parents already passed away, I miss them, that's why suddenly I feel like that.”

As I did not want the interviews to cause undue distress to participants, I tried to assess how the interviews affected the participants by asking about their interview experience. At the end of the interview, Amina said that the questions were not difficult to answer, because she was telling the truth. When the RA asked Amina how she was feeling after discussing her experiences with us, she said: “I feel happy. I feel some burden was released, because like, I feel like my parents asking me about my journey.” Amina's reflections suggest that the interview was emotional for her, but also cathartic, and it provided her with a rare opportunity to share her thoughts and feelings about her recent traumatic journey from Myanmar.

Case 2: Rashida

Twenty-five year-old Rashida had been discharged from the hospital 5 days before I interviewed her. She still wore her hospital bracelet around her wrist, as she believed it was important to show it to the UNHCR officer. She had been in hospital to deliver her baby after a complicated pregnancy, and her baby remained in the neonatal intensive care unit. He was ready for discharge, but the hospital would not release him until the bill was paid in full. Rashida and her husband borrowed money from a friend to pay her hospital bill, but they could not afford the baby's bill, so they had come to UNHCR to seek financial assistance.

Rashida's husband suffered from multiple health problems (some of which stemmed from a motorcycle accident) and had recently undergone surgery; she and her husband had approached and successfully obtained assistance from UNHCR to pay for his surgery. On the day of the interview she returned to UNHCR and appealed to the officer to provide assistance for her baby, she said:

I crying and begging in front of him [the UNHCR officer] that I have no money to discharge my son from the hospital. I beg to him, I cry in front of him, then finally

he helped me [by assisting with the hospital bill]. Ah if UNHCR wasn't here I don't know what will be happen on our Rohingya peoples.

Their financial difficulty stemmed from the fact that her husband worked irregular jobs, generally in construction, earning between RM20-35 (\$6.67-11.67) per day, as due to his injuries it was hard for him to work manual labour full time. He did not make enough money for them to subsist, which had direct implications for both Rashida and the baby's health; she said, "while I was pregnant with this baby, my husband was jobless during that times so I was starving during that time." UNHCR assisted by paying the baby's hospital bill, and after the baby was released from hospital he was given a follow-up appointment to get vaccinations, but Rashida did not take him because she could not afford the bus or taxi fare to the clinic. Moreover, the baby had stopped breastfeeding when he was admitted to the intensive care unit and now would only take expensive powdered formula, so Rashida had to borrow money in order to feed him.

When she was 4-years-old, Rashida and her parents left Myanmar and came to Malaysia. Her mother had worked in a restaurant, and the local Malay owner took pity on Rashida and offered to adopt her and give her a proper education. Rashida's parents initially agreed and she was raised by the foster family and admitted to a government school, but had to leave school after Grade 3 because she did not have Malaysian identity documents. While Rashida's mother ultimately refused to allow the family to adopt her, the acculturation and years of education Rashida received through her relationship with the foster family had a lasting impact on her life.

Having grown up in Malaysia, Rashida knew many locals and felt that their opinion towards refugees was generally negative; she said, "If they know that this is the foreigners, the Rohingyas...they will look down on them." She had previously worked at a textile shop and a restaurant, but she was fired from the shop because the owner decided he did

not want refugees working there, and she stopped working altogether after she suffered a miscarriage while at the restaurant. The restaurant owner withheld her wages and refused to pay her for over a month of work; when I asked her if she considered seeking recourse for the wages, she said, “I cannot do anything, how am I going to do, because being a refugee we can’t do anything...”

When asked to think about her life now and identify the things that have the greatest impact on her health, Rashida spoke broadly of things that affected the Rohingya community, including statelessness, lack of leadership, and how being denied education led to illiteracy and a lack of dignity. She said:

I’m looking for my better life, to go to a third country...we cannot see any better future in Malaysia...it is hopelessness I see in Malaysia...everything is already closed for our community, Rohingya community in Malaysia, they have no better educations. So if our Rohingyas community they are sent to the third country, then they can live in the peacefully and also dignity.

Despite the fact that Rashida had spent almost all of her life in Malaysia and was relatively integrated (i.e. she spoke the local language fluently, had a strong social safety net, etc.), she was like many refugees in that she placed her hopes for the future on being resettled to a third country.

My reflections on interviewing Rashida:

During the first interview at UNHCR, Rashida was one of the most articulate and reflective women to participate in the study. She linked immediate, personal experiences with broader conceptual ideas, and unlike most participants she reflected on the lives of the Rohingya community by situating them in their current social, economic, and political surroundings, speaking of issues such as statelessness, dignity, and the long term impact of being denied education. She willingly accepted my offer of a second interview, but shortly after the first interview she was evicted and she, her husband, and newborn infant went to stay temporarily in a friend’s house, and so the RA and I visited her there.

It was a single story house not far from Kuala Lumpur, located on a small plot of land. The house had two bedrooms, a bathroom, kitchen, and living room. The medium sized living room had a ceiling fan, open windows, and an old flat screen TV. Rashida, her husband and their

baby lived in a small bedroom, furnished with one wardrobe and with piles of clothing on the floor. While she and her husband slept on the floor, they had a cushion for the baby that had been given to them by a friend.

I had hoped to interview Rashida privately, but when I arrived Rashida sat down in the living room and seven other people who stayed in the house promptly sat down in a semi-circle around us. One was a teenage girl who had been orphaned; two were young men who had recently fled Myanmar and arrived in Malaysia after a horrific journey; two were children; and two were the couple who rented the house and had allowed Rashida and her husband to stay. With no privacy, I was reluctant to ask Rashida personal questions, so I started out by asking general questions about the neighbourhood etc. Before long, one member of the couple (the man) began talking about how he needed assistance from UNHCR for a minor medical problem, but thus far UNHCR had not provided him with any. He spoke for 40 minutes, expressing his frustration, asking for advice, repeating his problems and lack of solutions etc. He controlled the conversation – at many points cutting the interpreter and I off and speaking over us.

For these reasons the home visit proved to be challenging, and I ended up having to do a third interview with Rashida over the telephone. While the second interview did not generate useful data, it was nevertheless fruitful in that it enabled me to see that while there may have been drawbacks to conducting interviews at UNHCR, there were also advantages, namely that I was able to speak with the women alone, away from their husbands and families who may have talked over them/for them if they were in the interview room.

Case 3: Azu

When Azu was growing up in Myanmar, her parents faced many difficulties and struggled to support the family, so when she turned 13 they sent her to live with an uncle in a Thai refugee camp. After a year in Thailand she married one of her uncle's friends, and a few years after that she became pregnant. She had intended to deliver her baby at home in the refugee camp, but it was a complicated delivery and she had to be taken to hospital for an emergency caesarean section; 6 years later she delivered her second child, also by caesarean section. She and her husband found life in the refugee camp difficult, largely because they were unable to generate enough income to supplement the rations and support their family, and so they decided to leave their children with her uncle and come to Malaysia to try and establish a better life.

When asked about the differences between living in a refugee camp in Thailand and as an urban refugee in Malaysia, Azu said, “We will face a much of the difficulties there [in Thailand] so due to that we decide to come here. For the woman over there, they have no work opportunities for the womans. Here we can get a job.” While her children stayed in school in the Thai refugee camp, Azu and her husband worked hard and remitted money back to them each month; a relative had found Azu a job as a dishwasher, and within a year of working at the restaurant she was promoted to chef and her wage doubled. Her husband was also employed at the restaurant, and they worked 12 hour days, every day unless the owner decided to close the restaurant. Despite the long hours, Azu enjoyed her job and took pride in the fact that she and her husband worked hard and were able to support themselves and remit money (up to 200,000 kyats, \$214) back to her parents in Myanmar each month.

Her employer, a local man, treated them well, providing them with a decent wage (RM40 [\$13.3] per person per day) and a room to rent in a house near the restaurant. Azu said that her boss liked Rohingya people and hired them exclusively to work at the restaurant, which fostered a strong sense of community and made for a good work environment. Azu and her husband were fortunate in that they had a happy marriage and strong social support, including friends who would assist them if they ever needed help.

Azu had studied up to Grade 8 in Myanmar, and as an adult made a point of reading the newspaper and continuing to educate herself. She had no major health problems, and she stood out from all other respondents in that she was very proactive about staying healthy. She placed particular importance on nutrition: not only did she try to eat a balanced diet, she took great care in preparing the family’s meals (i.e. she bought chicken

and slaughtered it herself to make sure it was fresh, cooked with small amounts of oil in order to reduce cholesterol, maintained a hygienic kitchen, etc.).

Two years after Azu and her husband came to Malaysia, when they had stable employment and housing, their children came from Thailand to live with them. Azu placed high value on education, and after her children came to Malaysia they attended a UNHCR supported school. Like Rashida, Azu wanted to be resettled, primarily because she wanted her children to have a good education; she and her husband had already undertaken resettlement interviews, but their case had been put on hold because they wanted to resettle with their children (who at that point were still in Thailand).

Towards the end of the second interview it became evident that Azu was an exceptional case – she was employed in a job she liked, in good health, had no major security or financial issues, seemed happy in her roles as both wife and mother, and took a proactive approach to health. I explained to her that for the reasons above she stood out from the other participants, and asked her directly what she thought made her different from other Rohingya women in Malaysia, to which she replied:

So for our people, sometimes they didn't think about any positive thing, they only thinking about the negative things. Then ah, they will eat this and that and will take this and that due to lack of the educations...so for us we didn't take any leave, we always continue working and working and working. For us, we know how to earn the money, for those who was educated they know how to survive. So being a husband and wife we always, we always discussing about how to live peacefully, how to not have arguing. When my children come back from the school, then I will discuss with them why the education is very very important for us...I will teach them so what time you have to study, what time you have to sleep, everything I will teach them. As a parent you have to guide your children...we have to teach the children not to do the bad things, do the good things, you know like our Rohingya people sometimes they didn't teach their children, so they just leave the children like that, abandon the children like that they won't teach the right things.

My reflections on interviewing Azu:

Of all the interviews I did, this one stood out – the participant seemed forthcoming, resilient, articulate, and had built a very stable and happy life for herself. In my time with UNHCR I had never interviewed a Rohingya woman like her, and while this is likely because my tasks have focused on the most vulnerable refugees, Azu's participation in this study was important as it sensitized me to the fact that there are refugee women like this in Malaysia, who are working extremely hard and managing to build good lives despite the formidable challenges they face.

Conclusion

The three case studies presented in this chapter introduce a range of important themes that emerged from the qualitative interviews with female Rohingya refugees in Malaysia. Key issues – including fleeing Myanmar, seeking asylum in Malaysia, employment, health, response strategies, and resettlement – provide insight into how aspects of identity and the broad context in which refugees in Malaysia live manifested in the lives of individual refugee women. The purpose of using the case study format was to present detailed information about individual participants in a way that highlighted both the intersecting nature of aspects of identity (such as gender, race/ethnicity, etc.) and factors that affect Rohingya women's health (e.g. in the case of Amina, her journey to Malaysia, lack of income, barriers to medical care, etc.). The case studies above illustrate the holistic nature of these factors, and the extent to which one factor (such as Amina's journey to Malaysia) can have long-lasting implications for others (such as financial security, physical and psychological health, etc.). The micro level issues discussed in this chapter lay the groundwork for the following chapter, which provides a more comprehensive overview of the interview material.

Chapter 8: Interview Results

Introduction

In this chapter I review findings from the qualitative interviews I conducted with Rohingya refugees. The chapter has been structured in such a way as to clearly answer the main questions set out at the beginning of this dissertation:

- What are Rohingya women's main health concerns? Have they changed since they became refugees under the protection of UNHCR?
- How do they respond to these concerns?
- What barriers do they face in leading healthy lives in Malaysia?
- How willing/able are they to access services?
- According to Rohingya women, what are important determinants of health in the context of their lives in Malaysia?
- What social and environmental factors support their health and wellbeing? What factors put their health at risk?
- What strengths, assets, and response strategies exist within the Rohingya community?

The findings discussed in this chapter, and case studies presented in the previous chapter, provide a comprehensive overview of the data generated by this study and establish the basis for the in-depth discussion contained in the following chapter.

Health Changes Since Becoming Refugees Under the Protection of UNHCR

Most participants said they had not experienced major changes in their health since leaving Myanmar and becoming refugees. Two women said their health had become better since coming to Malaysia (e.g. one participant experienced psychosomatic symptoms in Myanmar but not in Malaysia). Seven participants said that their health had become worse, and while 2 of these women linked their worsening health to facets of their lives in Malaysia, the remainder stated that they had developed new health problems after coming to Malaysia but did not directly link these to their lives in the Malaysian context (e.g. one participant attributed her health problems to her age, which is a universal rather than context-specific factor).

A quarter of participants reported developing physical and/or mental health issues while trying to get to Malaysia or shortly after they arrived, which is not surprising given that many endured difficult boat journeys and were detained by agents and government officials upon arrival in Thailand and/or Malaysia. Moreover, the journey to Malaysia affected more than the women's health: for some women, it was also the root cause of financial insolvency (because the cost of the journey was so high), which in turn spurred a multitude of problems including inability to access health care, unstable housing, food insecurity, etc. As the journey to Malaysia emerged as key determinant of participants' health, it is discussed in detail later in the chapter.

Rohingya Women's Main Health Concerns

A minority of the women I interviewed said they were healthy and had no major health concerns; the majority, however, discussed a range of health problems that affected them and Rohingya women they knew. Pregnancy and reproductive health were mentioned more frequently and in greater detail than any other topic: while some woman said they had uneventful deliveries and received sufficient medical treatment, over half of participants⁷⁸ discussed pregnancy/reproductive health problems (including antenatal issues such as placenta previa and gestational diabetes; emergency caesarean sections; inability to access and pay for medical care during pregnancy, etc.).

Financial barriers prevented many women from receiving treatment for reproductive health problems; one woman, for example, explained that a distant relative of hers in Malaysia had:

⁷⁸ During analysis I made note of the number of times certain themes occurred; the resulting counts have no statistical significance, and are included at various points throughout this chapter to provide an indication of how many participants raised certain topics/themes during the interviews.

[A] problem in the baby, where the baby should be, ah she went to the hospital, she was admitted, when the doctor asked for 30,000 [*Malaysian ringgit*; \$10,000] to operate her...because of they don't have money the doctor keep her in the hospital, finally she died without treatment. (19)⁷⁹

Another participant, who reported having no prior health problems, had a complicated delivery at a government hospital in Malaysia: the baby was born with a serious medical condition and the mother required a post-natal surgical procedure and follow up treatment, but she refused the procedure as she could not pay for it. Not only did the family struggle to pay the initial hospital bill, but the baby required a feeding tube and expensive formula, which caused ongoing financial strain and inhibited the mother's follow up treatment.

One participant described the negative experience she had giving birth at a government hospital, and also noted challenges in accessing post-natal care; she said:

I gave birth at 11:15 [pm], they took my baby and I was in that room until 5am...after delivered the child they took the child and left me there. So I was very cold, I can't wake up, also didn't have a blanket. I was not eating anything, I can't drink, I have nothing there. I was alone inside. I feel scared and also I feel pain. Now I am 37-years-old, it's very painful after you give birth, so after that I still feel sick, when I went to the hospital or anything I feel uncomfortable because they are treating us differently. If a woman doesn't get good care after delivery, the condition would remain the same after that...it is hard to get better. (1: mother of four from Johor)

While the 3 participants cited above faced challenges accessing and paying for quality maternal health care, they were fortunate in that they were recognized refugees and were able to access some medical care; a number of the participants spoke of relatives and community members who

⁷⁹ In order to protect the anonymity of participants, I attribute quotations in this chapter to participants by citing the unique numeric codes they were assigned. When it is appropriate and helpful to have additional demographic information about the participant, I include such information in parentheses.

were not yet recognized refugees, and this prevented them from seeking maternal health care altogether.⁸⁰

Other health problems frequently cited during the interview included mental health issues (e.g. worry/stress, ‘overthinking,’ psychosomatic symptoms etc.), chronic health issues (e.g. diabetes, gastric issues, hypertension, etc.), infectious diseases (e.g. viral illnesses), and issues resulting from accidents/injuries. Approximately one-third of the women suffered from multiple health problems; one 58-year-old woman, for example, suffered from heart disease, diabetes, hypertension, and gastric problems. Another participant, a mother of eight living in Kuala Lumpur, was diabetic, had undergone eye surgery, and had also been hit by a car, resulting in a fractured leg and multiple hospital admissions; she said:

After I broken my leg then the first time I was admitted to the hospital regarding the leg, they plaster me until the knee, until the here [indicates her thigh] they put some what they called stilt inside because they want to straight my leg, but after two days maybe when I walk a little bit from my bed until the front I fell down again and my leg broken again, so I was admitted again to emergency ward and they plaster me the whole leg, I cannot move. Ah I was admitted three times. (9)

The woman eventually stopped going to the hospital for follow-up because she was unable to pay, and even after her leg had ‘recovered’ the residual injury restricted her ability to work and undertake everyday tasks. In addition to her own health problems, her husband had been hospitalized for 2 months after he suffered a heart attack; he had been discharged 5 days prior to the interview, and UNHCR had provided financial assistance because the family was unable to pay the medical bill. Her husband had been referred to another hospital for further medical treatment but had not gone because they could not afford the cost, and since neither she nor her

⁸⁰ Maternal health care for pregnant refugees in Malaysia is a complicated issue, with particular challenges related to access, security, and UN intervention; see Verghis (2012) for further information.

husband could work they were dependent on the support of one son who earned just RM20/day [\$6.66].

As this example – and the case studies – illustrate, participants' health concerns and response strategies were deeply embedded in and affected by the social and environmental contexts in which they lived; the remainder of this chapter considers linkages between those contexts, their response strategies, and their health and wellbeing.

