ACCESS OF CHIN AND ROHINGYA WOMEN REFUGEES AND ASYLUM SEEKERS FROM BURMA TO MATERNAL HEALTH SERVICES IN THE KLANG VALLEY, MALAYSIA

A thesis submitted for the degree of Doctor of Philosophy

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ABSTRACT

Barriers to accessing maternal health care are linked to adverse maternal health outcomes. Malaysia's success in terms of maternal health outcomes is attributed to accessibility to an integrated package of maternal and child health services that especially reached the poor and rural residents. Yet urban refugees in Malaysia face many barriers in accessing health care because of insecure legal status and several protection challenges.

This study aimed to assess the access of Chin and Rohingya refugees and asylum seekers from Burma to maternal health services in the Klang Valley, Malaysia, by: (i) examining the relationship between documentation status (being refugee/asylum seeker) and ethnicity (being Chin/Rohingya) to the dimensions of accessibility and utilization of care; and (ii) evaluating the differences in the patterns and levels of utilization of care between Chin and Rohingya refugees and asylum seekers. The accessibility dimensions include: nondiscrimination, physical, economic, and information accessibility.

The right to health definition of accessibility guided the study's conceptual and theoretical framework. This framework was used to demonstrate (i) its theoretical applicability for empirically examining accessibility to health care of a disadvantaged population; and (ii) the application of methodological tools not conventionally used to monitor the right to health.

A mixed methods research design including a cross sectional survey with 343 respondents and ten qualitative in-depth interviews was implemented. Additionally, the survey respondents' maternal health records were analyzed. Results were triangulated using these different methods and data sources. Quantitative and qualitative data were assessed separately with statistical and thematic analysis respectively, and outcomes were compared and discussed.

Multiple regression analysis revealed that after controlling for documentation status, ethnicity was significantly related to physical accessibility, information accessibility, and non-discrimination. Ethnicity offered some advantages/disadvantages to

navigate the health system with Rohingyas faring better than Chins. A higher proportion of Rohingyas took lesser travel time, received more maternal health information, and perceived lesser discrimination in healthcare than Chins. However, documentation status was moot to economic accessibility, measured by the *maternal health expenditure ratio* (ratio of out-of-pocket payments for maternal healthcare to annual family expenditure). After controlling for ethnicity, documentation status was significantly related to economic accessibility. Refugees had a higher median maternal health expenditure ratio. Documentation status was also significantly related to actual utilization of maternal health care, measured via number of antenatal care (ANC) visits. A higher proportion of refugees than asylum seekers obtained adequate ANC visits. However, utilization of maternal health care contributed to increased impoverishment for refugees. The qualitative research revealed the influence of complex contextual factors which mediated the women's access to maternal health care.

Notwithstanding the limitations of this study, which includes non-probability survey sampling, it has contributed: (i) to studies on accessibility by demonstrating the viability of the right to health framework as a sound conceptual and theoretical framework to examine the accessibility to health care of disadvantaged populations; (ii) to the under-developed body of knowledge on urban refugees, especially urban refugee health; and (iii) to the literature on maternal health by substantiating the importance of context, specifically legal status and ethnicity in mediating women's accessibility to maternal healthcare.

Key words: urban refugees; Chins, Rohingyas, health services accessibility; maternal health care; right to health; Malaysia.

DECLARATION

In accordance with Monash University Doctorate Regulation 17/Doctor of Philosophy and Master of Philosophy (MPhil) regulations, the following declarations are made:

I hereby declare that this thesis contains no material which has been accepted for the award of any other degree or diploma at any university or equivalent institutions and that, to the best of my knowledge and belief, this thesis contains no material previously published or written by another person, except when due reference is made in the text of the thesis.

The research, Project Number: CF10/0033 - 2010000020 was approved by the Monash University Human Research Ethics Committee (MUHREC), on 19 April, 2010.

Name SHARUNA ELIZABETH VERGHIS

ID [redacted]

SIGNED ……

DATE ……

This dissertation is dedicated to

My loving parents, Padma and (late) Jai Verghis,
For modeling a life of service to the poor and courage to take a stand against injustice

My husband and best friend, Xavier,
To our continuing journey to serve and be the change

My son, Devansh,
The joy of my life,
Your smile and laughter makes everything better

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As I look back at the road traveled, there is a sense of fulfillment and gratitude. Fulfillment, because the objectives of my PhD have already started coming to fruition. Gratitude, for all the experiences that enriched me in countless ways. This has been possible because of the support of so many people.

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TABLES

FIGURES

ABBREVIATIONS

ACR	Alliance of Chin Refugees
AIDS	Acquired immunodeficiency syndrome
ANC	Antenatal care
ANOVA	Analysis of variance
CEDAW	United Nations Convention on the Elimination of All Forms of Discrimination against Women
CPR	Contraceptive prevalence rate
CRC	United Nations Convention on the Rights of the Child
FANTA-2	Food and Nutrition Technical Assistance II
GLM	Generalized linear model
HIV	Human immunodeficiency virus
HMOs	Health maintenance organizations
ICESCR	International Covenant on Economic, Social and Cultural Rights
IDI	In-depth interview
IOM	Institute of Medicine
ILO	International Labour Organization
LMICs	Low-and middle-income countries
LRT	Light Rail Transit
MDGs	Millennium Development Goals
MMR	Maternal mortality ratio
MoH	Ministry of Health
MUHREC	Monash University Human Research Ethics Committee
NGOs	Nongovernmental organizations
NRS	Northern Rakhine State
OOP	Out of pocket
PLI	Poverty line income
PPC	Post-partum care

RA	Research assistant
RKI	Rekod Kesihatan Ibu (maternal health record)
RELA	Ikatan Relawan Rakyat (Malaysian Volunteer Corps)
RM	Ringgit Malaysia
RSM	Rohingya Society in Malaysia
SES	Socio-economic status
STIs	Sexually transmitted infections
TOP	Termination of pregnancy
UN	United Nations
UNHCR	United Nations High Commissioner for Refugees
UNIANOVA	Univariate analysis of variance
WHO	World Health Organization

CHAPTER 1: INTRODUCTION

In spite of dramatic declines in maternal mortality over the past two decades, it continues to be one of the "greatest unsolved public health issues of our time" (p.279), related significantly to barriers in access to maternal health services [1].

The likelihood of increasing health care inequities being the most significant source of health status disparities is growing[2]. In fact, diminished accessibility to maternal health care and receipt of sub-optimal care, are known to put non-citizen women at high risk of adverse maternal health outcomes[3].

As non-citizens, refugees and asylum seekers experience specific and adverse sexual and reproductive health vulnerabilities and outcomes. However, (as discussed in Chapter-3) accessibility to health care and social services has been found to mediate and reverse potentially poor health outcomes for these women, in all stages of mobility.

Currently, about half of the world's 10.5 million refugees are urban refugees[4], who unlike camp based refugees do not receive systematic assistance from UNHCR and the international community. Malaysia has one of the highest global caseloads of urban refugees and asylum seekers[5, 6], the majority of whom are from Burma and belonging to the Chin and Rohingya ethnic communities.

Lacking in legal status, urban refugees in Malaysia face a host of protection challenges and have a range of unmet needs, including accessibility to health care, which has been documented by several international non-governmental organizations (NGOs)[6-9]. However, to date, there is no known systematic research investigating urban refugees' access to maternal health care.

At the same time, the discourse on theoretical perspectives related to accessibility to health care has been fraught with conceptual and methodological challenges[10, 11]. In large part, this is due to the complexity and multi-dimensionality of the phenomenon, which has eluded measurement through single summary statistics. Thus, in public

health, access has largely been measured by focusing on the relationship between characteristics of the individual seeking care and of the health care system (as independent variables) and outcome measures such as utilization of care and satisfaction with care (as dependent variables). These measures and their theoretical frameworks have been critiqued as being less meaningful for disadvantaged populations[12, 13].

In this study, I examine some theoretical and practical questions with regard to the accessibility of Chin and Rohingya refugees and asylum seekers related to maternal health care.

I argue that the right to the highest attainable standard of physical and mental health[14] (Art.12), (henceforth called "right to health") definition of accessibility to health care[15] (paragraph 12 (b)), although comprising of normative principles, provides a substantive conceptual and theoretical basis to understand and interpret the accessibility of the study population to maternal health care. Departing from conventionally used measures of accessibility in access studies, I draw on other domains of public health to adapt and use indicators, which I argue, enables the measurement of accessibility to maternal health care using the right to health framework.

Using these indicators of access, I assess the relationship of documentation status (being refugee/asylum seeker) and ethnicity (being Chin/Rohingya) to the dimensions of accessibility proposed by the right to health definition. Additionally, the differences in the patterns and levels of utilization of maternal health care between Chin and Rohingya refugees and asylum seekers are evaluated. A mixed methods research approach is used to measure the dimensions of accessibility and utilization of care, and elaborate on the context of accessibility of the study population through quantitative and qualitative methods respectively.

In this way, I propose a different approach to assessing accessibility to health care using the right to health definition and suggest the application of this methodological approach to other populations. Additionally, the findings contribute to the literature on the under-researched topic of urban refugees and their access to maternal health care.

Given the broad range of intersecting themes in this study, the first few chapters synthesize the relevant literature including concepts, policies, and practices that have a bearing on the accessibility of Chin and Rohingya refugees and asylum seekers to maternal health care. In Chapter 2, I present the literature on urban refugees, reproductive health of refugees and asylum seekers in various stages of mobility, and scrutinize the relationship between their accessibility to maternal health care with their maternal health outcomes. In Chapter 3, I review the various theoretical models on access in public health, including their concepts and definitions of access. I also examine measurement approaches to accessibility and appraise these concepts, theories, and measurement approaches from the perspectives of the right to health and of non-citizens, and make an argument for the suitability of the right to health framework of accessibility for this study. In Chapter 4, I contextualize the research with information about Chin and Rohingya refugees and asylum seekers, their separate contexts of displacement in Burma, the protection environment in Malaysia, and their accessibility to health care within the broader landscape of Malaysia's significant achievements with regard to maternal health.

In Chapter 5, I describe the research design of the study including the justification for a mixed methods approach to the research questions. I also provide an overview of the research process including the research instruments, sampling, field work setting, recruitment of community research assistants, challenges encountered, and ethical issues I needed to consider.

The results are divided into two chapters. Chapter 6 presents the quantitative research findings and Chapter 7 includes the qualitative research findings. Finally, in Chapter 8, I interpret and discuss the findings within the contexts of the study objectives and the wider global and national discourses related to the research topic, make some recommendations, and conclude the dissertation.

Finally, although the words, Burma and Myanmar have the same meaning with 'Myanmar' representing the formal literary form and 'Burma' being the informal name, 'Myanmar' is also the dominant ethnic group of the country. The country's name was changed by the military rulers in 1989 without public consultation. Owing to the ethnic exclusiveness of the term, the democracy movement including Daw

Aung San Suu Kyi, uses the word Burma. As such, ‘Burma’, which is used in this dissertation, refers to the country, ‘Myanmar’.

CHAPTER 2: URBAN REFUGEES AND ASYLUM SEEKERS AND MATERNAL HEALTH

This chapter is divided into two sections. In the first section (Section 1), I review the literature on urban refugees and asylum seekers and elaborate on the importance of doing research with this population. In the second section (Section 2), I examine the literature for maternal health outcomes of refugees and asylum seekers and its relationship to their access to maternal health care.

SECTION - 1

2.1. REFUGEES AND ASYLUM SEEKERS

According to the 1951 United Nations Convention Relating to the Status of Refugees (the Refugee Convention), a refugee is any person who "*owing to well-founded fear of being persecuted for 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 residence as a result of such events, is unable or, owing to such fear, is unwilling to return to it*" (Article 1A(2))[16].

"An asylum-seeker is an individual who has sought international protection and whose claim for refugee status has not yet been determined"[17] (p.14).

The United Nations High Commissioner for Refugees (UNHCR) has no consistently applied definition of a refugee in an urban area[18]. But the term "urban refugee" is generally used for any refugee who does not live in a refugee camp, i.e. a restricted area, administered by the national/competent authorities or UNHCR, where aid and assistance is systematically granted on the basis of refugee status. Most urban refugees are self-settled refugees.

The review in this section will focus on the case of urban refugees, the category that the study population belongs to, their vulnerability context, the emerging issues related to their health and access to health care, UNHCR's policy on urban refugees, and the status of research on urban refugees.

2.2. THE CASE OF URBAN REFUGEES

According to the UNHCR, there are about 10.5 million refugees worldwide[4]. About half of the world's refugees who now reside in urban areas are called urban refugees. Developing countries host about 80% of the world's refugees and about 38% of all refugees live in the Asia Pacific region[19], where the majority of the countries lack a normative and legal framework for refugee protection[20, 21]. Although most urban refugees in the past were men, the current composition of urban refugees include large numbers of women, children, and older persons [22].

There are several factors that draw refugees to urban areas. These include: (i) the lack of personal security in camps[23]; (ii) access to health care unavailable in camps[24-26]; (iii) access to international links, especially to receive remittances from resettled relatives and friends overseas[23]; (iv) greater access to services than in rural areas[23]; (v) more options for resettlement because of the proximity to UNHCR offices in the country[23]; (vi) ability to hide undocumented status[27] and safety that the anonymity of urban areas bring[28]; (vi) increased livelihood opportunities[27]; (vii) formal and informal assistance available from UNHCR and non-governmental organizations (NGOs)[27]; and (viii) proximity to networks of fellow refugees whose social support is critical to their survival in a hostile environment[23]. The changing landscape of donor assistance in relation to refugees has also contributed to the rise in the numbers of urban refugees. Prominently, there has been a drop in the provision of humanitarian assistance toward refugee camps. This has been attributed to compassion fatigue as the absence of durable solutions persist[24, 29, 30]. In addition, unequal refugee burden-sharing[19, 31] and the move by traditional countries of resettlement toward a "proactive refuge regime" which seeks to find durable solutions in the refugee producing region[32](p.7),[33] have led to resettlement needs exceeding the availability of resettlement quotas. These are also factors that have been attributed to the rise in the numbers of urban refugees in countries of the global South.

2.3. VULNERABILITY AND RESILIENCE OF URBAN REFUGEES: DUALISM IN THE URBAN CONTEXT

Urban refugees face a myriad of protection and livelihood challenges that are generally not encountered in camps. The social, economic, and policy factors contributing to the protection challenges of urban refugees are: (i) host countries' laws/policies (or their absence) related to refugees; (ii) unavailability of public and private institutions which provide assistance to refugees; (iii) xenophobic attitude of the host country population toward refugees; and (iv) the complexity of the urban environment[24].

Refugees in urban areas generally lack legal status or special protection under domestic migration regimes including access to systematic assistance usually available to refugees in internationally managed refugee camps[34]. Thus, they end up sharing problems common to the urban poor in the form of overcrowded living conditions, violence, and poor access to health, basic services, and education[27, 32, 34-37]. However, they differ fundamentally from the urban poor and other marginalized populations in the host country because they (i) cannot return durably to their country of origin[35]; (ii) have lived through or witnessed violence, torture and other human rights abuses associated with conflict and displacement[24]; (iii) frequently lack supportive social networks; and (iv) may be formally excluded from the labor market and access to health care and education[38]. For example, urban refugees in Cairo are prohibited from attending public high schools[39], while urban refugees in Amman and Cairo have reported the unaffordability of health care[39, 40]. The context of the Malaysian urban refugee environment is described in Chapter 4.

The lack of legal status is a salient feature of the context of their vulnerability[24]. Countries of asylum are known to use a range of unfriendly and even hostile measures to manage urban refugees. These include exclusionary social policies which prevent their integration, securitization of their presence[1], and the criminalization of their undocumented status[28, 42]. This makes them vulnerable to

[1] According to Huysmans[41], securitization of migration is the political construction of migration as destabilizing domestic integration and posing threats to public order, national identity, and welfare provisions which gives rise to an institutional response that locates the regulation of migration within the protection of internal security. Towards this end, security discourses, policies, and technologies are mobilized to exclude migrants from the political and social fabric of the nation through putative links between migration, terrorism, and criminal activities. In this way, "a security continuum connecting border control, terrorism, international crime and migration" (p.760) is created.

arrests, arbitrary detention, extortion, and heavy penalties[23, 43, 44]. Their insecure legal status forces them into informal and unregulated work sectors and occupations lacking legal protection, which increases their exposure to exploitation by employers and landlords[32, 43]. The lack of legal status also prohibits their access to avenues of redress[27]. For example, East African urban refugees in Cairo who can only take up informal employment have reported high levels of racial discrimination and employment related risk exposures to physical, verbal, sexual, and emotional abuse[39]. The situation of asylum seekers is generally more insecure and perilous than that of refugees.

The vulnerability of urban refugees is also linked to xenophobic attitudes of the host population toward them. Such attitudes and State policies are related to the competition for scarce land, housing, urban infrastructure and other resources that go with modern day urbanization processes[37, 45]. As urban refugees compete with the local urban poor for inadequate physical and social infrastructures[23], they tend to be imaged as *costly burdens* by the State and UNHCR, and *vulnerable victims* by NGOs[32]; characterizations which can be disputed.

This is because urban refugees demonstrate resilience, empowerment, and problem solving capacities in creating refugee associations, communities and schools, generating new livelihoods, and helping their community members gain access to services[27] in the countries/cities where they reside. They have also shown entrepreneurial abilities and evidence that they are not an economic burden[45].

Studies focusing on these abilities of urban refugees reveal that while the urban context poses challenges for the effective protection of refugees and asylum seekers, it also offers opportunities for their survival and accessing of resources.

Urban areas proffer advantages in the form of economic opportunities, safety that anonymity in urban areas bring, and, access to social capital through social networks or “ethnic enclaves” of fellow refugees from the same country[24](p.276),[46]. In fact, social networks of relatives, friends, neighbors, and other community members are critical in obtaining financial support, information, and contacts to build livelihoods and access services, including to health care. These networks are particularly important where human smuggling may be the only recourse to escape persecution[32]. Membership in their ethnic communities also provides them with

opportunities to practice their traditions and derive psychological support[27]. Participating in such social/ethnic national and transnational networks entails responsibilities of providing reciprocal support to other family and community members in camps and urban areas in countries of origin, asylum, and resettlement [32, 47]. Grabska states that the disadvantage of relying on such familial and ethnic networks is that it leads to isolation from the host society[27].

2.4. HEALTH AND HEALTH CARE PROBLEMS OF URBAN REFUGEES

In many ways, the health vulnerabilities of urban refugees are related to their insecure legal status and their location within the ranks of the urban poor. As such, the risk factors pre-disposing them to illness include overcrowded accommodation, poor living conditions, inadequate access to clean water and sanitation, and food insecurity related to insecure livelihoods[35, 37].

The scarce information available on the health status of urban refugees indicates that, like other migrant populations, they experience enhanced vulnerability to poor health outcomes, particularly mental health[40, 48-51], and sexual and reproductive health[52-54]. Additionally, large numbers of urban refugees in countries like Jordan comprise of older populations with chronic diseases[33, 46, 53], reflecting the epidemiologic and disease profiles of middle income countries from where they originate[55].

Urban refugees experience many barriers to accessing health care because of their undocumented status[24], unaffordable cost of health care, linguistic barriers, discrimination from health care providers[26, 49, 56], and legal/policy directives prohibiting and/or restricting their access to health care[57]. As a result of such barriers, they are known to practice self-medication and purchase over the counter medication from pharmacies[58-60].

2.5. UNHCR POLICY ON URBAN REFUGEES

On the one hand, the poor access of urban refugees to services may be attributed to the shrinking protection space and limited access to durable solutions for refugees worldwide. However, UNHCR's policy on urban refugees which went through two iterations in 1997[61] and 2009[22], does not do much to provide robust guidance for the effective protection of this population.

The 1997 policy viewed urban refugees as *irregular movers* from camp sites with little acknowledgement of the problems that refugees were experiencing in refugee camps. Some scholars argue that this view of urban refugees as *irregular movers* reflected the view of States, especially in the global North, to contain and confine refugees and the refugee problem within the area of conflict[28, 62].

The 2009 urban refugee policy, however, is based on the principle that the rights of urban refugees are not "affected by their location, the means whereby they arrived in an urban area or their status (or lack thereof) in national legislation"[22] (paragraph 14). Yet, it is fraught with several ambiguities and contradictions.

The 1997 policy which was based on the model of self-reliance (vis-à-vis the former care and maintenance approach used in camps) was maintained in the 2009 version[22](paragraph 43). Bailey argues that the promotion of self-sufficiency is inappropriate in a context where they lack legal identity[28] and which would prohibit formal employment.

This critique could equally apply to the policy's view that urban refugees should access existing health care services and that parallel services should not be created[22] (paragraph 113). Most often, policy barriers prohibiting/restricting their use of public health services is related to their lack of legal status. That health care systems in some countries are already over-stretched does not help when they encounter additional pressures from the health needs of urban refugees[63].

Crisp and Refstie recommend the review of various underlying assumptions of the policy including the transience of refugee-hood[64]. This is an important issue as UNHCR statistics reveal that about 61% of the world's refugees remain trapped in protracted exile[4] without legal status and access to formal employment and services. Protracted exile includes "a situation in which 25,000 or more refugees of the same nationality have been in exile for five years or longer in a given asylum country"[4] (p.6).

Finally, the 2009 policy iteration shies away from the use of the terminology of *rights* and *protection* in favor of the non-legal terminology of *protection space*[65]*.* Edwards critiques the 2009 policy by stating that it does not acknowledge the contribution of urban refugees to the economies and communities they live in, is ambiguous about

the right to work of urban refugees, and although is “ambitious in its orientation, protection-focused, [and] broad in its coverage”, is “rather vague in its specifics” [65](p.49).

2.6. STATUS OF RESEARCH ON URBAN REFUGEES

In general, there is a dearth of research, particularly quantitative research, on urban refugees. This has been partly attributed to:

- The dispersion of urban refuges in the host community which makes the identification of their needs problematic[35].
- The peculiarities of the urban environment with socially invisible[66] frequently moving refugees and an unknown population of undocumented asylum-seekers which presents unique difficulties for data collection, sampling, and methodology[67].
- Methodological challenges including (i) definitional challenges regarding the boundaries of an urban area; (ii) absence of a sampling frame; (iii) heterogeneity of the refugee population; (iv) their adoption of other ethnic or national identities for survival and choice to be identified as such; and (iv) inadequate physical access to urban refugee lodgings which are often not well connected to transportation systems and infrastructural facilities[34].
- Security problems in the locations where urban refugees reside which increases refugees’ distrust of *outsiders,* given that they are victimized “by a predatory police force, by xenophobic neighbours and by random criminal attacks”[68] (p. 113).

Yet, in spite of these challenges, there are researchers who are adapting quantitative research techniques to achieve representativity[66, 69, 70] within ongoing debates about the kind of generalizations that can be realistically made and the standards of representativity that can be aspired[68]. However, given the financial and logistical (in)feasibility of raising dedicated funds for national surveys, especially by organizations located in the global South[71], the majority of urban refugee studies employ qualitative research methods [72, 73]. There is also a recognized need for multidisciplinary approaches to understand the complex phenomenon of urban refugees[67].

In terms of research themes, the majority of field reports and evaluation reports by international NGOs and UNHCR examine issues related to access to services [25, 26, 63, 74, 75]. Additionally, mental health has dominated the research on health outcomes of urban refugees[76-78]. Other research in Africa and the Middle East have examined the creative strategies developed by urban refugees to access resources and livelihood opportunities within the dualism of vulnerability contexts and empowerment opportunities in the urban environment [27, 47, 79-81]. While academic literature on urban refugees includes some focus on Asia[82-85], academic research on urban refugee health and maternal health is relatively under explored in this region.

SECTION - 2

2.7. MATERNAL HEALTH AND REFUGEES AND ASYLUM SEEKERS

This section focuses on refugee maternal health with special attention to: (i) the salience of access to maternal health services in reducing risk and improving maternal health outcomes for refugees; (ii) dilemmas of health care providers in providing reproductive health care to refugees; and (iii) research on refugee maternal health.

Reproductive health and maternal health have re-emerged on the international agenda in a major way. The significance of women's access to appropriate health services and special protection during pregnancy, childbirth, and post childbirth has been affirmed by the International Conference on Population and Development (1994) and the Beijing Declaration (1995). Additionally, rights enshrined in the Convention on the Elimination of All Forms of Discrimination against Women (1979)[86] and the International Covenant on Economic, Social and Cultural Rights (1966)[14] which have been ratified by several States, provide the basis for the attainment of maternal health. In recent years, the Millennium Development Goals (Goal 5), the focus of the UN special procedure on maternal health[87, 88], and the joint statement delivered by 83 Governments to the UN Human Rights Council, on March 16 2009, reaffirming their commitment to addressing maternal mortality as a human rights issue is evidence of the increasing attention being paid to maternal health.

The improvement of maternal health including the reduction of maternal mortality is a key indicator of the delivery and utilization of reproductive health services and women's status in society[89].

The reproductive health and needs of refugee women received global attention in the mid-90's[90] following the atrocities and sexual violence perpetrated during the conflicts in former Yugoslavia and Rwanda which had serious reproductive health implications[91].

International evidence suggests that women refugees and asylum seekers experience specific and adverse sexual and reproductive health vulnerabilities and outcomes. Exposure to conflict and military presence, gender and sexual based violence, poverty, social exclusion from family members and community, escalated domestic violence associated with war/conflict, and poor access to general and reproductive health information and services including services related to family planning, safe abortion and prevention and management of sexual and gender based violence, are among the contributing factors to a range of reproductive health problems including HIV infection and STIs[92-103].

Refugee status has been associated with several risks during pregnancy, birth, and post natal periods[104-106]. In addition to the social risk factors outlined above, risk factors for refuge maternal morbidity and mortality include: (i) cultural factors like female circumcision and female genital mutilation (FGM)[106, 107]; (ii) health factors like poor nutritional and health status, maternal anemia, and co-morbidities related to urinary tract infections, malaria, parasitic infestations, tuberculosis, sexually transmitted infections (STIs), and reproductive tract infections[103, 108-110]; and (iii) demographic profile and obstetric history related to early pregnancy, older mothers, higher parity, previous termination of pregnancy (ToP), previous adverse birth outcomes, shorter inter-pregnancy levels [92, 106, 108, 109, 111].

2.8. SALIENCE OF ACCESS TO HEALTH CARE SERVICES

In spite of the risks mentioned earlier, mediating factors like access to health care and social services have been found to reverse potentially poor health outcomes in all stages of mobility for refugee women. This will be analyzed in the context of (i) war/conflict; (ii) refugee camps; and (iii) traditional resettlement countries.

2.8.1. War and Conflict

Refugee women in war/conflict situations have consistently presented with poor maternal health outcomes, and countries in conflict and post conflict have among the highest levels of maternal mortality globally[99]. Poor access to family planning services, emergency contraception, and safe abortion services leading to unsafe abortion practices[99, 102] are known risk factors for maternal mortality among refugee women. Additionally, during complex emergencies, risk factors of refugee maternal health are related to deficient health systems, crumbling health services, lack of public transportation, conflict related risks, poverty, unstable environments, poor water supply and sanitation, and the need for women to constantly be on the move in search of safety[92, 96, 112-114]. Oftentimes, while on the move, they have had to deliver in forests and other such places and simultaneously deal with grief, loss, and providing for themselves and their children [105].

A classic example of the consequence of conflict for refugee maternal health outcomes is Sarajevo, which during the conflict was marked by (i) reduction in the number of live births, (ii) increase in perinatal mortality rates from 15·3 per 1000 live births before the war to 38·6 per 1000 post-war; (ii) increase in low birth weight babies from a rate of 5·3 to 12·8; and (iii) increase in congenital abnormalities. These health outcomes were accompanied by the destruction of health infrastructure including of hospital facilities, decrease in the availability of hospital beds, deaths of doctors and other medical staff, and provision of medical care in makeshift underground shelters and basements which were lacking in water and heating[113].

Another study found that low birth weight, stillbirths, neonatal deaths and maternal mortality in the conflict affected area of Mallavi in Sri Lanka were higher than the national averages[115]. Following that, a 2008 study of women's reproductive health concerns in six conflict affected areas of Sri Lanka attributed the risk factors for spontaneous abortions to lack of access to reproductive health services, stress and malnutrition related to the conflict, repeated pregnancies, and changes in gendered responsibilities[92].

Similarly, the reduced access of Palestinian refugee women to ANC and post-partum care (PPC) because of severe restrictions to their physical mobility is

reported to have led to an increase in home deliveries, induced deliveries, and deliveries at military check points[116].

2.8.2. Refugee Camps

There is mixed support for refugee status as a predictor of maternal morbidity and mortality in refugee camps where access to health care seems to have a mediating influence on maternal health outcomes. While some evidence associates poor maternal health to refugee women's poorer access to food, rations, and health care in some camp settings, the ease of access to health care in other camps have brought about favorable maternal health outcomes.

For example, a study on maternal mortality of Afghan refugee women in a refugee camp in Pakistan revealed that deaths due to maternal causes were the primary cause of death among women of reproductive age. Additionally, 60% of infants born to these women who died of maternal causes had died before or after their birth. Women who died of maternal causes experienced a greater number of barriers to health care (e.g. lack of knowledge on the part of the women, their families and home birth attendants of the danger signs of pregnancy and of available services, poor decision making capacity, unaffordable health care, distance to the health care facility, lack of transportation, and absence of timely and appropriate care once they had arrived at the health care facility). In all, 44 women reported experiencing 64 barriers[117].

Similarly, a study of camp based Burundian refugees in Tanzania[118] found poor pregnancy outcomes in terms of high fetal death rates and neonatal mortality rates and low birth weight. Additionally, maternal and neonatal deaths contributed substantively to overall mortality. Risk factors for these poor outcomes were attributed to higher parity and gestational malaria. The study also showed that women belonging to higher socio-economic strata prior to conflict experienced poorer pregnancy outcomes; suggesting inadequate life skills to survive in a refugee camp and possibly poor camp conditions.

Studies documenting the reproductive health outcomes of camp based refugees in Bosnia, Kosovo, Afghanistan, Pakistan, Yemen, and sub-Saharan Africa reveal the importance of the following barriers which hinder access and lead to poor maternal

health outcomes: (i) poor access to emergency obstetric care[99, 119]; (ii) distance to health facilities poor transport and communication systems[119, 120]; (iii) inadequate attention to chronic diseases[119]; (iv) poor access family planning services[121]; (vi) unaffordable reproductive health care[97, 115, 116]; (vii) poor referral linkages to hospital services[101, 119, 120]; (viii) unavailability of treatment for HIV positive refugees[101]; (ix) poor security while traveling to health care facilities[120]; (x) hours of operation of services[120]; (xi) perceptions of poor quality of services and facilities[120]; and, (xii) unsupportive attitudes and behaviors of health workers[120].

On the other hand, in the post stabilization phase, there is contrary evidence suggesting that pregnancy outcomes of refugee women may indeed be on par or better than those of the host population owing to access to reproductive health services in refugee camps. One study that reviewed reproductive health outcomes of refugee women in 52 refugee camps in Azerbaijan, Ethiopia, Burma, Nepal, Thailand, Tanzania, and Uganda in the (stable) post emergency phase revealed that camp settings had higher crude birth rates, lower maternal and neonatal mortality rates, and lower percentages of low birth weight. This was attributed to better access to skilled health professionals in these camp settings and access to nutrition[122]. Another study of camp based refugees and migrants from Burma on the Thai-Burma border attributed improved pregnancy outcomes to early diagnosis and treatment of malaria, and delivery by skilled birth attendants despite the low literacy levels of the women[123].

Similarly, Orach et al report a 2004 study done in Uganda which found that although maternal health care costs were higher for refugees than the local population, maternal mortality was 2.5 times higher in the local population[124]. In another 2007 paper Orach and colleagues report that although the cost of maternal health care was higher for refugees, utilization rates (attendance in antenatal care (ANC), institutional deliveries, and major obstetrical interventions) also exceeded those of the local population[125]. These and other studies[74] show that refugees in some camps had better access to health services than the host population, specifically access to better qualified health professionals, medication, and functional laboratory facilities, which also increased the per capita maternal health care cost for refugees.

A UNHCR review of service and survey data on reproductive health in camps in Nepal, Pakistan, Ethiopia, Kenya, Tanzania, Uganda and the Democratic Republic

of Congo (as cited in McGinn[91]) also found lower neonatal and maternal mortality rates in the refugee population than the host population, although the report cautions that there might be under/over reporting in service data. McGinn attributes high ANC coverage and availability of emergency obstetric services in the camps to these favorable outcomes [91]. Tangentially, Hafeez et al acknowledge that access to public health services provided for better maternal health outcomes for some camp based refugees in Pakistan[119]

Extending this evidence, van Damme et al demonstrate that the local population in Guinea had better utilization rates of obstetric services because of refugee assistance programs which increased the availability of health care and improved transportation systems. The rates for major obstetric interventions increased significantly in areas with a higher rather than a lower number of refugees[126].

2.8.3. Traditional Resettlement Countries

The pattern of mixed evidence for maternal health outcomes of refugee women continues in traditional resettlement countries. The maternal health risk factors outlined in the beginning of this section including maternal anemia, high parity, previous unfavorable birth outcomes, short inter-pregnancy intervals, co-morbidities related to infectious and chronic diseases, psychological trauma related to sexual assault, and psychiatric and psychological problems were reported in studies undertaken in several resettlement countries[107, 109, 111, 127-129]. Data from traditional resettlement countries also revealed that refugee status did affect: (i) low birth weight [108, 130, 131] (ii) premature birth[131, 132]; (iii) high rates of induced abortion because of inadequate access to contraception[127]; (iv) still-births[132-134]; and (v) perinatal deaths[106, 131], although some studies showed that perinatal deaths were higher among refugees from Sub-Saharan Africa vis-à-vis their counterparts from the Middle East, Southeast Asia, and Latin America[135].

Data revealing unfavorable maternal health outcomes were associated with: (i)delays in seeking care in a range of host countries, including Hong Kong, Britain, Ireland and Australia, France, and Sweden[108, 128, 136-139]: (ii) insufficient attendance in ANC [131]; and (iii) barriers to accessing health care.

Barriers to accessing maternal health care for refugee and asylum seeking women included: (i) legal barriers prohibiting or limiting the range of services, and/or demanding payment for services from asylum seekers[140-142]; (ii) linguistic barriers [107, 108, 127, 128, 130, 137, 143, 144]; (iii) transportation problems [130]; (iv) lack of childcare support[130]; (v) information barriers[145, 146]; (vi) cultural barriers including receiving care from male health care providers[106, 112], difficulty adapting to a medicalized view of pregnancy and childbearing[108, 137] and difficulty adapting to delivery in a sterile environment[128] (vii) economic barriers[134, 147]; and, (viii) cold weather[145].

However, favorable pregnancy and birth outcomes related to birth weight, gestational age, live birth[145, 148, 149], and lower infant mortality rates[130] were also reported by some studies on refugee women in traditional resettlement countries. In other studies, refugee women showed cultural adaptation to western obstetric practices related to ANC, delivery care and PPC[108, 136, 143], and appreciation for continuous pregnancy care [137].

Other tangential issues that frequently emerged in relation to the maternal health care of refugee and asylum seeking women in traditional resettlement countries were issues related to past traumatic experiences and/or reintroduction of female genital mutilation (FGM)[106], psychological distress[127-129], and domestic violence [106, 150].

2.8.3.1. Access Issues of Asylum Seeking Women in Immigration Detention

The poor access of asylum seeking women to maternal health care in immigration detention in traditional resettlement countries is another emerging theme in the literature. In some places, pregnant asylum seekers who were detained were denied access to care, contrary to existing policy[144]. Further, access to ANC, obtaining results of blood tests, and having interpreters during medical consultations was absent/poor [151, 152]. Additionally, the detention experience was associated with psychological distress, clinical depression, and suicidal ideation[153, 154] for some of the women for whom the psychological impact of detention was heightened by the fact that the pregnancy was a result of rape[154].

2.8.4. Guidance on Reproductive Health Interventions for Refugee Women

Many United Nations (UN), international, and national agencies have developed a substantial body of guidance documents and field reports[155-159] that highlight the effectiveness of targeted maternal health interventions to improve maternal health outcomes for refugee women[160, 161]. However, most of these documents focus on conflict situations and camp based refugees.

The reproductive health interventions suggested for refugee women in traditional resettlement countries reinforce the importance of concurrently addressing their psychological distress related to past traumatic events, current social, economic, and psychological stressors, and future concerns of deportation and uncertainty along with providing maternal health care. Thus, this body of literature emphasizes the need for a holistic approach, the importance of concomitant psycho-social interventions, trans-disciplinary teams and care approaches, and strong referral linkages between different agencies providing care, to realize effective access to maternal health care for this population[127, 162].

Guidance on maternal health interventions for urban refugee women awaiting a durable solution is lacking.

2.9. DILEMMAS OF HEALTH CARE PROVIDERS

An emerging theme from the literature on access of refugee women to reproductive health care in traditional resettlement countries relates to the dilemmas experienced by health care professionals who provide care to this population. These dilemmas span three themes: (i) role conflict; (ii) challenged capacities; and (iii) emotional and psychological costs of providing care.

2.9.1. Role Conflict

Kurth and colleagues highlight the discomfort experienced by health care providers of refugee women in terms of role-conflict. The role-conflict is in relation to their professional roles as physicians and care providers and expected role as gate keepers by asylum authorities determining refugee status and by health maintenance organizations (HMOs) demanding cost efficacy of treatment[127].

2.9.2. Challenged Capacities

Further, the multifarious health needs of refugee women seeking maternal health care surfaced as a challenge to the professional capacities of health care providers[127]. In particular, female genital mutilation (FGM) was a source of considerable concern as health care providers in resettlement countries lacked knowledge and experience in delivering infibulated women[107, 133, 137, 163].

2.9.3. Emotional and Psychological Costs of Providing Care

Studies in resettlement countries also indicate that health care providers and interpreters providing maternal health care to refugee women were equally affected by the women's ongoing issues of grief, loss, pain, fear, and abandonment, arising from their traumatic histories. The burden of care which involved managing the women's multiple health needs and coping with their traumatic histories included psychological costs for health care providers[127, 163].

Although the above are *supply side* issues, they are important for the discussion on access to maternal health care for this population for a few reasons. Firstly, State policy restricting access to health care for non-citizens is a key dimension of access and health care professionals are increasingly being instrumentalized by the state in implementing such policies. Gaudion and Allotey have discussed problems arising from linking immigration status to the provision of maternal health care to refugee women[162]. Secondly, the transnational mobility of people challenges the health system to adapt the cultural and ethical contexts of its health care provision to evolving demographic changes. This issue deserves greater consideration given the relativity of barriers to different persons. Not only do population characteristics define the unique experiences of access; equally important is the role of contexts in realizing access.

2.10. STATUS OF RESEARCH ON REFUGEE MATERNAL HEALTH

A 2002 systematic review by Gagnon et al on refugee women's reproductive health identified the following gaps in data on refugee maternal health: (i) maternal health outcomes; (ii) absence of a consistent definition of "refugee"; (iii) absence of representative sampling; (iv) paucity of population based studies; and (v) dearth of

studies comparing refugee and host population women, and different refugee populations. The authors state that the bulk of published research reviewed consisted of "unsystematic and uncritical reviews, published reports, or case reports, which provide insight into the particular situations of certain individuals" [106] (p.9).

A later review of literature on refugee reproductive health status by Esscher[164] found that most of the literature on the topic after 1994 was produced by UN agencies and NGOs and included needs assessments reports, lessons learned reports, guidelines, and manuals based on field experiences.

Austin identified the need for empirical evidence with regard to refugee populations living in camp and non-camp settings, and an examination of protracted emergencies [99].

Research on refugee maternal health including surveys and retrospective studies have mostly been undertaken in camp settings or traditional resettlement countries. To the best of knowledge, there is no systematic research to date on the access of refugee women to maternal health services in urban settings. Moreover, most of the quantitative studies on access in camps and resettlement countries use utilization rates which are not entirely useful for understanding access issues of urban refugees.

In a review of literature, in discussing reproductive health outcomes related to fertility of refugees, McGinn cautions against generalizing the findings of camp based studies in the stable post emergency phase to conflict settings [91]. Similar judiciousness would need to be applied in generalizing the learning regarding reproductive health outcomes and access to reproductive health services of refugees in conflict, refugee camps, and traditional resettlement country settings to that of urban refugees navigating highly complex urban environments without legal status.

2.11. URBAN REFUGEES AND ASYLUM SEEKERS AND MATERNAL HEALTH -SUMMARY

The first section on refugees and asylum seekers underscored the emerging importance of urban refugees within refugee populations. Their growing numbers and changing composition include more women and children than before. Yet, the

accompanying and exceedingly restrictive protection environment is attributed to the absence of a normative and legal framework on refugee protection in many countries, particularly in the Asia Pacific. Their lack of legal status along with xenophobic State policies and attitudes of host populations creates the context for their vulnerability and poor access to services, including to health care. However, the urban environment also offers opportunities for survival. Social/ethnic networks of refugees, both national and transnational, have been found to be salient in these survival strategies. The UNHCR urban refugee policy 2009 through its ambitious goals and vague articulation of entitlements does not provide robust guidance in strengthening the protection of urban refugees and asylum seekers. Finally, the topic of urban refugees remains an under explored area of inquiry.

The second section elaborated on the access of refugee women to maternal health care, and the maternal health risks and outcomes experienced by them. The salience of access in mitigating health risks and improving maternal health outcomes was highlighted. Specific vulnerabilities and access problems of asylum seeking women in detention, and challenges confronting professionals and interpreters providing maternal health care to refugee women were also identified. Finally, the review of research, guidance documents, and organizational field reports on refugee reproductive health indicates a dearth of data on the topic for urban refugees.

CHAPTER 3: WHAT IS "ACCESS?"

Having underscored the salience of accessibility to maternal health services in achieving positive maternal health outcomes for refugees, in this chapter, I review the various theoretical models related to health care accessibility and examine the definitions and concepts of access in these frameworks.

Owing to the abundance of literature on the topic of access (9,666 "journal articles" indexed with a MeSH heading of "health services accessibility" on PubMed by 2009 and updated to 80,242 by 2013 January), the review of literature on access in this chapter was undertaken in two steps. Initially, the theoretical models seeking to address the question, "what is access" were reviewed for their salient concepts and general strengths and weaknesses. The summary of this review is given in Appendix-1. Based on this review, in the next step reported in this chapter, the key concepts related to "what is access" in the above mentioned theoretical models were scrutinized using (i) the right to health definition of accessibility which guided the conceptual framework of this study; and (ii) the special concerns of non-citizens regarding access, since this is the category that the study population of refugees and asylum seekers in this project belong to.

In terms of the structure of this chapter, in the first section (3.1), I elaborate on the right to health definition of accessibility. In the second section (3.2), I explore concepts on accessibility in public health based on the theoretical models of access and empirical research on access. In the third section (3.3), I make an argument for using the right to health framework to assess the access of the study population to maternal health services. This argument is based on the review of concepts of access in the right to health and public health frameworks on access, and the congruence of these concepts with empirical research on access with non-citizens and refugees. The fourth section (3.4) focuses on measurement issues in empirical research on access. In the fifth section (3.5), I discuss measures that have been used in other domains of public health, although not always in access studies and argue for their suitability to this study using the right to health definition of access.

The sixth section (3.6) focuses on the accessibility of vulnerable populations to health services and methodological issues related to research on access.

Finally, in general, in adopting the common approach in the literature in which the terms *access* and *accessibility* are used inter-changeably, I also take the view that when viewed as a process, *access* and *accessibility* are similar meaning descriptors and the latter connotes ease in obtaining care. This is in contrast to Donabedian and Penchansky's view where *access* is an attribute of the health care system and *accessibility* is the noun form of the adjective "accessible"[165].

3.1. RIGHT TO HEALTH DEFINITION OF ACCESSIBILITY

The right to health definition of accessibility which is adopted in this study and outlined in General Comment 14 (paragraph 12(b))[15], identifies accessibility to health care in terms of four inter-related dimensions, namely:

- Non-discrimination: Health facilities, goods and services must be accessible to all, especially the most vulnerable or marginalized sections of the population
- Physical accessibility (safe physical reach) – The underlying determinants of health and health facilities, goods and services must be within safe physical reach for all sections of the population, especially vulnerable or marginalized groups
- Economic Accessibility (affordability) – Payments for the underlying determinants of health and health facilities, goods and services are affordable and based on the principle of equity, ensuring that these services, whether privately or publicly provided, are affordable for all, including socially disadvantaged groups. Equity demands that poorer households should not be disproportionately burdened with health expenses as compared to richer households.
- Information accessibility – This includes the right to seek, receive and impart information and ideas concerning health issues. However, accessibility of information should not impair the right to have personal health data treated with confidentiality.

Accessibility to health care services within this approach is located within a broader framework of institutional characteristics of a health care system that also include availability, acceptability, and quality of health care services. *Availability* means that

the socio economic determinants of health and the functioning public health and health-care facilities, goods and services, as well as programs are available in sufficient quantity. *Acceptability* means that health facilities, goods and services must conform to standards of medical ethics and cultural appropriateness. *Quality* means that health facilities, goods and services must be scientifically and medically appropriate and of good quality.

This definition of access, derived from an authoritative interpretation[166] of the normative content of Article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR)[14], is premised on the equality of opportunity to everyone to a system of health care[167]. It recognizes accessibility to health care as one of the determinants of positive health outcomes for people to lead healthy and *flourishing*[168] lives. It also acknowledges accessibility to the socio-economic determinants of health as a complementary component to accessibility to health care in achieving positive health outcomes[169].

Within this schema, it is the obligation of the State to generate the necessary conditions that promote health and reduce morbidity/mortality by guaranteeing the socio-economic determinants of health (namely the right to water, sanitation, food, housing, healthy occupational and environmental conditions, education, information), as well as the right to health care.

Echoing the call of Alma Ata and the Programme of Action of the International Conference on Population and Development (paragraph 43)[15], the right to health approach gives priority to primary and preventive health services over expensive curative health services which might benefit only a privileged segment of the population (paragraph 19)[15]. States also have some core obligations or minimum essential health services that are to be guaranteed under all circumstances, which among others, include access to essential drugs, control of epidemic and endemic diseases, reproductive, maternal (pre-natal as well as post-natal) and child health care, and immunization against infectious diseases (paragraphs 43 and 44)[15]. This approach upholds assistance to refugees and asylum seekers as an international responsibility (paragraph 40)[15]. Above all, it affirms the “right of access to health facilities, goods and services on a non-discriminatory basis, especially for vulnerable or marginalized groups” (paragraph 43(a)) as a core obligation of the State[15].

Un-divorced from the realities of finite resources in health care settings, it also advocates the "progressive realization" of health care entitlements in line with limited resources; but imposes immediate obligations that prohibit discrimination and promote the exercise of rights (paragraph 30)[15] within the resource constrained context.

The argument of health care as a human right is not without contestation. The libertarian argument which espouses private financing of health care and minimum standards of care for the poor[170], includes the position that health care is a commodity like others in the economic market place whose distribution should not be fettered by undue government regulation and subsidy[168]. This viewpoint is based on arguments that entitlements to health care are unrealizable within a context of limited resources, and coercive State practices related to cross subsidization of health care costs to finance that which is not a natural right, is a violation of individual rights[171]. Related to the Libertarian view are also the notions of (i) negative rights to health which requires States to refrain from harming people's health, and (ii) the right to keep the reward of one's earnings[172]; the latter supporting the view that health care is a privilege of those who are "willing and able to pay". Other arguments against health care as right are premised on principles that cross subsidization of health care is unfair in relation to those whose health problems are related to avoidable risk taking behaviors and medical non-compliance[173]. While this outlook resonates more with the health care scenario in the United States[170, 171], in Europe, State policies based on egalitarian principles lean towards horizontal equity in health care distribution (based on need) and vertical equity in health care financing (based on "ability to pay")[170].

There are other significant challenges related to the operationalization of rights based approaches to health and health care. These are discussed in Chapter-8.

3.2. KEY CONCEPTS IN THEORIES AND EMPIRICAL RESEARCH ON ACCESS IN PUBLIC HEALTH

In spite of access being an oft repeated word in policy and discussions related to the health care system, there is no agreed definition of the term in public health[10, 11, 174]. *Access* as a term has taken on multiple meanings and dimensions depending on the disciplinary fields it originated from [10, 11, 175] and the approaches used to study it [176, 177]. The diverse approaches used to study access have led to varied emphasis on

particular aspects of the various dimensions of access[11, 176]. Khan and Bhardwaj[11] quote a report by the Bureau of Health Professions which states that often "authors discuss the concept without defining it directly" [178] (p.62).

The multiplicity of concepts associated with access are evidenced in some of the predominant conceptual/theoretical frameworks like the Behavioral Model of Health Services Use by Aday and Andersen[179, 180], the "FIT" framework of Penchansky and Thomas[174], the Khan and Bharadwaj model [11], the Livelihood Model [181],and the Institute of Medicine(IOM) model of access [182] which have been reviewed in Appendix-1.

However, since the early seventies, the understanding of "what is access" in theoretical frameworks on access has spanned three key concepts including: (i) the availability of health services; (ii) utilization of health care; and (iii) barriers to obtaining care, with the continuing predominance of the latter two concepts to date. Along with these has been the recognition of the multi-dimensionality and dynamic nature of access which have created posers to the measurement of access [183].

3.2.1. Availability of Health Services

Access has been used synonymously with availability of health services by some scholars[176]. Freeborn and Greenlick defined access as the availability of personnel, facilities and services "at the time and place that they are needed through a well-defined and known point of entry" (p.69) at rates that are appropriate to their need[184].

3.2.2. Utilization of Health Services

In contrast, Donabedian[177] asserted that access is the "use of service, not simply the presence of a facility" (p.111). Aday and Andersen echoed this view by stating that "the proof of access per se is not the availability of services and resources but whether they are actually utilized by the people who need them"[179] (p.216). Additionally, they stated that access also refers to the quantity and quality of health service(s) received/delivered by those needing/providing care through the medical care system[179]. In making this distinction between accessibility and availability, Donabedian, Aday, Andersen and others drew attention to the plethora of factors (individual to ecological) which hinder the obtaining of care even when it exists. This

idea finds support from the World Health Organization (WHO) which states that, "care is not guaranteed simply by the existence of medical facilities"[185](pg.9).

Related to the view of Aday and Andersen that equates access with utilization of health services are other concepts of access that include potential and actual entry into the health care system[186], continuity in the receipt of care beyond gaining entry into the system[177, 187], and responsiveness and appropriateness of health services in relation to need[174, 177, 188, 189]; although Donabedian recognized that an evaluation of the 'need' for medical care may be different from the perspectives of the doctor and the patient[177].

3.2.3. Non-Utilization of Health Services

Aday, Andersen and others' emphasis on utilization of care[174, 175, 179, 180, 186-192] posed challenges to scholars like Lewis C. Lewis C et al in Fiedler[10] asserted that utilization of services is proof of access but cannot be equated with it because it fails to establish the causes for non-utilization of services; thus, indicating that non-utilization of health services is integral to the concept of access. Analogously, Fiedler states, "Access is the sine qua non of utilization"[10] (p.134). The view of access of Lewis C et al and Fiedler above is important as non-utilization of health services is an emerging global concern in relation to marginalized populations including non-citizens [193, 194].

3.2.4. Barriers

The ascendancy of barriers in the appreciation of access was consolidated by the recognition of an "intermediate phenomenon", between the extremes of availability and utilization of health care that served as a "set of obstacles" to seeking and obtaining care[195] (p.845).

In fact, negotiating obstacles or barriers is regarded as key to obtaining access[11, 179, 180, 196] and barriers are considered to be relative[11]. For example, the additional monetary costs and the opportunity cost of time associated with longer travel distance to a health care facility would have differential impacts on an affluent and a poor person requiring care.

Barriers have been classified variously in the literature on access.

Donabedian classified barriers as (i) financial; (ii) psychological (attitudes of physicians and provider-patient interactions); (iii) informational; (iv) socio-organizational (difficulties in obtaining timely appointments and differential care for persons of different social classes or disabilities); (v) spatial (efficient location distribution); and (vi) temporal (hours of operation, organization of emergency care)[177, 197].

Khan and Bharadwaj categorized barriers into those that relate to the production of health care services (e.g. number/type of providers, services provided and institutional arrangements) and to their utilization, and posit that barriers are inter-linked[11].

The IOM model following a typology of three types of barriers, *structural, financial* and *personal/cultural*, described *structural barriers* as "impediments to medical care directly related to the number, type, concentration, location, or organizational configuration of health care providers", f*inancial barriers* as barriers that "restrict access either by inhibiting the ability of patients to pay for needed medical services or by discouraging physicians and hospitals from treating patients of limited means", and p*ersonal and cultural barriers* as barriers that "inhibit people who need medical attention from seeking it or, once they obtain care, from following recommended post treatment guidelines"[182] (p. 39).

Frenk classified barriers as *ecological obstacles* which relate to the location of the sources of health care, *financial obstacles* or prices charged by providers, and *organizational obstacles* that relate to modes of organization of health care resources[195].

3.2.4.1. Conventional Barriers

Some barriers that have traditionally been associated with poor access and/or utilization of health care include: distance from the health facility[198-206]; transportation barriers[198, 203, 207, 208]; longer travel time[199, 209]; longer waiting time at health facilities[210-213]; appointment delays[213]; non-availability of extended/out-of-hours

care[214, 215]; non-availability of a regular source of care[203, 216-220]; cost of health care[198, 221]; gender disparities[222-226]; low income[227, 228]; and, linguistic barriers[215, 229-235].

3.2.4.2. Non-Traditional Barriers

In recent times, however, there is growing recognition of the role of nontraditional factors like social support, availability of community resources, and, social exclusion at health facilities in mediating the ability to access health care services[236-239], especially with regard to immigrants[240], and women [241]. These could also be called psycho-social barriers.