Response Strategies

Participants employed a wide range of response strategies when confronted with health issues and – more generally – the challenges they faced living as refugees in Malaysia. Most responded to mild or moderate illnesses by self-administering pharmaceuticals (i.e. over the counter medicine) or traditional medicine (usually remedies purchased at local shops or made at home by boiling various types of leaves). Some participants, particularly those who faced financial barriers, reported self-administering treatment in lieu of seeking professional medical advice.

Many women said that while their first response was to wait and try to manage the illness on their own, they would seek medical treatment (usually at government hospitals or UNHCR-supported NGO clinics) if their condition worsened or persisted. Roughly a quarter of participants mentioned taking proactive measures to foster health (e.g. eating nutritious food, walking etc.), but nearly half said that they did nothing to improve their health or prevent illness; while some women said this was due to limited resources (i.e. they could not afford to seek

medical advice, buy vitamins, etc.), others said they did nothing because ultimately God was responsible for people's health.⁸¹

Participants discussed three other response strategies of note: working hard, seeking assistance, and focusing on religion and the future. One woman described how important it was that she was employed – not only because of the economic benefits, but also because she felt working hard and keeping busy was good for her health. For some, working seemed to be a means of establishing control and order in their lives, which on many levels seemed tumultuous and out of control; this finding parallels the work of Russell & Seeley (2009), who found that working hard was an important way in which HIV-infected people in Uganda strove to regain control and normalcy following a period of disruption. Working hard and 'struggling for health' was a response strategy employed by Azu (see case study in Chapter 7), who believed that while God was ultimately responsible for determining her health, this did not absolve her of the need to work hard and take responsibility for her own choices; she said:

Every decision on God's hands, so if he can he will make us die by today also. So he's the one who give us the disease. We have to struggle for our health, we cannot wait for the God to keep us well.

Seeking assistance from UNHCR was a response strategy some participants employed to obtain resources they needed to improve their health and wellbeing.⁸² Some participants expressed confusion or dissatisfaction with the assistance process at UNHCR (e.g. 5 participants did not know how or found it difficult to request assistance, more than 6 participants had requested assistance but never received a response etc.), yet it was clear that even for these women the very act of seeking help provided them with hope and a sense of relief (i.e. that they

⁸¹ Religion played a key role in structuring participants' beliefs about illness and recovery, and it is discussed in depth later in the chapter.

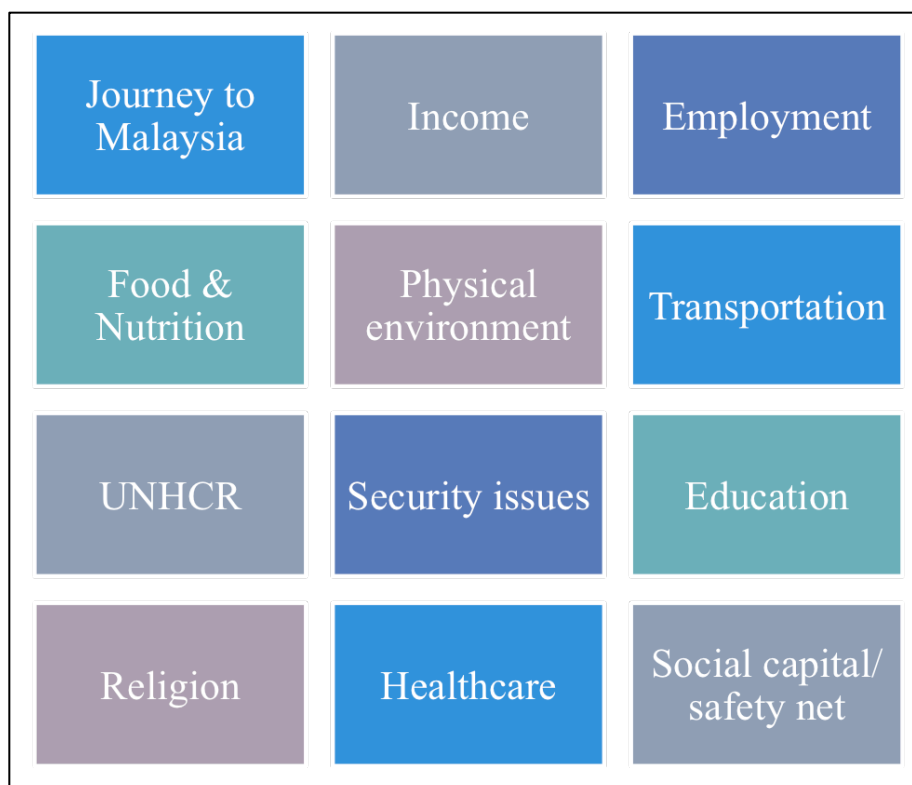
⁸² Approximately 7 participants had previously received UNHCR assistance, over 15 had never received assistance, and 5 were not even aware UNHCR provided assistance.

had taken concrete action to better their situation). The fact that so many participants claimed to need assistance is indicative of the challenges they reported in leading healthy lives in Malaysia; these challenges, as well as more about UNHCR assistance, are discussed below.

Determinants of Health, Barriers to Leading Healthy Lives, and Access to Health Services

Key factors that affected the health of Rohingya women are presented in Figure 2 and discussed in detail below. It is relevant to note that many of these factors did not have inherently negative or positive health implications, rather, the effects they had on participants varied based on their individual circumstance (e.g. while food and nutrition negatively affected the health of women who suffered from food insecurity, it positively affected the health of women who had sufficient food and balanced nutrition).

Figure 2: Factors Affecting the Health of Participants



Fleeing Myanmar & the Journey to Malaysia

One way to delineate the forced migration journeys of people fleeing their homeland is to consider them in three distinct stages: pre-flight, when refugees are in their country of origin; flight, when they are traveling to a country of asylum; and post-flight, when they arrive and settle in a country of asylum (S. L. Thomas et al., 2008). While the primary focus of the interviews was to gather information on the post-flight lives of Rohingya women, some participants spoke at length about their journey to Malaysia, noting the effects it had on their physical and mental health, and that the cost of the journey – including bribes, fees, and extortion money – had left their families deep in debt, with no foreseeable way to repay it. One participant described the pre-flight situation for Rohingya women in Myanmar before the recent conflict, and why she decided to flee:

So being a Muslim they never recognize us, and citizenship of Myanmar, so due to that we face a lot of the difficulties and harassment from the government of Myanmar, from the Burmese peoples... The situation in Myanmar is very worsen than in Malaysia, so they will, they will kidnap the womans, Rohingya womans then they will bring them and kidnap them, then they will kill them. So in the meantime also, so we cannot traveling in, travel legally. We cannot, we are not allowed to travel legally to anywhere, any village. After thinking about that, so I say that how long should I live like this?...It's better for me to fled from the country, to save my life. (11: 30-year-old mother of three who had been in Malaysia 8 years)

She went on to say that she had witnessed her sister-in-law being raped, and that such crimes were carried out with impunity:

She dead instantly after she been raped by the Burmese people. For the Muslim people, if they go and make any complaint about that, they Burmese government will ignore, ignoring all of the complaints will ignorings... being a Rohingya everything's injustice for us. (11)

Twelve of the women I interviewed had left Myanmar in the last 3 years, and 5 had been in Malaysia one year or less. Two participants said they traveled to Malaysia by plane (i.e. after

obtaining illegal documents in Bangladesh), and 6 said they traveled by boat. Most boats disembark in Thailand first, and some participants who had landed in Thailand were arrested, detained, or held captive in the jungle by armed agents who extorted money from them to secure their passage to Malaysia.

Generally, the conditions on the boats were deplorable: passengers were kept in overcrowded areas, not allowed to stand or move, and received inadequate food and water. One participant's daughter-in-law had arrived in Malaysia 18 days prior, following a hard boat journey on which some passengers had died; the participant said, "people came together with her in the boat, three of them passed away, died, instantly their body was thrown into the sea," and when asked if she knew what they died of, she said "starving, dehydrate, cannot eat anything, thinking a lot. Due to that" (32: 58-year-old widow).

One participant had endured a 15-day boat journey to Thailand with her young children. They were arrested by Thai police on arrival and she was sentenced to 7 months, during which time she was separated from her children, who were kept in another part of the prison. After their release, her husband had to pay an agent even more money to smuggle them into Malaysia. Another woman and her children were also arrested in Thailand: her young son was deported back to Myanmar alone, while her young daughter was kept in another part of the detention centre. After one year she and her daughter were deported back to Myanmar, and they had to undertake a second arduous journey to Malaysia.

Taking into account the situations Rohingya women encounter during the flight and pre-flight stages of migration can help us better understand their health status in Malaysia because, as Moore & Marfin (1993) state, the health problems facing displaced populations are "compounded by the deprivations that initiated the migration" (p. 935). Findings from this study

provide insight into the pre-flight, flight and post-flight circumstances of Rohingya women: among the most salient points are that some of those very recently arrived in Malaysia fled situations of violence and impoverishment in Myanmar, they endured conditions of extreme deprivation on the boat and while being held in Thailand, and the cost of their flight contributed to the post-flight debt-load, poverty, and insecurity they faced in Malaysia.

Income

“In this country, no money means no food, no education, no treatment. Even sometimes we want to eat something, we can’t afford it” (22: 25-year-old mother of two who had been in Malaysia less than a year). Lack of income was a major issue raised by participants, many of whom explicitly mentioned how hard it was to survive in Malaysia because they needed to pay for rent, food, transportation, necessities for their children, and (in some cases) medical bills. Not only was insufficient income an issue for women who were unemployed (or whose husbands were), but participants who were part of a family in which someone was working also spoke of not being able to manage, and of struggling to earn a living wage (i.e. the minimum income needed to meet basic subsistence needs). One participant said her husband could earn up to 80RM/day (\$26.67) doing construction, but his work was inconsistent and did not generate enough money for her family to subsist. Another participant, a widow with a heart condition, said:

First of all, it’s very difficult to find a job. Then I working as a rubbish collector...[making] 20-25 *ringgit* (\$6.67 – 8.33). I spending for the meals, I have four children, it wasn’t good enough. Now I lost my ability to work. One of my son, haven’t turned 18 yet, 18-years-old, so he is the one who currently supporting the family financially. (33: 45-year-old widow in Kuala Lumpur)

Those who could not generate enough income by working resorted to other means: one woman sold her jewellery in order to pay her husband’s medical bills, while other women borrowed

money. Participants borrowed from various sources, including friends, family, and money-lenders, and some were unsure how they would repay their loans since their salaries (and/or their husbands') were insufficient to survive on, let alone repay debts.

Not all women lacked sufficient income – Azu and her husband were able to provide for their family and even remit money to family in Myanmar; she said, “we make money and then send back money to our country to our parents. We are working and we use the money to pay our children’s school fees, and for our daily expenses, the daily meals” (34). Azu was an exception, however, as both she and her husband worked full time, which was not feasible for participants who were unable to find or undertake employment.

Employment

Participants frequently raised the issue of employment during the interviews; as one woman said, “In Malaysia if you can make the living, then you can stay properly, nicely. So if you have no money, nobody will care about you,” (31). Most women who worked undertook difficult jobs for low pay because their family depended on their earnings (e.g. one woman worked as a cleaner in a hospital, one sold religious books on the street, another had worked 12-hour-days at a laundrette, all earning between RM20-30 [\$6.67-10] per day). Two women mentioned that their jobs contributed to health issues; one participant, who worked as a dishwasher, said:

If the husband not working they [Rohingya women] need to go and find a work by themselves. When they are working they will have to be sick because they are too cold, sometimes too hot so it make them sick...I’m working night shift, which is from 5pm until 5am the next morning which is 12 hours...when I came back to my house, I will not directly sleep I will prepare my children’s clothes, I will wash their clothes, I will clean the house, I will cook for them. Sometimes I have not enough sleep at all. (7: married mother of three)

Some participants were compelled to work when their husbands became ill, unemployed, or deceased; one woman, who had resorted to begging after she was widowed because she was unable to provide for her young children, said:

My son's age was 9-years-old when my late husband passed away so, um I am ashamed to say but I, I have to say also I was working as a beggar during that time. I was not able to work at that time, I worked as a beggar...I bring my children because all of them is very small, and I cannot keep them in somebody house because they were asking money – for each person 200 *ringgit* (\$66.7). Due to that I bring them all together with me. (33)

A quarter of participants wanted to work but found it difficult to secure and/or maintain employment; one woman who had been in Malaysia for 30 years said:

It's very difficult for the Rohingya women to work, and also make a living. Without the husband it is very difficult for them to survive, and without the UNHCR card they often harassed by the police on the way [to work]. (5)

Another woman I interviewed had recently been detained when authorities raided her workplace, yet because she and other participants had family members relying on their salaries, they continued to work despite long hours, security risks, low pay, and resultant stress and health problems.

In their 2010 article on refugee women in Malaysia, Buscher & Heller (2010) highlight employment-related challenges similar to the ones mentioned by participants (e.g. risk of arrest, withheld pay, etc.) to support their argument that while in some settings livelihoods help protect women from sexual abuse and exploitation, “for a refugee woman in Kuala Lumpur having a job increases her vulnerability to gender-based violence, arrest, detention and extortion” (p.20). While Buscher & Heller do not note any advantages to refugee women in Malaysia being employed, for some of the women I interviewed, working helped improve their physical and mental wellbeing and increased their income, knowledge, and freedom. One participant partly

attributed her health problems to staying home and leading a sedentary lifestyle, and she sought employment as a way to improve her condition; she said:

I find out that I have a diabetes problem. Then I was like lazy in my house, I just lie down in there, till I became very fat. Then my friend advised me like, you should do some work. If you just sit in your house, you're doing nothing, maybe you become paralyzed one day, because you are so big now. So I was like, ok, I find a job... before this I never work, because I have no work. But after I falling sick, I know that if I sit down things are going to be worse so nowadays I'm doing work in a hospital, as a cleaner. (19: 40-year-old married mother of five)

Recognizing the advantages of refugee women being gainfully employed in Malaysia does not negate the need to address concomitant challenges or risks; it does, however, underscore the value of developing appropriate and dignified opportunities for refugee women in Malaysia to support themselves and their families.

Food and Nutrition

The concept of food insecurity encompasses an inability to obtain sufficient quality and/or quantity of food using socially acceptable means (Mikkonen & Raphael, 2010, p.26). Of the women interviewed, nearly a third explicitly mentioned having experienced food insecurity at some point since they left Myanmar. When women were unable to obtain enough food they executed a variety of response strategies, including accepting gifts of food from neighbours, begging food from neighbours, and restricting food consumption. One participant, with eight children, said:

I just feel disappointed, I feel very very very sad because I was staying since I came to Malaysia there is a few, there is a time, a few days me and my husband didn't eat anything because we want to feed our children. We didn't eat anything at all. (9: married mother of eight in Kuala Lumpur)

The claims made by some participants' that food insecurity affected their families are aligned with nutritional surveillance data gathered in Malaysia (IOM, 2011), which showed a high

prevalence of wasting⁸³ (13.5%) among Myanmar refugee children aged 6-59 months.⁸⁴ The narratives of participants in this study provide useful insight into the response strategies of refugees experiencing food insecurity, a topic discussed in the following chapter.

Physical Environment

A growing body of research exploring the relationship between housing and health situates housing as a key determinant of health (cf. Acevedo-Garcia et al., 2004; Dunn, Hayes, Hulchanski, Hwang, & Potvin, 2006; Gibson et al., 2010). Acevedo-Garcia et al. identify three main pathways through which housing affects health: area characteristics (e.g. safety of the neighbourhood; access to amenities etc.), internal housing conditions (e.g. exposure to dangerous structures or toxic substances; rodent infestations etc.), and housing tenure (e.g. renting as opposed to owning, risk of eviction etc.). One participant faced many issues with her accommodation and neighbourhood, and she specifically mentioned issues pertaining to these three pathways. Her husband had irregular employment and the family was limited in what they could afford, thus they were paying RM200/month (\$66.70) to rent a room in an area she perceived to be unsafe. She, her two children, husband, and sister (who was visiting) all stayed in one small room and shared a kitchen and bathroom with two other families (12 people total), with whom they did not get along. Their room had poor air ventilation and was infested with ants, cockroaches, mosquitos and other insects, and the participant expressed her concern with the negative health consequences of their housing situation, saying:

⁸³ The two main indicators of malnutrition used by the WHO are wasting (weight for height ratio) and stunting (height for age); wasting is “generally indicative of recent and severe weight loss, often associated with acute starvation and/or recent disease. Wasting is considered the best indicator of acute malnutrition and a strong predictor of mortality among children under age five,” (IOM, 2011).

⁸⁴ In response to the IOM data, UNHCR conducted a subsequent study on nutrition among refugees in Malaysia; while results are not publicly available, findings showed a lower prevalence of wasting, which indicates there may have been methodological issues in the initial study.

I feel always tense when I was in my area because the place that I'm living is not too good, not too clean, and the place is not too nice. So I was...I keep thinking about my health, my children's health, my husband, so it made me falling sick.
(21)

Many participants experienced issues such as these, related to the poor quality of accommodation as well as inability to pay rent, and constant threat of eviction.