3.2.5. Normative Concerns

Some theorists who proposed conceptual/theoretical frameworks explaining "what is access", at times, also considered tangential normative issues related to *efficiency, effectiveness*[180], and *equity*[189, 242]. Accordingly, *effective access* equates with clinical impact/benefit of a health intervention[243], and an improvement of health status or satisfaction levels because of utilization of services[180]. *Efficient access* relates to the rational use of resources and when the level of health status or satisfaction corresponds to the amount of health care services utilized[180].

The discussions on *equity* in relation to accessibility revolve around (i) equity in the distribution of health care; and (ii) equity in health care financing. However, the complex ethical issue of equity[243], a matter of *fairness*, is as contentious an issue as access itself[244, 245], with Libertarian, Utilitarian, Marxist, Rawlsian, egalitarian[170], and Confucian [243, 246-249] ideological perspectives punctuating the discourse with different conceptualizations of equity. Further, normative criteria such as equity have been found to be in conflict with other criteria such as efficiency [250].

Although Andersen asserted that his behavioral model was non-normative [180], he and Aday sought to explicate equity of access as utilization of care that was proportionate to need [189].

Indeed, "clinical need" and "capacity to benefit" from the health intervention[251] have been the predominantly proposed criteria in relation to equity in health care

distribution, while the “ability to pay” criteria has dominated the discourses on equity in health care financing [170].

“Need” has been conceptualized variously in access literature with no cross-disciplinary consensus[244]. Bradshaw’s classification of need as normative, expressed, felt, and comparative[252] is a commonly used taxonomy. The WHO weighed in on the aspect of need by recommending *horizontal equity*, “providing health care (both personal and public health) to all those who have the same health need”, and *vertical equity*, “providing preferentially to those with the greatest need” [253] (p.18).

“Ability to pay”, “a complex empirical question” [254] (p.233) derives from the economic model of consumer behavior wherein “demand” for goods/services simultaneously constitutes the *willingness* and *ability to pay*. The term gained prominence from the 1970s to 1980s with the push from the World Bank and International Monetary Fund (IMF) to introduce user fees in health care in low and middle income countries. User fees were promoted on the basis that people are willing and able to pay for services[254, 255]. The economic rationales[256] supporting this view included (i) research revealing the price inelasticity of demand for medical care[257, 258] which would make it feasible to generate additional revenue for the health care sector; (ii) promotion of efficiency in resource allocation and consumption of medical services; and (iii) promotion of equity through cross-subsidization, cost-recovery, and cost-sharing systems which would make additional funds available for the poor. However, user fees also garnered criticism for contributing to catastrophic health expenditures and converting health into a private good within a private-market model [259]. Integration of concerns of equity within the debate on user fees brought about the concepts of *horizontal equity* (those of “same ability to pay making the same contribution”), and *vertical equity* (those of “unequal ability to pay making appropriately dissimilar payments for health care”) in health care financing[170] (p.1819). A current definition of “ability to pay” includes “the capacity to generate economic resources through income, savings, borrowing or loans - to pay for health care services without catastrophic expenditure of resources required for basic necessities”[260] (p.6).

Empirical literature, however, has largely situated horizontal equity within the context of health care delivery/distribution (equal need-equal opportunity criteria) and

vertical equity within the context of health care financing (ability to pay criteria/progressive system of financing)[170, 261].

Other themes such as quality of care related to discrimination[262], equality of opportunity in obtaining health care[262, 263], access to information to make informed choices about health care utilization[263], and the dynamics of power/position manifested in political struggles at societal, economic, technical, cultural, political and ethical levels[264] have been cited as critical to understanding equity of access to health care.

Right to health scholars recognize health equity as an ethical issue that is congruous and related to human rights and link it to systematic disparities between more and less advantaged social groups[265]. The right to health definition of access incorporates the consideration of equity, non-discrimination, access to health information, and participation, which are considered moot to accessibility to health care by many scholars. Moreover, the concept of economic accessibility in the right to health aligns with the concept of vertical equity in health care financing.

However, although health equity and human rights approaches "share foundational concepts", equity belongs to the domain of ethics and the two approaches have "different languages, perspectives, and tools for action" [266] (pg.1).

3.3. RATIONALE FOR THE RIGHT TO HEALTH APPROACH TO ACCESS

Having laid out the definitions and concepts that are key to access in the right to health and in public health, in this section I argue that the right to health definition of access provides a sound conceptual framework for this study for the following reasons: (i) its theoretical cogency; (ii) suitability as an analytical framework; and (iii) the position of maternal health within the right to health. I also argue that based on empirical research on access with non-citizens and refugees, it is an appropriate framework to anchor the present study.

3.3.1. Theoretical Cogency

The concepts related to access in the right to health approach are not new; they are reflected in public health literature, notably since the Alma Ata Declaration [267]. In the

right to health definition of access, various concepts in the different theoretical frameworks and empirical findings from public health research on access coalesce into a coherent normative framework that can be theoretically applied to various contexts.

Accessibility to health care is most often a problem for disadvantaged and vulnerable populations. As such, it is imperative that a framework to understand accessibility addresses the specific exclusions of such populations. The theoretical cogency of the right to health framework derives from its "preoccupation with vulnerable and disadvantaged groups" [268] (p.7) and its normative base of equality and non-discrimination which equips it to address the unique exclusions experienced by such populations.

However, even if normative debates are set aside, the right to health definition of access provides a sound theoretical basis because of its consistent empirical groundedness in wider contexts of access to health care of disadvantaged populations. The theoretical advantages of a right to health definition of access derive from the following factors:

3.3.1.1. Distinction between *Availability* and *Accessibility*

The right to health framework provides clear definitions delineating availability from accessibility. Availability refers to functioning public health and health-care facilities, goods and services, as well as programmes which have to be available in sufficient quantity[15] (paragraph 12(a)) and accessibility refers to fours overlapping dimensions of non-discrimination, physical access, economic access, and information access[15] (paragraph 12(b)). Further, only the right to health approach explicitly defines the components of public health and health care goods, services and facilities included in its definition of accessibility. Most frameworks use the terms health care and medical care interchangeably[269].

The conceptual difference between availability and accessibility is especially important for non-citizen populations like refugees who encounter numerous barriers in accessing available care or who might not take advantage of available services even where they are accessible [270].

3.3.1.2. Accommodation of the Concept of Barriers

Barriers are considered salient in negotiating access[179, 180, 192, 196]. The four inter-related dimensions of access could be said to correspond to the concept of "barriers" in public health through the following logic. The four interlinked dimensions[15] represent conditions that need to be fulfilled to enjoy equality of opportunity to a system of health care. Thus, if these conditions are not fulfilled, it could be assumed that these four dimensions correspond to the public health concepts of spatial, financial, information, and psycho-social barriers to accessing health care. The normative content of the right to health argues for the removal of all barriers that impede women's access to health services, including for sexual and reproductive health[15] (paragraph 21). The right to health definition of access (paragraph 12(b)) when read in conjunction with the inter-related dimensions of availability (paragraph 12(a)) and acceptability (paragraphs12(c)) in General Comment 14, strengthens arguments for universal access to health care.

3.3.1.2.1. Three Delays Model: Obstetric Emergencies and Barriers

In looking at barriers to accessing health care, the right to health model is also congruous with the Three Delays Model of Thaddeus and Maine [271]. The Three Delays Model links maternal mortality to factors/barriers that impede access to care between the onset of an obstetric emergency and negative maternal health outcomes. Hunt and Mesquita[88] compare the factors contributing to the three delays with the dimensions of accessibility in the right to health model. They state that the *delay in the decision to seek care* and its attendant factors related to the status of women, illness characteristics, distance from the health facility, financial and opportunity costs, previous experience with the health care system, and, perceived quality of care are reflected in the dimensions of physical accessibility, economic accessibility, and nondiscrimination in the right to health framework. The *delay in the arrival at a health facility* because of factors related to travel time from home to facility, availability and cost of transportation, and condition of roads link to the aspect of physical accessibility in the right to health model. Finally, the *delay in the provision of adequate care* related to the adequacy of the referral system, shortage of supplies, equipment, and trained personnel, and competence of available personnel is connected to the (i) availability of services, personnel, medicines, and socio-economic determinants of health, and (ii) quality of care, which are the

interrelated and essential elements contributing to the right to health in General Comment 14,paragraphs 12 (a) and (d) [15].

3.3.1.3. Inclusion of Psycho-Social Dimensions of Access

Even though they are normative principles, the right to health framework of access addresses two psycho-social barriers to access not found in the other frameworks, although their significance is increasingly reiterated in empirical research on access in public health. These barriers are pertinent to those with insecure legal status and belonging to minority groups. They include (i) the element of safety in spatial access and of (ii) the role of discrimination in accessing care. These two psycho-social barriers link to the structural context of access and are discussed below.

3.3.1.3.1. Psycho-social Dimension: Safety in Physical Access

Refugees and asylum seekers experience ongoing fear of arrest and intimidation by enforcement authorities and host societies which impedes their spatial mobility and access to essential services[9, 44, 272, 273], including to health services[274]. This links with the emerging body of empirical research which reveals avoidance or delay in seeking care by non-citizens, especially asylum seekers and the undocumented, for fear of being detected, arrested, and deported[275-288].

It also links with empirical evidence on the importance of safety in contributing to recovery and functional outcomes in those who have experienced trauma[289]. Thus, for refugees, as people who have experienced trauma, the sense of safety would be important to achieve positive functional outcomes such as seeking health care when required. Negative functional outcomes could contribute to negative patterns of health care utilization.

The right to health conceptual framework facilitates the consideration of these aspects of access by incorporating the dimension of safety in spatial access.

3.3.1.3.2. Psycho-social Dimension: Discrimination

Similarly, the negative impact of perceived discrimination, especially on grounds of race and ethnicity, on utilization of services has also been evidenced in empirical

research[290-294]. *Perceived discrimination* refers to the "effects of individuals' perceptions of individual acts of discrimination" [290] (p. 895) based on stigmatizing characteristics related to minority status (such as race, ethnicity, disability, sexual orientation, criminal background). Perceived discrimination and perceptions of unfair treatment have been found to negatively impact:(i) health status[290, 295, 296]; (ii) health behaviors[297]; and (iii) health care utilization in the form of under-utilization of health care[290], avoidance of health care[294, 298], delays in utilizing care[291, 292, 299, 300], non-adherence to treatment[291], and delays in filling prescriptions[301].

Discrimination as a barrier to accessing care is related to neglect, getting unfair consideration in the distribution of resources, disenfranchisement[302], being treated differently to other patients, and being stereotyped[303] within the health system.

Refugees experience stigma with regard to their refugee status and racial profile[109], which often leads to experiences of negative social responses to illnesses[233], and unsympathetic services[152, 304] in their encounters with the health system.

Although race has been acknowledged by theorists like Aday and Andersen as one of the predisposing variables influencing access, their theoretical model still requires the mediation of psycho-social factors to make the conceptual links between race and health services utilization. The right to health approach on the other hand provides a useful framework to identify and analyze psycho-social determinants of health care utilization related to its proscribed grounds of discrimination. It also allows for the examination of multiple exclusions and compounded discrimination in accessing health care. The behavioral model on the other hand has been criticized for being anchored in studies related to the "dominant-culture middle class populations" which are not sensitive to the context of poor and low income women[13] (p.150) and low income populations in general[12].

3.3.1.4. Consideration of Information Accessibility

The right to health definition of accessibility includes information accessibility as one of the core dimensions of access. The consideration of information accessibility is vital to the study population's access to health services given the language and communication barriers experienced by them[276, 305-311]

3.3.1.5. Consideration of Non-Utilization of Services

The concern for non-utilization of health services within the discourse on access finds support in a right to health approach to accessibility which accords primacy (i) to equality and non-discrimination so that disadvantaged populations enjoy the same access as advantaged populations; and (ii) to health systems to provide accessible services in a transparent, participatory, and non-discriminatory manner [308].

3.3.1.6. Consideration of Multidimensionality

A common underlying premise of the major theoretical frameworks is that accessibility is a complex and multidimensional phenomenon, both conceptually and operationally. Aday and Andersen used the dimensions of the characteristics of the health care system and the population, potential and realized access, and effective, efficient and equitable access to explain their model of access[179, 180, 189]. Penchansky used the dimensions of availability, accessibility, affordability, accommodation, and acceptability[174]. Donabedian pointed to the socio-organizational and geographic aspects of access as well as the dimensions of initiation and continuity of care[312]. Khan and Bharadwaj highlighted the spatial and aspatial dimensions of access[11]. The IOM model augmented the understanding of access by introducing the dimensions of treatment adherence, appropriateness of treatment, and quality of care[182]. The right to health definition of access supports a multidimensional view of access through its definition which includes the four inter-related dimensions of non-discrimination, physical accessibility, economic accessibility, and information accessibility[15] (paragraph 12(b)i-iv).

3.3.1.7. Salience of Political Context of Health Policy

The improvement of accessibility to health care services is an expressed or implicit goal of health policy around which most theories of access to health services have been constructed[174, 179, 190, 313]. Additionally, theorists have located this goal of access within the broader domain of the political context [179].

This consideration of access within its political context is an important insight which has much relevance today, especially for refugees and asylum seekers and other non-citizens. The behavioral model assumed that the goal of health policy was to

improve access. However, often in contemporary times, the objective of the health policy directed toward non-citizens is to disallow access, or provide restricted access; sometimes only to emergency care. Policies which seek to restrict migrants' accessibility to health care are meant to serve as a deterrent to utilization of services[140, 282, 287, 314] and to migration to destination countries[315, 316]. Such a policy outlook is usually guided by the health and health financing system in the country, its legal systems, migration and asylum history[282], political will, and public debate [317].

Although the proponents of the behavioral model did not apply a political analysis to their study of access and related health policy, the incorporation of health policy in the conceptual framework of access and its place within the political domain points to an important issue that requires consideration in studies on access, especially for non-citizens.

The right to health framework supports such a view and makes the adoption of an equitable and non-discriminatory national health policy by the State a necessary condition to achieve access to health care[15] (paragraphs 36 and 53).

3.3.2. Suitability as an Analytical Framework

Within the right to health approach, the definition of access which is part of the AAAQ framework (Availability, Accessibility, Acceptability, and Quality of/to health care and the determinants of health) is a more appropriate analytical framework for policy analysis than the tripartite typology of State obligations to respect, protect, and fulfill human rights which is more suited to legal analysis[318]. This analytical framework has been applied to thematic contexts like the World Trade Organization[318], maternal mortality[319], neglected diseases[320] , mental health[321], and sexual and reproductive health[322] .

3.3.3. The Position of Maternal Health

The right to health approach recognizes maternal and child health as an obligation of comparable priority[15] paragraph 44(a)), and affirms the equal access of all women without distinction to health care services, especially to maternal health care services, increasing the suitability of this approach to the current study.

Access to reproductive health care services for women in the right to health approach includes the right to appropriate pregnancy, confinement and post natal services, including free services where required [86](Art 12.2), [323](paragraph 26).

Thus, as stated earlier, the right to health approach offers unique advantages for studying the access to health care and maternal health care of marginalized populations like refugees because of its theoretical strengths.

3.4. ACCESSIBILITY: MEASUREMENT

In this section, I will review some of the common quantitative measures of access related to: (i) utilization rates; (ii) barriers to access: and (iii) satisfaction with care, that have been used in access studies and highlight key issues. Individual measures of access have been separately described and reviewed in Appendix-2.

The measurement of access is relative and linked to the manner in which access is defined[189, 324, 325]. For example, whether access is seen as gaining entry into the system or beyond that as receiving continued care has varied implications for what will be measured[325]. Measures of access incorporating the appropriateness of utilized care would also vary depending on the specificities of illness, health need in question, and whether there are universally accepted clinical standards to treat these illnesses[326]. This complexity is escalated in areas of medicine where criteria for care and clinical standards related to the management of medical problems are lacking or are only broadly defined[189]. Considerations of whether definitions of access include or exclude vulnerable populations with specific needs, or whether health outcomes should be used as a basis to evaluate access would also vary the variables to be included in the study and the study design itself[15, 327]. Moreover, studies of why and how a program might impact access and the impact of a program on health outcomes calls for the separate use of process and outcome indicators of access respectively[191].

On the other hand, measurement of equity in access and in health care utilization studies has frequently considered matching patients' needs with services received[188, 189, 191]. Criteria to judge if need has been met (equity criteria) has included health status which could either be viewed as an outcome indicator (to see the impact of medical care) or a process indicator (to see how those with lowest

health status are faring in terms of access and care, if it is assumed that access to care cannot depend on the ability to pay)[191]. Measurement of equity of access which has benefitted from public finance, income distribution and redistribution, and labour economics is still a growing body of knowledge[170]. Some of the problems of measuring equity of access are attributed to it being a "complex ethical concept that eludes precise definition"[243] and the lack of consensus on the definitions related to access, need, and equity. As such, most often, utilization of health care has been used as a proxy for measuring equity of access to health care[244].

Thus, the measurement of access also depends on the conceptual framework of the study or the policy goals underpinning health policies[324].

As it can be seen, the complexities involved in measuring access are more than one. The underlying problem of the absence of an agreed definition of access and when access is equitable[10] exacerbates the challenge to find common measures of access. The inter-linkages between the different dimensions of access[174] is another poser for access measurement efforts.

Given these conceptual complexities with regard to measuring access, attempts to develop comprehensive access measures run the risk of being too "broad and nonspecific"[180] (p.4). Owing to these factors it has been said that the measurement of access often depends largely on the purpose and the audience for whom it is intended[325].

In general, most access measures conceptualized and operationalized in research include individual level, population level, and health care system[186] measures.

The IOM model uses health care system and population level measures including (i) the quantity of health care provider rates, (ii) population utilization rates of preventive health interventions and secondary/tertiary care, and (iii) rates of population health outcomes [182].

Given the inability of the individual health care user to provide accurate information about the health care system, access measures in relation to the health care system have generally focused on how health system characteristics are reflected in the

utilization of care (e.g. quantity and type of medical specialists available at the regular source of care), and the content of care (e.g. details of medical tests performed, referrals made, discussion on treatment options offered) [328].

As such, individual level access measures have been more widely used in attempts to measure access. Individual level access measures are related to (i) **service utilization** relative to need; (ii) **characteristics of the health care system and the population** that impede/facilitate the utilization of care (like availability of regular source of care, financing schemes, geographical availability of health care, availability of type of care, travel time, waiting time, operation hours, income of the user, insurance coverage etc); and, (iii) **user perspectives on barriers to required care** (e.g. inability and/or delays in obtaining care) and **satisfaction with care** which are in turn associated with health care utilization. Individual level access measures have often been linked to their effect on health outcomes, finances, and work of health care users[328].

Different individual level measures have been used in access research by the proponents of the different conceptual frameworks on access. While the characteristics of the health system and of the population are known to influence entry into the system, outcome indicators or measures of utilization of services, and satisfaction with services are said to validate the securing of access and the nature of access obtained [10, 186, 329].

Of all the individual access measures, utilization rates and satisfaction measures have been most widely applied in empirical on access research and provide tangible evidence of care obtained. Barriers to access have been less easy to measure. Finally, although there have been various efforts to measure access, they fall short of providing a single summary measure for access owing to the multi-dimensionality of the concept.

3.4.1. Utilization Rates

The pre-occupation of policy makers with the need to increase utilization rates in the 1960's when the behavioral model was developed, vis-à-vis concerns about financial costs in the last three decades, had a hand in access measures being conceptualized in terms of utilization rates[180]. Utilization rates as a measure of

access were used by proponents of the behavioral model, the FIT model, the livelihood model, and the IOM committee, although they had variously used different utilization measures to measure access. The World Health Organization also supports the use of utilization rates as a proxy measure of access in conflict areas owing to estimation problems with coverage[330].

Some of the measures using utilization rates are: the Use-Disability Ratio, Symptoms-Response Ratio, Mean Number of Physician Visits, Use of Emergency Care for Primary Care, Episode of Illness Measure, Chen's ratio, Medical Severity Index, and Use-Continuity Measures[331]. In addition, specific utilization measures were developed to assess access to ANC, like the Kessner Index, the Kotelchuck Adequacy of Prenatal Care Utilization and the GINDEX. Individual summaries and critiques of each of these measures are provided in Appendix-2.

The general critique, however, is that some of these utilization measures are wholly dependent on either self-reports and recall or on physician records, they do not reflect preventive services, and do not always equal need[191, 332]. Additionally, their focus on illness related medical care makes it unsuitable to the condition of pregnancy which is not an illness. Importantly, these utilization rates fail to recognize that access must precede utilization and that factors influencing utilization would also impact access[10]. The latter is especially critical to understanding access issues of disadvantaged populations like refugees for whom non-utilization of care and negotiating barriers to gain entry into the system and to use care post entry are moot.

Further, indicators of access related to maternal care, i.e. the Kessner Index, the Kotelchuck Adequacy of Prenatal Care Utilization and the GINDEX.A, focus only on (late) ANC and do not conform to the clinical standards of care recommended by WHO[333].

Other indicators to measure utilization of maternal health care include the (i) use of skilled birth attendants at birth[334]; and (ii) whether postpartum care (PPC) had been obtained[335].

The indicator of *institutional delivery* is related to the use of skilled birth attendants. It finds support in evidence related to standards of care that associate institutional

delivery with positive maternal health outcomes. Campbell et al in reviewing published and grey literature, including systematic reviews of effective single and multiple interventions and program evaluations related to strategies to reduce maternal mortality indicate that a health centre intrapartum-care strategy "can be justified as the best bet to bring down high rates of maternal mortality"[336] (p.1284). Such a strategy involves women routinely opting to deliver in a health centre, with midwives as the main providers, but working with other care providers in a team [336].

For the postpartum period, the variable to ascertain access could include the universally recommended PPC visit recommended by WHO[335] which recommends that for healthy mothers and healthy babies (women and babies without any problems), the first PPC visit take place within 48 hours of delivery.

3.4.2. Barriers to Access

A common criticism leveled against access research is the tendency to explain access on the basis of single aspects such as *usual source of care* or *cost*[12, 313]. There is growing recognition that such an approach fails to appreciate various barriers that low-income populations contend with to obtain care. As such, there is an acknowledgement of the need to develop measures that assess barriers encountered in the care-seeking process and examine the role of these barriers on health behavior and health care utilization[12]. However, given the complexities involved in directly measuring barriers to access, a common route to assessing barriers has been to view utilization rates and satisfaction scores as function of barriers which can in turn confirm the "hypothesized importance" of the barriers [10] (p.129).

3.4.3. Satisfaction with Care

In access literature, satisfaction with care is discussed both as a process indicator affecting subsequent utilization rates and as an outcome indicator of utilization. The literature on satisfaction with care in access has revolved around satisfaction with health system characteristics (e.g. with availability of services, waiting time, regular source of care, cost, convenience, coordination of services) and with process characteristics (interaction with health care providers and their technical and inter-personal skills)[191, 328].

A general critique of the use of satisfaction scores as a measure of access is that it fails to makes a conceptual distinction between access and existing measures of satisfaction regarding quality of care[325].

3.5. PROPOSED MEASURES OF ACCESS FOR THE STUDY

This study seeks to measure the access of the study population to the four dimensions of access in the right to health framework on accessibility which has previously been argued to correspond to barriers if conditions for their realization are not met. In addition, the study seeks to assess the study population's utilization of maternal health care focusing on ANC alone. The right to health framework does not provide indicators to measure access. In this section, I review and propose the applicability of indicators to assess these barriers, drawing on literature from traditional access studies and other domains of public health. I also provide the rationale for the indicator adopted by this study to measure the utilization of ANC.

3.5.1. Non-Discrimination

Conventionally, empirical research on access has indirectly examined the impact of race and ethnicity on access by assessing the relationship between utilization rates and race/ethnicity[337]. However, an emerging body of research in the study of health and health care inequalities using the concept and measure of *perceived discrimination in health care* can be used to examine non-discrimination. A multi-item measure which has been successfully validated and implemented in studies measuring perceived personal discrimination in a health care setting [338-340] has been found to be more sensitive than single-item measures in measuring perceived discrimination in relation to utilization of health care [340].

The use of perceived 'discrimination' to measure 'non-discrimination' is rationalized by a violations approach, which is one of the ways in which a right to health lens can be used to examine the realization of accessibility. It is also rationalized by viewing the right to health dimensions of access as barriers, with discrimination comparing to psycho-social barriers to accessibility. This measure could further validate qualitative approaches examining exclusions and discriminatory provisions in laws, policies, programs, and processes which inhibit access to health care.

3.5.2. Physical Accessibility

In the context of maternal health, evidence establishing the importance of referrals for obstetric emergencies and the consequent significance of physical accessibility[271] in reducing maternal morbidity and mortality makes it an important dimension of overall accessibility.

Barriers to physical accessibility in empirical research on access are usually measured using distance from the health facility[198-206, 341]; transportation barriers[198, 203, 207, 208]; and travel time[199, 209].

Travel time has been proposed for this study because it is regarded as a better predictor of physical access. The following are the reasons: (i) real travel distances may exceed cartographic "straight-line" distances when there are transportation difficulties or poor road conditions[238, 342, 343]; (ii) travel time includes the opportunity cost of time spent on competing domestic and income-generating activities[238, 342]; (iii)travel time is a strong predictor of access to health services for urban populations[10]. It also predicts satisfaction with care[174]. Travel time has also been used as a proxy indicator to assess if there is a regular source of care[328]. Additionally, the length of travel time could be considered a proxy for exposure to safety and security risks in physical mobility, and could be said to influence the decisions of refugees and asylum seekers to seek health care. As such, the indicator of travel time could be said to meet the criteria of "safe physical reach" for physical accessibility.

The suitability of this measure for this study population derives from: (i) their dependence on public transport facilities which are poor especially in the periphery of the Klang Valley; (ii) the opportunity cost of time in terms of daily wage earning activities, since most refugees work in the informal sector without labor protections including protected time to seek health care[344]; and (iii) the amenability of time as a proxy for exposure to threats of arrest, which has been found to impede physical mobility and accessibility in such populations.

3.5.3. Economic Accessibility

Economic accessibility in access literature has often been measured indirectly by looking at the relationship between utilization rates of care and its corresponding predictors like income and health insurance[227, 345-347] and the price of health services[345, 347].

Although not commonly used in traditional access studies, catastrophic health expenditure[348-350] which has been adapted to maternal health care costs[228, 351], is a suitable indicator for measuring the affordability (economic accessibility) of maternal health services in this study. This has generally been used in health financing and poverty studies to examine the impact of out-of-pocket health expenses (OOP) on a household.

Unaffordable out of pocket health payments are usually accompanied by household poverty, exclusion from financial risk protection/pooling mechanisms, and moderate to high use of health services[350]; characteristics that are applicable to the study population. In the short term, unaffordable OOP health payments require sacrificing the consumption of basic needs by a household[350, 352]. In the long term, they often result in decisions by households to avoid accessing health care or lead to situations of further impoverishment and reduced household welfare, if they do access care[348, 350]. Poor households are expected to experience a higher impact of such unaffordable and adverse out of pocket health expenses[350, 353, 354]. Additionally, the unemployed with the elderly, the disabled, and the chronically ill are more vulnerable to such adverse impacts[350, 355].

Catastrophic health expenditures and maternal health expenditure ratios are usually calculated as the proportion of out of pocket health care costs to total family non-food expenditure after adjusting for household size.