The type of accommodation in which participants lived, and their level of satisfaction with it, varied significantly (e.g. some participants lived in small flat houses with only their nuclear families, while others rented single rooms in houses or apartments shared by up to three other families). Participants discussed a range of area characteristics that affected their health and wellbeing, some of which were positive (such as living near hospitals and mosques, having caring neighbours etc.). One participant directly linked housing and area characteristics to health, saying:

For myself, I don't like big cities. I don't like the flats, I don't like the close close house, I like the situation in the village, in townhouse, because in townhouse we have a single house...the children can play in the playground and everything, because when we feel satisfied [with] the place we are living, the health condition become good, but if we stress with the situation or the atmosphere which is place we live in, so the situation of the health also decrease. (1: 37-year-old woman living in Johor)

Other participants noted area and housing characteristics that negatively affected their health: 3 said their homes had flooded in the past (one had to evacuate and seek shelter in a nearby school, and spoke of the mud and dirt that covered her home when they returned; another noted that in the season after the flood she experienced asthma and other health conditions). Another 3 women felt unsafe in areas near where they lived or worked due to

the recent outbreak of violence between the Rohingya and other Myanmar refugees in Kuala Lumpur.⁸⁵

One participant spoke in detail about an incident in which a group of men robbed her home one night when she was alone with her children. They had held a knife to her throat and threatened to kill her, then took all her valuables. The family moved following the robbery, but the emotional and financial impact of the incident still affected the participant deeply:

Even though we already move from that house, in this house somebody came and knocked the door, I will not open. I will hug my children and be quiet, because of the feeling scared. And sometime when people moving around from in front of my house I will feel scared until I don't know what to do, I will lock everything...after the incident, the robbery incident, life become worse. (11: 30-year-old married mother of three)

Unstable housing tenure was another source of stress for some of the participants, as lack of income meant that they struggled to find affordable accommodation and were at ongoing risk of eviction. At the time of the interview, 3 women were more than 2 months behind in rent, and 5 women said they had been evicted while in Malaysia (some multiple times). One participant was at imminent risk of eviction, as she and her son had just spent all of their money to secure the release of her son's recently-arrived wife from agents; she said:

So my house owner, if I can't afford to pay the house rent then he will chase us out by saying that you are the rubbish, so you are the rubbish, go ahead. And then they will say so if I couldn't pay the house rent please vacate the house immediately, go and find another house...it happened yesterday to me. (32: 58-year-old widow with six children)

The most salient point to be made through the examples above is that participants identified key mechanisms through which housing affected their lives and health (i.e. living in substandard

⁸⁵ During data collection for this study (June 2013) violent clashes broke out between different groups of Myanmar nationals in Kuala Lumpur, leaving at least three people dead; unfortunately, online articles from The Star newspaper published at the time of the attacks were amended in July 2013 and much of the information removed (Bedi, 2013; The Star, 2013).

accommodation, unstable tenure etc.), and these mechanisms were closely linked to other determinants discussed in this chapter, such as insufficient income resulting from unemployment, large medical bills, smuggling family members to Malaysia, etc.

Transportation

Many participants discussed issues related to transportation, and in most instances transportation was depicted as a barrier to accessing health care, education, and UNHCR; as one participant said, “without the transportation fee how could I go and meet with the doctor? I have financial problems,” (5). Financial and transportation issues were among the most substantial barriers preventing women from accessing health care, and some participants stated the cost of transportation to and from the hospital – not the cost of medical treatment – was what prevented them from accessing medical care. For example, 2 participants noted that it only cost RM7.50 (\$2.50) to see the doctor, but the transportation cost of getting to and from the doctor cost up to three times as much, and since the cumulative cost was too much for them to pay they did not go. Other participants struggled to find suitable yet affordable modes of transportation, including one who noted that while the bus was the cheapest, she had been the victim of two transportation related accidents⁸⁶ (being hit by a car and falling while getting off the bus), and due to her injuries she now had to take taxis, which were more expensive.

Among the most serious transportation related issues reported by participants was difficulty getting to and from UNHCR. UNHCR has one office in Malaysia (located in Kuala Lumpur), but half of the women I interviewed lived very far from Kuala Lumpur,⁸⁷ and these women spent a lot of money and up to 7 hours on a combination of trains, buses, and taxis to

⁸⁶ Transportation related accidents were mentioned by 2 other participants - one woman's child died after being hit by a car on the highway, and one woman's husband was injured in a motorbike accident.

⁸⁷ Nearly half of the participants lived in the states of Penang, Johor, and Kedah, while the others lived the Klang Valley (Kuala Lumpur and its suburbs). See Chapter 7 for details.

reach UNHCR. One woman from Kedah had paid an inflated sum (RM500/\$167.00) to bring all of her children to UNHCR for a registration appointment, as the bus driver had charged her more for each ticket because she did not have Malaysian ID. Even women who lived relatively near to the office struggled to pay for transportation; one woman living in a nearby area (Ampang) said, “If I come to the UNHCR I have to spend 30-40 *ringgit* (\$13.33) for me, for the transport, but I have no money for that. I have not any transportations,” (31). Findings from this study suggest that traveling to UNHCR is prohibitively expensive for some refugees, which can have direct consequences on their health and lives because it can take months or years for refugees to get appointments for registration or resettlement, and missing the appointments may cause important processes to be delayed or put on hold.⁸⁸

UNHCR and Security Issues

“If UNHCR wasn’t here I don’t know what will be happen on our Rohingyas peoples, we only hope to UNHCR. Our hope is all to UNHCR, not to others” (Rashida). UNHCR Malaysia was a dominant and recurrent theme throughout the interviews, and findings from this study corroborate Freedman’s (2010) assertion that “UNHCR must also be viewed as a huge bureaucracy and one that holds tremendous discursive and institutional power over refugees,” (p. 597). Participants were highly cognizant of the power UNHCR had over their lives, and while some were disillusioned with what they perceived to be a bureaucratic imbroglio, others were resourceful and persistent in trying to navigate UNHCR’s programs and policies. This is evident in the following examples, which illustrate some of the mechanisms through which UNHCR affects the lives and health of refugees in Malaysia.

⁸⁸ This directly relates to health in that asylum seekers must have a UNHCR card before they are entitled to 50% off medical care at government facilities; furthermore, UNHCR Malaysia can usually only consider providing financial and medical assistance to recognized refugees.

Refugee status and UNHCR card. One selection criterion for this study was that participants were recognized refugees,⁸⁹ and thus all of the women I interviewed had UNHCR cards or were being given them that day. Yet many women spoke of issues they (or women they knew) faced before they had a UNHCR card, including being unable to access health care, difficulties registering with UNHCR, and security issues. One participant described the case of her neighbour, a young Rohingya woman who was 8-months pregnant and unregistered: she had allegedly seen a doctor who told her they would not assist with her delivery unless she had a UN document, and gave her a memo to take to UNHCR. The woman travelled over 4 hours to reach the UNHCR office, but due to the high number of people waiting to be registered UNHCR is unable to register asylum seekers immediately, so the woman was advised to return home and wait for the office to call. The participant described the situation, saying:

This lady tried to cry, to beg from the people [at UNHCR] but nobody listened to her...until today she keep crying because the doctor already answered her question, telling that we can't help you to give birth here because you have no ID at all. So I'm like very sad to see her even though until today she keep crying, I tried to advise her not to cry, because if you cry it will effect her child, but she can't listen because she is feeling very scared. (11)

Asylum seekers can register with and obtain a community card from refugee associations, and many mother and child clinics in Malaysia accept these cards as valid identification, yet some pregnant asylum seekers who do not have an official UN document are unwilling to seek medical treatment because they fear being turned away or arrested. One participant, a married mother of five who had been in Malaysia for 13 years, witnessed this happen:

⁸⁹ As noted earlier, there is an important distinction between people 'registered with' and 'recognized by' UNHCR. Asylum seekers – people who have claimed asylum but who have not yet had their refugee claim adjudicated – can be registered with UNHCR. Asylum seekers are distinct from people who have already gone through the adjudication/refugee status determination process and have been determined to have a legitimate refugee claim, as these people are considered 'recognized refugees' under the protection of UNHCR.

I bring one girl who pregnant, and I bring her to deliver in hospital. After she deliver, there is a officer from the detention camp, came to the hospital and bring her and her children to the camp...because she don't have UN card. She bring the child as well, the baby...After she got arrested she got sentenced in Malaysia for 6 month because of no ID. After 6 months, she and her child, the baby, was deported to Thailand. This person actually my husband's biological sister. So after a few months her husband give the money to the agent to bring her back. After she came here, she came back to Malaysia the husband has the UN card, so husband applied for her. (19)

Security issues such as detention and deportation – often the result of not having a UNHCR card – emerged as a key theme in this study, and are discussed below.

Security. Many of the women in this study had encountered security issues during their time in Malaysia, the most pervasive of which was they and/or their family members being arbitrarily detained.⁹⁰ Four participants had been detained in Malaysia, 2 of them were released after less than 2 weeks, and the 2 others were deported to Thailand.⁹¹ One participant was woken in the middle of the night by officials entering the home where she lived with her family and other refugees; she was forced to wake her baby and bring him to the detention centre, and he stayed with her in her cell until she was released 12 days later. In describing what happened when her house was raided, she specifically noted the officials' disregard for the refugees' UN documents; she quoted the officer as saying, “‘you are rude because of this UN card, this UN card does no use’ – then the police officer stepped on the UN card” (12).

⁹⁰ This corroborates findings from the recent survey the International Rescue Committee conducted with over 1000 Myanmar refugee households in Malaysia, in which 42% of participants reported that one or more members of their household had been arrested in the past year, nearly all because they did not have legal documents; according to the report, refugees were detained, “from less than 24 hours to more than a year, with most reporting between a week and six months. Almost all participants described the conditions and treatment in detention as bad or very bad” (Smith, 2012, p.13).

⁹¹ While the Malaysian government has said that refugees with UNHCR cards and asylum seekers registered with UNHCR will not be detained, all 4 participants with whom I spoke had a UN card or registration letter when they were detained (this discrepancy has also been documented by other sources; see Dateline, 2011).

None of the women reported being mistreated while in detention, nevertheless the experience of being detained was traumatic and caused lasting psychological stress. RELA raided the home of one woman and detained her and her family; she was 4-months pregnant at the time, and said she was very scared, cried constantly, and felt like ghosts were haunting her and her unborn child. Despite the fact that she had a UN card, an immigration officer told her it could take UNHCR months to secure her release, and she was given the option of being deported to Thailand or remaining in detention indefinitely; she summarized the experience, saying:

I feel like something going to, there is something disturbing me because I was pregnant I don't want to lost my child, I don't want to lost myself as well, so I said to my mom, 'mom I cannot stand this anymore, I cannot wait until 5 more months because this thing, like I can't eat anything, I can't sleep well, so if anything happen to me or my child I don't know what would happen to my husband...I make a decision – next time when the officer came to us for deportation, I will agree, I will go.' (14: 20-year-old married woman living in Kuala Lumpur)

Participants were cognizant of the ongoing risk of being arrested or detained in Malaysia, and in some instances their fear and anxiety around this permeated their daily lives and decisions (i.e. by preventing them from seeking medical treatment, causing them to hide in the jungle during immigration raids etc.).⁹² Some participants were very anxious about friends and family who had been detained, such as one woman who had come to UNHCR that day to seek help for her 11-year-old son who had a serious disability and had already spent one and a half months on his own in multiple detention camps. His mother said:

I feel very sad because of my son got arrested when he was very small...now he's in Malaysian camp, my son is paralyzed, he cannot walk. The immigration officer sent my son to the immigration camp. I already sent a few letters to tell about my son, he keep crying for a long time. (13: 27-year-old married mother of three from Penang)

⁹² Uneven urban development in Kuala Lumpur and surrounding areas has meant that there are “plantations or pockets of jungle scattered in and around urban areas” and many refugees and asylum seekers flee to these areas to hide and avoid being apprehended by authorities during immigration raids that occur in the urban neighbourhoods where a high concentration of refugees/asylum seekers live (Nah, 2010, p. 29).

She had reported the case to UNHCR once before, and UNHCR had issued a letter to help secure her son's release, but when they took the letter to immigration the officer said her son had been moved to a different detention camp.

It was evident during the interview with this participant (and with 2 other participants, whose families had been victims of violent crime) that some refugees were frustrated by what they perceived to be a lack of responsiveness from UNHCR officials and Malaysian authorities in helping them resolve security issues and bring perpetrators of crimes to justice. While the woman above continued to engage with UNHCR and immigration to secure her son's release, other refugees had resigned themselves to enduring injustices and had little hope their problems would be resolved.

None of the women I interviewed discussed their detention experiences in detail, and I did not press them with questions because it was evident that they found it upsetting. One woman, for example, had spent 7 months in a Thai jail, and when I asked her what that experience was like, she replied: "There is nothing to say. As per you know it would feel very, very painful, upset, I keep crying" (25). Given these limitations, this study does not add substantively to the scant published evidence on the experiences of female refugees in Malaysian detention.⁹³ Nonetheless, the traumatic events experienced by participants in this study (i.e. being detained and deported), and the documented rights violations in the detention facilities described in the existent literature (AI, 2011) both suggest that security issues threaten the health and wellbeing of Rohingya women in the post-flight Malaysian context.

⁹³ cf. Amnesty International's 2011 report, which devotes a small section to the experiences of male and female refugees from Myanmar in Malaysian detention centres; and the report by Smith, 2012 which contains a small amount of information on Myanmar refugees in Malaysian detention centres, but does not consider the different experiences of males and females.

Health policies and assistance. It is interesting to note that while participants highlighted multiple, authentic benefits of having a UNHCR card, many fundamentally misunderstood one key UNHCR policy pertaining to health: a 2006 circular issued by the Malaysian government entitles recognized refugees to receive a 50% discount off the foreigners' rate⁹⁴ at government hospitals, yet many of the women I spoke with did not understand the discount and mistakenly believed that UNHCR had paid 50% of their bill (when in actuality most of them had received the discount they were entitled to). The frequency of this misunderstanding suggests that a segment of the refugee population is not fully informed about their rights with regards to health care in Malaysia, and potential ramifications are twofold: firstly, they may not know to request the discount to which they are entitled and secondly, even if they do receive the 50% discount, they may mistake it for UNHCR paying 50% of their bill and therefore not approach UNHCR for medical assistance.

The issue of financial and medical assistance issued by UNHCR featured prominently in many of the interviews. Some participants spoke of not knowing how to request assistance, or of finding the process of asking for assistance difficult (i.e. they were not able to write a request letter because they were illiterate; they did not know how to send letters via fax, etc.). Many participants said they had asked for assistance and waited indefinitely to hear back. For example, the woman whose house had been burgled and whose young son had a serious medical condition, said:

My three of children become very very very weak because of the sickness. I was very scared but I still asked help from UNHCR officer, but UNHCR officer what they do, what they do is they will make a photocopy of this report, they say OK we

⁹⁴ According to the *Fees Act (Medical) 1951 for Foreigners*, Malaysian Government hospitals charge foreigners three times more than Malaysian citizens for medical treatment (Ministry of Health Malaysia, 2013a, 2013b).

will go and we will tell the person in charge, then after that day they didn't say anything, no feedback from them they just make a photocopy, go back, I don't know they did or did not do. (11)

Another woman implied that some of the refugees requesting assistance lied in order to obtain it, she said:

It doesn't mean we don't want to ask for help, but the thing is even though we came for the [UNHCR card] renewal they ask us a lot of thing, it's like confusing us. So because of that we don't want to ask for help from UN. Like some people came here and lied to UNHCR, they gave untrue story they believe, but when we came telling the real story, the true story, they don't want to believe. (19: 40-year-old married woman who had lived in Malaysia 13 years)

This statement substantiates, from the perspective of a refugee, what academics have labeled a “culture of disbelief” among state representatives and aid workers who question the validity of claims made by asylum seekers and refugees, and their need for assistance and protection (Finch, 2005, p.60; see also Eastmond, 2007; Harrell-Bond, 1999). Yet such doubts are not one sided, as refugees also question the validity of decisions made by UNHCR: some participants in this study felt that UNHCR did not give assistance to the refugees who needed it most, and one even suggested that UNHCR discriminated against Rohingya refugees, saying:

I feel unpeace because I can see that UNHCR helping other people and I appreciate that, I'm not complaining about UNHCR, UNHCR helping a lot of people, but the thing is sometime they are helping the people who don't need it. But people who need? They didn't get anything...If we count by the ethnicity, Rohingya ethnicity, what I see is the Rohingya people averagely is very very less, in the 100 people only two people got the help from UNHCR: I can see by my own eyes that other ethnicity, other people can get much more help than Rohingya people. (19)

The amount of assistance some participants had received from UNHCR varied significantly: some had received substantial assistance (such as one woman who claimed UNHCR paid RM16,000 [\$5,333] for the cost of her daughter's surgery and provided 6 months financial

assistance), while other women had requested assistance many times but had never received it; one participant in particular spoke of it during the interview, saying:

Since 20 years ago I never asking any assistance from the UNHCR, since I facing difficulties recently, then I asking help from the UNHCR. After my husband was falling sick, they told me that they do not want to provide any assistance to my husband for getting treatment. (31: 43-year-old widow whose husband had passed away due to complications of a stroke)

A UNHCR officer had recently made a visit to her home, assessed the situation, and decided that she was not eligible for assistance, yet this woman continued to ask for assistance throughout my interview with her. She exemplified the response strategy identified at the start of the chapter, whereby the very act of requesting assistance took on symbolic value as a crucial step towards managing problems over which she had limited control; she said, “right now I was in a miserable life, miserable life so due to that I submit this letter to lighten my burden” (31). Yet this participant also noted that another person actually wrote the letters she submitted to UNHCR (as is the case for many illiterate refugees) and during my interview with her she showed me one of these letters and it was evident that she did not know what it said or what department it was addressed to.

While UNHCR influences and mediates a substantial part of the socioeconomic and political context in Malaysia as it relates to refugees, and the agency’s policies have a decisive influence on the lives of refugees (both individually and collectively), the examples above indicate that some refugees either misunderstand or are unaware of important UNHCR policies (such as registration, assistance, and resettlement), and that this can have far-reaching effects on their health and lives.

Education

Participants' levels of formal education varied widely: some women had received no education, others had studied up to Grade 8 in Myanmar, and a few had attended UNHCR supported learning centres in Malaysia. Language skills varied widely: there were exceptional cases like Azu (who could read and write in Malay, Rohingya, and Burmese), while other participants were illiterate and spoke only Rohingya language. Low levels of literacy prevented some participants from reading medical memos given to them by their doctor, prescription information and instructions, and even the UNHCR pamphlets written in Burmese (which provide information on medical conditions, free health clinics etc.).