Family expenditure rather than income is used as the denominator in this ratio because consumption expenditures are considered to be a better indicator of effective income or purchasing power, especially for poor families for whom income may be “subject to random shocks”[350] (p. 973), while expenditure is considered to be less erratic and more consistent over time[356]. Observed food expenditure is deducted from the overall family expenditure to more realistically reflect the budget

share of maternal health expenses and is referred as “capacity to pay” in the literature[228, 350, 351, 355]. Deduction of food costs from the overall expenditure of the family captures more effectively the family’s economic resources available for maternal health care given that non-discretionary costs like food costs absorb a considerable proportion of the overall family expenditure in poor families[349, 356]. Where a large number of families live below the poverty line, measuring maternal health care expenditure as a proportion of “capacity to pay” is considered a better indicator than annual family expenditure including food costs[350].

Based on the above, it can be argued that the indicator of maternal health expenditure ratio meets the criteria of affordability and addresses the concern of poverty impacts of health care expenditures in General Comment 14 (paragraph 12 (b)).

The rationale to apply this concept (the impact of out of pocket health costs on a family’s capacity to meet its basic needs) to ascertain economic accessibility in this study is based on the fact that:

i. Maternal health care costs for refugees and asylum seekers are out of pocket in nature.
ii. This population is excluded from risk pooling mechanisms because of their “undocumented status”.
iii. The majority of refugees and asylum seekers in Malaysia earn an income that is below the poverty line income set by the Malaysian government under for Peninsular Malaysia[357].

3.5.4. Information Accessibility

While the right to a particular language may be unjustifiable in transnational spaces, the right to communication is a valid human right[358]. Proficiency in language mediates access[358]. Linguistic barriers are known to hinder communication, thereby impeding access to health care, including preventive care, and contributing to needless diagnostic procedures, risks of medical errors, and poor treatment adherence and follow up[359, 360]. At the same time, the assessment of access necessitates consideration of the required clinical content of care[326, 328].

Based on the above considerations, a quantitative variable to measure information accessibility was developed based on the clinical content of the WHO model of ANC. This model requires only four visits for a normal pregnancy and puts a premium on information in its three components for basic care which include: (i) screening for health and socio-economic conditions that enhance risks leading to negative maternal health outcomes; (ii) providing beneficial and evidence based therapeutic interventions; and (iii) educating pregnant women on safe birth preparedness, complications/emergency preparedness, and health promotion[333]. Considering the importance of health education in this model, the variable developed to measure information accessibility in this study focuses on key maternal and child health information items that need to be provided to and obtained by the pregnant women from the health care provider in relation to ANC, labor, and PPC, as per WHO's guidelines. The details of the tool that was developed to measure information accessibility for this study is given in Chapter 5 on research design.

3.5.6. Utilization of Antenatal Care

In general, utilization of ANC has been measured via (i) timing of ANC, (ii) amount of ANC or number of ANC visits, and (iii) content of ANC obtained[182, 361].

This study focuses on ANC alone for the measurement of utilization of maternal health care. As such, the amount of ANC, i.e., a total of four ANC visits adjusted for gestational length has been adopted as the variable to measure utilization of maternal health care, in this study. This measure derives from the WHO model of ANC for normal pregnancies[333].

In the first step, this model separates pregnant women requiring routine ANC from those requiring specialized care. It then makes the following recommendations for a normal pregnancy regarding the timing of initiation of care and number of visits.

- Initiation of care and periodicity of visits including the first visit preferably before week 12, second visit close to 26 weeks, third visit around week 32 and fourth visit between weeks 36-38.
- A minimum of four ANC visits are recommended for normal pregnancies requiring routine care.

Such a model of focused ANC following a standardized risk assessment, emphasizes assessing the mother's health status, early detection and treatment of diseases, screening for anemia and HIV and AIDS and prevention of low birth-weight, providing counseling related to nutrition, STIs, HIV and AIDS, healthy pregnancy and safe delivery, providing tetanus immunization, malaria prophylaxis, iron and folic acid tablets, and helping women select a trained birth attendant or institution to deliver their babies. As such, health prevention and promotion including screening, testing, counseling, immunization, and preventive medication, as well as emergency and complicatedness preparedness are important components of the package of care [362].

3.6. ACCESSIBILITY OF VULNERABLE POPULATIONS TO HEALTH CARE & METHODOLOGICAL ISSUES RELATED TO RESEARCH ON ACCESS WITH VULNERABLE POPULATIONS

In the context of accessibility to health care, vulnerable populations have been identified either as those in need of medical care, having a disability, being limited in functioning [328], or embodying population characteristics that signal deficits in social and ecological resources and supports[275, 363-366] required to protect oneself from harm following exposure to health risks[367].

There is increasing evidence that socially vulnerable populations disproportionately experience risk exposures to their health arising from poor access to health care among other factors[314, 368, 369]. The socially vulnerable often also experience vulnerability in relation to the health care system through barriers to accessibility, neglect and unequal access to resources within the health system, and compromised patient autonomy[302]. Vulnerability hinders accessibility to health care[370] while potentially also being a consequence of poor accessibility.

Populations who disproportionately experience access problems resulting in avoidance, delays and non-utilization of health care include: the homeless[371]; the elderly[372-376]; non-citizens like refugees, asylum seekers and migrants especially undocumented migrants[140, 221, 270, 276, 306, 310, 377-387]; sex workers[388]; incarcerated populations[140, 389-392]; people with mental illnesses, disabilities and chronic illnesses; racial and ethnic minorities[393-397]; sexual minorities; and, the medically uninsured[190, 373, 398]. Rural populations also experience several hardships in relation to access to health care, especially those with special medical needs[399-404].

Refugees and asylum seekers experience barriers similar to other non-citizens when accessing health care including: (i) language barriers[233, 276, 305-307, 309, 310]; (ii) information barriers[233, 305, 306, 309]; (iii) financial barriers[233, 276, 306]; (iv) transport barriers[305, 306, 310]; (v) acculturation difficulties and cultural barriers[276, 306, 307, 310, 405]; (vi) difficulties leaving work and lack of time[378], and (vii) lack of knowledge of the health system and benefits they can avail[18]; and (viii) perceived discrimination[56]. Additionally, asylum seekers, like undocumented migrants, often face legal restrictions when accessing health care[140, 305, 316, 406, 407]. They are also known to mistrust/fear the medical system arising from a concern that they might be arrested/deported and/or that a health problem might affect their residency status and employment opportunities[18, 276, 306, 309, 311, 408].

Two conditions need to be met in measuring the access to health care of vulnerable populations: (i) vulnerable populations need to be identified; and (ii) appropriate measures of access need to be used to capture their unique vulnerability contexts. Identifying vulnerable populations is often problematic because of the lack of social visibility of this population which is often related to their stigmatized and illegal behavior(s) and identity and the absence of a sampling frame[409, 410]; although innovative approaches such as Respondent Driven Sampling (RDS), Time-Space based sampling among others are being attempted and adapted to circumvent challenges posed to randomly sampling such populations[410-413]. Such methodological problems are also true of refugee and asylum seeking populations, an issue which will be discussed later in this dissertation.

3.7. WHAT IS "ACCESS?"- SUMMARY

In summary, access is a multi-dimensional and dynamic phenomenon involving interactions between the person seeking care, the health care system, and the context in which the person and the health care system are located. This conceptual complexity makes it difficult to measure access (i) directly; and (ii) using single summary measures.

Refugees and asylum seekers constitute a vulnerable population. Empirical studies provide evidence on the numerous barriers this population experiences in accessing care in general.

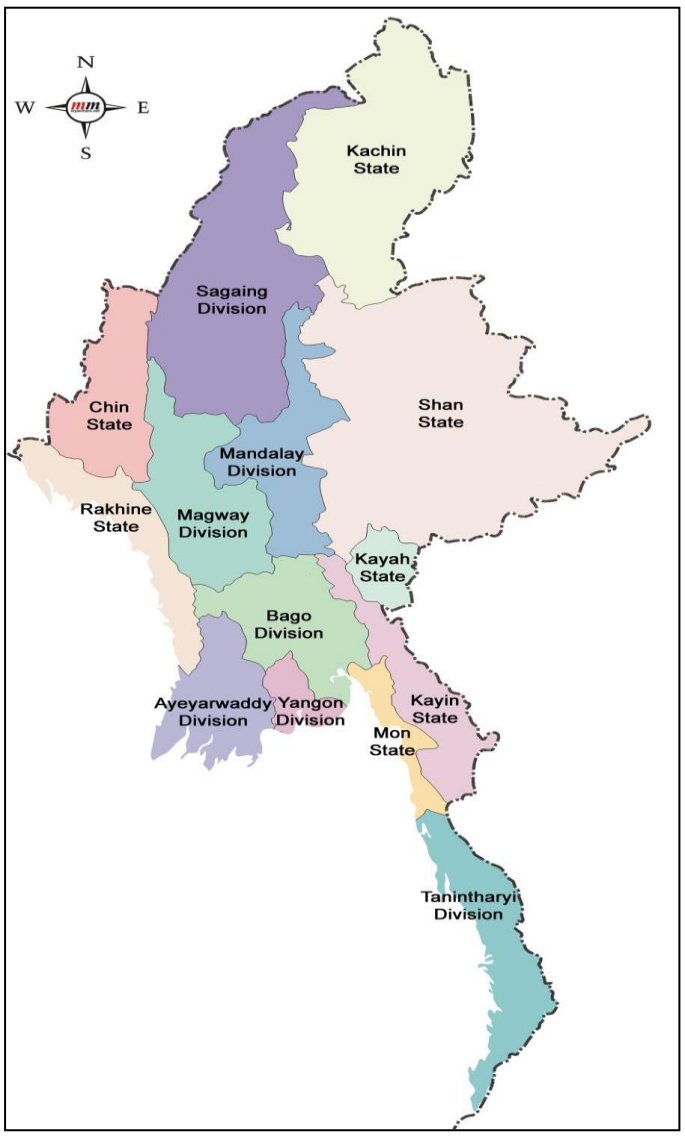
Most empirical studies on access to date have used health service utilization measures and satisfaction scores which are considered outcomes of access. These measures are not very useful for vulnerable populations like refugees and asylum seekers who are known to avoid, delay, or not utilize health care services.

Barriers to accessibility which are an important dimension in the negotiation of care for vulnerable populations like refugees have greater relevance for the measurement of accessibility of this population. There is increasing recognition of the need to develop new measures to assess barriers to access.

With consistent empirical groundedness, the right to health approach provides a sound conceptual and theoretical framework for examining barriers to care especially for disadvantaged populations. This is especially true when this framework is combined with measures of access borrowed from various domains of public health including those outside of access studies.

CHAPTER 4: THE RESEARCH CONTEXT - CHIN AND ROHINGYA REFUGEES IN BURMA AND MALAYSIA

FIGURE 1: MAP OF BURMA



SOURCE: http://www.myanmars.net/myanmar-**map/myanm**

Having reviewed refugees and asylum seekers' problems to accessing maternal health services, and approaches to measuring their accessibility to and utilization of maternal; health services, in this chapter, I provide contextual details of the research. The first section (4.1) provides background information on the study population, specifically, their unique histories of displacement in Burma. The second section (4.2) provides background information on their country of exile, Malaysia, where I describe the protection environment and the access of refugees and asylum seekers to health care in general. In the third section (4.3) I discuss the significance of accessibility to health care in relation to Malaysia's achievement of its remarkable maternal health outcomes. I also review what is known about the reproductive and maternal health of non-citizens and refugees in the country.

4.1. BURMA: BACKGROUND AND CAUSES OF DISPLACEMENT OF CHINS AND ROHINGAYS

Burma is a very ethnically diverse country with over 135 ethnic groups and 100 dialects and languages spoken[414]. It is also ethnically fractured. Consequently, the country has endured one of the most dire forced migration crises globally.

South states that the conflict in the last few decades has spurned three types of forced migration: (i) armed conflict-induced displacement related to fighting and counter-insurgency operations, and/or related human and food insecurity; (ii) State-society conflict-induced displacement which occurred in the post armed conflict period and involves displacement related to development and military occupation; and (iii) livelihoods/vulnerability-induced displacement arising due to poor governance, limited opportunities for livelihood, change to cash economy, poor access to education, health care and services, and food insecurity. Chin state has been affected by armed-conflict induced displacement while Arakan state from where the Rohingya hail, has been affected by State-society conflict-induced displacement. Almost the entire country has been affected by livelihoods/vulnerability-induced displacement [415].

4.1.1. Displacement of Chins

The Chin, a Tibeto-Burmese nation/people composed of about six main groups (Aso, Cho (Sho), Khuami (M'ro), Laimi, Mizo (Lushai), and Zomi (Kuki)) which can be sub-divided into at least 60 different sub-groups including the Mara, and speaking more than 20 mutually distinct languages, live in the mountain ranges along Burma's western border into Mizoram in north-east India. About 90% of the Chin are Christian and are united through a common history, geographical homeland, traditional practices, religious faith, and ethnic identity [416].

Rapid militarization of Chin state since 1988 [416, 417] led to widespread human rights violations related to extrajudicial killings, arbitrary arrest and detention, military conscription, arbitrary taxes, and forced labor [416]. A population based assessment by Physicians for Human Rights[417] revealed a prevalence of forced labour in 91.9% of households whose members were forced to porter military supplies, sweep for landmines, labor as unpaid servants, build roads, and do hard labor. Other violations included torture of ethnic Chins, abduction and killing of civilians with

impunity, and coerced conscriptions of children under 15. State-sanctioned systematic rape, torture, and killing of ethnic Chin women at all times and places, especially by the military and without impunity, has also been reported. Consequently, the women were reported to have experienced unwanted pregnancies, vaginal infections and psychological trauma. In the absence of support systems in Burma and burdened by the stigma of rape, some women fled to India[418]. Further, systematic religious persecution of ethnic Chins included destruction of churches, replacement of crosses on mountains with Buddhist pagodas for which the Christian Chin had to supply labor and money, prohibition of construction of new churches, disruption of church services by the military and physical assault, abduction, torture and killing of church pastors by Burmese soldiers [419]. In addition, 43% met FANTA-2 (Food and Nutrition Technical Assistance II project) definitions for moderate to severe household hunger[417, 420].

Currently there are some 150,000 Chins are reported to be seeking refuge in India and Malaysia, and hundreds of thousands are estimated to have moved to other parts of Burma[416].

4.1.2. Displacement of Rohingyas

The Rohingya, identified by the United Nations as "Muslim Residents of Northern Rakhine State (NRS)"[421], are an ethnic, linguistic, and religious minority[422] living mainly in the three townships of Maungdaw, Buthidaung, and Rathedaung in northern Rakhine state (formerly known as Arakan state) in Burma[423]. They are Sunni Muslims who are ethnically linked to the Chittagongian Bengalis[422].

The UNHCR estimates that there are about 800,000 Muslim residents in NRS (otherwise known as the Rohingya)[421], comprising about 90% of the population in that area[423].

Chris Lewa, a leading expert on Rohingya issues, attributes the problems of the Rohingya to a series of systematic exclusions of this population from the nation building process post-independence, starting with the 1982 Citizenship law introduced by the military[422]. The Citizenship Law 1982 imposed by General Ne Win created three categories of people: (i) *citizens* or those belonging to one of the 135 national races or who could prove that their ancestors had lived in Burma before the

Anglo-Burmese war of 1824-25; (ii) *associate citizenship* which was given to those whose application for citizenship under the 1948 Act was pending on the date the Act came into force; and (iii) *naturalized citizenship* which was only given to those who could provide decisive proof of entry and residence before Burma's independence on 4 January 1948, who had proficiency in one of the national languages and whose children were born in Burma. The Rohingya could not meet the requirements of the new citizenship law[422]. Owing to this and a nationwide census in 1983 from which they were excluded[424], the Rohingya were neither counted as citizens not foreigners [422]. They were rendered stateless [424].

Lewa, other scholars, and international agencies opine that the deprivation of citizenship has enabled the government to unmoor a host of arbitrary, repressive, and restrictive administrative policies and practices against the Rohingya [421, 425-428]. These include policies requiring them to: (i) apply for permission and pay a fee to travel outside their village with the consequences that if they travel without permission or overstay their time pass, their names will be removed from the family list and/or they would be liable for prosecution under national security legislation; either of which would necessitate that they leave the country; (ii) apply for permission and pay a fee in order to marry, including a guarantee by the couple that they will not have more than two children; and (iii) register the birth of children against a fee; although since 1994 the issuance of birth certificates were stopped which exacerbated the problem of statelessness for the community. The Rohingya are also banned from employment in civil service and from studying medicine and engineering locally[422, 425, 426, 429].

Further, women and girls are systematically raped and are extremely vulnerable to human trafficking because of their lack of legal status[425]. Forced labor (including forced child labor) for the construction of border fences, roads, bridges and culverts and other army infrastructure, portering, maintenance of army camps, patrol duties at night, collection of logs, bamboo poles, and stones, and cultivation/ plantation work persists unabated even after the general elections in November 2010[430]. Access to education and health care is poor and they are discriminated against by the mostly Rakhine/Burmese staff at such places[422]. Other human rights violations include systematic violence and discrimination by the Burmese border military, known as the NaSaKa[431], extrajudicial killings, destruction of mosques or ordering them to be emptied, perpetrating violence directly on the Rohingyas or

provoking others to practice discrimination against them with the intent of forcing them to leave Burma[424]. Over the years, these human rights violations have led to waves of exodus of the Rohingya out of Burma.

Currently, about 200,000 Rohingyas are estimated to live in exile in Bangladesh in squalid conditions and under the constant threat of arrest and deportation[431], with tens of thousands seeking refuge in Malaysia and the Middle East [426].

4.2. MALAYSIA: CHIN AND ROHINGYA REFUGEES AND ASYLUM SEEKERS

TABLE 1: REFUGEES AND ASYLUM SEEKERS REGISTERED WITH UNHCR

Ethnic Group	Numbers (Adult and Children)	
Chin	32,535	
Rohingya	28,555	
Others	34,582	
Total	95,672	
Adult Male-Female Disaggregated Data		
	Male	**Female**
Chin	16,701	7,219
Rohingya	16,947	3,708
Source: UNHCR, Malaysia, 31 May, 2013		

In Malaysia, the Chin and the Rohingya communities are the largest ethnic categories of exiled populations from Burma. As of June 2013, Malaysia hosted an estimated 95,672 refugees and asylum-seekers that are registered with UNHCR in Malaysia; another 10,000 are as yet unregistered[432]. The breakdown of Chin and Rohingya refugees and asylum seekers is given in Table-1 .Malaysia's refugee population is one of the largest global case loads of urban refugees[6].

Malaysia is the other major destination of Chin refugees besides India. In recent years, problems in accessing UNHCR in India has prompted Chin refugees to move to Malaysia[433]. On other hand, there have been waves of Rohingya arrivals to Malaysia; starting in the late 1970's when the military offensives against the Rohingyas led to their massive exodus out of Burma, and later around 2006 following the Malaysian government's announcement to grant work/residence permits to this community. However, this move was aborted following allegations of fraud[434]. Nevertheless, the influx continues owing to the ongoing ethnic violence against them in Rakhine State [435], [436].

4.2.1. Protection Environment in Malaysia

Refugees and asylum seekers in Malaysia like the Chins and the Rohingyas lack legal status and rights contemporaneous with refugee status because the country is not a signatory to the 1951 UN Convention Relating to the Status of Refugees or its 1967 Protocol, although it is bound by international law on the principle of *non-refoulement,* a universally accepted principle of customary international law. The country has never had a system of adjudicating asylum claims, although it allowed UNHCR to operate for status determination during the arrival of Vietnamese refugees to Malaysia in the 1970's and 1980's [437]. Since 2001, it has ceased to make financial contributions to UNHCR's operations in Malaysia [437]. However, it has allowed UNHCR to continue its operations to the present day, albeit without a formal agreement; prompting international organizations to dub UNHCR's interventions with the government on behalf of refugees as "ad hoc" [8]. As registration with UNHCR does not confer legal immigration status, the majority of these populations remain in Malaysia in an irregular situation.

Thus, refugees and asylum seekers are subject to the provisions of the Immigration Act 1959/63 (Act 155), whereby any person who enters or remains in Malaysia illegally is liable to prosecution, which may result in detention, corporal punishment in the form of whipping, a fine, and/or deportation. In 2005, Malaysia legislated for the involvement of civilian groups (Malaysian Volunteer Corps, Ikatan Relawan Rakyat, RELA) to participate in immigration operations which were reported to be violent[274].

Refugees in Malaysia lack the formal right to work. The three major labor laws in Malaysia, i.e. the Employment Act 1955, the Trade Union Act 1959, and the Industrial Relations Act 1967 which cover only non-citizens with legal authorization to work/live in the country exclude refugees and asylum seekers from labor protections since they are deemed "illegal" under the immigration law.

Thus, the "illegal" status of refugees and asylum seekers in Malaysia poses many challenges to their protection and accessing of health care services[433].

4.2.2. Urban Refugees' Access to Health Care in Malaysia

Based on limited information available from NGOs and UNHCR's operational partners running health care services for refugees, mental health[438, 439], upper respiratory tract infections, rheumatic diseases, skin problems, gastritis, diabetes mellitus and hypertension [440] are some of the common health problems experienced by refugees in the country. But, refugees experience many problems in accessing health care [440].

The regulatory framework related to health care and non-citizens actively prevents the access of non-citizens including refugees and asylum seekers to public hospitals. Non-citizens in Malaysia are required to pay "foreigners rates" at government hospitals. There is quite a considerable difference in the user fees paid by citizens and non-citizens. For example, for outpatient treatment, citizens pay RM1 while non-citizens pay RM15. For deposits for admission into third class wards for maternity care, citizens pay RM15 while non-citizens (including foreign spouses of Malaysian men) pay RM800. See Table-2 for more details.

TABLE 2: WARD DEPOSIT CHARGES: CITIZENS AND NON-CITIZENS

Table1: WARD DEPOSIT[2] – HOSPITAL KUALA LUMPUR						
Ward Class	**Medical**		**Surgery**		**Maternity and O&G**	
	Citizen	**Non-Citizen**	**Citizen**	**Non-Citizen**	**Citizen**	**Non-Citizen**
First class	RM 700	RM 1400	RM 1100	RM 2200	RM 800	RM 1400
Second class	RM 200	RM 600	RM 400	RM 1000	RM 350	RM 1000
Third class	RM 20	RM 400	RM 30	RM 800	RM 15	RM 800
Source: Ward Deposit (cited June 16, 2013). Available from: http://www.hkl.gov.my/						

Following meetings between UNHCR and Ministry of Health (MoH) in June 2005, the latter agreed to provide UNHCR recognized refugees with a 50% discount on

[2] 1 USD = Malaysian Ringgit 3.2 approximately as on July 5, 2013. Available from: http://www.oanda.com/convert/classic

fees charged to foreigners at government hospitals[357]. However, this is also unaffordable for most refugees who are prohibited from formal employment in the country [440, 441]. Asylum seekers are denied access to discounted health care. At times, health care access at public hospitals is denied by enforcement and hospital authorities who are unaware of the MoH policy granting refugees a 50% discount off foreigner's rates. There are reported cases of refugees and asylum seekers who have been threatened with arrest by hospital authorities because of their inability to settle their hospital bills[442]. Others barriers to health care include language barriers and poor physical accessibility[440, 443]. In general, refugees and asylum seekers are said to be afraid to seek medical treatment for fear of arrest[9].

With regard to infectious diseases, MoH subsidizes the treatment for HIV and tuberculosis for registered refugees and allows Adherence Support Community Counselors (managed by an NGO) to facilitate translation for refugees from Burma seeking treatment for these two diseases at two State run hospitals in the Klang Valley[444].

4.3. MATERNAL HEALTH OUTCOMES IN MALAYSIA: SIGNIFICANCE OF ACCESS TO MATERNAL HEALTH SERVICES

Malaysia's success story in terms of maternal health outcomes has been widely recognized [445]. Strategies to reduce the maternal mortality ratio (MMR) from around 280 to 62 per 100,000 live births between 1957 and 2005[446] have been attributed to a multi-pronged strategy including strong political will, development of health infrastructure, increase in the quantity, quality and geographical distribution of skilled human resources, strengthening of referral mechanisms, and increase in institutional deliveries [447-449].

The rapid decline in maternal mortality is especially attributed to expanded access to an integrated package of maternal and child health services and ensuring that such efforts reached the poor[445, 447].

Reproductive and Maternal Health Context for Chin and Rohingya Refugees in Malaysia

In general, there has been little research on the maternal health outcomes of refugees and asylum seekers in Malaysia. The scant information available indicates

that refugees and asylum seekers may be experiencing a range of difficulties in accessing reproductive health services.

For example, a study conducted by UNHCR and the Women's Refugee Commission in 2011 revealed a contraceptive prevalence rate (CPR) of 34.2% for modern methods and 42.2% for any method in the study population, a paucity of accurate family planning information, and a reliance on community leaders, and peers for family planning and reproductive health information[450]. This could be because family planning services are only accessible to those with a refugee card. Asylum seekers do not have access to family planning services.

There are operational partners of UNHCR who help to facilitate health care services for refugees when accessing government services fails. Recently, one local NGO based in Kuala Lumpur began skeletal ANC services comprising a medical checkup. This service operates only on weekends for refugee and asylum seeking women. However, such NGO services are usually "minimally staffed and lack adequate funding to cover the cost of referrals for more serious cases"[451]. According to UNHCR, refugees' access to ANC in general, is wanting[444].

Undocumented women in detention including refugees have reported lack of care and poor living conditions which at times led to pregnancy loss[452].

A study by Zulkifli et al with migrant women in Sabah, Malaysia, attributes their late initiation of ANC partly to negative environments[453]. Another retrospective study of maternal deaths in Malaysia in the years 1995–1996 indicates that 21.4% of sudden maternal deaths accrued to immigrant women, mostly in East Malaysia[454, 454]. In a newspaper report, the State Health Director of Sabah, attributed the high maternal mortality in the state to undocumented migrants who do not seek ANC and arrive with complications at hospitals during the time of delivery when it is too late[455].

The stark contrast between citizens and non-citizens in maternal health outcomes and related accessibility to maternal health care is evidenced in Malaysia's Millennium Development Goals (MDG) progress reports. In 2005 Malaysia's MDG-5 report attributed 42.0% of all maternal deaths to non-Malaysian women, especially the undocumented, and cited limited access to maternal health services as the contributing factor[456]. The 2010 MDG report did not provide figures but stated that,

"Based on data from Sabah, the MMR [maternal mortality ratio] for immigrants is much higher than that of citizens. These are often undocumented immigrants of lower socio-economic status and with little education. They have high parity as they do not practice contraception. They do not receive antenatal care and often deliver in an unsafe environment, where deliveries are conducted by untrained birth attendants. These mothers present late with complications and have very poor outcomes"[457] (p.72-73). In contrast, the 2010 MDG attributed the long term decline in the aggregate MMR from 44 per 100,000 live births in 1991 to 27.3 in 2008 to "national commitment to improve maternal health, as reflected through the allocation of resources for health care; access to professional care during pregnancies and childbirth; and increasing access to quality family planning services and information" [457] (p.71).