The health implications of this are potentially life threatening.⁹⁵ This is exemplified by the experience of an illiterate woman (described in Chapter 5) who had not understood the medical note given to her by a doctor, and thus did not know she had been referred to hospital due to a potentially life-threatening heart condition. One woman I interviewed was taking many types of prescription medication (which she pulled out of her purse to show me), but she was not sure what the medication was or what it did. Rashida, who had received 4 years of education at a Malaysian school, directly identified such lack of education and low health knowledge as a problem facing Rohingya women, saying:

I have seen a lot of the Rohingya people don't know about their health condition, don't know about their health problems... the main thing is the education, if we go around and see the education is very important. I know what is the disease that I face right now, I know. Ok, if I go to the pharmacy or meet with the doctor I know what the medicine have been given to me by doctor or pharmacy, I can read. But for the others women if they don't know they will ask the help from the

⁹⁵ A significant body of research has explored the relationship between literacy and health, and findings from one systematic review of this literature (DeWalt, Berkman, Sheridan, Lohr, & Pignone, 2004) suggest that people with low literacy "had poorer health outcomes, including knowledge, intermediate disease markers, measures of morbidity, general health status, and use of health resources. Patients with low literacy were generally 1.5 to 3 times more likely to experience a given poor outcome," (p. 1228).

husband... So, the husband will go and ask his friend also, the friend also was uneducated, they also doesn't know about the health problems.

Like Rashida, many of the women vocalized how important education was for the Rohingya community. One woman mentioned that because she had attended school in Myanmar she understood the value of education, and she had taken initiative to provide education for Rohingya children in her community; she said:

Me and my husband tried to open a school in our place because we are seeing that a lot of Rohingya children are uneducated, a lot of them. So what I, what me and my husband did is we make a decision like, this thing make damage on the children mind so what should we do?... For the Rohingya because they are uneducated, people look down, look them down. So people won't respect them. So due to that education is more important for our Rohingya peoples. (11: 30-year-old married mother of three)

This sentiment was echoed by many of the women I interviewed, who were very aware of the consequences of limited education and were determined to ensure that their children received the education they themselves had been denied. One woman said: "I want to give education to my children because we already destroyed our lives with no education, I don't want that to happen to my child," (25), while Rashida said, "I see the Rohingyas communities and they not take care of their health problem and become worsen, so my wish is to see me, my family, and my children have a better education and also live in dignity, live in dignity and have a better life." While participants directly associated lack of education with Rohingya women's limited health knowledge and health-supportive behaviour (such as exercising, trying to eat a balanced diet etc.), they also felt that being uneducated contributed to the social stigma they experienced (such as a lack of dignity, and being looked down on).

When considering education in the context of urban refugee women, it is important to expand discussion beyond formal education to include other meaningful forms of learning (such

as skills training, language skills etc.), and to recognize that knowledge is gained in a myriad of ways, of which formal education is only one. Azu read newspapers and books in order to increase her knowledge of health issues. Another participant noted that while she had never been taught about medical issues, she used her visits to the doctor as an opportunity to learn; she said, “I never learned about the medical, medical study anything, but when we went to someplace like we went to clinic or anything they give us medicine so we can learn from that, like which medicine to take” (1). Some of the participants – including the two cited above – had learned Malay language, actively sought out health information, and had developed skills and strategies for living and functioning in Malaysia; these women were autodidactic learners with a strong capacity for adaptation, assets that supported their health and wellbeing and potentially mitigated negative consequences of limited formal education.

Religion

Religion was frequently mentioned throughout the interviews, and prayer and other religious practices were an important source of comfort in some participants’ lives. As one woman said, “Praying one day five times we will feel peace in our heart. When we feel peace in our heart there is a lot of tense inside our head or in heart will gone, so it help a lot,” (1).⁹⁶ Nearly half of participants used prayer to assuage their difficulties and pain, and participants’ belief that health problems could be cured through religion seemed linked to their perception that God was omnipotent. For example, many of the women made statements like the following, expressing in a variety of ways the decisive power they believed God had over their lives:

“everything is depend on the God, whatever the God do is for our good” (8);

⁹⁶ Participants spoke predominantly about their personal religious beliefs/practices being a source of comfort and support rather than organized religious institutions; the most direct link to religious institutions was made by a few participants who had gone to beg outside of mosques.

“my God which is Allah, keep providing them food and protection” (26);

“the decision [about health problems] is on God’s hands.” (25)

Some participants directly expressed their belief that God determined who became sick, and one woman phrased this in a way that is aligned with the tenets of an SDH approach – rather than stating that God determined who became sick, she implied that God determined social and environmental factors, which in turn make people sick:

Actually, the disease come from the Gods, so those who are not able to take the food nicely, cannot stay nicely, stay healthy, so they will face, they will face the health problems. (32: 58-year-old widow with six children)

Over the course of reviewing interview transcripts it became clear that religion was one of the most consistently mentioned themes, and that ‘God’ was among the most direct and prevailing responses to a central objective guiding this study, which was to identify what Rohingya women believe are important determinants of health in the context of their lives in Malaysia.

Healthcare

Nearly two-thirds of participants said they had sought treatment at a Malaysian hospital or clinic, and that the staff had treated them fine or well. Four women said they (or their relatives) had been treated differently and/or discriminated against because they were refugees. One participant, who had taken her mother-in-law to a government hospital, said they had been “treated like refugees, different than Malaysians,” (28) and she believed the doctor sent them off without providing requisite care. She said because of that experience her mother-in-law did not want to go back to a government hospital, and subsequently passed away from her sickness. Aside from this participant, few women indicated that perceived discrimination deterred them from seeking treatment, and 2 participants explicitly said that even though they felt discriminated against they still went to hospital because they needed treatment to recover.

Most of the discussion around health care focused on barriers to care. One of the questions I asked participants was if they or any Rohingya women they knew had ever needed medical treatment but not gone to see a doctor: a minority of participants said no, all the women they knew saw a doctor if they were sick. Nevertheless, the majority answered yes and highlighted multiple barriers to care. Three participants mentioned language problems, 5 cited lack of time and information, and not possessing a UN card, but by far the greatest barrier that prevented women from seeking medical care was lack of income to pay for transportation and treatment (cited by 21 participants). One participant said:

This kind of case is a lot...sometime when we went there [to hospital] we need to pay 7 *ringgit* 50 *sen* (\$2.50), which some of us can afford, some of us cannot. So every time when we went there they need to pay, ah sometimes more than that, so because of that they won't go to hospital. (23: 25-year-old married mother of two)

Another participant said:

I have the same pain, which is on my chest and on my stomach, I really want to go for a doctor, but before I go I was thinking about the financial, nobody giving us the money, we cannot afford that amount, so I didn't went to get treatment. (21: 42-year-old married mother of five living in Kuala Lumpur)

In the past I have spoken with male Rohingya refugees who did not seek treatment because they were scared or because they doubted its efficacy, but the women I interviewed gave no indication that they did not seek treatment for these reasons. As money really did seem to be the primary barrier for most participants, I tried to confirm this by asking one participant if she would get treatment if money was not an issue, and her answer was clear: "if I had money, of course I would go to clinic" (13).

Four participants said they (or Rohingya women they knew) were denied treatment at government facilities because of their refugee status or because they could not pay; one woman said, "previously, my young young children, when they falling sick I would bring them to the

hospital – so if I have money they will treat us, if I have no money they won't treat us" (17: 35-year-old widow with six children). She and her children had been turned away because they could not pay the nominal fee, so she went to a pharmacy and got medicine instead. Inability to pay for treatment not only prevented some participants and their children from receiving care, but also their husbands. The woman above, whose children were denied treatment, said: "My late husband was suffering from the stroke previously...the reason he passed away is because he could not afford getting the treatment" (17).

Findings from this research are largely aligned with those from Asgary & Segar's (2011) study, which also identified discrimination, affordability, linguistic differences, and fear of deportation as barriers to care among asylum seekers in the U.S.. Results from this study also corroborate Asgary & Segar's more nuanced findings, in particular that a sense of fatalism towards sub-optimal health may impede health-seeking behaviour (discussed in the following chapter of this dissertation).

Social Safety Net/Social Capital

The SDH model developed by the WHO (CSDH, 2010) identifies 'social-environmental and psychosocial factors' as intermediary determinants of health, Dahlgren & Whitehead (1991) note the importance of 'social and community networks,' in their SDH model, and Mikkonen & Raphael (2010) identify the 'social safety net' as a key determinant of health. While these terms overlap significantly, in the context of this study the concept of a social safety net best encapsulates the informal networks (e.g. friends, community associations etc.), services (e.g. health care provided by NGOs) and formal organizations/protection schemes (e.g. UNHCR) that support Rohingya refugees. Closely related is the notion of social capital, which Hancock (2001) describes as "the 'glue' that holds our communities together. It has both an informal aspect

related to social networks” as well as “more formal forms of social capital that result from society’s investment in social development that ensures people have equitable access to such basic determinants of health as peace and safety, food, shelter, education, income and employment” (p.276).

UNHCR serves as the foundation of the social safety net for many refugees in Malaysia, as it provides both legal protection and a range of support services (e.g. the Social Protection Fund provides small grants toward refugee self-help projects; the Community Development Unit engages refugees in leadership and livelihood training, adult learning etc.) (UNHCR, 2013g). Yet most of the programs and support services offered by UNHCR are clustered around Kuala Lumpur, rendering them inaccessible to refugees who live in other parts of the country. This highlights a key element of the social safety net: it is not a static, egalitarian entity, nor does it protect refugees equally; this is particularly true in urban refugee settings like Kuala Lumpur, where access to services (including those offered by UNHCR) is varied and many features of the social safety net are temporary and informal (i.e. support services are often offered on an ad-hoc, short term basis; social networks change frequently as large numbers of Rohingya refugees arrive and are resettled to third countries etc.).

While participants were differentially protected by features of the social safety net, findings from this study strongly suggest that the social safety net mitigated intermediate determinants of health for all participants to varying degrees: for example, social support from friends and neighbours protected some women from eviction and food insecurity by providing them with food, employment and housing opportunities; UNHCR’s medical and financial assistance program benefited some participants much the way a social welfare system would; and some women found a sense of comfort and belonging in psychosocial and community

support.⁹⁷ Data generated from this study illustrate various ways in which Rohingya refugees are providing and receiving material and psychosocial support to/from each other (largely through social networks and associations), and indicate that one way to effectively support the health and wellbeing of Rohingya women may be to strengthen features of the safety net.

Conclusion

In this chapter I identified and discussed factors that affect the health and wellbeing of Rohingya women in Malaysia, including: their journey from Myanmar to Malaysia, income, employment, food and nutrition, transportation, the physical environment, UNHCR, security issues, education, religion, healthcare, and the social safety net.

The narratives of participants provide insight into how health issues can manifest in the lives of refugees, and how key events can trigger a “cascade of events” (Pourgourides, 2006, p. 56) that accumulate and compound the impact of the original incident. Rashida, for example, was fired and her wages were withheld because of her refugee status, in addition to which her husband was in a motorcycle accident. Their subsequent underemployment resulted in insufficient income to pay their hospital bills; food and housing insecurity; and psychological distress, amongst other things. Not only does this example demonstrate how various factors interacted to affect the health of a refugee woman, but the efficacy of her response strategies in helping her mitigate the challenges illustrates the importance of the social safety net as a health-protecting factor (i.e. she drew on multiple facets of the social safety net, including financial/medical assistance from UNHCR, psychosocial support such as borrowing money and staying with fellow refugees, etc.).

⁹⁷ These findings are well aligned with a recent study of refugees in South Africa, which found that social networks were the most important factor influencing the ‘success’ of forced migrants in urban areas (which they defined as physical security and accessing food, employment, and housing) (Krause-Vilmar & Chaffin, 2011).

While determinants of health were presented under separate sub-headings in this chapter for clarity, the case studies and examples illustrate a myriad of ways determinants interacted, overlapped and potentially compounded each other, forming what Strel & Schilperoord (2010) refer to as a “web of interrelated factors”⁹⁸ (p. 268) affecting refugee health. Take, for example, the interrelated factors pertaining to Rohingya women and employment: findings from this study illustrate that while the urban environment provided participants with a range of illegal employment opportunities (such as service jobs, selling items on the street etc.), being employed exposed some them to risk factors (such as exploitation and detention); yet being underemployed often meant that participants lacked income, which limited their access to healthcare, food, housing, etc. I introduce the notion of a ‘web of interrelated factors’ here because, while I conducted nearly 40 interviews and was able to identify from them determinants of health that affect the health and wellbeing of Rohingya women, I did not find these easy to order (linearly or hierarchically) or desegregate from each other. I therefore draw on the notion of a ‘web of interrelated factors,’ not to supersede the robust determinants of health framework around which this study was conceived, but to provide an integrative way of considering and framing results which incorporates tenets of both SDH and intersectionality, discussed in the following chapter.

⁹⁸ This term is akin to what epidemiologists refer to as the ‘web of causation,’ which Nancy Krieger dates back to 1960; it is predicated on the belief that “population patterns of health and disease can be explained by a complex web of numerous interconnected risk and protective factors” (N. Krieger, 1994, p. 887).

Chapter 9: Discussion

Introduction

I begin this chapter by linking results from the qualitative interviews with the theoretical underpinnings of this study. Specifically, I consider the relevance of an intersectionality approach (Crenshaw, 1991; Hankivsky & Christoffersen, 2008) in framing and understanding the qualitative interview data, and draw on intersectionality to consider what might exist at the nexus of factors such as refugee status, statelessness, gender, and race/ethnicity. I then explore linkages between the themes identified in the previous results chapter, and consider the sentiments of fatalism and hope that underpinned them. Following this, I compare and contrast interview results with findings from other research with refugees (Asgary & Segar, 2011; Khawaja et al., 2008), and discuss issues of vulnerability, resilience, and agency amongst female Rohingya refugees. Lastly, I situate findings in the context of the conceptual framework for SDH developed by the WHO (Solar & Irwin, 2010), and argue that while additions need to be made to reflect unique features of the research context, it is an effective framework through which to critically consider SDH among urban refugees in Malaysia.

Intersectionality

Guruge & Khanlou (2004) advocate for an intersectionality approach in research involving refugees, arguing that such a mode of inquiry “create[s] space for the exploration of how various dimensions of social identity, such as race, gender, and class, as well as education, citizenship, and geographical locations, intersect to influence the health of immigrant and refugee women” (p.33). The growing body of literature on intersectionality (cf. Crenshaw, 1991; Hankivsky et al., 2010; Herk et al., 2011; McGibbon & McPherson, 2011; Winker & Degele, 2011; Yuval-Davis, 2006) shaped this study in two key ways: it informed the theoretical

underpinnings of the research (see Chapter 4 of this dissertation), and it guided data analysis by helping me conceptualize and delineate how factors such as gender and race/ethnicity interacted and compounded each other to affect the health and wellbeing of participants.

According to the UN (2000), intersectionality:

Specifically addresses the manner in which racism, patriarchy, economic disadvantages and other discriminatory systems contribute to create layers of inequality that structure the relative positions of women and men, races and other groups. Moreover, it addresses the way that specific acts and policies create burdens that flow along these intersecting axes contributing actively to create a dynamic of disempowerment. (Section C: Intersectional subordination of women)

The Rohingya women who participated in this study clearly identified layers of inequality in the context of their daily lives (such as social and political barriers that restricted their access to basic services such as health and education; discriminatory treatment by Malaysian nationals and authorities, etc.). Not only did they discuss how factors such as food insecurity and living conditions (i.e. intermediary determinants of health) affected their lives, but some were also cognizant of the decisive interaction between structural determinants – such as UNHCR’s policies, the broader political context, their socioeconomic status and position as refugees, etc. – and intermediary determinants they experienced in their daily lives.

Rashida, for example, recognized that a root cause of many issues facing Rohingya people was their stateless status. She understood that the Malaysian government did not recognize refugees nor want to grant refugees citizenship, and she clearly linked her outsider status to the material hardship and discrimination she experienced in Malaysia. Rashida also knew from her own experience that public policies in Malaysia denied Rohingya refugees the right to education, and that being uneducated subsequently restricted their ability to do anything other than low-status jobs, and limited their health knowledge and treatment-seeking behaviour.

In effect, she identified ‘layers of inequality’ in the context of her own life and, more broadly, in the lives of Rohingya refugees.

Over the course of my three interviews with Rashida, she not only spoke of SDH in reference to her own life, she also shared her thoughts and opinions on Rohingya people more broadly (as did some other participants), which enabled me to consider how layers of inequality manifested at multiple levels (i.e. for individuals as well as for Rohingya women as a group more generally). To understand how multiple forms of discrimination affected participants on an individual level, we can consider the case of Amina. Amina’s age, gender, race/ethnicity, and poor economic status contributed to her risk of being sold by the agents who trafficked her to Malaysia. Moreover, due to discrimination based on her race/ethnicity and illegalized status she was unable to access medical treatment and faced a range of economic disadvantages in Malaysia, including housing and food insecurity.

In the context of this example, an intersectionality framework can be used to problematize the reductionist tendency to isolate and implicate individual categories of identity as being the sole source of inequity or discrimination (e.g. Amina’s gender alone did not put her at risk of being sold/trafficked; rather, multiple factors, including her gender, age, race/ethnicity, and poor economic status affected her risk). As Yuval-Davis (2006) points out, the purpose of intersectionality is to “analyse the differential ways in which different social divisions are concretely enmeshed and constructed by each other and how they relate to political and subjective constructions of identities” (p.205). This has important implications for refugee women, because at UNHCR, categories of identity such as gender, disability, etc. may form the explicit criteria that are used to determine which refugees are prioritized for assistance. While this can be a way to identify and support the most vulnerable refugees, it can also generate a

system whereby individuals under the already burdensome ‘refugee’ label are reduced to one or more sub-categories, which then become inclusionary/exclusionary criteria for assistance and access to services (Muecke, 1992; Yuval-Davis, 2006).

Zetter has authored seminal works on issues surrounding the refugee label, and his 1991 article in particular explores conceptual and implementation challenges stemming from the way in which stereotyped identities assigned to refugees are converted into bureaucratic categories that ultimately determine anything from assumed needs to life chances. While the UNHCR constructed identity of a vulnerable refugee might be the sum of individual categories (e.g. Rohingya, woman, widow/single parent), this fails to account for how dimensions of identity intersect; moreover, it fails to consider the role of personal, socioeconomic, and political context in mediating how features of identity are embodied by refugee women, and how “discrimination, inequality, poverty could [also] provide some of the primary prisms through which the world is experienced” (Brough et al., 2003, p. 194).

For example, I interviewed four women who would have been classified by UNHCR as having an added vulnerability because they were widows/single parents, yet for these women, mediating factors affected the degree to which their status as single women/widows translated into vulnerability (i.e. all four women spoke the local language, had been in Malaysia 20 years or more, and had 4-6 children, some of whom were adults, factors which were potentially protective). Conversely, participants such as Amina would not have been classified as having added vulnerabilities,⁹⁹ yet she was one of the more vulnerable women I interviewed (i.e. she was pregnant and had limited access to primary medical care, difficulty meeting subsistence

⁹⁹ Due to the fact that she did not fit the primary categories used to classify vulnerability, i.e. she was not suffering from a serious medical condition; she was not a single parent or woman at risk; she was not a minor or elderly, etc.

needs, etc.). Findings from this study highlight challenges associated with using isolated features of identity to categorize refugees as having (or not having) added vulnerabilities. Many of these challenges stem from the fact that features of identity intersect rather than exist in isolation, and mediating factors (such as family size, employment status, social support, etc.) greatly affect the degree to which features of identity translate into vulnerability. One way to mitigate these challenges would be to use tenets of an intersectionality approach to inform the way in which vulnerable refugees are identified and assessed, a proposition I consider in greater depth in my recommendations to UNHCR.

Fatalism and Hope: Constructing Timelines of the Past, Present, and Future

Beyond contesting the limitations of hierarchical and/or additive understanding of categories of identity, reviewing findings from this study using an intersectionality approach allows us to consider what might exist at the nexus of factors such as refugee status, statelessness, gender, and race. For example, because Rohingya refugees in Malaysia are stateless, they are unable to return to Myanmar – yet they are also illegalized in their country of asylum, meaning they cannot work, attend school, own property, etc. For years, Rohingya refugees in Malaysia were denied resettlement to third countries (Crisp, Obi, & Ulmas, 2012), and though they are now eligible, the queue takes years and even then some refugees are not ‘accepted’ by resettlement countries.¹⁰⁰ As such, most Rohingya refugees – including those who participated in this study – live in a state of limbo (HRW, 2000). The way this structures their hopes, plans and beliefs about the future has important implications for their health and health-seeking behaviour, and results from this study suggest that the uncertainty generated from the

¹⁰⁰ Resettlement countries set the criteria for which refugees they will accept; these criteria can include country of origin, race/ethnicity, criminal record, and added vulnerabilities (such as serious medical conditions), amongst other things.

intersection of race, statelessness and refugee status affected participants' level of investment in the built and social environment, as well as their motivation to overcome barriers to health care, examples of which are discussed below.

Many of the women I interviewed constructed narrative timelines – permeated with a sense of fatalism and transience – in which they situated themselves as outsiders: they recognized that they had fled a country to which they could not return, and that they were illegalized in Malaysia. The women's words manifested a human translation of the term stateless: they did not belong to any country and no country belonged to them. As one participant said, “We cannot go back our country because definitely we will be killed. If we stay in Malaysia also people don't like that we are here, so what should we do? We have nothing, nowhere to go” (11).

While a few participants expressed a sense of resignation about their own lives, nearly all of the women I interviewed were hopeful that things would be better in the future – if not for themselves, then for their children. One participant said:

I know my life is destroy, whatever I face in my life is finish, I don't want to talk about it anymore. Like the life I never, in my life I've never been happy, I never feel independent, I never felt freedom, so I hope that my children will feel happy in their life, will gain some education...If we stay here my children have no future in Malaysia. So I was thinking I want to be resettled, I want to go for another country, because we already have nothing in our life, so I don't want my children's future also destroyed. (8: married mother of 3 who had lived in Malaysia for 24 years)

Statements like this were relatively common, and support what Knudsen (1990) identified as a tendency among refugees to cognitively conflate elements of three temporal phases (the past, present, and future). This, Knudsen argues, “creates continuity and gives meaning to life courses which have been shattered by dramatic events” (p. 122). Participants in this study often constructed their narrative using the three phases identified by Knudsen, linking select events

from their past (in Myanmar), with the present (in Malaysia), and projections of their future (in a resettlement country); as one participant articulated:

Maybe tomorrow, the day after tomorrow I will die by anytimes, by anytime I will die, so I'm thinking about my children's future. So better I resettle fast to third country. In Myanmar I was landless, homeless, stateless, I have nothing. I cannot return back to Myanmar, they are fighting, riots there. (33: 45-year-old widow with four children)

Many participants described their lives in Myanmar with reference to hardship, violence, and struggle. These themes also permeated their accounts of Malaysia, but so did gratitude and appreciation. Numerous participants acknowledged that the challenges they faced in Malaysia were more manageable than those in Myanmar.¹⁰¹

Despite acknowledging that life in Malaysia was better than life in Myanmar, the majority of participants framed their lives in Malaysia as interim, and set their hopes on a future in a third country. A minority of participants (4) said they were content living in Malaysia and did not want to be resettled, but the majority saw resettlement as a solution to the problems they faced in Malaysia, and as their only chance for a better future; as Rashida said, “we cannot see any better future in Malaysia, we only can see in the third country.”

Findings from this study both corroborate and differ from the results of other research with refugees, and the work of Asgary & Segar (2011) and Khawaja et al., (2008) provide particularly interesting points of comparison. For example, in their research with Sudanese refugees already resettled in a third country (Australia), Khawaja et al. noted participants' tendency to concentrate on the future. They identified this as, “a positive cognitive style of

¹⁰¹ This form of positive reframing has been mirrored in other research with refugees, including Khawaja, White, Schweitzer, & Greenslade's (2008) study in which participants expressed that no matter what hardship they faced in their country of asylum, it was better than life in Sudan.

focusing on future hopes and aspirations,” (p.508) which helped refugees to persevere through difficult circumstances, to set goals, and to sustain their sense of purpose. While Khwaja et al., considered refugees’ focus on the future to be a positive cognitive style, Asgary & Segar studied barriers to health care amongst asylum seekers in America, and found that asylum seekers there had a hard time conceptualizing a healthy future. More broadly, they found that:

It is the psychological effect of trauma, compounded by uncertainty during the asylum process, that may contribute to the resignation to suboptimal health and fatalism we observed, wherein being granted asylum status takes on symbolic value as a potential endpoint to suffering and obtaining legal residence usurps health-seeking behavior. (p. 516)

While there are clear parallels between findings from this study and those reported by Asgary & Segar (2011) – notably participants’ resignation to sub-optimal health and fatalism – there are also key differences. While Asgary & Segar found that asylum seekers had “difficulty conceptualizing a healthy future,” (p.516) many of the Rohingya women who participated in this study envisioned the future would be better than the present. This may, in part, be a proverbial ‘grass is always greener’ scenario, whereby Rohingya women have high expectations for resettlement in the U.S., which likely differ from those who initially seek asylum in the U.S. and are facing the realities of living in the country. Interestingly, while focusing on the future appeared to be a positive cognitive coping mechanism for some Rohingya participants (as suggested by Khawaja et al.), their focus was notably on a future that would take place in another country, and some women put their life on hold in the expectation that things would be better when they were

resettled. Thus resettlement took on symbolic value as a panacea for their current hardships and, in some cases, impeded positive health behaviours.¹⁰²

For example, one participant had already survived two bouts of cancer, but had resigned herself to being unable to get follow-up treatment because of financial constraints. She desperately wanted to be resettled, in part because she believed that for those refugees, “who been resettled to the third country, so their health will become cured after they been resettled” (5: married mother of four who had been in Malaysia for 30 years). Not only did some participants’ preoccupation with resettlement impede positive health behaviour, but some participants’ (like the one cited above) fervid beliefs that resettlement was the only solution to their problems led them to consider high-risk behaviour.

This participant had a husband who was ill, and while their resettlement process had already been initiated, they did not want to wait any longer and were considering making a dangerous, clandestine boat voyage to join their daughter in Australia. When I asked her if she understood how risky it was to board a boat full of asylum seekers bound for Australia, she said, “It’s better to die than suffer from this desperate situation. Also if I stay here I will die one day” (5). This example supports my earlier assertion that the uncertainty stemming from the intersection of factors such as race, statelessness and refugee status structured participants’ hopes, plans and beliefs about the future: this participant believed that her survival depended on reaching a third country, to the extent that she was considering risking her life to get there.

¹⁰² The term positive health behaviour is used here to indicate behaviours such as physical activity and seeking medical treatment that “promote health and prevent disease” (Gilmour & Ramage-Morin, 2010, Health Behaviours section). It is contrasted with risk behaviour, which is behaviour that jeopardizes health.

Gender

Scholars working in public health have noted the divergence between what researchers sometimes assume is important to the health of a community and what community members themselves identify as important (Riley, Ko, Unger, & Reis, 2007). In the context of this study, gender exemplified this divergence: scholars have recognized sex and gender as key determinants of health (Benoit & Shumka, 2009; Solar & Irwin, 2010), yet most participants in this study did not explicitly identify sex and gender as something that affected their health and lives. Despite the fact that most participants did not identify the importance of gender, findings from this study substantiate the assertion that gender affected their health, and that in addition it underpinned, intersected, and compounded other health determinants.

Numerous examples support the aforementioned claim. First, various statements made by participants indicate that sex and gender rendered them differentially vulnerable to SGBV in Myanmar, Thailand, and Malaysia. For example, three participants spoke of the widespread rape of Rohingya women in Myanmar, and one had witnessed a female relative being raped. Amina witnessed a young Rohingya woman being sexually harassed by agents in Thailand, and noted that women had greater difficulties than men during the boat journey from Myanmar (for example, they received less food than the men). Once in Malaysia, participants continued to be at risk of SGBV: one participant, for example, was a survivor of domestic violence; the agent holding Amina threatened to sell her to a man who wanted a wife, etc.

While the examples above illustrate how sex and gender directly affected the health of female Rohingya refugees, gender also affected the women's health indirectly,

in ways that become evident when we consider, as Ompad, Galea, Caiaffa, & Vlahov (2007) suggest, “the role of gender as a social construct that shapes personal health behaviors and health-related societal structures” (p. i43). For example, many of the factors that affected the health of Rohingya women who participated in this study were influenced by – and mediated through – their husbands. This was evident in the fact that some participants hardly ever left their homes and on the rare occasions they went outside, their husbands accompanied them. One participant, a married 20-year-old living near Kuala Lumpur, had been in Malaysia nearly a year, yet she was not aware that UNHCR provided any type of assistance to refugees. She said she never went far from the house, and when I asked what she would do if she needed to leave the house with her baby but her husband was at work, she said: “I will wait for my husband, I will wait for my husband. I just follow whatever my husband say” (2). When I asked if she thought living in Kuala Lumpur had affected her health, she replied:

For me there is no difference because I will follow wherever my husband bring me, if he bring me here then I will stay here, if he bring me into the forest also I will just stay in forest, I have no problem with that as long as my husband together with me I am happy. (2)

The first part of the quotation indicates that the participant is acquiescent to her husband (to the extent that she would live in a forest if he brought her there), yet she did not imply that her reliance on her husband was constraining, on the contrary, she iterated numerous time that being with him made her happy. While this participant portrayed her relationship with her husband as a positive one, it was clear that he mediated many of the factors that affected her health (e.g. when she left the house, where their family lived, etc.).

Other participants indicated that their health was negatively affected by their husbands. One was a survivor of domestic violence in her past and current marriages: the RA described this

participant's situation by saying, "her first husband also violence on her, the second husband also violent on her, [she] just um keeping quiet and stay at home" (20: 25-year-old married mother of 3).¹⁰³ Rashida noted that, "in our Rohingya community, for the woman, husband is the one who makes the decisions," and that this was stressful because, "the male and the female their thought is different, not the same... So due to that, if we want to make them understand they won't understand what we face." Seven participants said that decisions pertaining to their health (e.g. whether to go to the doctor or hospital, what to do when they became ill, etc.) were made by their husbands, while 14 women said that they made decisions about their health by themselves. The extent to which some participants' health and lives were dependent on and influenced by their husbands has quite practical implications, as it suggests that in order for health programs and services to be effective and sustainable, the most appropriate way to reach the Rohingya community may be to include both women and men (rather than targeting women exclusively).

Aside from the few women who explicitly identified gender as a determinant of health, most mention of gender and gender-related differences was quite nuanced. One participant, for example, described how her daughter-in-law had recently hid in the Malaysian jungle for three days to avoid an immigration raid; when I asked if she had gone alone or with her husband, the participant said, "[her] husband followed her. She's alone, she's female, where's she going to go without the husband?" (32: 58-year-old widow from Penang).

While it could be argued that the excerpt above, and the others before it, indicate a lack of autonomy on the part of Rohingya women, superficial readings of text fragments such as these can oversimplify and decontextualize participants' words from broader issues of gender and

¹⁰³ I informed this participant that there were mechanisms in place for her to report this abuse to UNHCR, and explained the support services that would be available to her should she choose to do so, but ultimately she decided she did not want to report it.

displacement, colonialism, culture, and religion (Abu-Lughod, 2002; Hyndman, 2010; Manchanda, 2004). This is particularly true in the context of displacement, where the disruption of gender roles, coupled with interventions by humanitarian organizations to provide basic necessities and implement women's empowerment programs, is perceived by some refugees to be disempowering, emasculating, and a sign of social and moral decay (Horn, 2010).

The female refugees I interviewed did not express such perceptions (i.e. their statements did not indicate that they found assistance to be disempowering, a sign of social and moral decay, etc.), but in order to gain balanced insight into the gendered perceptions of Rohingya refugees in Malaysia I would need to interview male Rohingya refugees as well. While incorporating the perspectives of male refugees is beyond the scope of this dissertation, the findings summarized in this section support two key arguments: gender was an aspect of identity that greatly affected the health of female refugees in this study, and in many instances participants' husbands had a decisive influence over their lives and health. These arguments serve as the foundation for discussion in the following section, in which I draw on examples of power, resilience and agency among participants to support the contention that while their husbands and circumstances greatly affected participants' health and wellbeing, they were not passive victims whose fate was determined by their husbands or circumstances, but rather they were resilient women whose actions often mediated the impact of social determinants of health.

Vulnerability, Resilience, and Agency

Public and academic discourse on refugees often frames refugees in terms of their vulnerabilities (Freedman, 2010), and the notion of refugees as a powerless and vulnerable population has, at times, been perpetuated by agencies and NGOs in order to raise awareness of humanitarian situations and support fundraising activities (Rajaram, 2002). Yet an increasing

number of scholars are eschewing the notion of refugees as categorically vulnerable, and advocating for greater recognition of the ways in which refugees are resilient (cf. Munt, 2012; Pulvirenti & Mason, 2011a, 2011b; Thomas, Roberts, Luitel, Upadhaya, & Tol, 2011).

Resilience can be defined as “particularly successful or unpredicted adaptations to trauma, stress, risk and other negative life experiences” (Pulvirenti & Mason, 2011b, p. 39), and while it is often delineated at an individual level (i.e. some people possess superior attributes or skills that make them resilient, while others do not), Pulvirenti & Mason argue that this conceptualization tends to over-emphasize “the importance of internal or individual attributes to the detriment of wider institutional, structural or social influences” (p.40). They highlight an approach advocated for by scholars such as Y. Chan (2006) in which resilience is seen as “a process between the individual, family and social environment” (p.40). Hancock (2009) posits that there are multiple spheres of resilience (personal, community, and ecological) and that “there is in fact a reciprocal relationship between resilient people and resilient communities” (p.B-24). The conceptualizations of resilience highlighted above are well aligned with the tenets of intersectionality and SDH, and are useful in framing results from this study.

For example, participants in this study adopted numerous strategies in response to food insecurity, some of which were more innovative and effective than others. Rather than taking this to mean that some women were more resilient than other women, a more nuanced understanding suggests that participants executed various adaptive strategies, and their broader social environments affected the success of these strategies. For example, a few participants solicited gifts of food from neighbours, a strategy that was only successful because their neighbours had more than enough food to feed their own families, and a willingness to share. One participant used to take her children out to beg, and the efficacy of this strategy would also have been

affected by the social environment (i.e. donations would have varied depending in which neighbourhood the participant was, as would the risk of being detained while begging, etc.).

One participant responded innovatively when confronted with food insecurity: she would go to a market and collect old vegetables that had been thrown away, then cook them and feed them to her children. This strategy is aligned with the individual-family-social environment form of resilience noted by Y. Chan (2006), in that the woman, demonstrating individual resilience, undertook an uncommon strategy – akin to what some might deem positive deviance¹⁰⁴ – to feed her family, which involved obtaining food from the social-environmental context in which she was embedded. This is one of many examples of how the refugee women who participated in this study executed agency by employing resilient and adaptive strategies in order to function within their challenging surroundings.