4.4. THE RESEARCH CONTEXT - CHIN AND ROHINGYA REFUGEES IN BURMA AND MALAYSIA - SUMMARY

This chapter on the research context provided the contextual details of the displacement of the study population in Burma and the protection environment in Malaysia. The forced displacement of the Chin and the Rohingya people from Burma has been attributed to gross human rights violations associated with ethnic and religious persecution, militarization of ethnic minority dominated states, and development induced displacement. The ensuing human rights violations have led to an exodus of these populations to Burma's neighboring countries, including Malaysia. However, owing to the absence of a protection environment in Malaysia, they experience ongoing threats to their security and lack access to basic services, including to health care and maternal health care. In fact, the goal of the health care policy toward non-citizens is deter/limit their use of health services. The limited information available indicates that non-citizens including undocumented migrants and refugees have poor access to reproductive health services, which is said to contribute to their poor maternal health outcomes, particularly in the state of Sabah.

CHAPTER 5: RESEARCH DESIGN

In order to assess the access of Chin and Rohingya refugee and asylum seeking women in the Klang Valley to maternal health care, this study used both quantitative and qualitative methods. In this chapter, I outline the research design for the study and describe the data collection and data analysis methods.

In the first section of this chapter (5.1) I define the research purpose and questions. In the second section (5.2), I explain the conceptual framework of the study. In section three (5.3), I provide further details on the independent and dependent variables of the study. Specifically, I explain the operationalization of the dependent variables that were proposed in Chapter 3 to assess the four dimensions of access and utilization of maternal health care in this study. I also explain the rationale for the choice of the independent variables. In section four (5.4), I outline the quantitative and qualitative methods used in the study including the sampling and recruitment of respondents, tools used, data collection process, and challenges encountered. Section five (5.5) elaborates on the data analysis procedures. Lastly, in section six (5.6) I explore some of the ethical considerations related to this study.

5.1. RESEARCH PURPOSE AND QUESTIONS

Chin and Rohingya women refugees and asylum seekers as two contrasting categories of forced migration populations in terms of their profile, level of community organization, and access to community resources, present with differing predictors of access to maternal health services.

The Chins are well organized as a community, are better resourced, and have a higher third country resettlement rate compared to the Rohingyas. The Rohingyas, a stateless people in Burma, are less formally organized and as such may have less access to social capital and community resources. They have experienced the brunt of protracted exile in Malaysia because of lower resettlement rates. However, the refugee recognition rate of the Rohingyas is higher than that of the Chins.

5.1.1. Research Purpose

To ascertain the dimensions of access to and utilization of maternal health services of Chin and Rohingya women refugees and asylum seekers in the Klang Valley, in relation to their documentation status and ethnicity.

5.1.2. Research Questions

1. What is the relationship between **documentation status** (refugee/asylum seeker) and **ethnicity** (Chin/ Rohingya) of the study population to access to maternal health services in terms of (i) the **dimensions of access**, and, (ii) **utilization of maternal health services**?
2. What are the differences in the **patterns** and **levels of utilization** of maternal health services of Chin and Rohingya women refugees and asylum seekers in the Klang Valley?

5.2. CONCEPTUAL FRAMEWORK OF THE STUDY

According to Miles and Huberman, "A conceptual framework explains, either graphically or in narrative form [diagrams are much preferred], the main things to be studied - the key factors, constructs or variables - and the presumed relationships among them"[458](p. 18). A conceptual framework is an important research tool that defines the contours of the research, enables the researcher to make meaning of the findings, and facilitates consistency and clarity in the communication of the findings[459].

A conceptual framework using a human rights based approach seeks to understand: (i) barriers to non-fulfillment of rights; (ii) the extent to which rights are fulfilled; and (iii) actual/potential violation of rights[460, 461].

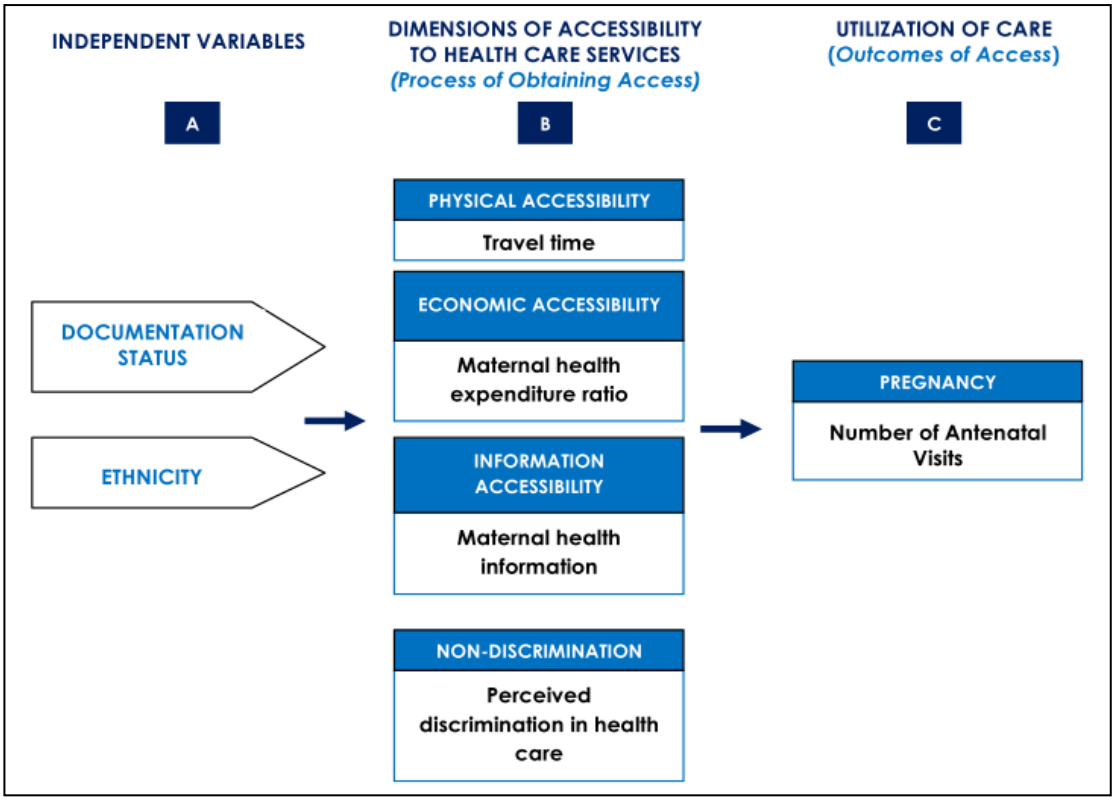
As such, the conceptual framework for access in this study comprises of three components and is reflected in Figure-2:

i. (A), which comprises the independent variables, documentation status and ethnicity
ii. (B), which constitutes the four interlinking dimensions of access according to the right to health approach which need to be satisfied to realize equal opportunity to a system of health care. It had been argued earlier that these

dimensions (non-discrimination, physical accessibility, economic accessibility, and information accessibility) correspond to psycho-social, spatial, financial, and information barriers in public health literature which need to be negotiated to access health care. Within a right to health approach they could be said to correspond to barriers to fulfillment of rights or actual/potential violation of rights;

iii. The utilization of maternal health services in (C), corresponds to examining the extent to which rights are fulfilled within a right to health approach. It also links with the widely held premise in public health that utilization of services is the validation of access.

FIGURE 2: CONCEPTUAL FRAMEWORK OF ACCESS TO MATERNAL HEALTH CARE SERVICES OF CHIN & ROHINGYA REFUGEES AND ASYLUM SEEKERS



Another view to the two components, B and C, is that the dimensions of access or (B) could be said to reflect the *process of obtaining access*, while utilization of care or (C) reflects the *outcomes of access*.

The assessment of access in this framework adopts the *personal health services* versus *health systems* or *population health* approach in public health. In terms of human rights, it adopts the approach of monitoring the individual *enjoyment of the*

right to health vis-à-vis an approach that monitors the extent to which the state has met its obligations, although it is recognized that these two approaches are not mutually exclusive.

5.3. DATA: OPERATIONALIZATION OF QUANTITATIVE VARIABLES TO ASSESS ACCESSIBILITY TO MATERNAL HEALTH SERVICES

5.3.1. Independent Variables

The choice of documentation status and ethnicity as independent variables (Component A in Figure-2) derives from the salience of legal status and ethnicity in urban refugee literature [24] where legal status determines the context of vulnerability, and, ethnicity offers social support and social capital to negotiate barriers to accessing services and resources[27]. The comparative effects of (i) being a refugee or an asylum seeker, and (ii) Chin or Rohingya, on accessibility to maternal health care are examined through the independent variables, documentation status and ethnicity respectively.

5.3.2. Dependent Variables: Dimensions of Access and Utilization of Maternal Health Care

The operationalization of the dependent variables of the study proposed in Chapter 3 are described below.

5.3.2.1. Non-Discrimination (Health services must be accessible to all especially the marginalized and vulnerable)

The variable used to assess non-discrimination is P*erceived Discrimination in Health Care* related to race. A dichotomized multi-item measure which had been previously successfully validated and implemented[338-340] was adapted to suit the situation of refugees in the Malaysian context. This adapted measure was used to assess the study population's self-reported perception of discrimination in health care based on race while obtaining ANC, delivery care, and PPC.

The adapted multi-item measure to assess *Perceived Discrimination in Health Care* related to racial identification asks whether the following events had ever taken place in a health care facility when the woman was obtaining ANC, delivery care, and PPC: (i) have you ever been treated with less courtesy than others because of

your race?; (ii) have you ever been called names because of your race?; (iii) have you ever been made to feel inferior because of your race?; (iv) have you ever been shouted at because you could not understand and speak the language?; (v) have you encountered nonverbal forms of discrimination like isolation/indifference because of your race?; (vi) were you ever talked to as if you were stupid or foolish because of your race?; and (vii) have you ever been ignored and not attended to because of your race?. Separately, respondents were also asked: (i) has a government health facility ever not accepted your UNHCR card?; (ii) have you ever been refused pregnancy, delivery or post-delivery care?. Perceived reasons for such treatment were also elicited.

Cronbach's alpha coefficient for the seven item measure of perceived discrimination in health care was 0.911.

5.3.2.2. Physical Access (Safe physical reach)

Physical accessibility was assessed using travel time. The reasons supporting travel time as a better indicator of physical access were discussed in Chapter 3. As such the respondents were asked the amount of time it took them to travel to a health facility to obtain ANC, delivery care, and PPC.

5.3.2.3. Economic Access (Affordability)

Economic Accessibility was measured by the ratio, *Maternal Health Expenditure Ratio* and is represented as:

$$\frac{\text{Total Maternal Health Expenditure}}{\text{Total Annual Family Expenditure less Food Costs} \,/\, (\mathbf{A}_h + \mathbf{0.5K}_h)^{0.75}} \times \mathbf{100}$$

where Total Maternal Health Expenditure includes the total cost for the most recent pregnancy, delivery, and post-delivery care per person. Total Maternal Health Expenditure in this study includes direct and indirect costs. Direct costs include consultation fees, user payments at public clinics and hospitals, costs of inpatient and outpatient care, and of drugs. Costs of traditional medicine were excluded. Only costs pertaining to institutional delivery were included. Indirect costs include costs of transportation and food/water costs for the day for the respondent seeking care and her companion.

Total Annual Family Expenditure Less Food Costs includes the non-discretionary expenses of the family in the corresponding year of total maternal health care cost. Family per adult equivalent expenditure is adjusted using the adult equivalence scale,$(A_h+0.5K_h)^{0.75}$ where A_h is the number of adults in the family h, and K_h is the number of children 0–14 years old. This scale and parameter values have been used in the Asian/Malaysian context previously (p.95)[462, 463].

5.3.2.4. Information Access (The right to seek, receive and impart information)

With regard to maternal health, the new WHO ANC model requiring only four visits for a normal pregnancy puts a premium on: (i) providing health information related to safe birth preparedness, complications/emergency preparedness, and health promotion; and (ii) obtaining health information through screening for health conditions that enhance risks and lead to negative maternal health outcomes [333].

Considering the importance of these factors above and based on the WHO recommended content of maternal health information that needs to be provided to and elicited from the pregnant woman[333], the *Maternal Health Information* tool was developed. This tool comprises of nine key maternal and child health information items provided to and obtained by the respondent from the health care provider in relation to pregnancy, labor, and post-delivery phases. The nine items in the *Maternal Health Information* measure are whether health care staff: (i) asked about medical history; (ii) gave advice/information about diet and nutrition; (iii) discussed the place of birth; (iv) gave information about recognizing the danger signs during pregnancy; (v) advised what to do if there is a problem during pregnancy such as bleeding, convulsions, fits; (vi) discussed child spacing and family planning; (vii) talked about sexually transmitted diseases, HIV and AIDS; (viii) gave information or advice on how to take care of the baby; and (ix) discussed how to get to the health facility if there was an emergency.

Cronbach's alpha coefficient for the nine item measure of maternal health information was 0.839.

5.3.2.5. Dependent Variables: Utilization of Care

The indicator for utilization of ANC is number of ANC visits made.

In keeping with the view that the measurement of access be linked to the required clinical content of care[191, 326, 328], the standards related to this indicator were guided by the recommendations in the WHO model of ANC[333] which comprises a minimum of four ANC visits for normal pregnancies (adjusted for length of gestation).

Although initially, there were plans to use institutional delivery as another indicator, it had to be dropped because of the small number of cases reported for those who had non-institutional (home) deliveries.

5.4. RESEARCH METHODS

This study utilizes a mixed methods approach using both quantitative and qualitative methods in data collection, analysis, and reporting of the study findings. A Concurrent Nested Design guided the study according to the typology of research designs featuring mixed methods of Creswell[464]. Qualitative data helps to explore the quantitative data in greater depth and the embedded qualitative method allows the study to address a different question than the dominant method[464].

5.4.1. Quantitative Method

5.4.1.1. Study Population

The quantitative research sample included UNHCR recognized refugees and self-identified asylum seekers (including UNHCR registered and unregistered asylum seekers) belonging to the Chin and Rohingya communities from Burma.

5.4.1.2. Inclusion Criteria

1. Women refugees and asylum seekers who identify themselves as Chin or Rohingya
2. Fit the official definition of refugees or self-identify themselves as asylum seekers
3. Reside in the Klang Valley
4. Pregnant respondents should be more than five months pregnant
5. Those who had recently delivered (in the past one year) in the Klang Valley
6. Are willing to participate in the study
7. Those who accessed maternal health care outside the Klang Valley

The exclusion criteria comprised of all conditions that were inconsistent with the inclusion criteria.

5.4.1.3. Sample

A review of literature on sampling techniques used in refugee research reveals that either random sampling on a large scale is initiated through epidemiological databases and governmental/health organizations or purposive sampling is applied to qualitative approaches. The problem with obtaining statistically representative samples of refugees is attributed to their lack of social visibility and hidden nature which excludes their enumeration in national data sets[66].

Such a problem with sampling frames also confronted this study. As such, snowball sampling was pursued.

While a non-probabilistic sampling strategy cannot assume and correct the selection biases like random sampling designs which are anchored in the rationale of probability theory, it can if "methodically and carefully executed … produce an empirically sound sample"[465](p.102). It can also allow the deduction of the extent to which findings from a sample are generalizable to the population of interest[466].

Aligning with other refugee research initiatives, this study too used multiple initiation points for the snowball chains, a small number of links, increased sample sizes as far possible, and attempted to achieve proportionate quotas for key variables in order to reduce selection bias and increase cross sectional representation in non-probability sampling[66].

In terms of quotas, reproductive age subgroup was the key variable used in determining the sample composition. The quota assigned to the different reproductive age subgroups (puberty to 49) of the study population attempted to reflect UNHCR statistics at the time of planning the research. See Table-3 for details.

TABLE 3: PROPORTION OF REPRODUCTIVE AGE SUB-GROUPS IN UNHCR STATISTICS AND IN THE STUDY SAMPLE (%)

Age Group	Chin Refugee		Chin Asylum Seeker		Rohingya Refugee		Rohingya Asylum Seeker	
	Research	UNHCR	Research	UNHCR	Research	UNHCR	Research	UNHCR
14 to 15	0.0	0.0	0.0	0.0	3.8	0.0	0.0	0.0
16 to 20	21.2	20.4	11.4	20.4	23.6	21.9	44.4	48.9
21 to 25	37.2	32.5	54.4	37.5	27.4	17.3	30.6	25
26 to 30	26.5	23.9	20.5	24.4	26.4	17.4	13.9	9.1
31 to 35	9.7	12.0	11.4	9.8	11.3	16.1	8.3	6.8
36 to 40	4.4	7.1	2.3	5.5	7.5	12.4	2.8	6.8
41 to 45	1.0	2.8	0.0	1.9	0.0	9.9	0.0	3.4
46 to 50	0.0	1.3	0.0	0.5	0.0	5.0	0.0	0.0
Total	**(n) %**	**(n) %**	**(n) %**	**(n) %**	**(n) %**	**(n) %**	**(n) %**	**(n) %**
Total	**(113) 100.0**	**5850(100.0)**	**(88) 100.0**	**(911)100.0**	**(106)100.0**	**(2160) 100.0**	**(36) 100.0**	**(88) 100.0**

Source: UNHCR statistics at 27.10.2009

Other variables aimed to provide representation included geographical location and whether they had just delivered or were pregnant. In addition, for the Chin, attempts were made to have a mix of the Zomi and the Lai, the main sub-ethnic groups living in Malaysia. For the Rohingyas, diversity in sample composition was sought out by recruiting a mix of the different types of Rohingya women in Malaysia: (i) those who were born and raised in Malaysia; (ii) those who had come to Malaysia in the last 5-10 years; (iii) newcomers who had come from Burma; and (iv) newcomers who came from the refugee camps in Bangladesh. Newcomers were defined as those who had lived in Malaysia between 5 months to a year (a minimum of five months of pregnancy being the inclusion criteria for those who were pregnant).

The proposed (dictated by the availability [or lack] of resources) and realized quantitative research sample size and composition are given in Table-4. The numbers of UNHCR registered Chin and Rohingya women refugees and asylum seekers at the time of planning the research are given in Table-5. This study included asylum seekers who were both, registered and unregistered with UNHCR. The discrepancy in the planned and realized numbers and composition was because of a change in UNHCR's registration policy. Following a brief intensive mobile exercise including a simultaneous process of asylum claim registration and refugee recognition, there was a sudden drop in the numbers of asylum seekers by the time the data collection began. As such, it was difficult to find even unregistered asylum seekers.

TABLE 4: PROPOSED AND REALIZED SAMPLE SIZE AND COMPOSITION

	REFUGEE		ASYLUM SEEKER		TOTAL	
	PLANNED	REALIZED	PLANNED	REALIZED	PLANNED	REALIZED
CHIN	100	113	100	88	200	201
ROHINGYA	100	106	100	36	200	142
TOTAL	**200**	**219**	**200**	**124**	**400**	**343**

TABLE 5: CHIN AND ROHINGYA WOMEN REFUGEES AND ASYLUM SEEKERS REGISTERED WITH UNHCR@ 27-10-09

	CHIN	ROHINGYA
REFUGEES	5850	2160
REGISTERED ASYLUM SEEKERS	91	88
Source: UNHCR, Kuala Lumpur		

Overall, refusal rates were very low. Only one woman from the Rohingya community refused to participate in the study. She was a single unmarried mother and may have assumed that participation in the survey would require her to disclose details she was did not want to.

5.4.1.4. Recruitment of Study Participants

Recruitment: Chin

The recruitment of Chin refugees and asylum seekers was done with the support of the Alliance of Chin Refugees (ACR), an umbrella body of 17 sub-ethnic Chin groups, with a membership of more than 40,000 members. See Appendix-7A for details of ACR.

Following discussions on the membership details and database (more than 40,000 members) of ACR, 3000 random numbers were generated from an online random number generator and given to the leader of the Chin organization. The organization was requested to recruit 200 study participants. Towards this end, ACR appointed a Chin woman volunteer with the organization to make phone calls to their members according to the numbers generated, to ascertain their appropriateness as per the study's inclusion/exclusion criteria, and their willingness to participate in the study. The woman volunteer was briefed on the ethics of consent and confidentiality prior to making the phone calls to potential respondents. The woman volunteer contacted potential study participants by telephone and set up interviews at a time and place preferred by the respondent, if she agreed to take part in the study. There

were no issues with the recruitment of refugees. But, by the time the 33rd asylum seeker was recruited, snowball and purposive sampling had to be used because it became impossible to locate asylum seekers fitting the inclusion criteria. Multiple snowball chains were initiated directly through the various affiliate groups of the main Chin organization, Protestant and Catholic Chin fellowships, Malaysian faith based organizations working with Chin refugees, and the Chin women we had interviewed. On the whole, it was not possible to recruit the planned number of asylum seekers even through these multiple snowball chains.

Geographical representation during recruitment focused on areas with a high density of the Chin population, namely, Pudu, Kampong Pandan, Cheras, Subang, and Kepong.

Recruitment: Rohingya

The recruitment of Rohingya refugees and asylum seekers was done with the support of the Rohingya Society of Malaysia (RSM). See Appendix-7B for details of RSM.

Although RSM did have a membership database, this was limited to its members in a few locations. Moreover, Rohingya community organizations operate differently from the Chin organizations. While the smaller sub-ethnic Chin organizations have come together under two umbrella bodies, individual Rohingya groups functioned autonomously. Additionally, each housing estate with a high density of Rohingyas had their own formal and informal local leader(s). The research team (researcher and RAs) then directly contacted other formal and informal leaders in areas where RSM did not have a base.

One again, with resource constraints in mind, housing estates with a high density of Rohingyas were selected in Klang, Ampang, Gombak, Cheras, Puchong, and Selayang. With the help of these formal and informal community leaders in these housing estates, Rohingya families were identified and mapped. In two different areas, we enlisted the help of two Rohingya petty traders who sold bread and dry snacks on motorbikes in these areas every day. These two petty traders assisted us in mapping the Rohingya families in these two areas. Following the identification and mapping in an area, if families had a female member who fit the inclusion

criteria, they were invited to participate in the study. The RAs who were already working in the Rohingyas community initiated the recruitment exercise.

In addition, recruitment efforts for Rohingya asylum seekers were made through multiple snowball chains by asking the various women we had interviewed if they had friends in other parts of the Klang Valley who fit the inclusion criteria. Further, the research team tagged on to a major immunization drive taking place for Rohingya children in different parts of the Klang Valley in a bid to reach Rohingya asylum seeking women. NGOs working with Rohingyas were also contacted for support in recruitment. In spite of these various efforts, the numbers of asylum seeking respondents that could be recruited fell far below the anticipated number.

5.4.1.5. Community Research Assistants (RAs)

Prior to the data collection, community research assistants (RAs) were recruited. Attention was paid to heterogeneity and specificity in refugee community characteristics during the selection of the RAs[467]. To minimize bias in the information gathered and in the role of community gatekeepers[467], a wide net was cast in identifying and recruiting the RAs, drawing on contacts among refugee community organizations, UNHCR, refugee church groups, NGOs with refugee staff, and personal contacts.

Six RAs were recruited. Three of them were community health workers with experience of working with local NGOs and UNHCR; and one of these two women was a trained nurse with about 20 years of work experience in Malaysia. Two others were unpaid voluntary community workers with the Chin refugee organization. Another was a community school teacher. Five of them had tertiary qualifications and were fluent in Burmese and English. The sixth was fluent in Burmese and Bahasa Malaysia. The Chin RAs also spoke some of the predominant dialects of the Chins.

Three trainings were organized for the RAs. The report of the first training which was conducted in Monash University and has been provided in Appendix-3 as an example, to throw light on the formation of the RAs. Two more similar trainings were conducted. In addition, there were several refresher sessions prior to field visits for

data collection which emphasized aspects of the questionnaire and ethics of the research.

5.4.1.6. Tools

Data for the survey was acquired through a (i) standardized questionnaire; and (ii) the Rekod Kesihatan Ibu (RKI) or maternal health record.

- *Questionnaire*

A structured questionnaire with closed and open ended questions was developed to capture the bulk of the quantitative data. The questionnaire (given in Appendix-4A) comprised of the following sections:

1. Section 1 – Demographic data.
2. Section 2:1 – Pregnancy history.
3. Section 2:2 – Utilization of care for those currently pregnant.
4. Section 2:3 – Utilization of care for those who had recently delivered.
5. Section 3 – Physical accessibility, which obtained information about travel time, mode of transportation and fears and security threats experienced during travel.
6. Section 4 – Economic accessibility, which elicited information on family income and expenditure, maternal health care expenditure, and sources of financing of maternal health care expenditure.
7. Section 5 – Information accessibility, which asked if nine key maternal and child health information items were provided to and obtained by the respondent from the health care provider in relation to pregnancy, labor and post-delivery phases
8. Section 6 – Non-discrimination, which sought information on self-reported perception of discrimination in the health care setting based on race, while obtaining ANC, delivery care and PPC
9. Section 7 – Social support, which elicited information on sources of social support available, frequency of availability of such support, and kind of social support provided by refugee community organizations.
10. Section 8, which sought feedback related to the general experience of physical accessibility, economic accessibility, information accessibility and nondiscrimination with regard to ANC, delivery care & PPC.

Cognizant of issues of language and communication in research with immigrant populations[468, 469], the questionnaire development adopted the translation/back-translation technique[470]. The development of the English language questionnaire used Brislin's (as cited in Geisinger[468]) recommended rules for successful translation like, short simple sentences, active words, using specific rather than general terms, avoiding sentences with two verbs suggesting different actions, and using words that translators are familiar with among others.

The original questionnaire in English was translated into Burmese by a Community Health Worker attached to UNHCR whose specific task in UNHCR included the development of Burmese health information materials and translation of health information materials to Burmese for the agency. The questionnaire was then verified by a bilingual expert (a medical educator) who was proficient in English and Burmese in keeping with the requirements of language and content competency in the translation of research instruments[468, 471]. This person made changes to two terms related to pregnancy and obstetric history. It was then back translated into English by another bilingual health professional. A comparison of the back translated and original version of the questionnaire revealed minor changes; for example the word "spouse" was replaced with "husband", "aid" was replaced with "support".

The questionnaire was pre-tested via multiple iterations with four groups of refugees and asylum seekers fitting the profile of the proposed study participants before it was finalized. It was tested for cultural sensitivity, appropriate use of language, duration of the interview, and to check if the tool was capturing the desired information. The participants in the four groups offered feedback in terms of adding extra questions or re-phrasing existing questions, e.g.: (i) change of terminology regarding documentation status, i.e. to use the words "have a UNHCR card" for refugees and "have a UNHCR letter" for asylum seekers; (ii) add a category called the "undocumented" for asylum seekers who were waiting for their turn to file their asylum claims with UNHCR; (iii) add a category, "do not want to be employed", in the question on employment, for those who chose to stay at home and take care of their children; and (iv) add a question to elicit feedback on feelings of safety when travelling to obtain maternal health care.

The final Burmese version was again verified by the bilingual medical educator for accuracy and linguistic equivalence.

The questionnaires used during the pilot testing phase were not included in the final analysis and none of those who participated in the testing of the instrument were included in the sample population.

- *Rekod Kesihantan Ibu (RKI)*

With the consent of the study participants, the RKI was photocopied prior to administering the questionnaire. The RKI was ignored only for pregnant women who had not in initiated ANC by the day of the interview, or women who delivered and had not obtained ANC.