The individual-family-social environment understanding of resilience can also be expanded to consider how participants responded to broader issues of power. There is an inherent power imbalance between refugees and the agencies that serve them, and agencies such as UNHCR have significant control over refugees (Harrell-Bond, 2002; Marfleet, 2007). Harrell-Bond (1999) argues that this power imbalance is epitomized by the fact that many refugees refer to UNHCR as their father or mother, as in doing so refugees are “positioning themselves as totally dependent for their survival on the organisation which had assumed authority over them” (p. 14). Findings from this study support this assertion. One participant, Rashida, likened UNHCR to her parents, saying: “We only hope to UNHCR, our hope is all to UNHCR not to others...UNHCR

¹⁰⁴ The basic premise of positive deviance is that, “in most settings a few at-risk individuals follow uncommon, beneficial practices and consequently experience better outcomes than their neighbours who share similar risks,” (Marsh, Schroeder, Dearden, Stermin, & Stermin, 2004, p. 1177); the concept has grown steadily since the 1970’s, and is most frequently applied to situations involving child health and nutrition. In the example provided here, the risk is that if too many women took up this strategy it may render the strategy ineffective.

have looked after us as parents, as parents, so we are very very grateful for that.” Yet positioning themselves as dependent on UNHCR for survival does not necessarily mean that refugees are powerless, indeed this very positioning may be a way of executing agency; as Freedman (2010) states:

Refugees often feel the need to tell stories about their own ‘powerlessness’ in order to gain certain advantages from UNHCR officials or from other aid agencies...this re-appropriation of stories of ‘powerlessness’ and ‘victim’ status can be seen as a form of agency on the part of refugees who adapt their strategies for survival to the dominant representations created by those providing aid to them. (p. 600)

It could be argued that Rashida, the participant who referred to UNHCR as her parents, re-appropriated her vulnerable status in order to obtain assistance from UNHCR. She was aware of how difficult it was to obtain assistance from UNHCR, yet she had received medical and financial assistance multiple times and seemed to use emotional distress (perhaps strategically) in her petitioning. In describing how she asked for assistance, she said: “I have cried in front of the officer...I crying and begging in front of him that I have no money to discharge my son from the hospital, I beg to him, I cry in front of him, then finally he helped me.”

Lastly, the individual-family-social environment conceptualization of resilience can help us consider why some refugees in the study led happier, healthier lives than others – in other words, what factors contributed to highly-functional, ‘exceptional’ participants such as Azu. On an individual level, numerous factors strengthened Azu’s ability to adopt effective response strategies, including: positive cognitive processes;¹⁰⁵ good physical health; and having been

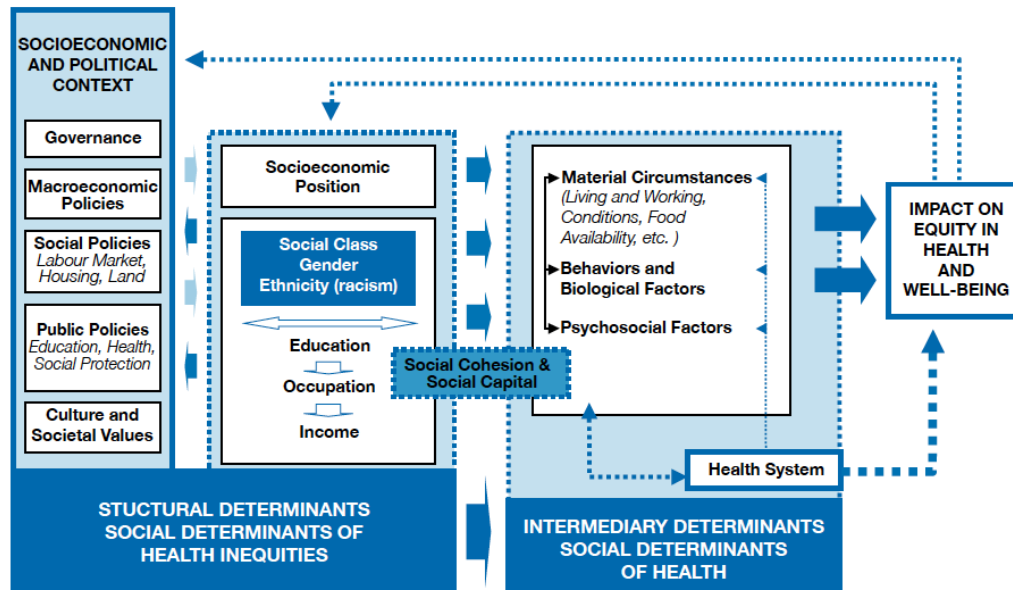
¹⁰⁵ I use the term ‘positive cognitive processes’ to denote affirmative “interpretations and perceptions of oneself and one’s situation,” (Khawaja et al., 2008, p. 492), as opposed to the negative cognitive processes of refugees who internalize aspects of their life circumstances such as persistent poverty, outsider status etc. as reflective of themselves.

educated to secondary school level (as a result of which she was literate, spoke three languages, had knowledge of positive health behaviour such as physical activity and nutrition, etc.). In terms of her family, Azu had a good marriage, healthy children, and a strong extended family that had looked after her children so she and her husband could work. On a social environment level, Azu had a good job, a kind employer, stable and secure housing, and was part of a supportive community of Rohingya refugees. This web of factors (and more) operating on the level of individual-family-social environment improved Azu's ability to respond to the challenges associated with being a refugee in Malaysia, yet considering resilience on any one of these levels alone would fail to incorporate the range of factors that allowed her to adopt resilient strategies under conditions of adversity.

Findings in the Context of the CSDH Framework

In the previous results chapter I outlined a nexus of interrelated factors that affected the health of Rohingya women, and I will now consider how these findings fit within the CSDH framework. In a broad sense, the CSDH framework provides structure and terminology that is useful in framing results from this study. For example, Solar & Irwin clearly distinguish between key terms such as structural and intermediary determinants, which I draw on throughout this dissertation (see Figure 3).

Figure 3: The CSDH Framework



(Solar & Irwin, 2010, p. 48)

Many structural and intermediary determinants recognized in the CSDH and other SDH frameworks (such as gender, race/ethnicity, education, material circumstances, and the health system) (cf. Mikkonen & Raphael, 2010; Solar & Irwin, 2010) were also found to be key determinants of health affecting Rohingya refugee women. The most notable difference related to participants' status as forced migrants. This is because while migration status does not feature prominently in existing the CSDH model, refugees' status as forced migrants is arguably an important structural determinant of health. Furthermore, unlike the general population, key aspects of the socioeconomic and political context that shapes refugees' lives are determined by organizations like UNHCR. UNHCR and migration status are therefore examples of structural determinants emerging from this study that, while not explicitly mentioned in the CSDH model, are nevertheless aligned with the framework and can be integrated into it (a notion discussed further in Chapter 10).

Findings from this study did, however, illustrate challenges associated with the measurement of some determinants, including those explicitly noted in the CSDH model. This is, in large part, because the impermanence and insecurity that permeate the lives of refugees in Malaysia means that while the essence of some determinants is the same, it can be more challenging to measure them or fit them into a linear framework. For example, education, occupation and income (often considered to collectively indicate socioeconomic status) feature prominently as structural determinants of health in the CSDH framework. In this framework, education is generally measured by the level completed (i.e. none, primary and secondary school, etc.), occupation is measured by class (ranging from unskilled manual labourers to professionals, such as doctors and lawyers), and income is measured by household income (Bonney et al., 2007).

Yet it would be very difficult to measure the education of refugees in Malaysia by level alone, because the type and quality of education they have received differs significantly and does not allow direct comparison (e.g. women in this study had no formal education, or were educated in a combination of government schools in Myanmar, refugee camps in Thailand, public schools in Malaysia, religious institutions, UNHCR learning centres, etc.). Nor is occupational class an effective form of measurement, as many Rohingya participants performed unpaid work in the home (such as raising children, cooking, and cleaning) that went unrecognized, and those who did work undertook a small variety of informal, low-prestige jobs (such as cleaners, dishwashers, etc.). Furthermore, since it is illegal for refugees to be employed in Malaysia, they lack the basic protection that normally benefits those with a legal occupation (such as minimum wage, workers' compensation for injuries sustained at work, regulations on dismissal, working hours, etc.). Lastly, income is not a very effective measure because not all Rohingya women receive an

income in the sense of monetary reward in exchange of labour; rather, many use subsistence methods such as bartering and trading, or obtaining food/assistance from UNHCR, etc.

The authors of the CSDH guide acknowledge that “in many settings these standard measures will not provide adequate sensitivity in quantifying degrees of wealth or poverty” and, importantly, that “problems in measuring socioeconomic position are likely to affect the poorest and most marginal individuals in society disproportionately” (Bonney et al., 2007). While the authors suggest alternate measures for computing SES in low-income countries (such as examining individual and household wealth using indicators such as material possessions and access to services), they also acknowledge that no measures are appropriate and effective in all settings, and they suggest that policy makers identify country and context specific quantitative measures of socioeconomic status (which, while worthy, is beyond the scope of this research).

The examples discussed (education, income and occupation) illustrate some of the challenges associated with measuring determinants in the uncertain and variable context in which illegalized refugees live. Over the course of data collection and analysis I found my focus shifting away from measuring individual determinants, not only because of the conceptual and practical challenges outlined above, but because the immediacy of the needs of the participant population (including material deprivation and barriers to essential services) led me to the more practical task of delineating interconnections between factors affecting participants’ health and identifying points of intervention.

Results from this study illustrate a “web of interconnected factors” affecting the health of Rohingya women, a notion which was introduced and discussed in Chapter 8 of this dissertation. Findings also indicate that while the context in which female Rohingya refugees in Malaysia live is characterized by risks (of exploitation, arbitrary detention, eviction, etc.), the social safety net

is simply not strong enough to mitigate many of these shocks, and one critical incident – such as the death of their husband or developing a serious medical condition – can trigger a cascade of events, which accumulate and compound the impact of the original incident. Education and income formed key nexuses in the web of factors affecting the health of Rohingya women, and appeared to have great potential to mitigate or compound critical incidents. For example, women with sufficient income were better able to access medical care, had greater food security etc.; women who had learned Malay language were able to communicate with medical personnel and UN staff, could read medication instructions and health information pamphlets, and were qualified for a greater range of employment, etc.

Education (in the form of language and skills training, basic health education, etc.) and income generating activities (formal and informal employment, co-operative businesses, microcredit initiatives, etc.) are thus points of intervention (discussed further in Chapter 10) with the potential to stabilize and improve various dimensions in the lives of refugee women in Malaysia. Fortunately, UNHCR has the infrastructure to initiate and target social protection, education, health, and community development programs that incorporate education and income generating components for Rohingya women. One way I will disseminate results from this study is by providing UNHCR with a list of recommendations, and one of these recommendations contains specific suggestions for the initiation of programs such as these.

Conclusion

This chapter brought together a nexus of ideas related to the theoretical underpinnings of the study, findings from the qualitative interviews, the CSDH framework, and other relevant scholarship on issues related to refugee health. At the start of the chapter, I discussed how the intersection of various aspects of identity differentially affected the health and lives of Rohingya

women, and later in the chapter I expanded this discussion to consider how participants affected (and were affected by) the broader socioeconomic context in which they were embedded. Quotes and examples demonstrated that uncertainty stemming from the intersection of race/ethnicity, statelessness and their illegalized status structured participants' hopes and beliefs about the future, and in some instances contributed to behaviours that jeopardized their health. This finding is particularly relevant, because while it has been noted that one challenge in the field of SDH is convincing governments to make the long-term investments required to address inequities in SDH (Bonney et al., 2007), findings presented here suggest that questions about how intersecting dimensions of social identity – particularly those antecedent to oppression and inequity – affect how willing and/or able refugees are to engage with the social conditions that affect their health in their country of asylum.

This study provides unique insight into features of identity, social structure, and the socioenvironmental context that affect the health and wellbeing of Rohingya women in Malaysia. As Pavlish (2005) notes in her research with refugee women, “health organizations cannot simply impose new social structures to support better health for women,” (p. 891). Findings generated by this study are therefore pertinent to academics, NGOs and UNHCR (i.e. people and organizations trying to support the health and wellbeing of Rohingya women in Malaysia), as they provide information that can be used to identify points of intervention within existing social structures.

Beyond providing the basis for recommendations regarding how to improve the health and wellbeing of Rohingya women, findings from this study provide concrete examples of the ways in which refugees exercise agency, examples that problematize the ubiquitous assumption that refugee women are all powerless victims (Freedman, 2010). The importance of challenging

this assumption is articulated by Outwater, Abrahams, & Campbell (2005), who – in reference to complex issues related to power, gender relations, and sexuality in the spread of HIV in South Africa – argue that, “to ignore the acts of agency in the minute day-to-day practices and struggles and presume they do not exist through victim status is stripping these communities of their voices” (p. 149).

If those studying SDH in refugee communities disregard the spectrum of illness and health (Antonovsky, 1996) and focus entirely on illness, or if they fail to recognize the agency refugees have within their lives and communities, they similarly will be stripping refugee participants of their voices. This study aims to demonstrate an alternative approach: one that improves understanding of determinants of health among female refugees by considering the instrumental role of the broader sociopolitical context in structuring their lives, and extending discussion beyond refugees’ needs and vulnerabilities to consider their resilience and agency. Ultimately, this approach is well-aligned with the seminal work of Muecke (1992), who argued that far from the widespread, pathologized perception of refugees, “refugees present perhaps the maximum example of the human capacity to survive despite the greatest of losses and assaults on human identity and dignity” (p.521).

Chapter 10: Conclusion

Introduction

The purpose of this study was to identify and generate empirical evidence on social determinants of health among female Rohingya refugees in Malaysia. Specifically, it generated knowledge on Rohingya women's main health concerns, factors that support their health and put their health at risk, barriers they face in leading healthy lives in Malaysia, and their response strategies to the aforementioned challenges. Findings from this study have both theoretical and practical implications, and are particularly timely given the tenuous sociopolitical situation surrounding the Rohingya people in Myanmar, and the increasing number of Rohingya asylum seekers fleeing to Malaysia (Thomson Reuters Foundation, 2013; Verghis, 2012). In this chapter I briefly review the design of the study and data it generated, consider the implications of its findings, and identify potential areas of future research.

Research Approach and Methods

The research design for this study was qualitative, and I used an exploratory, applied research approach to consider social determinants of health among Rohingya women. The primary research method I employed was semi-structured interviews with Rohingya refugee women. I also reviewed UNHCR financial assistance documents based on assessments conducted with Rohingya refugee women, and this information was used to provide context and background to the semi-structured interview data. The semi-structured interview data were analyzed using an inductive process of thematic analysis (Burnard, 1991; Patton, 2002) whereby themes and sub-themes emerged directly from the data rather than a pre-existing framework.

The theoretical basis of the study is rooted in intersectionality (Hankivsky & Christoffersen, 2008; McGibbon & McPherson, 2011; Yuval-Davis, 2006), a paradigm built on

the work of Crenshaw (1991), predicated on the notion that “various dimensions of social stratification—including SES, sex, gender, ethnicity, race, age and others—can add up, or cumulate, to great disadvantage for some groups of people” (Hankivsky et al., 2010, p. 8). As intersectionality problematizes the notion that individual aspects of identity (e.g. gender) can be considered in isolation from others (e.g. age, race/ethnicity, etc.), it provided particularly suitable grounding for discussion surrounding the efficacy of using individual aspects of identity to categorize vulnerable refugees.

Ethical Issues

Over the course of this study I confronted numerous theoretical and practical issues related to the ethics of conducting research with refugees. As has been reported in other research with refugee participants, the women who participated in this study were confronting issues related to poverty (AI, 2010); traumatic pre-flight and flight experiences (Khawaja, White, Schweitzer, & Greenslade, 2008); domestic violence (Horn, 2010); and mental and physical illness (Hollifield et al., 2002), and such issues provide compelling rationale to extend discussion regarding research ethics beyond nonmaleficence, to include issues of assistance and intervention. Some scholars (Mackenzie et al., 2007; Turton, 1996) advocate that those conducting research have a responsibility to assist and ameliorate suffering in the lives of participants. While many would agree with this philosophically, it is more challenging to determine how, logistically, researchers should endeavour to assist and alleviate the suffering of participants.

One key ethical issue in this study was determining a suitable form and quantity of compensation. During data collection I responded to the significant variation in need amongst participants by providing a base level of compensation (in the form of a food parcel) to every

participant, and additional food to those who appeared to be more greatly in need. While in the planning phase of the study I did not intend to give different levels of compensation to participants, but during data collection the urgent material needs of a few participants provided compelling justification to do so. Ultimately, I resolved that in this particular context – where all participants were illegalized refugees and some were failing to meet their basic subsistence needs – supplementing the food parcels of the most needy participants, though unequal, was more equitable, ethical, and responsive.

There were also instances where participants revealed more extensive needs (e.g. need for medical or financial assistance, legal advice, etc.), and in such cases my ability to respond to these needs was predicated on my involvement with UNHCR. The complex health, social, and legal issues affecting many participants – and the concomitant ethical issues of involving them in this research – sensitized me to the benefits of having support and guidance from an institutional partner at the field site. For example, a key advantage of my affiliation with UNHCR was that the organization has established response protocols, medical referral systems, financial resources, and trained officers to whom I could refer vulnerable participants. Moreover, having worked closely with the Individual Assistance Department at UNHCR gave me in-depth knowledge of UNHCR's policies, the efficacy of existing health programs, the institutional culture, available resources and limitations, etc., which enabled me to distil my findings into recommendations that were context-appropriate.

Despite the potential benefits of conducting research with refugees in affiliation with UNHCR, there is a paucity of published information on how to navigate the practical and ethical complexities of such a relationship, in particular when conducting short-term, non-participatory research. My experience conducting this study provides insight into ethical and practical issues

related to conducting refugee research in affiliation with a humanitarian organization, and stands to make a contribution to this particular lacuna of knowledge.

Findings

Background and contextual information were presented in a document review chapter (Chapter 6), and empirical findings from this study were presented in two subsequent chapters: a case study and demographic data chapter (Chapter 7), and interview results chapter (Chapter 8). Together, the evidence presented in these chapters answers the research questions guiding the study (set out in Chapter 1 and restated in Chapter 8).

Document Review

The financial assistance documents contained a range of information related to Rohingya women and their social support, family composition, employment, housing/living conditions, health and more. Key issues discussed in the documents pertained to safety and security (e.g. SGBV, arrest/detention); health conditions (e.g. hypertension, diabetes, HIV); food insecurity; inability to pay rent/risk of eviction; and community support. In addition to providing information on the aforementioned topics, Chapter 6 provides insight into the types of assistance available for refugees in Malaysia, and institutional practices that determine its distribution. The issue of assistance was one of many areas of overlap between the document review and interview data; others included health concerns, barriers to care, food and housing insecurity, community support, and security issues.

Semi-structured Interviews

Key themes that emerged from the interviews include fleeing Myanmar and the journey to Malaysia; Rohingya women's health concerns, response strategies, and barriers to care;

food/housing insecurity and the social safety net; UNHCR and security issues; education; and employment and income.

Fleeing Myanmar and the journey to Malaysia. Twelve participants were relatively new arrivals, having arrived in Malaysia in the last 3 years. Some spoke at length about their journey to Malaysia, noting the deleterious effects it had on their physical and mental health, and that the cost of the journey – including bribes, fees, and extortion money – had left their families deep in debt. Recent reports, investigations, and firsthand accounts claim that Rohingya people who flee Myanmar on boats are at risk of starvation, dehydration, exploitation, human trafficking, and SGBV (Channel 4 News, 2013; Corben, 2013; HRW, 2013b; UNHCR, 2012); the accounts provided by Amina and other participants in this study support these assertions. Furthermore, data from this study highlight the physical, material, and psychosocial consequences that continue to affect Rohingya people arriving by boat long after they reach Malaysia.

Health concerns, response strategies, and barriers to care. Participants' primary health concerns related to reproductive health, mental health, and chronic illnesses (e.g. hypertension, diabetes). For many participants, their initial response when they experienced health issues was to try and manage it on their own (often by self-administering pharmaceuticals, traditional medicine, prayer) and seeking medical care if their conditions persisted. Discussion of health issues and response strategies was closely linked to the barriers participants faced in accessing health care, which included insufficient income to pay for transportation and treatment, language issues, and not having requisite identity documents (i.e. prior to obtaining their UNHCR card/letter).

Food and housing insecurity, and the social safety net. Nearly a third of the women I interviewed explicitly mentioned experiencing food insecurity at some point since leaving Myanmar, and unstable housing was another source of stress for some participants (at the time of the interview, 3 women were behind in rent, and 5 had been evicted while in Malaysia). Participants attempted to manage these risks by drawing on informal aspects of the social safety net (e.g. seeking temporary housing or food from friends and community members) as well as formal aspects of the social safety net (e.g. assistance from UNHCR), but these were not always enough to mitigate the challenges participants faced, leaving some unable to meet basic subsistence needs.

UNHCR and security issues. UNHCR serves as the foundation of the social safety net for refugees in Malaysia, as it provides both legal protection and support services. Many participants were aware of this, and discussed at length the various means through which UNHCR structured and affected their lives (e.g. by providing protection in cases of detention, medical and financial assistance, education, etc.). Participants expressed a range of positive and negative opinions regarding the efficacy of UNHCR at addressing their needs and concerns, and these data were particularly relevant when I was distilling findings into recommendations for UNHCR.

Education. Education emerged as a key theme in this study. It was evident that education and resultant skills/levels of knowledge affected participants' ability to function in Malaysia (e.g. women who could read Burmese language were able to read health brochures, information pamphlets provided by UNHCR; those who could speak Malay could communicate with medical staff and had a greater chance of obtaining employment, etc.). Obtaining education for their children was also a recurring theme among participants, who were aware of the consequences of

limited education and wanted their children to receive the level and quality of education they themselves had been denied.

Employment and income. Employment was another recurrent topic during the interviews, and many participants expressed their desire and/or need to work, as well as the challenges they faced finding and maintaining employment. While some participants noted concerns surrounding employment (such as exploitation, the health impact of long hours and manual tasks, etc.), others mentioned the freedom and satisfaction they got from being employed. Employment was closely linked with income – used in this context to denote a salary, remittances or financial assistance, the ability to borrow or solicit donations of money, etc. – which was a common and overarching issue discussed by participants. For the refugee women who participated in this study, insufficient income was often the root cause of food and housing insecurity, and inability to afford transportation, necessities for their children, medical care, etc.

Discussion

While information generated by the document review and data from the semi-structured interviews overlapped, the two are complementary rather than directly comparable. This is, in part, because while added vulnerability was a selection criterion for being considered for financial assistance, it was not a factor in the selection of women I recruited for semi-structured interviews.¹⁰⁶ Other differences in the information contained in the document review and interviews stemmed largely from their distinct purposes – for example, the financial assistance documents were created to assess the distribution of humanitarian assistance among vulnerable refugees, whereas the interviews gathered data on pre-flight, flight, and post-flight conditions

¹⁰⁶ As noted in Chapter 4, most interview participants were recruited from the registration waiting area at UNHCR, which meant the primary purpose of their presence at UNHCR that day was to be issued a new/renewed refugee card, not to seek assistance. Every refugee in Malaysia is required to renew their card periodically, so these women were completing an administrative task required of all refugees.

and social determinants of health. As such, the interviews provide greater insight into topics related to Myanmar and the journey to Malaysia, overarching factors that affect women's lives in Malaysia (i.e. education, refugee status, resettlement), and more nuanced issues such as lack of dignity, discrimination, fatalism and hope.

In Chapter 9 I considered such issues in detail, noting the ways in which participants constructed narrative timelines – permeated with a sense of fatalism and transience – in which they situated themselves as outsiders. I drew on an intersectionality approach to frame discussion of a nexus of factors, including refugee status, statelessness, gender, and race/ethnicity, and argued that in the context of Malaysia, intersecting dimensions of identity – particularly those antecedent to oppression and inequity – affect how willing and/or able some Rohingya refugees are to engage with the social conditions that affect their health. I then highlighted the importance of recognizing the resilience – and not only the vulnerability – of refugee women, and of conceptualizing resilience not solely as a character trait but as the execution of strategies whose efficacy depends on the broader social environment. Lastly, I considered how findings fit within the CSDH model, an issue discussed in the following section.

Theoretical Implications

The theoretical underpinnings of this study were greatly influenced by a social determinants of health approach and, more specifically, the determinants of health framework developed by the CSDH (Solar & Irwin, 2010). While applying such a framework to forcibly displaced populations necessitates adaptation, ultimately this study illustrates that the framework can be an effective means through which to critically consider structural and social determinants of health among urban refugees. The importance of this rests in the fact that to date there has been little research on SDH among refugees (or other forced migrants), and the efficacy of

applying existing SDH frameworks in the context of forced migration was therefore unexplored.

The CSDH framework effectively informed the study design, research tool (i.e. interview guide) and the way in which results were framed. By conceiving of structural and intermediary determinants of health cited in the CSDH model as illustrative rather than definitive, I was able to adapt the model to include determinants of health that proved important in the context of this study. For example, urbanization – specifically, the fact that there are no camps in Malaysia and all refugees are therefore considered urban – arguably forms a seminal part of the socioeconomic and political context for refugees in Malaysia, affecting the implementation of UNHCR policies related to urban refugee health, education, assistance, etc. UNHCR itself occupies a key part of the socioeconomic and political context for refugees in Malaysia, as the organization dictates much of what a government normally would (including refugee status determination, policies on refugee assistance, etc.). The government of Malaysia’s policy on refugees (which is the root cause of their illegalized status) also forms a crucial part of the socioeconomic and political context, in that it prevents them from legally accessing the labour market, education, public/social protection schemes, etc.

Refugee status (and, more specifically, the stateless and illegalized status of Rohingya refugees in Malaysia) formed part of participants’ socioeconomic position, fundamentally affecting (and often limiting) their level of education, occupation, and income, as well as social determinants of health (such as material circumstances and psychosocial factors). In order to assess SDH among women refugees in Malaysia using the CSDH framework, it was particularly important to acknowledge and account for the impact of their illegalized status, as it proved to be both inceptive and overarching, linking what might otherwise appear to be disparate

determinants of health. Ultimately, participants' stateless and illegalized status in Malaysia emerged as a key nexus in "patterns of systematic disadvantage that undermine the well-being of people whose prospects for good health are so limited that their life choices are not even remotely like those of others" (Gostin & Powers, 2006, p. 1054). Moreover, participants' illegalized status affected the design and feasibility of recommendations stemming from this study (discussed below).

This study also questioned the utility of using pre-determined features of identity as a structuring mechanism to categorize vulnerable refugees and shape refugee assistance programs. The implications of this argument are twofold. Critically assessing the mechanisms through which humanitarian assistance is delivered to refugees has broad theoretical implications for the SDH approach; this is because, as Solar and Irwin (2009) argue, while it is increasingly acknowledged that SDH affect the health of individuals, "it is much less common to aver that the quality of SDH is in turn shaped by the policies that guide how societies (re)distribute material resources" (p. 25). Pragmatically, integrating an intersectionality approach into vulnerability assessment/assistance programs could be a way to more effectively identify and address the needs of vulnerable refugees, an issue taken up in the following section.

Program/policy Implications

Results from this study have implications for program and policy development, primarily in the Malaysian context though they could be extrapolated more broadly. Clearly, the most effective way to stabilize and improve various dimensions in the lives of refugee women in Malaysia would be for the government to amend pertinent laws so that refugees are no longer illegalized. The foremost step towards this would be for Malaysia to accede to the 1951 Convention on refugees; other important policy amendments would be to provide refugees in

Malaysia with the right to work and access education. Currently, UNHCR engages with the government and advocates for improved policies pertaining to refugees, and while I strongly support continuing such efforts, I do so with the recognition that amending national refugee policy is ultimately the purview of the government.

The following recommendations stemming from this research are therefore directed at UNHCR, as it forms a crucial part of the socioeconomic and political context and implements a range of programs and policies that are more amenable to change. Given that these recommendations are directed at UNHCR, the points of intervention I discuss below are social/economic/humanitarian in nature rather than legal/political.

As data from this study clearly indicate, the nature of refugees' needs – at times urgent and interconnected – requires an integrative, multi-faceted response. Yet limited resources necessitate the prioritization of areas of intervention. In the following discussion I highlight areas that have potential to improve the lives and health of Rohingya women in Malaysia and would be particularly beneficial to prioritize/invest in.

Education is a priority for Rohingya women, and it would be a key area to invest in given the potential immediate and long term gains. Such investment could entail increasing adult learning opportunities in the form of English language classes¹⁰⁷ and providing health education and skills/livelihood training. The potential outcomes of such investment could be significant; for example, a refugee who speaks some English (or Malay) is better able to communicate with doctors, has greater access to health information, is more likely to secure employment, etc. Further, the education department at UNHCR could assist Rohingya refugees by continuing to

¹⁰⁷ Many refugees in Malaysia will eventually be resettled to an English speaking country, and given that English is widely spoken in Malaysia, the long term benefits of learning English may be greater than learning Malay language.

support learning centres for Rohingya children; subsidizing costs for parents who are unable to pay school fees; and encouraging school feeding programs.

Another area that stands to benefit Rohingya women in Malaysia is greater livelihood support, a particularly important point of intervention given the repercussions of insufficient income. Livelihood support could take the form of skills training (specifically targeted to the type of jobs available to refugee women in Malaysia); income generating opportunities (co-operatives, microfinance programs, etc.); and referrals and support for refugees seeking formal employment.¹⁰⁸ Multiple departments could address issues of food insecurity (e.g. one means of doing so would be to encourage/support school lunch programs for refugee children), as well as expand information dissemination to refugees about the UNHCR and NGO services available to them. This is particularly important for refugees who live far away from Kuala Lumpur and have limited access to the UNHCR office (e.g. innovative methods including text-messaging and social-media could be employed to disseminate information about important policies and programs).

Lastly, as mentioned in the previous section on theoretical implications of this research, findings from this study suggest that one overarching issue to be considered by organizations assisting refugees is to incorporate tenets of an intersectionality approach into the frameworks used to assess vulnerability. The basis for this assertion is evident in data from the qualitative interviews. They indicated that multiple aspects of identity – including gender, marital status, physical ability, age, etc. – intersected. The extent to which they increased or diminished a refugee woman's vulnerability (and what exactly she was vulnerable to, be it food insecurity,

¹⁰⁸ Some of these recommendations, such as microfinance programs, have been implemented by UNHCR Malaysia in the past but they tend to be short term and target specific genders/ethnicities, not necessarily Rohingya women.

inability to access health care, etc.) depended on the life circumstances in which she was embedded, such as her length of time in Malaysia, family composition, etc. In other words, the aspects of identity that are commonly used to categorize vulnerable refugees did not inherently translate into vulnerability, and rather than conceptualizing vulnerability categorically, it was more appropriate to understand it as both relative and dynamic. Thus, rather than using individual aspects of identity (such as age) to categorize vulnerable refugees and justify material assistance, a more nuanced approach would be to consider the intersecting nature of aspects of identity, and assess vulnerability along a continuum rather than in fixed categories (CASA, 2003).¹⁰⁹

It is also important to extend critical analysis of vulnerability beyond an individual level by acknowledging that UNHCR policies and procedures affect (and potentially create) vulnerability among refugees. As an independent evaluation of UNHCR community services in multiple countries highlighted, there is a “tendency to attribute vulnerability to particular categories of the population, rather than failings within the refugee-assistance regime itself” (CASA, 2003, p.34). Such failings may include insufficient resources to assist refugees, policies that restrict assistance for particular groups, and “the uncritical use of standard criteria by UNHCR staff and many IPs [implementing partners],” which “frequently leads to the overlooking of non-obvious areas of vulnerability” (CASA, 2003, p.35).

Such arguments are aligned with the work of Clark (2007), who suggests “posing the question 'Vulnerability to what?' will thus provoke an analysis of power structures and hence greater understanding of root causes of, and appropriate responses to, vulnerability than the

¹⁰⁹ One way of doing this could be to develop a system of measurement with points for various dimensions of identity and circumstance (which could be weighted), as well as some absolute categories.

categorical 'vulnerables' approach” (p.10). The question ‘vulnerability to what’ provides a simple yet effective point of inquiry through which to begin unpacking layers and processes of vulnerability. Furthermore, it is a tangible way to mitigate potential challenges involved with reconciling on-the-ground realities with recommended action (i.e. adapting existing frameworks to reflect a more nuanced assessment of vulnerability).

Recommendations for Future Research

Given the increasingly tense sociopolitical context surrounding the stateless Rohingya people of Myanmar, and the continuing flow of Rohingya asylum seekers embarking on dangerous boat voyages to neighbouring countries, research that generates knowledge regarding the lives and health of Rohingya refugees is likely to remain pertinent for the foreseeable future. In light of the number of Rohingya asylum seekers detained in inhumane conditions and embroiled in human trafficking syndicates in Thailand (HRW, 2013c; HRW, 2013d; Reuters, 2013), Thailand is a particularly apposite site for future research pertaining to Rohingya people. There is also a continued need for research involving urban refugees in Malaysia, especially because many Rohingya asylum seekers enter Thailand en route to Malaysia, which constitutes their preferred, eventual destination. In particular, it would be pertinent to expand upon this study and compare SDH and response strategies of male Rohingya refugees in Malaysia, as males make up the larger proportion of Rohingya refugees in Malaysia, and they are confronted with challenges and vulnerabilities that are distinct from those affecting Rohingya women and males in other refugee groups.

Lastly, given the steady urbanization of the global refugee population, further research into social determinants of health among other populations of urban refugees is required. In light of unprecedented humanitarian challenges stemming from recent events in Syria, it may be

particularly beneficial to conduct such research with Syrian refugees who have fled to urban areas in Egypt, Iraq, Jordan, Lebanon and Turkey (UNHCR, 2013h). Such research would be beneficial on multiple levels, as even small scale research could improve context-specific humanitarian operations, and advance our understanding of social determinants of health among refugee populations by providing points of comparison from different urban settings.

Final Remarks

The applied qualitative research design of this study generated results that offer insight into the present-day living conditions, needs, and response strategies of Rohingya refugee women in Malaysia, and informed recommendations for program and policy development. It must be acknowledged, however, that there are financial, logistical, and temporal limitations on what humanitarian organizations can do to support refugee health. The vital need for political will and cooperation to address SDH cannot be overstated, and is articulated by the United Nations High Commissioner for Refugees, who said, “there are no humanitarian solutions to humanitarian problems, there are only political solutions” (Guterres, 2010, Preface).

A critical disjuncture exists between the evidence on SDH and the persistent failure to address the root causes of inequity. We know that too many people in world struggle with atrocious living conditions, acute stress, and malnutrition, and that these conditions make them differentially vulnerable to health problems (Marmot, 2007). More importantly, we also know that “this unequal distribution of health-damaging experiences is not in any sense a ‘natural’ phenomenon but is the result of a toxic combination of poor social policies and programmes, unfair economic arrangements, and bad politics” (WHO, 2011, p. 1).

The stateless and illegalized Rohingya refugees in Malaysia suffer health problems, indignities, and blatant rights violations as a result of the ‘toxic combination’ cited above. While

the complicated socio-political context surrounding the Rohingya people is a topic of concern on both humanitarian and international agendas (EBO, 2009; HRW, 2013a, b, c; The Guardian, 2013), there has been little tangible progress towards a solution to the deep-rooted issues underlying their persecution and subsequent flight from Myanmar. It is my belief that a regional, rights based solution is both necessary and possible, and that academics, journalists, and humanitarians have an important role to play, an integral part of which begins with advocating on behalf of the Rohingya people.