Data in the RKI included risk factors during pregnancy, past pregnancy history, timing of initiation of care, and number of visits.

In relation to past termination of pregnancy, there were differences in many cases between the recorded history in the RKI and self-reports of the women. Although the women attributed it to language and communication problems, it is possible that the sensitivity of the information prevented them from disclosing this to the health care providers. In such cases, the self-report was considered rather than the written information in the RKI.

Almost all women had their user fee receipts stapled to their RKIs (usually done by the staff at the maternal health clinic) and in almost all the cases the number of receipts tallied with the number of visits in the RKI. Almost all women who had delivered also had their hospital inpatient fee receipts stapled to their RKI along with the discharge note (reportedly done by the hospital staff) which had details about the delivery, including place of delivery, induction of labor, normal/complicated delivery, and weight and gender of the child; the last item was ignored in this research. This allowed for cross checking the records with self-reports on place of delivery and cost of delivery, although there are standard fees for refugees and asylum seekers respectively for normal deliveries.

5.4.1.7. Data Collection

Most Chin respondents preferred to meet the researcher at their neighborhood organizational office, school, or church. Thus, the woman volunteer of the Chin refugee organization who contacted potential respondents also arranged the logistics of implementing the survey in schools, churches, and offices belonging to the affiliates of ACR. Batches of respondents were invited to participate in the survey during separate time slots according to their area of residence. The ample space made available by the community organizations and organizing the survey in batches according to specific and separate time slots, capped the number of interviewees at any one time and ensured privacy between participant and the community research assistants during the data collection. However, because most women came with their babies or older children who demanded their mother's attention, the research process had to accommodate these realities. I carried food, toys, coloring materials, and paper on every field visit and often helped to take care of the children while their mothers were administered the survey.

The survey for the Rohingyas was conducted in their homes. Many of the Rohingyas shared houses with other families. Given the differences in the cultural context of the Rohingyas and the Chin, the research team spent considerable time building rapport with the families of the Rohingya respondents before the interview took place. If women were unsure about whether their husbands would appreciate their participation in the study, we ensured that we met the husband, explained the research to him and got his approval to proceed with the interview. Considerable time was spent building confidence with the husband and family of the woman in order to be able to interview the woman in private. Almost all the women took us to their bedrooms to be interviewed. If there was no one in the house at the time of the interview, we used the living room. The walls of some of the rooms were made of wood in several cases and we had to speak softly to maintain privacy and confidentiality. Most often, the husbands did not object to our request to interview their wives in private because they saw maternal health as a "woman's issue" and probably did not find it threatening. As in the case of the Chin, the research process had to accommodate the needs of small children seeking their mothers' attention during the interview process.

For both communities, the women showed eagerness to speak and share beyond the questions we asked. Many of them asked us not to forget them and to return to visit them.

Since the Kesihatan Ibu (RKI) or maternal health record was one of the tools of data acquisition, both Chin and Rohingya respondents were informed that the survey could only be administered if they had their RKI. A day before the survey they were once again reminded to bring their RKI or have it ready if we were visiting them.

I was present for the majority of the data collection events and was on hand to address queries from the research assistants if necessary. If I was present, I checked every survey form for completeness and accuracy (checking it also against the RKI) before the respondent left.

If I did not accompany the RAs, they only administered five questionnaires after which they had to bring back the questionnaires to me. I then checked the questionnaires for completeness and cross checked self-reports with the RKI. This procedure was initiated for quality control purposes.

After every data collection exercise, I updated the profile of the overall sample I had acquired and recalibrated the recruitment strategy to obtain the most representative sample through future data collection efforts, based on the sample characteristics identified earlier. When I had acquired an appropriate and adequate sub-sample, I discontinued further data collection.

My grass roots work with the refugee community and the role of some of my community research assistants as health workers and community volunteers was definitely an advantage in building trust and confidence with the study participants and their families. However, owing to this, I was always careful to emphasize that this endeavor was unrelated to my organizational role and to UNHCR's refugee recognition process.

5.4.2. Qualitative Method

Qualitative data provides complementarity to quantitative data by describing and explaining relationships and variations[472], and clarifying conceptions of findings[473]. It

also helps to bring to the foreground the context of the evidence, thus allowing for a holistic consideration of all available evidence to improve public health[473].

In this study design, the quantitative data from the survey was complemented by qualitative data (QUAN → qual). The objective of the complementary qualitative research was to increase the appreciation of the context of accessibility of the study population to maternal health services. This objective is consistent with evidence highlighting the specific importance of context in mediating the access of women in low and middle income countries (LMICs) to ANC[362], and the recognition of the role of qualitative research in providing insights about specific contexts mediating maternal health care[474].

Data sources for the qualitative data include (i) in-depth interviews; and (ii) data from the Rekod Kesihatan Ibu which was qualitatively analyzed.

The methodological rationale of in-depth interviews includes its ability to maintain the topical focus of the interview while allowing the exploration of other related topics that might not have occurred to the interviewer. This provides a "rich, deep and textured picture" which is "locally produced in and through the 'simple' method of producing topic-initiating questions"[475] (p. 315).

5.4.2.1. Study population

- *In-Depth Interviews*

The sampling approach was iterative. Although initially the plan was to purposively draw a sample that was representative of ethnicity and documentation status, developments enfolding as the survey progressed led to a different approach. Firstly, the survey yielded a very small number of cases for those who did not obtain ANC and had non-institutional (home) deliveries, making statistical analyses difficult. A non-institutional delivery is a very rare phenomenon in Malaysia given the advances made in its maternal health services. Most cases of non-utilization of ANC and all cases of non-utilization of an institutional delivery were only found in the Rohingya community. Additionally, it was also very difficult to recruit Rohingya participants for the survey because of the small number of Rohingya women in the Klang Valley, especially those meeting the inclusion criteria.

Given these considerations, there was a need to address the knowledge gaps emerging in the quantitative component of the study in relation to (i) those who did not utilize care and/or under-utilized care in relation to ANC and delivery; and (ii) the Rohingyas who were under-represented in the survey. As such, the qualitative research sampling strategy utilizing purposive sampling was adapted to include those respondents who had in the survey demonstrated the following patterns of utilization of care: (i) delayed care; (ii) non-utilization of care; and (iii) the use of emergency care because of (i) and (ii). This also allowed Rohingya respondents to receive a greater focus in the selection of respondents for the qualitative research. This approach is consistent with the right to health orientation of this study demanding attention for neglected and disadvantaged groups[268], those experiencing inequalities, and those who are hard to reach. In all, 10 in-depth interviews were conducted. The profiles of the 10 in-depth interview respondents are given below.

TABLE 6: PROFILES OF IN-DEPTH INTERVIEW RESPONDENTS

RESPONDENT	PATTERN OF UTILIZATION OF CARE	CONSEQUENCE OF PATTERN OF UTILIZATION OF CARE	ETHNICITY	DOCUMENTATION STATUS
IDI-1	• Non – utilization of ANC • Home delivery		Rohingya	Refugee but undocumented at the time of pregnancy and delivery because her UNHCR card had been robbed in a snatch theft incident
IDI-2	• Non – utilization of ANC • Home delivery • No PPC • No immunization for child		Rohingya	Asylum Seeker
IDI-3	• Non – utilization of ANC • Home delivery • No PPC • No immunization for child		Rohingya	Asylum Seeker
IDI-4	• Non – utilization of care • Home delivery		Rohingya	Refugee
IDI-5	• Birth before arrival & delayed care • Use of emergency care	Delivered on the road	Rohingya	Refugee
IDI-6	• Birth before arrival & delayed care • Use of emergency care	Delivered on the road	Rohingya	Refugee
IDI-7	• Irregular/underutilization of care		Rohingya	Asylum Seeker

RESPONDENT	PATTERN OF UTILIZATION OF CARE	CONSEQUENCE OF PATTERN OF UTILIZATION OF CARE	ETHNICITY	DOCUMENTATION STATUS
IDI-8	• Non – utilization of care	• Hemorrhaged during pregnancy • Use of emergency care	Chin	Asylum Seeker
IDI-9	Delayed initiation of ANC		Chin	Asylum seeker pending registration (undocumented)
IDI-10	Delayed initiation of ANC		Rohingya	Asylum seeker pending registration (undocumented)

Rekod Kesihatan Ibu

In addition, the Rekod Kesihatan Ibu (maternal health record) of 18 respondents who had used only private and/or NGO ANC was analyzed qualitatively for the type of care obtained. This was because the survey had shown that those who had solely utilized private and/or NGO ANC had obtained less than adequate care, which was linked to access problems. Once again, the objective of unravelling the exclusions in accessing care, prompted this analysis.

5.4.2.2. Recruitment

As described in 5.4.2.1. the three categories of respondents who had experienced negative patterns of maternal health care utilization were contacted during the implementation of the survey and asked if they would like to participate in an in-depth interview.

5.4.2.3. Tool

An in-depth interview guide (given in Appendix – 5A) was used to obtain narratives of participants' experiences with access problems. The in-depth interview guide was pre-tested.

Although open-ended questions on the following topics were explored during the interview, it was iteratively adapted as the situation demanded.

i. Forced migration history
ii. Nature of access problems related to maternal health and coping strategies

iii. Perceived functional social support in relation to access to maternal health care. Functional support is a subjective dimension of perceived social support[476], with the most commonly cited forms of functional support being: (i) emotional support; (ii) instrumental/tangible support; (iii) information support and guidance; (iv) appraisal support related to self-evaluation; and (v) social companionship[239]. Perceived availability of functional support is generally preferred to realized support, which is confounded with need[239] and which corresponds better to wellbeing[477]. Given the role of ethnic enclaves and refugee networks in facilitating the access of urban refugees and asylum seekers to resource[24], ethnicity was explored in terms of the social support offered in facilitating access to maternal health care.

5.4.2.4. Data Collection

A community research assistant supported the interview process by translating. Training was conducted with the community research assistant to explain the differences between translation and interpretation, and to reinforce the issues of research ethics, especially of confidentiality.

The interviews were audio taped with the consent of the respondent. The interviews lasted about an hour for most respondents. For some of the respondents, I returned to do follow up interviews.

PROBLEMS IN DATA COLLECTION

The data collection took almost a year (2010) because of several problems. Firstly, UNHCR's mobile registration exercise which began shortly before data collection started, reduced the numbers of asylum seekers. Recruiting asylum seekers was a very labor intensive process. There were days I drove for more than 100 Kms just to administer three or four questionnaires.

Secondly, three of my RAs who had been unemployed in 2009 when I initiated discussions with them, had all acquired jobs by the time the data collection began; allowing them to do the data collection only on weekends. The other three RAs were already employed full time when I had approached them. Given the importance of trust in working with hard to reach populations, and the competencies

and good standing of my RAs in the community, I elected to continue to work with them, albeit at a slower pace.

Thirdly, one key local level informal leader began to make demands for money without adequate assurance that logistical support would be forthcoming. While I sympathized with the dire situation that community leaders work in, I lacked the resources to accommodate such a request. Moreover, it would violate the parity in relationships that had been established with other local leaders. Hence, I decided to disengage with the person on the matter of the research. But this had to be managed constructively; which took time. In the end, we reached an agreement and the leader gave us the list of members in his residential area and allowed the data collection to continue without any hindrance. Two of my RAs contacted the residents by phone to check their appropriateness and willingness to participate in the research.

The other issue was that it took longer time to do the research with the Rohingya participants. Given the manner in which familial are spousal relationships are organized, it was imperative that trust was first built with the husbands and older women in the family (like mothers-in-law) before we interviewed the women. Often, one or two visits were made initially to build rapport before we were able to administer the questionnaire.

There were several times we had to cancel and re-schedule appointments to conduct the survey because there had either just been a raid by enforcement authorities and the refugees in the area had temporarily left the place, or because local leaders who were assisting us in organizing the logistics and participation of the women had to attend to urgent community matters.

Finally, given the stress of undertaking such an endeavor, I had to also keep track of my RAs to make sure that they well and well taken care of.

5.5. DATA ANALYSES

In this section, I detail the approaches to analyses of the quantitative and qualitative data.

5.5.1. Quantitative Data Analysis

The data from all 343 questionnaires were entered into a spreadsheet. The entered data was cross-checked and then imported into SPSS ver. 19 for Microsoft Windows. Frequencies of all the responses coded into the 255 variables were first taken to identify data entry and/or coding errors. Variables and cases where the values or scores fell outside the permitted or possible range of values were checked against the responses obtained in the questionnaires and the errors so identified were corrected. Once satisfied that coding errors were eliminated and the data was clean, outliers and skewness in the distribution of the data were treated through elimination and log-transformation and recoded as appropriate to the research questions. Care was taken to ensure that the log transformed variables were approximately normally distributed.

The data set was next subjected to systematic analysis using standard procedures. Univariate analysis was first carried out on the data set to understand the spread and nature of the data: descriptive statistics, frequency counts, measures of central tendency and measures of variability were obtained.

Bivariate analysis was next applied to explore the relationships between variables (independent and dependent), measures of association noted and the type, direction and strength of association were measured for variables of interest that revealed significant association (X^2, Fisher's exact test and Pearson's correlation). Two-sided p-value <0.05 was considered statistically significant.

Inferential analyses were conducted on variables that manifested significant association. T-test and ANOVA were applied to determine significant differences in various dimensions of access to maternal health care between the study groups (documentation status and ethnicity).

Regression analysis and logistic regression models, examining interaction effects were applied to variables that were significant in the inferential analysis. The enter method was used for the regression analyses.

5.5.2. Qualitative Data Analysis

I transcribed five of the interview recordings that had been done in Bahasa Malaysia (3), English (1), and a combination of English and Hindi (1).

A Chin research translator transcribed and translated one interview from Chin dialect, while a Burmese translator transcribed and translated four interviews done in English with Burmese translation. To ensure the quality and accuracy of the interviews and translation, the interviews were audio recorded, transcribed verbatim, and translated into English. Clear and detailed transcription instructions were given to the transcribers/translators to maintain the quality of the transcripts and anonymity of the data. A bilingual English-Burmese language expert reviewed the translated transcripts to verify the accuracy of the translation.

Thematic analysis, an accepted robust method for analyzing complex qualitative information[478], was used to analyze the qualitative data.

The six phases identified by Braun and Clarke[478] were followed in the analysis: (i) familiarisation with the data, (achieved through immersion in the data via repeated reading of the transcripts and note-taking); (ii) generating initial codes (using open coding inductively and axial coding deductively, with the right to health definition of access serving as the theoretical framework for deductive coding); (iii) searching for themes (merging codes into potential themes); (iv) reviewing themes (by ascertaining that the themes "work in relation to the coded extracts and the entire data set" [pg. 87]); (v) defining and naming themes (in relation to the "overall story" that the data tells [pg.87]); and (vi) producing the report.

Prevalence of a theme was recorded as an occurrence of the theme across the data set[478]. Themes were coded using the methods of "repetition" (themes recurring regularly in the text) and "constant comparison" (systematically searching for similarities and differences in the themes across the data set)[479].

The thematic analysis resulted in the identification of seven themes which are reported later in Chapter 7.

A case study approach was used for the presentation of the qualitative research findings. Such an approach was chosen because of its amenability to examining contextual issues where contextual conditions are very relevant to the phenomenon of the study[480]. As such, it provides a thematic lens to understanding the role of context in the study population's access to maternal health services, particularly those experiencing problems of accessibility.

5.6. ETHICAL CONSIDERATIONS

The study received clearance from the Monash University Human Research Ethics Committee (MUHREC). The research was explained to all participants both verbally and in writing through an explanatory statement, and written consent was obtained. Given my grass roots work with refugees, I was careful to explain at the start of every interview that I was doing this research in my personal capacity and participation in the research would not bring about any personal material advantages to participants in terms of UNHCR registration or any other benefit.

Since the recruitment of the participants had been done by a community volunteer attached to the refugee organization and/or formal/informal leader, participants were given another chance at the time of the interview to withdraw without consequences. This measure was to address problems arising from imbalances in power between them and *gate-keeping* entities and community leaders [467] who had recruited them earlier.

All participants were informed that they could pass over any question that they did not wish to answer and were free to withdraw from the study at any point in time without consequences.

The research presented some ethical problems during data collection. Three respondents (in separate situations) showed symptoms of slurred speech, forgetfulness, difficulty concentrating, and exhaustion variously. We found out that all three of them had not slept for several days prior to the interview. Although the women were keen on completing their survey, we suspended the administration of the questionnaire and told them that we would return at another time when they were feeling better. Two women took up our offer to help them explore the need for mental health assistance; which confirmed that they had clinical depression. Another woman accepted the offer; but when arrangements were made for her, we found out that she had left Kuala Lumpur for her home town (she had been born and raised in Malaysia).

Although the original view was that goals of reciprocity would established at the level of the community[481], it was difficult to ignore some of the problems encountered. With the consent of the women referrals were made when problems were detected.

For women who had delivered at home and had not received PPC, referrals were made for PPC checkups for the women and immunization for the children. Community health workers from my organization accompanied the women and the children and assisted them in negotiating the health system. One woman who had just delivered stated that the pregnancy had been the outcome of rape. Appropriate mental health and reproductive health interventions had been arranged for her as per UNHCR's guidelines for women who have experienced sexual and gender based violence. Vitamins, iron supplements and monetary assistance for delivery were facilitated by raising donations for two pregnant women; one who had just lost her husband in an accident a week before the interview, and another whose husband was in immigration detention. A referral was also made to UNHCR to expedite the release of the man in detention. Mental health help was facilitated for the woman who lost her husband. Although referrals for registration of births of babies whose mothers had delivered at home had been made, they were all unsuccessful because of legal barriers related to the issue. Proof of hospital records of ANC/birth are one of the imperatives which these women lacked.

Although my RAs often told me that listening to these stories was stressful and I was concerned about the impact of these events on them, they showed tremendous strength and resilience. Only one RA took up the offer of debriefing services that I had arranged for them.

CHAPTER 6: RESULTS-QUANTITATIVE

This chapter presents the findings of the quantitative research. In the first section (6.1), I present the study population characteristics. In the second to fifth sections (6.2 to 6.5), I present results related to the four dimensions of accessibility, namely, (i) non-discrimination; (ii) physical accessibility; (iii) economic accessibility; and (iv) information accessibility. The sixth section (6.6) covers results related to the utilization of care. Finally, I summarize the quantitative research findings in 6.7.

Before proceeding to the presentation of results, I would like to address some issues related to the analysis and findings.

The first pertains to Bonferroni adjustments. The Bonferroni correction is conventionally applied when a family of tests is conducted on the same data set assuming that all are testing a common null hypothesis. Since the present study was exploratory, the family of tests to be conducted was not pre-determined. For this analysis, I chose to treat each test independently with a view to gain insights into the effect of the study variables on the outcomes. A step-by-step approach was followed escalating the analysis (from simple bivariate analysis to inferential analysis and logistic regression models), where significant effects were observed. In an exploratory investigation such as this, it would be counterproductive to apply Bonferroni adjustments[482]. At best, the Bonferroni adjustments can be applied retrospectively. Thus, I did not purposively pursue Bonferroni adjustments. However, SPSS does make automatic Bonferroni corrections for pair wise comparisons of column proportions in cross tabulations[483]. Additionally, it also makes Bonferroni adjustments for one-way ANOVA and GLM Univariate analyses[483]. As such, the results related to cross tabulation, one way ANOVA and GLM Univariate analyses in the study are Bonferroni adjusted although these were not actively pursued.

The second relates to the measure for effect size associated with tests for difference between two groups, i.e. the R^2. Although the R^2 values in several of the analyses in

the study are discernibly low, the argument of Reidpath and colleagues that R^2 fails to capture cumulative effects [484] could well be applied here, if one were to assess the R^2 in this study in terms of its population level and long term effects.

6.1. STUDY POPULATION CHARACTERISTICS

6.1.1. Socio-Demographic Characteristics

In total, the data for the present analysis was obtained from 343 respondents.

TABLE 7: STUDY POPULATION-DISTRIBUTED BY ETHNICITY AND DOCUMENTATION STATUS

	CHIN		ROHINGYA		TOTAL	
	n	%	n	%	n	%
REFUGEE	113	56.2	106	74.6	219	63.8
ASYLUM SEEKER	88	43.8	36	25.4	124	36.2
TOTAL	201	100.0	142	100.0	343	100.0

The documentation status and ethnicity wise distribution of the sample population is given in Table-7.There were more refugees (*n* = 219) than asylum seekers (*n* = 124), and Chins (n=201) than Rohingyas (n=142) respondents.

The socio-demographic characteristics of the study participants are given in Table-8.The age of the respondents ranged from 14 years to 44 years with the mean age of the total study population and of both the groups being about 25years.This is also consistent with UNHCR data (see Table-3) that the majority of the women refugees and asylum seekers are between 20 to 30 years of age.

At the time of the study, the respondents had been living in Malaysia from anywhere between one month to 30 years. The mean period of living in Malaysia was significantly more for refugees (5.45, SD=6.18) than asylum seekers (M=1.73, SD=2.69) ;($t(323.639) = 7.576$, $p<0.001$),and for Rohingyas (M=7.45, SD=7.16) than Chins (M=1.80, SD=1.39);($t(148.500) = 9.287$, $p<0.001$).

Close to half the population had obtained primary education and a sizeable number had completed high school. The proportion of those with no formal education and primary education was higher for the Rohingyas than the Chins, while a higher proportion of Chins had completed secondary school, university and higher professional qualifications ($\chi^2=34.373$; $df=3$; $p<0.001$).

TABLE 8: SOCIO-DEMOGRAPHIC CHARACTERISTICS BY DOCUMENTATION STATUS AND ETHNICITY

	STUDY POPULATION		BY DOCUMENTATION STATUS				BY ETHNICITY			
			Refugee		Asylum Seeker		Chin		Rohingya	
N	**343**		**219**		**124**		**201**		**142**	
	N (SD)		**N (SD)**		**N (SD)**		**N (SD)**		**N (SD)**	
AGE										
Mean ± SD	25.04 (5.55)		25.19 (5.83)		24.79 (5.02)		25.30(5.18)		24.68 (6.03)	
Minimum	14		14		17		17		14	
Maximum	44		44		38		44		40	
LENGTH OF RESIDENCE (IN YEARS)										
Mean ± SD	4.13 (5.47)		5.45 (6.18)		1.73 (2.69)		1.80 (1.39)		7.45 (7.16)	
Minimum	0.1		0.1		0.2		0.2		0.1	
Maximum	30.0		30.0		24.0		12.5		30.0	
	n	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**
EDUCATION										
Primary	156	45.5	101	46.1	55	44.4	78	38.8	78	54.9
High school	117	34.1	71	32.4	46	37.1	92	45.8	25	17.6
University / Higher professional	11	3.2	5	2.3	6	4.8	8	4.0	3	2.1
No formal education	59	17.2	42	19.2	17	13.7	23	11.4	36	25.4
MARITAL STATUS										
Married	334	97.4	214	97.7	120	96.8	197	98.0	137	96.5
Divorced/ Widowed/ Single	9	2.6	5	2.3	4	3.2	4	2.0	5	3.5
EMPLOYMENT STATUS										
Part/full time employed	18	5.2	13	5.9	5	4.0	4	2.0	14	9.9
Unemployed	233	67.9	145	66.2	88	71.0	180	89.6	53	37.3
Do not want to work	92	26.8	61	27.9	31	25.0	17	8.5	75	52.8
SPOUSE'S EMPLOYMENT STATUS										
Employed	318	92.7	202	92.2	116	93.5	188	93.5	130	91.5
Unemployed	25	7.3	17	7.8	8	6.5	13	6.5	12	7.3
REFUGEE ORGANIZATION MEMBER										
Member	201	58.6	112	51.1	89	71.8	199	99.0	2	1.4
Non-Member	142	41.4	107	48.9	35	28.2	2	1.0	140	98.6

The overwhelming majority of the women in both categories (by documentation status and ethnicity) were married.

The majority of the respondents in both categories of documentation status and ethnicity were unemployed (out of work but seeking paid employment) while a substantial number did not want paid employment. A higher proportion of Rohingyas (9.9%) were employed part/full time than the Chins (2.0%), whereas a higher proportion of Chins (89.6%) were unemployed (those who have actively sought work but have been unable to find work) compared to Rohingyas (37.3%). A higher proportion of Rohingyas (52.8%) than Chins (8.5%) also chose not to work (χ^2=104.281; df=2; p<0.001).

Only a minority of the respondents' spouses were unemployed. There was no difference in the spousal employment status between the refugees and the asylum seekers and Chins and Rohingyas.

There were significantly more Chins who belonged to a refugee organization than Rohingyas (p<0.001, two-sided Fisher's exact test). Only two Chin respondents did not belong to a refugee organization whereas only two Rohingya respondents belonged to a refugee organization.

6.1.2. Maternal Characteristics

With regard to maternal characteristics, the following data had been solicited: (i) maternal age; (ii) gravidity; (iii) parity; and (iv) if the respondent had been pregnant or had recently delivered at the time of the interview. In both categories, the majority of the women had delivered recently at the time of the interview. See Figures 3 and 4 and Table-64 in Appendix-6 for the maternal characteristics of the study population.

In both categories, the majority of the study participants were between 20 to 29 years of age. The Rohingya group had almost twice as many teenage pregnancies in comparison to the Chin women, and there was a small difference in the distribution of advanced maternal age in the two ethnic groups (χ^2=16.88, df=3, p=0.001).

FIGURE 3: MATERNAL CHARACTERISTICS BY DOCUMENTATION STATUS

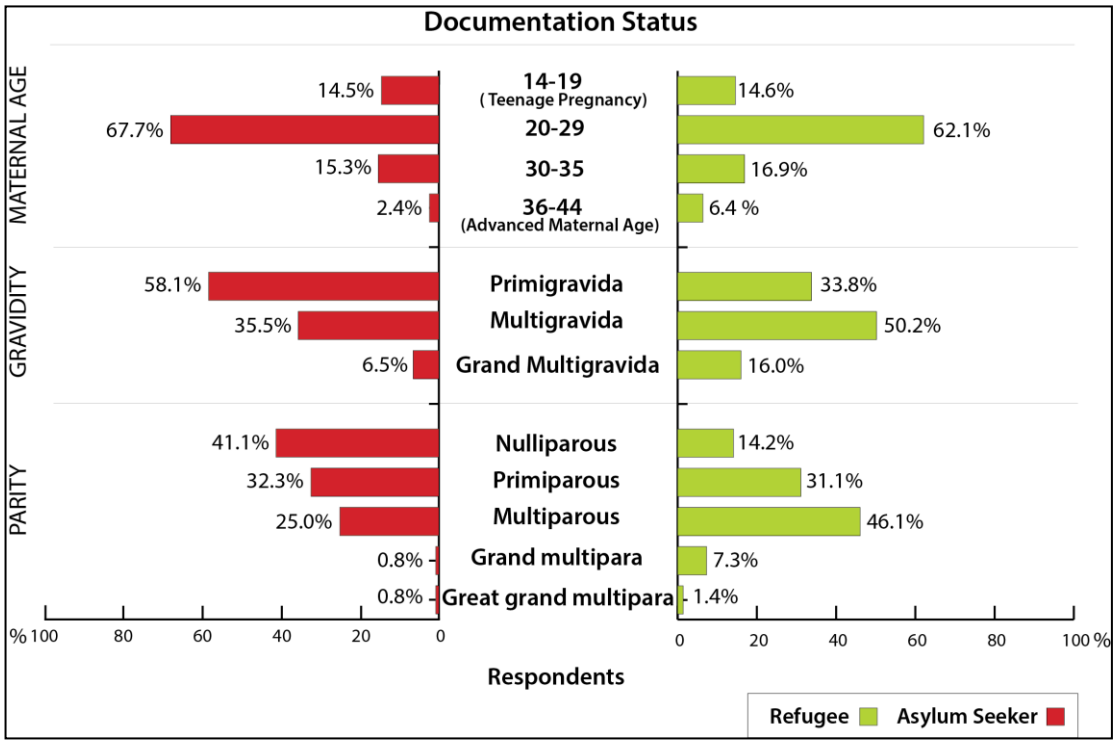
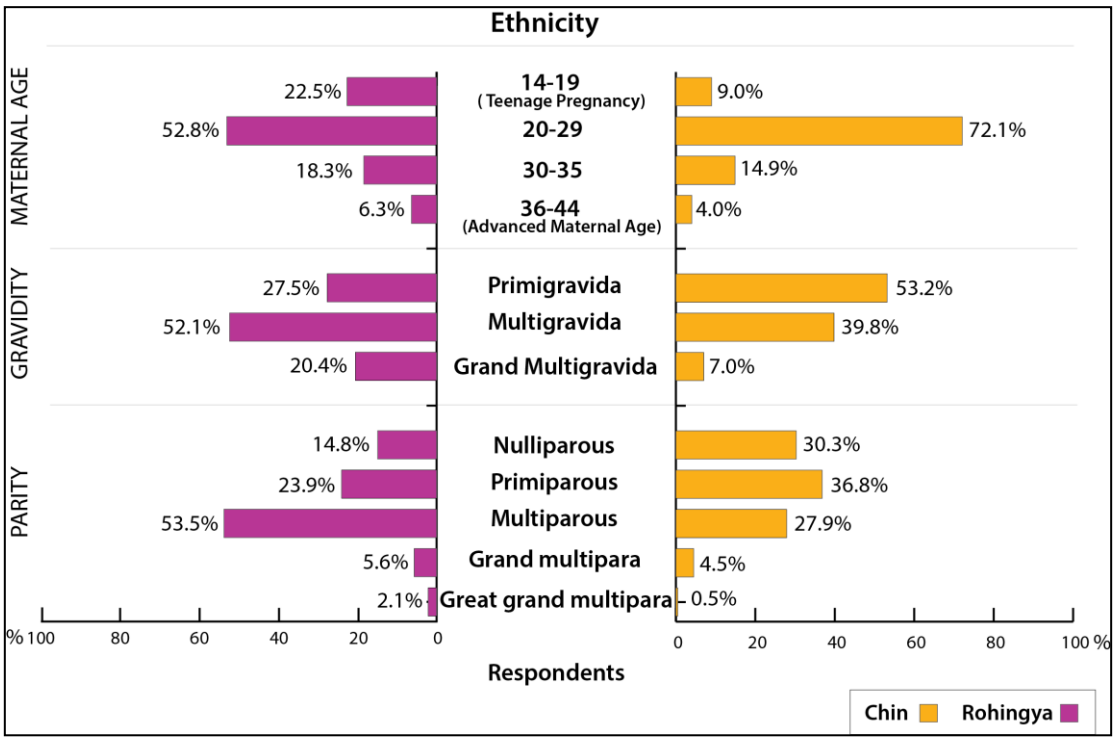


FIGURE 4: MATERNAL CHARACTERISTICS BY ETHNICITY



With regard to gravidity too, Rohingya women had more than twice the proportion of grand multigravidas than the Chins (20.4% and 7.0% respectively), while the Chins had a significantly higher proportion of primigravidas (53.2% versus 27.5% respectively). Between refugees and asylum seekers, asylum seekers had a significantly higher proportion of primigravidas than refugees (58.1% versus 33.8% respectively), while refugees had a higher proportion of multigravidas (50.2% versus 35.5% respectively), and grand multigravidas (16.0 versus 6.5% respectively). Pearson's chi-square applied to gravidity and documentation status, and gravidity and ethnicity rendered a significant association of gravidity with documentation status (χ^2=20.529; df=2; p<0.001) and ethnicity (χ^2=27.812; df=2; p<0.001) respectively.

In terms of parity too, the Rohingya women had a significantly higher proportion of multiparous and great grand multiparas, while the Chins had the higher proportion of primiparous women (χ^2=29.129; df=3; p<0.001). The distribution of parity between refugees and asylum seekers revealed that refugees had a higher proportion of multiparas, grand multiparas and great grand multiparas compared to asylum seekers who had a higher proportion of nulliparous respondents (χ^2=40.271; df=3; p<0.001).

There were more refugees (72.6%) than asylum seekers (34.7%), and more Rohingyas (67.6%) than Chins (52.7%) who had recently delivered at the time of the interview respectively (p<0.001, two sided Fisher's exact test, p=0.007, two sided Fisher's exact test).

6.1.3. Pregnancy Risks

Risk factors contributing to complications during pregnancy may arise from pre-existing maternal disorders, physical and social characteristics, obstetric history, and problems that may develop during pregnancy, during labor, and delivery [485].

Based on data given in the Rekod Kesihatan Ibu (maternal health record), 23 pregnancy risk factors were recorded. Of these only 15 of the most common risks were retained for analysis. Given that 141 of the 343 respondents were pregnant and yet to deliver, problems (like fetal position and unengaged fetal head) which usually get resolved by the time of delivery were excluded from the list of risks

although they could present complications if unresolved. The distribution of the number of risks and their disaggregation by documentation status and ethnicity is given in Table-9.

TABLE 9: NUMBER OF PREGNANCY RISKS BY DOCUMENTATION STATUS AND ETHNICITY

			BY DOCUMENTATION STATUS				BY ETHNICITY			
			Refugee		Asylum Seeker		Chin		Rohingya	
	n	Col %	n	Co l%	n	Col %	n	Col %	n	Col %
N	**343**	**100.0**	**219**	**100.0**	**124**	**100.0**	**201**	**100.0**	**142**	**100.0**
No Risk	127	37.0	76	34.7	51	41.1	98	48.8	29	20.4
1 Risk Factor	138	40.2	81	37.0	57	46.0	74	36.8	64	45.1
2 Risk Factors	51	14.9	38	17.4	13	10.5	24	11.9	27	19.0
3 Risk Factors	19	5.5	18	8.2	1	0.8	5	2.5	14	9.9
4 Risk Factors	6	1.7	4	1.8	2	1.6	0	0.0	6	4.2
5 Risk Factors	1	0.3	1	0.5	0	0.0	0	0.0	1	0.7
6 Risk Factors	1	0.3	1	0.5	0	0.0	0	0.0	1	0.7

Out of the study population of 343 respondents, 127 study participants did not present with any pregnancy risk. The remaining 216 respondents presented with one to six pregnancy risks. Of those who presented with pregnancy risks, the proportion of those who experienced one risk (40.2%) exceeded the proportion of those who experienced two to six risks. Of those who presented with pregnancy risks, 63.9% had one risk only. Those who had up to two risks accounted for 87.5% of all those who presented with risks.

Pearson's chi-square applied to the number of pregnancy risks and documentation status yielded a significant association between the two variables (χ^2=13.988; df=6; p=0.030) as did the association between pregnancy risks and ethnicity (χ^2=41.739; df=6; p<0.001).

The types of risks and their distribution by documentation status and ethnicity are given in Table-10.

Risk factor prevalence was highest for anemia (*hemoglobin<11 gm/*dl) in the total study population (40.82%). Refugees and asylum seekers presented with 42.92% and 37.10% of cases of anemia respectively, a difference that was not statistically significant (p = 0.306, two-sided Fisher's exact). On the other hand, statistical

significance was found between anemia and ethnicity (p<0.001, two-sided Fisher's exact test) with 54.22% of Rohingyas and 31.34% of Chins accounting for those with anemia in the study population.

A history of abortion accounted for the second highest risk factor prevalence (19.24%). A higher proportion of refugees than asylum seekers (23.29% versus 12.10% respectively; p=0.015, two-sided Fisher's exact test), and Rohingyas than Chins (30.99% versus 10.95% respectively; p<0.001, two-sided Fisher's exact test) accounted for those with a history of abortion.

A body weight of less than 45Kgs was not found to be significantly associated with documentation status (p=0.805, two-sided Fisher's exact test) or ethnicity (p=0.326, two-sided Fisher's exact test). But among those who had a history of perinatal death, the proportion of Rohingyas was higher than Chins (9.15% versus 1.99% respectively; p=0.004, two-sided Fisher's exact test).

TABLE 10: TYPES OF PREGNANCY RISKS BY DOCUMENTATION STATUS AND ETHNICITY (N=216)

	STUDY POPULATION		BY DOCUMENTATION STATUS				BY ETHNICITY			
			Refugee		Asylum Seeker		Chin		Rohingya	
	n	Row %	n	Row %	n	Row %	n	Row %	n	Row %
Hb<*11g*/dl	140	40.8	94	67.1	46	32.9	63	45.0	77	55.0
H/O Abortion	66	19.2	51	77.3	15	22.7	22	33.3	44	66.7
Weight <45 Kg	18	5.3	11	61.1	7	38.9	13	72.2	5	27.8
H/O Perinatal death	17	5.0	11	64.7	6	35.3	4	23.5	13	76.5
Edema	15	4.4	9	60.0	6	40.0	10	66.7	5	33.3
Bleeding during pregnancy	11	3.2	10	90.9	1	9.1	2	18.2	9	81.8
H/O Infant death	9	2.6	7	77.8	2	22.2	1	11.1	8	88.9
Post date	9	2.6	8	88.9	1	11.1	1	11.1	8	88.9
Hypertension	8	2.3	6	75.0	2	25.0	4	50.0	4	50.0
H/O BBA (Birth Before Arrival)	6	1.8	4	66.7	2	33.3	3	50.0	3	50.0
Gestational Diabetes Mellitus	6	1.8	5	83.3	1	16.7	1	16.7	5	83.3
Rh-ve	3	0.9	2	66.7	1	33.3	2	66.7	1	33.3
Last Child Birth >12 years	2	0.6	1	50.0	1	50.0	1	50.0	1	50.0
H/O Post-Partum Hemorrhage	1	0.3	0	0.0	1	100.0	0	0.0	1	100.0
Multiparity>5	21	6.2	94	67.1	46	32.9	10	4.98	11	7.74

6.2. NON DISCRIMINATION

The variable used to assess non-discrimination, *Perceived Discrimination in Health Care* related to racial identification*,* is a dichotomized multi-item measure that assesses the perception of discrimination in health care based on race.

6.2.1. Perceived Discrimination in Health Care

For all analyses from this point forward, those who did not receive ANC e (n=12) were excluded from the analysis. Only those who had sought ANC (n=331) were considered for the analyses.

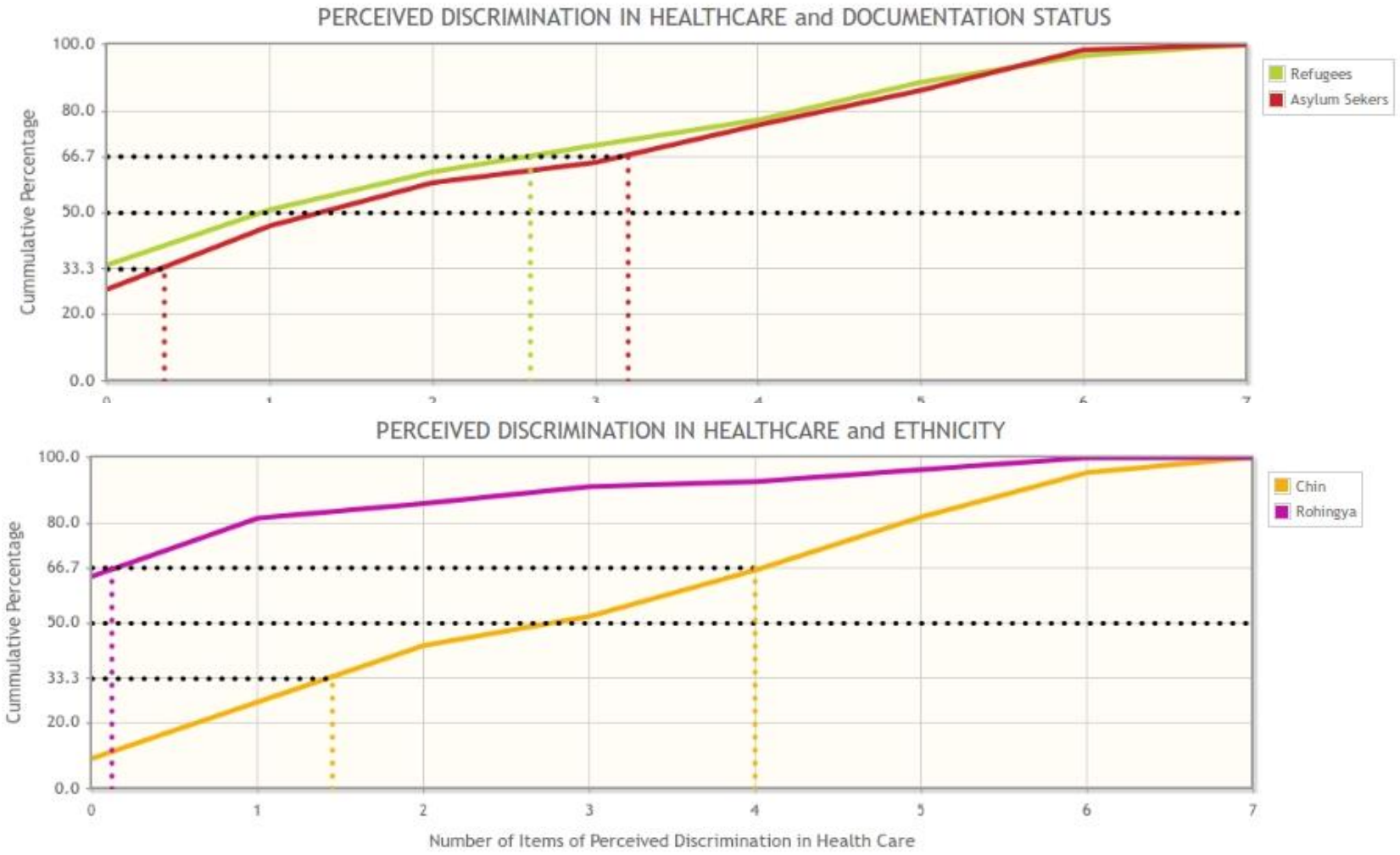
6.2.1.1. Count of Perceived Discrimination in Health Care

At the outset, a simple count of the seven items of perceived discrimination in health care was taken. See Table-11. About 32.0% of the study population did not perceive any discrimination in health care. About 225 (68.0%) study participants had perceived at least one form of discrimination while seeking maternal health care. A higher proportion of Rohingyas than Chins (64.2% versus 9.3%; χ^2=128.043; df=7; p<0.001) did not perceive any discrimination in health care. There was no significant association between documentation status and perceived discrimination in health care (χ^2=5.254; df=7; p=0.629).

TABLE 11: NUMBER OF ITEMS OF PERCEIVED DISCRIMINATION IN HEALTH CARE

	STUDY POPULATION		BY DOCUMENTATION STATUS				BY ETHNICITY			
			Refugee		Asylum Seeker		Chin		Rohingya	
	n	Col %	n	Col %	n	Col %	n	Col %	n	Col %
N	331	100.0	214	100.0	117	100.0	194	100.0	137	100.0
0 Items	106	32.0	74	34.6	32	27.4	18	9.3	88	64.2
1Item	57	17.2	35	16.4	22	18.8	33	17.0	24	17.5
2 Items	39	11.8	24	11.2	15	12.8	33	17.0	6	4.4
3 Items	24	7.3	17	7.9	7	6.0	17	8.8	7	5.1
4 Items	29	8.8	16	7.5	13	11.1	27	13.9	2	1.5
5 Items	36	10.9	24	11.2	12	10.3	31	16.0	5	3.6
6 Items	31	9.4	17	7.9	14	12.0	26	13.4	5	3.6
7 Items	9	2.7	7	3.3	2	1.7	9	4.6	0	0.0

FIGURE 5: NUMBER OF ITEMS OF PERCEIVED DISCRIMINATION IN HEALTH CARE

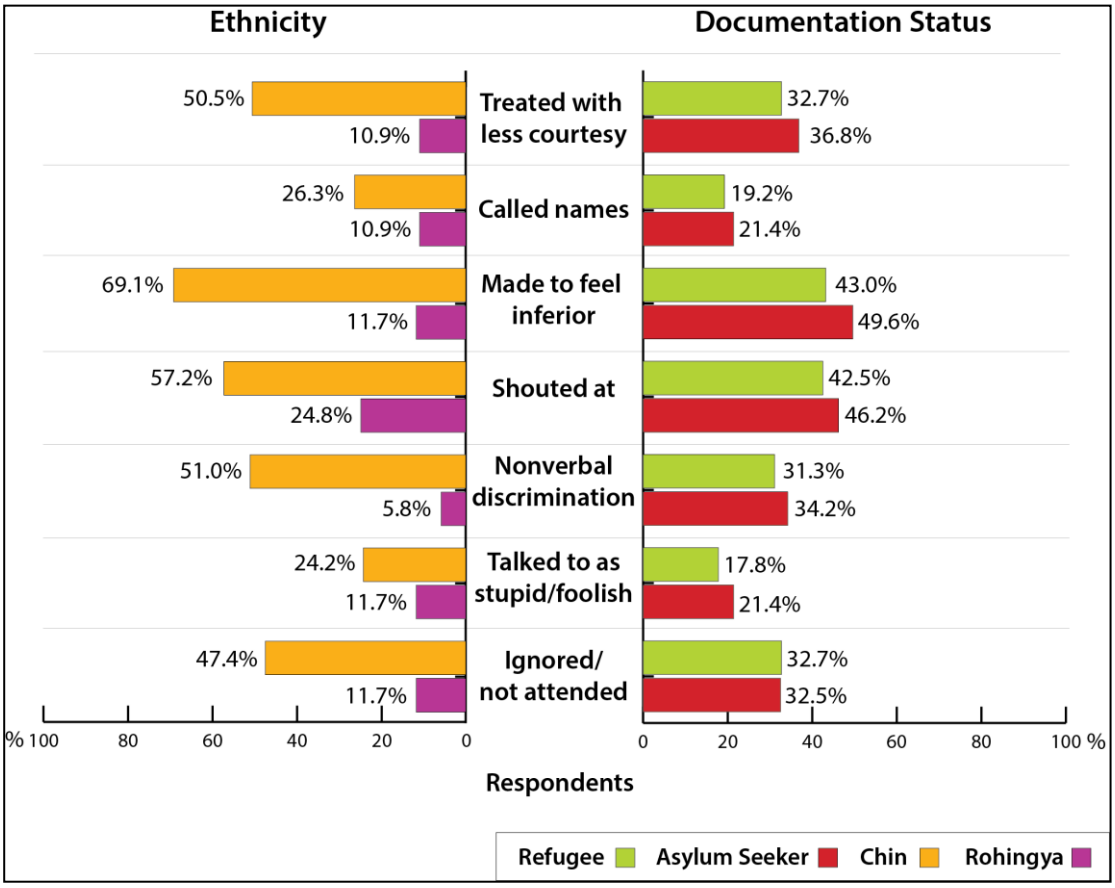


6.2.1.1. Distribution of Items of Perceived Discrimination in Health Care

The adapted multi-item measure to assess *Perceived Discrimination in Health Care* asks whether the following events had ever taken place in a health care facility when the women were accessing ANC, delivery care, and PPC: (i) have you ever been treated with less courtesy than others because of your race?; (ii) have you ever been called names because of your race?; (iii) have you ever been made to feel inferior because of your race?; (iv) have you ever been shouted at because you could not understand and speak the language?; (v) have you encountered nonverbal forms of discrimination like isolation/ indifference because of your race?; (vi) were you ever talked to as if you were stupid or foolish because of your race?; and (vii) have you ever been ignored and not attended to because of your race?

Cronbach's alpha coefficient for the seven item measure of perceived discrimination in health care was 0.911.

FIGURE 6: DISTRIBUTION OF ITEMS OF PERCEIVED DISCRIMINATION IN HEALTH CARE BY DOCUMENTATION STATUS AND ETHNICITY



The distribution of the seven items of perceived discrimination by documentation status and ethnicity is shown in Figure-6 and Table-65 in Appendix-6.

The items “made to feel inferior” and “shouted at” because they did not know the language were reported by 45.3% and 43.8% of the study population respectively.

In general, a higher proportion of Chins than Rohingyas reported perceived discrimination in health care. Each of the items of perceived discrimination was significantly related to ethnicity at the 0.05 alpha level (two-sided Fisher's exact test). The difference in the proportion of Chins and of Rohingyas who reported perceived discrimination in health care was most conspicuous in relation to perceptions of being made to feel inferior (69.1% versus 11.7% p<0.001, two-sided Fisher's exact test) followed by perceptions of non-verbal forms of discrimination (51.0% versus 5.8% p<0.001, two-sided Fisher's exact test), of being treated with less courtesy (50.5% versus 10.9% p<0.001, two-sided Fisher's exact test) and of being ignored/not attended to (47.4% versus 11.7% p<0.001, two-sided Fisher's exact test). Documentation status was not related to any of the items of perceived discrimination in health care.

6.2.2. Rejection of UNHCR Card

Separately, respondents were also asked if a government health facility had refused their UNHCR card. See Table-12.

TABLE 12: REJECTION OF UNHCR CARD BY A GOVERNMENT HEALTH FACILITY

	STUDY POPULATION		BY DOCUMENTATION STATUS				BY ETHNICITY			
			Refugee		Asylum Seeker		Chin		Rohingya	
	n	Col %	n	Col %	n	Col %	n	Col %	n	Col %
N	331	100.0	214	100.0	117	100.0	194	100.0	137	100.0
UNHCR Card Rejected	51	15.4	51	23.8	0	0.0	35	18.0	16	11.7
UNHCR Card Not Rejected	163	49.2	163	76.2	0	0.0	73	37.6	90	65.7
Not Applicable -asylum seekers	117	35.3	0	0.0	117	35.3	86	44.3	31	22.6

This question was answered by only 214 refugees who had such cards;117 asylum seekers who had sought ANC were excluded from the analysis because the question was not applicable.

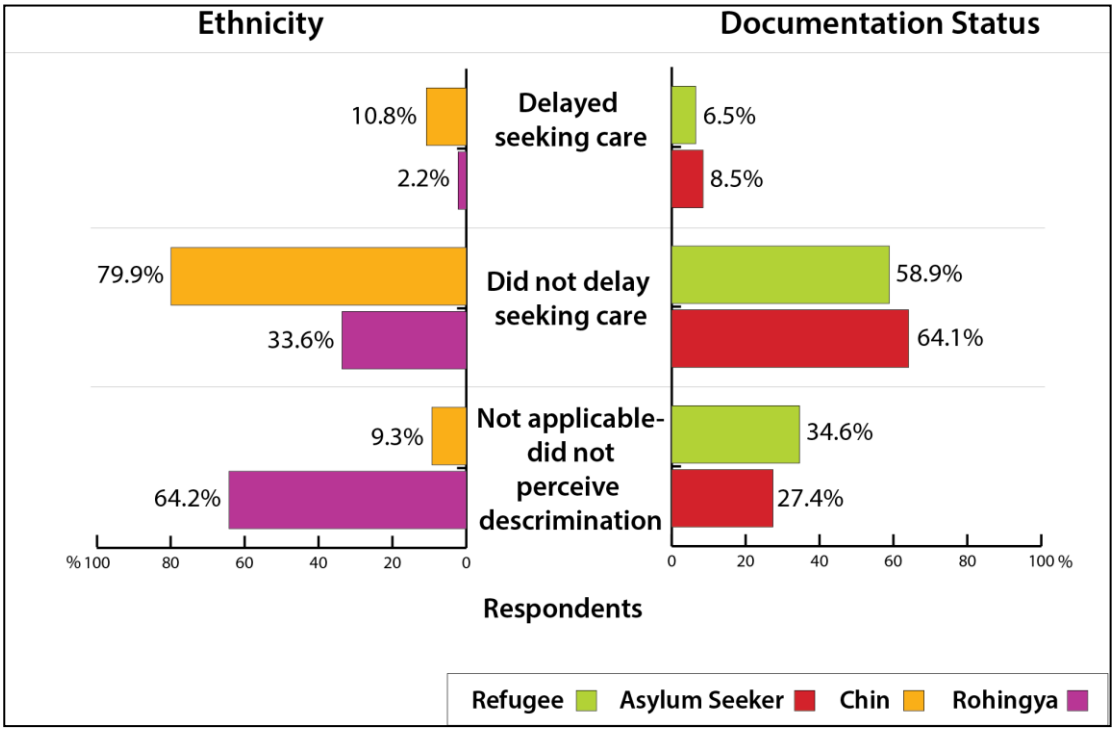
In all, 51 refugee respondents stated that their UNHCR cards had been rejected by government health care facilities. A higher proportion of Chins than Rohingyas had their UNHCR cards rejected (18.0% versus 11.7%, χ^2=25.651; df=2; p<0.001).

6.2.3 Coping with Discrimination

6.2.3 1. Delay in Seeking Maternal Health Care

Respondents were asked if they had delayed seeking maternal health care because of perceived discrimination in the health facility. See Figure-7 and Table-66 in Appendix-6.