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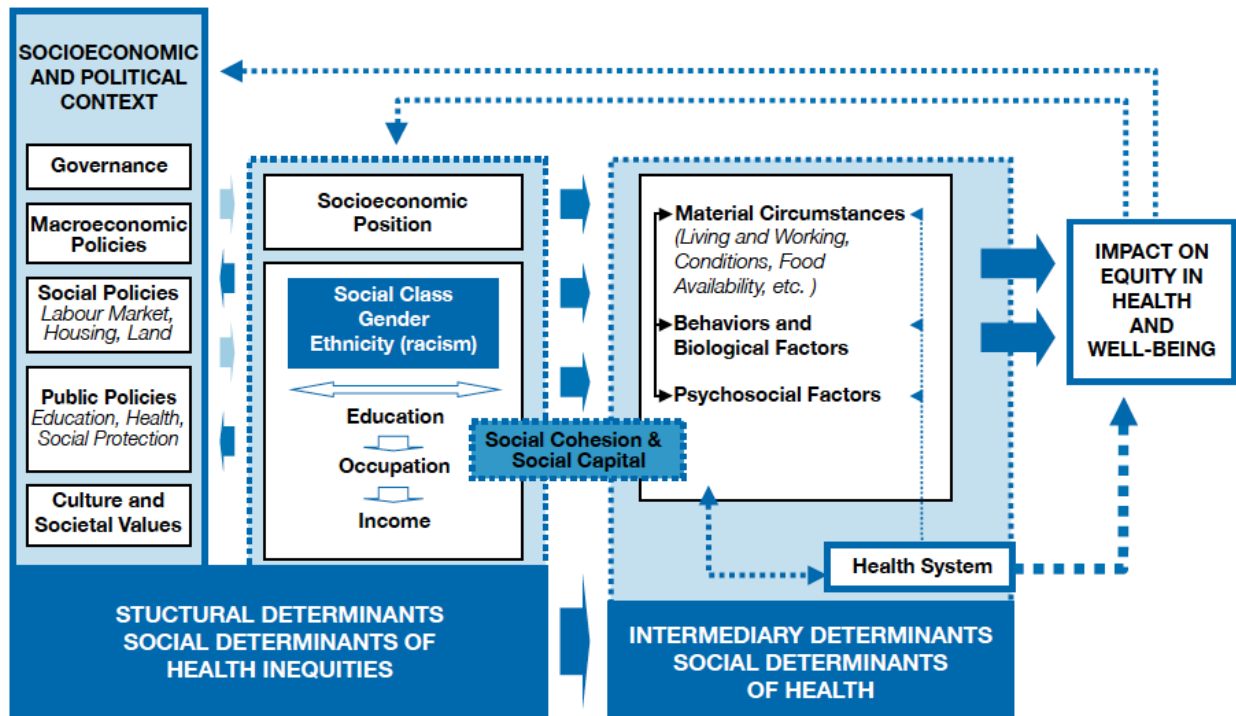
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Appendices

Appendix A

Commission on Social Determinants of Health Conceptual Framework



(Solar & Irwin, 2010, p. 48)

Appendix B

Interview Guide

Participant #: _____ Date: _____

Interview Questions

- 1) Can you tell us about the last time you had a problem with your health?
 - a) What did you do, if anything, to improve your condition?
What was the outcome? (e.g. do you feel as though your condition became better or worse, etc.)

- 2) We are interested in understanding what kinds of mental and physical health issues Rohingya women have and how they deal with them in Malaysia.
 - a) Do you know about home remedies for women's health problems? Under what circumstances would you/other women use them? How did you learn about them? In what ways are these remedies effective?
 - b) How does your religion/faith shape the thoughts and beliefs you have about health? When would you/other Rohingya women turn to religion for guidance regarding medical issues?
 - c) Can you tell me about some of the things you and the women you know do to be healthy and avoid getting sick?
 - d) Are you aware that UNHCR can provide health-related assistance? Who do you know who has approached UNHCR for medical assistance? How did you/they respond to the help/advice received?

- 3) Since you have been in Malaysia, have you or women you know needed medical care but did not get it? Can you tell me about the time(s) when this happened? What were the barriers that prevented you/her from receiving medical care?

- 4) Who is normally involved in making decisions regarding women's health – do women make decisions on their own, or do other people play a role in decisions concerning women's health (e.g. husband, friends, relatives, etc.)?

- 5) Has your health changed since coming to Malaysia? In what way has it changed?
 - a) What were your main health concerns or health problems when you were in Myanmar? Did you live in a city or a rural area in Myanmar?
 - b) How would you/women you know deal with health issues when you were in Myanmar?
 - c) Have you or any of the women you know developed new/different health problems since coming to Malaysia?

- 6) Can you take us through an average day in your life?
 - a) When do you wake up, how often do you leave the house etc.?

- 7) When you think about your life now in Malaysia, what aspects of your life have the greatest effect on your health?
 - a) How and why do [previous response/s] affect your health?
- 8) Living in a big, urban city like Kuala Lumpur can have both positive and negative effects on your health.
 - a) What are some of the ways living in the city has been beneficial for your health?
 - b) What are some of the ways living in the city has been harmful for your health?
- 9) What do you consider to be important health concerns or illnesses affecting Rohingya women in Malaysia?
 - a) In your opinion, what causes [these illnesses/diseases]?
 - b) What resources, within yourself or your community, help you/other Rohingya women respond to these illnesses?
- 10) When you think about the future, what do you expect for yourself and your family? Do you anticipate this will cause changes in your health? What kind of changes/why? Do you think about this happening in Malaysia or in another country?
- 11) If she or her family needed assistance for a medical problem (or another type of problem), do they have extended family, friends or people within the Rohingya community that they could turn to for assistance?
- 12) Is there anything we haven't talked about that you would like to add? Do you have any questions for me?
- 13) Addition questions to try and ask when appropriate:
 - a) How old are you?
 - b) How many children do you have?
 - c) What area do you live in?
 - d) How long have you been in Malaysia?
 - e) Do you speak Malay?

Appendix C

Assessing Validity

Below is a list of techniques, compiled by Whitemore et al. (2001), which can be used to consider issues of validity in qualitative research. Each of the 29 techniques is listed in bold, followed by a brief description of how it was employed in this study (or, in a few instances, why it was not), and/or the chapter in which it is discussed in this dissertation.

1. **Developing a self-conscious research design:** the qualitative research design employed in this study is described and justified in Chapter 4.
2. **Sampling decisions:** the purposeful sampling strategy employed in this study is described in Chapter 4.
3. **Employing triangulation:** this study employed triangulation through the use of multiple methods (document review, interviews, etc.) and the integration of multiple, distinct perspectives (including Rohingya women, UNHCR staff, and the researcher).
4. **Giving voice:** the semi-structured interviews were one method of generating narratives and ‘giving voice’ to participants, by allowing participants to express themselves without restriction in answering the questions posed.
5. **Sharing perquisites of privilege:** this study did not disrupt traditional research/participant roles or share prerequisites of privilege in the way that community based research might. However, the RAs and UNHCR interpreters with whom I conducted the research took on a valued role in the study, and participants were compensated with food parcels in order to address known issues of food insecurity within the refugee population.
6. **Expressing issues of oppressed group:** this dissertation extensively considers issues related to a persecuted minority group.
7. **Articulating data collection decisions:** data collection decisions are explained in detail in Chapter 4 and Chapter 5.
8. **Demonstrating prolonged engagement:** I was affiliated with UNHCR/working with refugees in Malaysia for more than a year while preparing and then conducting this research, and I remained affiliated with UNHCR/working with refugees in Malaysia at the time of writing this dissertation.
9. **Demonstrating persistent observation:** I conducted informal observation of the refugee population over the course of my time at the research site.
10. **Providing verbatim transcription:** all interviews were transcribed verbatim and the translations were checked for accuracy.
11. **Demonstrating saturation:** refer to explanation in Chapter 4.
12. **Articulating data analysis decisions:** Data analysis decisions are discussed in Chapter 4 and Chapter 6.
13. **Member checking:** I did not formally present findings to participants for feedback, as I had already left the research site (I undertook the majority of data analysis in Canada). However, I informally checked the accuracy of my understandings and interpretations with participants and/or the RAs during interviews.

14. **Expert checking:** findings were reviewed by my university advisory committee (who have academic expertise) and my supervisor at UNHCR (who has extensive knowledge of issues surrounding refugee health and refugees in Malaysia).
15. **Performing quasistatistics:** basic figures related to the document review and interview data are presented in Chapters 6 and 8.
16. **Testing hypotheses in data analysis:** I did not test hypotheses in data analysis.
17. **Using computer programs:** I used Dedoose data analysis software.
18. **Drawing data reduction tables:** Simple data reduction tables are presented in Chapter 7.
19. **Exploring rival explanations:** I did not explore ‘rival’ explanations per se, because I did not perceive the findings to be oppositional. Rather, in this dissertation I explore common themes in the interview data (such as the extent to which participants requested financial assistance) while at the same time acknowledging exceptions and alternatives to these themes (see Chapter 7, the case study of Azu, who was self-sufficient and did not mention assistance).
20. **Performing a literature review:** a review of literature related to refugees and SDH is presented in Chapter 2, and literature related to Myanmar, the Rohingya people, and the situation of refugees in Malaysia forms the basis of Chapter 3.
21. **Negative case analysis:** I analyzed outlying/exceptional cases in detail (see for example the case study of Azu, Chapter 7).
22. **Memoing:** I made notes while undertaking and transcribing the interviews (about emerging patterns and themes, possible links between themes, questions I had, etc.).
23. **Reflexive journaling:** I made notes after each interview. The topic of reflection is discussed in Chapter 4.
24. **Writing an interim report.** I did not write a formal interim report, though I reported my progress regularly to my supervisors (in both written and verbal forms) during data collection and analysis.
25. **Bracketing:** Bracketing has been defined as a process in which a researcher ‘suspends’ their personal beliefs in order to “observe the unfiltered phenomenon as it is at its essence, without the influence of our natural attitude—individual and societal constructions, presumptions, and assumptions” (Gearing, 2008, p. 63). As this study was informed by a constructionist approach, I reject the notion of suspending one’s beliefs in order to observe ‘unfiltered’ phenomenon, and thus I did not employ bracketing (though I did try to explicate potential biases, assumptions etc.).
26. **Providing an audit trail:** I prepared a detailed audit of the translation errors identified in the transcription review.
27. **Providing evidence that support interpretations:** evidence supporting my interpretations is presented in Chapters 6, 7, and 8.
28. **Acknowledging the researcher perspective:** I acknowledge and discuss my perspective as a researcher at various points in this dissertation, including Chapters 4 and 6.
29. **Providing thick descriptions:** Thick descriptions are provided in Chapters 7 and 8.

Appendix D

Information Sheet/Script for Verbal Consent

Study title: Forced Migration, Urbanization and Health: Exploring Social Determinants of Health Among Urban Refugees in Malaysia

Funded by: International Development Research Centre (Canada)

Overview: You are invited to participate in a study that is being conducted by Caitlin Wake, a doctoral student at the University of Victoria, Canada. As a graduate student, I am required to conduct research as part of the requirements for a doctoral degree in Social Dimensions of Health. If you have any questions you can contact me by emailing caitw@uvic.ca or calling UNHCR at 03-2118-4800 and asking to speak with Cait in IAD. If you have questions or concerns after the completion of the study, you can contact UNHCR at the number above and ask to speak with officer [name included in hard copy documents] in IAD.

Supervisor: This study is being conducted under the supervision of Dr. Margot Wilson, Faculty of Graduate Studies and Department of Anthropology, University of Victoria, Canada. Dr. Wilson can be reached at gsadean1@uvic.ca

Purpose and Objectives: The purpose of this research project is to better understand the social and environmental conditions Rohingya refugee women in Malaysia live in, and how these conditions affect their health.

The objectives are:

- To increase understanding of the main health concerns of Rohingya women in Malaysia, and how they respond to those health concerns
- To generate information that can be used by UNHCR and community organizations to support the health of Rohingya refugee women in Malaysia

Importance of this Research: There is a lack of information on the health of Rohingya women in Malaysia. This research will improve understanding of how the health of Rohingya women has changed since they became refugees, what their main health concerns are, and how they address these concerns. This information is important because it can help inform the development of programs and policies to support the health of Rohingya women.

Participant Selection: This study aims to include a diverse range of female Rohingya refugees, and an effort will be made to recruit participants of various ages (minimum age 18, no maximum).

Your participation in this study is entirely voluntary. Whether you choose to participate or not will have no effect on your status with UNHCR.

What is involved: This study involves taking part in an interview where we will ask questions about your health concerns, how you respond to them, and how your living conditions affect your health. It will take place at UNHCR, and will last approximately 1 hour.

We are also conducting second, follow up interviews with some of the participants. Cait may ask you at the end of the first interview if you would be willing to participate in a second, follow up interview. If you consent to a follow up interview, it will take place at your home or at the UNHCR office, whichever you prefer, and will involve discussing issues raised in the first interview in more detail.

An audio recording and written notes will be taken, and later a full transcription will be made. Please be advised that (anonymized) information gathered about you for this study will be stored in an online program called Dedoose located in the United States. Your real name will not be included in the information stored in Dedoose, however, your anonymous data may be available to U.S. security under the U.S. Patriot Act because the data will be stored on a U.S. server.

Inconvenience: Minimal inconvenience is expected as a result of your participation in this study, as the primary commitment required of you is the time it takes to participate.

Risks: The risks associated with your participation in this study are no greater than the risks you encounter in everyday life. However, answering questions about your life and health during the interview may cause you to feel stressed, emotional, embarrassed or fatigued. To address these risks, we can take a break or end the interview at any time, or if you feel that you would benefit from speaking with a counselor we can arrange for you to be referred to ACTS or Tzu-Chi for counseling free of charge. Please remember that you do not need to discuss topics that cause you distress, so if a question upsets you and you do not want to answer it you are under no obligation to do so.

There is a possibility that there may be issues regarding translation (i.e. intentional or unintentional mistranslation). The researcher will review transcripts and audio recordings to minimize the likelihood/consequences of this happening, and should you have any concerns about translation please contact the researcher (Cait); if necessary she will involve a neutral, third-party translator to assist in resolving any issues.

Should you choose to disclose any incidents involving physical and/or sexual violence (regardless of whether the incident took place in Myanmar or Malaysia) during the interview, you will be advised how to report the incident to UNHCR if you decide you would like to do so. If you do not want to report the incident to UNHCR, you are under no obligation to do so, and the research team will not share your information with UNHCR. If you choose to report an incident to UNHCR, you will be able to speak with a UNHCR officer who may offer you services such as counselling or medical care.

Benefits: Your participation in this study will help us learn about the lives and health needs of Rohingya refugees in Malaysia. While participating in this study may not benefit you directly, it is anticipated that the findings will be used to inform programs and policies to support the health

of refugees in Malaysia, and you and/or members of the Rohingya refugee population may benefit from these efforts in the future.

Compensation: As a way to compensate you for your participation, you will be given a small food packet containing some essential food items. If you would not participate if the compensation was not offered, then you should decline.

Right to Withdraw: Your participation in this research should be completely voluntary.

- 1) You have the right to choose not to take part in the research.
- 2) You can stop the interview at any time or ask that the recorder be turned off.
- 3) You have the right to withdraw (to stop participating in) the research project at any point in time, without explanation or consequence.
- 4) If you choose to withdraw this will NOT adversely affect your relationship with any unit at UNHCR or those providing services at the local health clinics.
- 5) If you withdraw during or after the interviews and before data analysis has started, you will have the option of allowing the data generated from your participation in the study to be excluded from data analysis.
- 6) If you choose to withdraw at any point after having given verbal consent to participate, you will still receive full compensation.

Researcher's Relationship with Participants: The researcher who will conduct the interviews, Cait, is conducting the study in collaboration with IAD, the unit that manages medical/financial assistance at UNHCR. To help prevent this relationship from influencing your decision to participate, please be advised that your responses will never be linked to your UNHCR file, and participation will not positively or negatively affect your access to UNHCR services/support. Please also note that Cait, the researcher, is not currently employed by or paid by UNHCR.

Anonymity: As a participant in the interviews you will not be anonymous to the researcher; however, data from this study (i.e. interview transcripts and audio recordings) will be anonymized. Your responses will not be personally identifiable and your real name will not be disclosed. You will be given a research number, and this number is what will be used to identify you in the data analysis software, research reports, and publications.

Confidentiality: While the interviews will be audio recorded, your real name will not be recorded or used. Any personal information that could be used to identify you (such as your phone number) will be kept strictly confidential and separate from the interview data. Access to personal information will be restricted to the researcher (Cait), and electronic files will be stored on a password protected computer. No staff from UNHCR will have access to your personal information. The research assistant/interpreter involved in this project has agreed to protect the privacy of participants and keep the data generated through this study confidential.

Disposal of Data: Electronic and print documents containing your identifying information will be kept on file for one year after data collection is completed (June 2013 – June 2014). Afterwards, electronic files will be erased and paper copies will be shredded.

Dissemination of Results: It is anticipated that the results of this study will be shared in the following ways: the results will be discussed in my doctoral thesis; they may be discussed with Rohingya refugees; and they will be shared with UNHCR. The results may also be shared with health related NGOs in Malaysia (Buddhist Tzu-Chi, ACTS), published in an article, or presented at scholarly meetings/conferences.

Contacts: Individuals that may be contacted regarding this study include the researcher Cait and her supervisor Dr. Wilson (contact information is listed at the beginning of the sheet). You may also verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria (+1-250-472-4545 or ethics@uvic.ca).

If you have any questions after the completion of the study, please call 03-2118-4800 and ask to speak with IAD.

PARTICIPANT: # .

Oral consent. Interviewee gave verbal consent to the following:

Your oral consent indicates that you understand the above conditions of participation in this study, that you have had the opportunity to have your questions answered by the researcher, and that you agree to participate in this research project.

Date (DD/MM/YR): -----

Interviewer signature: -----

RA signature: -----