FIGURE - 7: COPING WITH DISCRIMINATION IN HEALTH CARE-DELAY IN SEEKING MATERNAL HEALTH CARE: BY DOCUMENTATION STATUS & ETHNICITY



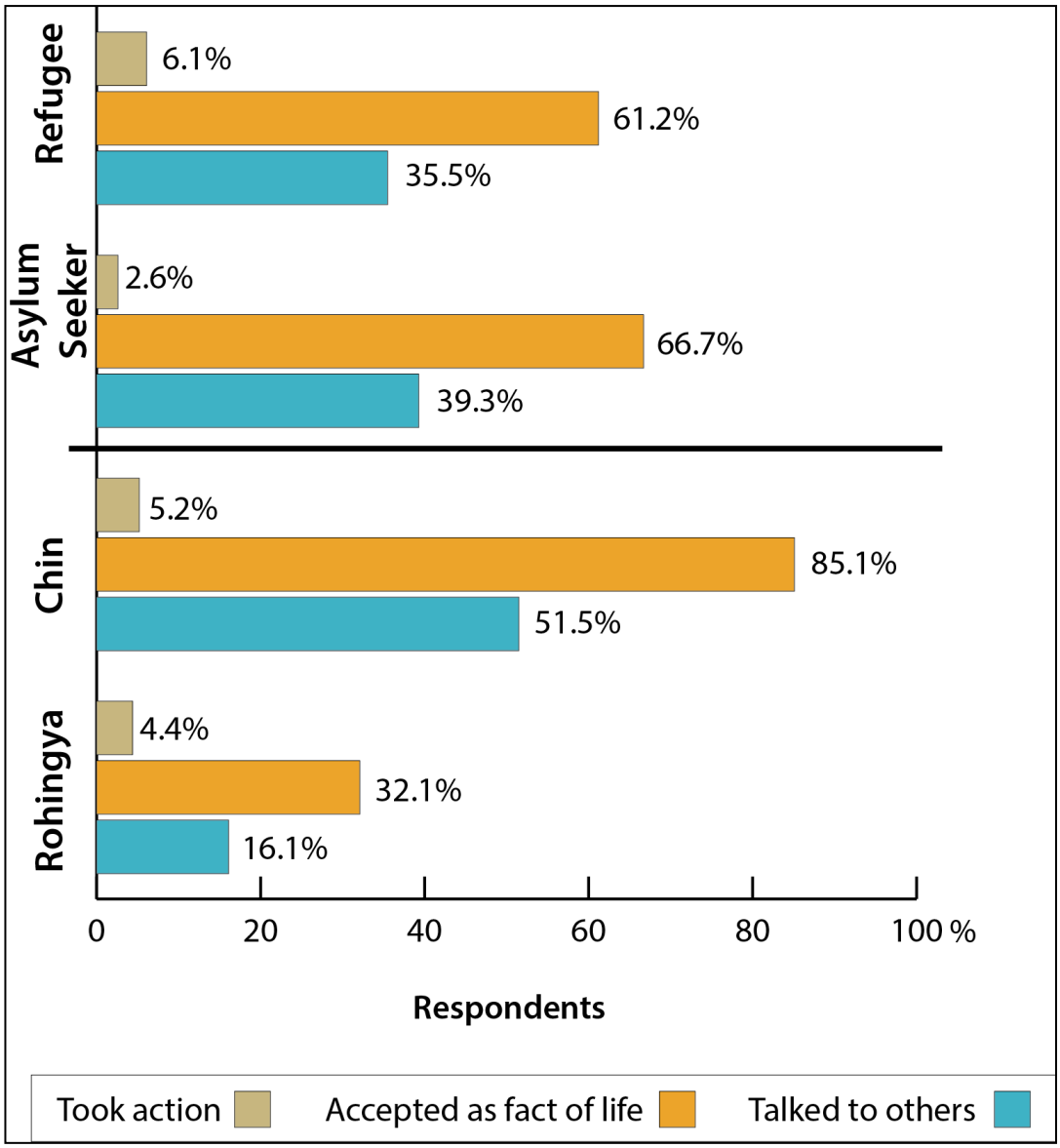
Overall, 24 out of the 225 respondents who had perceived at least one form of discrimination in the health care facility had delayed seeking maternal health care because of this perception. A higher proportion of Chins than Rohingyas (10.8%

versus 2.2%; χ^2=112.352; df=2; p<0.001) had delayed seeking maternal health care because of perceived discrimination in the health facility. Documentation status was not related to delays in seeking maternal health care because of perceived discrimination in health care (χ^2=1.994; df=2; p=0.369).

6.2.3 2. Other Forms of Coping with Discrimination

Other forms of coping with discrimination in health care that were explored included if respondents had (i) taken any action in the health care facility; (ii) accepted it as a fact of life; and (iii) talked to family and friends about it. Figure-8 and Table-67 in Appendix-6 details the coping responses of the participants.

FIGURE 8: COPING WITH DISCRIMINATION IN HEALTH CARE: BY DOCUMENTATION STATUS & ETHNICITY



The majority of the study population (63.1%) accepted discrimination as a fact of life. A little over a third of the study population talked to friends and community members about the experience of discrimination as a form of coping. A small minority (4.8%) took action at the health facility by complaining and asking for attention variously.

6.2.4. Relation between Perceived Discrimination in Health Care and Documentation Status and Ethnicity

The previous sections showed that ethnicity was associated with each of the items of perceived discrimination in health care and to the forms of coping.

In order to explore further the nature of the relationship between ethnicity and discrimination in health care, a Mann-Whitney U test was conducted to determine differences in the number of items of perceived discrimination between Rohingyas and Chins. The Mann-Whitney test was chosen because the count of perceived discrimination items was ordinal. The test showed a statistically significant difference in the number of items between Rohingyas (median=0) and Chins (median=3), U=4479.000, Z=-10.501, p<0.001.

There was no statistically significant difference in the number of perceived discrimination items between asylum seekers (median=2) and refugees (median=1, U=11645.500, Z=-1.073, p=0.283.

PCA was used to reduce the seven perceived discrimination items to obtain a single measure of perceived discrimination in health care. This was used as the dependent variable in the linear regression analysis.

The correlation between pairs of perceived discrimination item responses was assessed by tetrachoric correlation. The tetrachoric correlation coefficient measures the correlation between two independent dichotomous variables. It assumes that the dichotomous observed measurements have underlying continuous latent traits and arise from a dichotomization of a continuum at a given threshold[486]. Respondents with a response strength greater than the threshold are assumed to respond in the affirmative and vice versa for negative responses.

Tetrachoric correlations were estimated using the program TETRA-COM, an SPSS program for computing tetrachoric correlations which has been found to compute accurate point estimates, and standard errors and confidence intervals that are correct for any population value [486].

The tetrachoric correlations between the perceived discrimination items were found to be positively and significantly correlated ($p<0.05$). See Table-13 below for the tetrachoric correlation coefficient matrix.

TABLE 13: TETRACHORIC CORRELATION COEFFICIENT MATRIX - PERCEIVED DISCRIMINATION IN HEALTH CARE ITEMS

	Treated with less courtesy	Called names	Made to feel inferior	Shouted at	Nonverbal discrimination	Talked to as stupid/foolish	Ignored/ not attended
Treated with less courtesy	1.000						
Called names	0.232	1.000					
Made to feel inferior	0.564	0.763	1.000				
Shouted at	0.593	0.524	0.594	1.000			
Nonverbal discrimination	0.646	0.528	0.764	0.630	1.000		
Talked to as stupid/foolish	0.340	0.728	0.579	0.573	0.583	1.000	
Ignored/not attended	0.796	0.478	0.611	0.587	0.779	0.621	1.000

A Principal Component Analysis was conducted using the tetrachoric correlation coefficients matrix. An examination of the scree plot showed one dimension accounting for 65.59% of the variance. The factor score representing perceived discrimination was calculated from this.

The distribution of the perceived discrimination scores were negatively skewed with some outliers. A natural log transform was applied after making appropriate adjustments to avoid negative (non-transformable) values.

Pearson's correlation revealed a negative and very weak non-significant relationship between documentation status and perceived discrimination score ($r=0.055$, $p=0.322$, $n=331$). A positive and moderate correlation was revealed for the perceived discrimination score and ethnicity($r=-0.545$, $p<0.001$, $n=331$).

In the next step, documentation status and ethnicity were both included in the regression analysis. The regression results showed a significant model (adjusted R^2=0.297, F(1,330)=70.864, p<0.001). The overall model fit was R^2=30.2%. Ethnicity was found to be significantly associated with the perceived discrimination factor score (β=0.561, p<0.001], while documentation status was not (β=0.071, p=0.136). A change in ethnic identity from Rohingya to Chin was expected to increase the perceived discrimination factor score by 0.240 units. See Table -14 for details.

TABLE 14: SUMMARY OF MULTIPLE REGRESSION RESULTS WITH DOCUMENTATION STATUS AND ETHNICITY AS INDEPENDENT VARIABLES AND LOG TRANSFORMED PERCEIVED DISCRIMINATION IN HEALTH CARE AS DEPENDENT VARIABLE

Independent Variables	B	SE B	β	t	p
Documentation Status	0.031	0.021	0.071	1.494	0.136
Ethnicity	0.240	0.020	0.561	11.846	<0.001

B= unstandardized beta coeff.
SE B=standard error
β=standardized beta coeff
t=t-test statistic
P = significance value
Ethnicity = Ethnic group of respondent, Rohingya or Chin
Documentation Status = Documentation Status of respondent, Asylum Seeker or Refugee

6.2.4.1 Adjusting for Proficiency in Bahasa Malaysia

The findings on information access revealed that language proficiency in Bahasa Malaysia was significantly related to both documentation status and ethnicity.

A simple linear regression established that proficiency in Bahasa Malaysia was statistically associated with the perceived discrimination factor score, F(1, 330)=6.101, p=0.014, accounting for only 1.8% (R^2) of the explained variability. The perceived discrimination factor score was expected to decrease by 0.067 units with a change in proficiency in Bahasa Malaysia from “poor” to “good”.

Given the above results, the fact that one of the perceived discrimination items was related to language proficiency, and the possible confounding effect of language proficiency in Bahasa Malaysia on perceived discrimination amongst the groups of interest in this study, the linear regression was repeated using the process of stratification of confounders[487]. Linear regression analysis was applied to examine the effects of documentation status and ethnicity on the perceived discrimination

factor score while controlling for those who rated their language proficiency in Bahasa Malaysia as “good”.

A (R^2 = 12.6%) significant model emerged (adjusted R^2=0.201, F(2,76)=10.589, p<0.001) which showed that ethnicity (β=0.475, p<0.001) remained significantly associated with the perceived discrimination factor score vis-à-vis documentation status (β=0.020, p=0.192). See Table-15.

TABLE 15: SUMMARY OF MULTIPLE REGRESSION RESULTS WITH DOCUMENTATION STATUS AND ETHNICITY AS INDEPENDENT VARIABLES AND LOG TRANSFORMED PERCEIVED DISCRIMINATION IN HEALTH CARE AS DEPENDENT VARIABLE AFTER ADJUSTING FOR PROFICIENCY IN BAHASA MALAYSIA

Independent Variables	B	SE B	β	t	p
Documentation Status	0.016	0.082	0.020	0.192	0.848
Ethnicity	0.240	0.053	0.475	4.547	<0.001

B= unstandardized beta coeff.
SE B=standard error
β=standardized beta coeff
t=t-test statistic
P = significance value
Ethnicity = Ethnic group of respondent, Rohingya or Chin
Documentation Status = Documentation Status of respondent, Asylum Seeker or Refugee

Interaction Effect: Documentation Status, Ethnicity, and Language Proficiency in Bahasa Malaysia

Since the individual regression analysis with ethnicity, and language proficiency in Bahasa Malaysia were significantly associated with perceived discrimination in health care, and it being conceivable that acting together they could increase or decrease this experience, a GLM UNIANOVA analysis (after excluding outliers) was applied to examine interaction effects between documentation status, ethnicity and language proficiency in Bahasa Malaysia. The analysis did not show a significant interaction effect between documentation status and ethnicity F(1, 324)=0.001, p=0.979, between documentation status and language proficiency in Bahasa Malaysia F(1, 324)=0.006, p=0.941, and between ethnicity and language proficiency in Bahasa Malaysia F(1, 324)=0.102, p=0.754.

6.2.5 Non-Discrimination: Summary of Results and Conclusions

The variable to measure non-discrimination is *Perceived Discrimination in Health Care* and comprises seven items that assess the perception of discrimination in health care based on race.

Table-16 gives the summary of variables analyzed for the section on non-discrimination and the significance of the independent variables in relation to the dependent variable.

The analysis of perceived discrimination in health care shows that ethnicity was significantly associated with all the dependent variables, whereas documentation status was not related to a single dependent variable. This indicates that ethnicity was the more important of the two independent variables in the analysis of discrimination in accessibility to maternal health care.

Overall, the majority of the study population (68%) reported at least one form of perceived discrimination in health care. The majority (63.1%) also accepted discrimination as a fact of life. Tangentially, only a small minority (7.3%) reported that they delayed seeking maternal health care because of perceived discrimination in the health facility.

Rohingyas experienced less discrimination than Chins. Each of the seven forms of discrimination was experienced by a higher proportion of Chins than Rohingyas. Even among refugees, a higher proportion of Chins than Rohingyas had their UNHCR cards rejected by the government health care facilities. This could be related to Rohingyas' higher mean period of residence in Malaysia (7.45 years) compared to the Chins (1.8 years), greater proficiency in Bahasa Malaysia, and shared religion with the dominant population in Malaysia, which might offer better opportunities to assimilate into the local population.

However, a higher proportion of Chins than Rohingyas coped actively in dealing with the perceived discrimination in health care, whether it was through complaining and asking for attention at the health facility, or talking about it to family and friends.

TABLE 16: SUMMARY OF PERCEIVED DISCRIMINATION IN HEALTH CARE AND SIGNIFICANCE OF INDEPENDENT VARIABLES

Dependent Variable	Higher Value of Dependent Variable and/or Higher Proportion of Study Population Sub-Groups	Analysis	Significance of Independent Variable	
			Documentation Status	Ethnicity
Number of perceived discrimination items	Chin	Chi Sq.	p=n.s	✓
Perceived discrimination: Treated with less courtesy	Chin	Two sided Fisher's Exact	p=n.s	✓
Perceived discrimination: Called names	Chin	Two sided Fisher's Exact	p=n.s	✓
Perceived discrimination: Made to feel inferior	Chin	Two sided Fisher's Exact	p=n.s	✓
Perceived discrimination: Shouted at	Chin	Two sided Fisher's Exact	p=n.s	✓
Perceived discrimination: Nonverbal	Chin	Two sided Fisher's Exact	p=n.s	✓
Perceived discrimination: Talked to as if stupid/foolish	Chin	Two sided Fisher's Exact	p=n.s	✓
Perceived discrimination: Ignored/not attended	Chin	Two sided Fisher's Exact	p=n.s	✓
Coping with perceived discrimination: delay seeking maternal health care	Chin	Two sided Fisher's Exact	p=n.s	✓
Coping with perceived discrimination: Take action	Chin	Two sided Fisher's Exact	p=n.s	p=n.s
Coping with perceived discrimination: Accept as fact of life	Chin	Two sided Fisher's Exact	p=n.s	✓
Coping with perceived discrimination: Talk to friends and family	Chin	Two sided Fisher's Exact	p=n.s	✓
Relationship between documentation status and ethnicity with perceived discrimination	Increase in perceived discrimination with change in ethnic identity from Rohingya to Chin	Multiple linear regression	p=n.s	✓
Relationship between documentation status and ethnicity with perceived discrimination	Increase in perceived discrimination with change in ethnic identity from Rohingya to Chin	Multiple linear regression after controlling for proficiency in Bahasa Malaysia	p=n.s	✓
Interaction between documentation status, ethnicity, and proficiency in Bahasa Malaysia in relation to maternal health information access		GLM UNIANOVA	Doc status*Ethnicity	p=n.s
			Doc status*Lang. Proficiency in Bahasa Malaysia	p=n.s
			Ethnicity*Lang. Proficiency in Bahasa Malaysia	p=n.s

6.3 PHYSICAL ACCESSIBILITY

The variable to assess physical access is travel time.

In addition to assessing the relationship between documentation status and ethnicity and travel time, the examination of results related to the travel time of the study population considered the related difficulties of (i) the refugee protection environment and its ability to trigger anxiety provoking incidents; (ii) the intrapersonal dimension of negative emotions and fears of the respondent related to the unfavorable protection environment; and (iii) transportation.

6.3.1 Mean Travel Time

The mean travel time for obtaining ANC, delivery care, and PPC is given in Table-17.

TABLE 17: TRAVEL TIME TO ACCESS ANC, DELIVERY CARE, AND PPC

	STUDY POPULATION	BY DOCUMENTATION STATUS		BY ETHNICITY	
		Refugee	Asylum Seeker	Chin	Rohingya
ANC					
N	331	214	117	194	137
Mean ± SD	25.56(20.36)	25.56(18.62)	25.56(23.29)	27.91(23.19)	22.23(14.97)
Median	20.0	20.0	20.0	20.0	20.0
Minimum	5.0	5.0	5.0	5.0	5.0
Maximum	180.0	120.0	180.0	180.0	90.0
Delivery Care					
N	197	158	39	106	91
Mean ± SD	30.82(22.0)	30.77(23.41)	31.03(15.27)	36.36(21.35)	24.36(21.08)
Median	30.0	27.50	30.0	30.0	15.0
Minimum	5.0	5.0	10.0	5.0	5.0
Maximum	120.0	120.0	60.0	120.0	120.0
PPC					
N	145	120	25	57	88
Mean ± SD	21.48(15.91)	20.39(14.90)	26.72(19.63)	24.53(16.78)	19.51(15.10)
Median	15.0	15.0	20.0	20.0	15.0
Minimum	0.0	0.0	0.0	0.0	0.0
Maximum	120.0	120.0	88.0	88.0	120.0

In most cases, respondents obtained ANC and PPC from the same primary care and maternal health clinic. This could account for the similar mean travel time for

ANC and PPC. The minimum time of zero minutes for PPC is because the health worker from the primary care/maternal health clinic visited the respondent at home.

There was no significant difference (t(329) = 0.002, p=0.998) between the travel time of refugees (mean=25.56 minutes; SD=18.62) and asylum seekers (mean=25.56 minutes; SD=23.39) for ANC. For travel time for delivery, there was also no significant difference (t(195) =-0.066, p=0.948) between refugees (mean=30.77 minutes; SD=23.41) and asylum seekers (mean=31.03 minutes; SD=15.27). The same was observed in the travel time with regard to PPC between refugees (mean=20.39 minutes; SD=14.90) and asylum seekers (mean=26.72 minutes; SD=19.63), (t(143)=-1.823, p=0.070).

However, the difference in the mean travel time for ANC was significant (t(326.569)=2.709, p=0.007) for the Chin (mean=27.91 minutes; SD=23.19) and the Rohingyas(mean=22.23 minutes; SD=14.97). The travel time for delivery was higher for the Chin (mean=36.36 minutes; SD=21.35) than the Rohingya (mean=24.36 minutes; SD=21.08),(t(195) = 3.955, p<0.001).There was no significant difference (t(143) = 1.869, p=0.064) in the mean travel time for PPC between Chins(mean=24.53 minutes; SD=16.78) and Rohingyas (mean=19.51 minutes; SD=15.10).

6.3.2 Fear Factor

The definition of physical access under the right to health includes “safe physical reach”. The experience of safety which is very important for populations like refugees that have experienced trauma, is influenced by external security threats as well as intrapersonal difficulties that contribute to their sense of insecurity[289]. Further, previous studies have shown that physical mobility of refugees and asylum seekers is impeded by fears of arrest and of being robbed[357].

As such, respondents’ fears and anxieties in relation to physical access were explored by asking if they had fears/anxieties about physical travel related to obtaining maternal health care and if they had experienced any actual anxiety provoking incidents corresponding to their perceived fears.

Out of 343 respondents, 294 reported feeling fear while traveling to obtain maternal health care.

3.2.1. Feelings of Fear

Table-18 below gives the details of those who experienced feelings of fear while traveling to obtain maternal health care (disaggregated by documentation status and ethnicity). Regardless of documentation status, the majority (85.7%) reported feelings of fear. A higher proportion of asylum seekers versus refugees experienced feelings of fear when traveling to obtain maternal health care (93.5% versus 81.3%, p=0.002, two sided Fisher's exact test). About 88.7% of Rohingyas and 83.6% of Chins reported feelings of fear when traveling to obtain maternal health care (p=0.211, two sided Fisher's exact test). A higher proportion of refugees than asylum seekers (18.7% versus 6.5%) and Chins than Rohingyas (16.4% versus 11.3%) did not experience feelings of fear during travel.

TABLE 18: FEELINGS OF FEAR WHILE TRAVELING TO OBTAIN MATERNAL HEALTH CARE

	STUDY POPULATION		BY DOCUMENTATION STATUS				BY ETHNICITY			
			Refugee		Asylum Seeker		Chin		Rohingya	
			n	Col%	n	Col %	n	Col %	n	Col%
N	343	100.0	219	100.0	124		201	100.0	142	100.0
Felt fearful	294	85.7	178	81.3	116	93.5	168	83.6	126	88.7
No feelings of fear	49	14.3	41	18.7	8	6.5	33	16.4	16	11.3

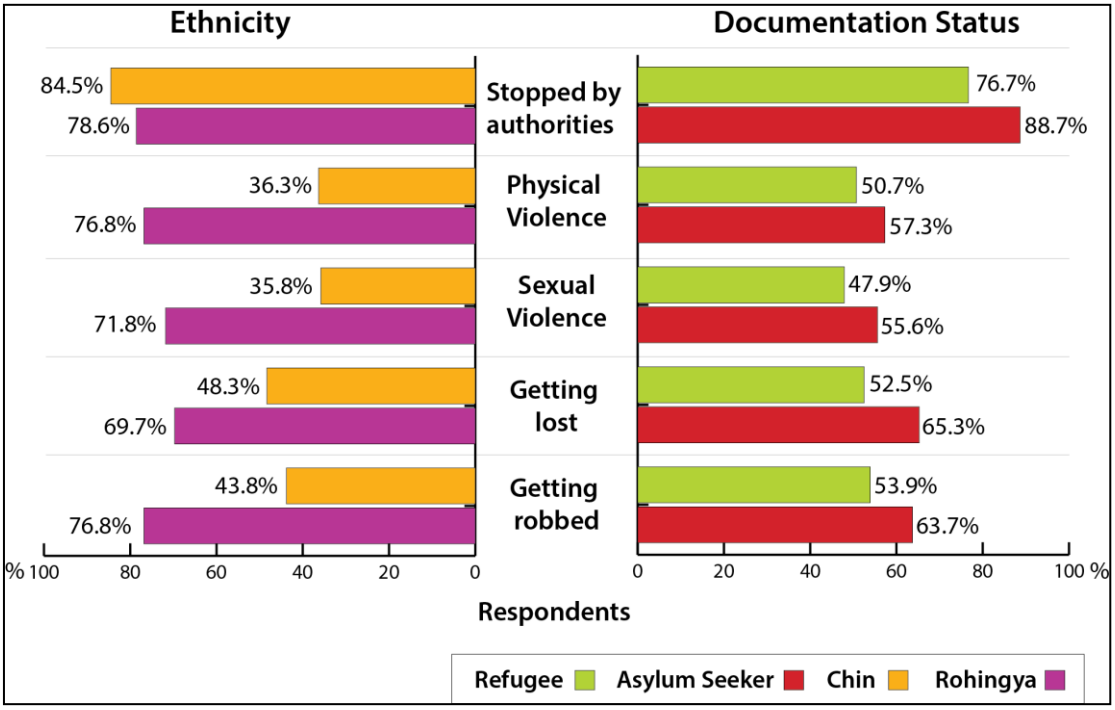
6.3.2.2 Reasons for Fear

The reasons cited for feeling fearful are given in Figure-9 and Table-68 in Appendix-6.

The fear experienced by the most number of respondents was of being stopped by enforcement authorities. A higher proportion of asylum seekers than refugees experienced this fear (88.7% versus76.7% respectively) while a higher proportion of Chins than Rohingyas (84.5% versus 78.6%) were afraid of being arrested by enforcement authorities. Documentation status (p=0.006, two sided Fisher's exact test) was significantly associated with fears of being stopped by authorities; not ethnicity (p=0.208, two sided Fisher's exact test).

The second greatest fear related to getting robbed. A greater proportion of asylum seekers than refugees (63.7% versus 53.9%; p=0.088 two sided Fisher's exact test), and Rohingyas than Chins (76.8% versus 43.8%; p<0.001 two sided Fisher's exact test) experienced this fear.

FIGURE 9: REASONS FOR FEELING FEAR: BY DOCUMENTATION STATUS & ETHNICITY



With regard to the fear of getting lost, a higher proportion of asylum seekers than refugees (65.3% versus 52.5%; p=0.023, two sided Fisher's exact test), and Rohingyas than Chins (69.7% versus 48.3%; p<0.001, two sided Fisher's exact test) had this fear.

The fears of sexual and physical violence were significantly associated with ethnicity (p<0.001, two sided Fisher's exact test in both cases), while they were not associated with documentation status (p=0.179, two sided Fisher's exact test and p=0.261, two sided Fisher's exact test respectively).

Given the importance of safety in relation to the right to health definition of physical access, and the particular significance of the experience of safety, including its intrapersonal dimensions, in this population, an examination of the relation between perceived fear with documentation status and ethnicity was explored.

Logistic regression analysis was performed to ascertain the effects of documentation status and ethnicity on the likelihood that respondents would/would not feel fearful. Respondents who had not sought ANC were excluded from the analysis. Feelings of fear were modeled as a categorical variable in terms of whether the respondent did or did not experience fear. The logistic regression model was statistically significant $\chi^2(2) = 12.106$, $p < 0.05$. The model explained 6.4% (Nagelkerke R^2) of the variance in feeling fearful. Of the two independent variables, only documentation status was statistically significant (as shown in Table-19 below). Asylum seekers' odds of feeling fearful were 3.5 times greater than that of refugees. The error rate for the model is about 14.2%. The details of this logistic regression analysis are given in Table 19 below.

TABLE 19: LOGISTIC REGRESSION ANALYSIS WITH DOCUMENTATION STATUS AND ETHNICITY AS INDEPENDENT VARIABLES AND FEELINGS OF FEAR AS THE DEPENDENT VARIABLE

n=331						
Independent Variables	**e^{β}(odds ratio)**	**SE β**	**Wald's χ^2**	**df**	**p**	**β**
Constant	0.046	0.462	44.440	1	<0.001	-3.079
Documentation Status	3.483(1.544-7.857)	0.415	9.041	1	0.003	1.248
Ethnicity	1.818(0.933-3.543)	0.340	3.087	1	0.079	0.598

6.3.2.3 Self-Reported Level of Fear Regarding Travel for Maternal Health Care

On the whole, about 63.3% of the population reported feeling high and very high levels of fear while traveling to obtain maternal health care (See Table-20 below). A higher proportion of asylum seekers rather than refugees (61.3% versus 32.0%) experienced very high levels of fear, and a higher proportion of refugees experienced low and no fear compared to asylum seekers (17.8% versus 4.0%), although a higher proportion of refugees also experienced high and moderate levels of anxiety, (χ^2=41.169; df=4; p<0.001).

Likewise, a higher proportion of Rohingyas experienced very high and high (57.0% and 26.8% respectively) levels of fear while a greater proportion of Chins than Rohingyas (11.9% versus 3.5%) experienced low levels of fear. A higher proportion of Rohingyas than Chins (6.3% versus 3.0%) did not experience any fear while traveling to obtain maternal health care (χ^2=56.632; df=4; p<0.001). See Table-20.

TABLE 20: FEAR LEVEL WHEN TRAVELING TO OBTAIN MATERNAL HEALTH CARE

	STUDY POPULATION		BY DOCUMENTATION STATUS				BY ETHNICITY			
			Refugee		Asylum Seeker		Chin		Rohingya	
	n	%	n	Col %	n	Col %	n	Col %	n	Col %
N	343	100.0	219	100.0	124		201	100.0	142	100.0
Very High	146	42.6	70	32.0	76	61.3	65	32.3	81	57.0
High	71	20.7	60	27.4	11	8.9	33	16.4	38	26.8
Moderate	82	23.9	50	22.8	32	25.8	73	36.3	9	6.3
Low	29	8.5	26	11.9	3	2.4	24	11.9	5	3.5
None	15	4.4	13	5.9	2	1.6	6	3.0	9	6.3

6.3.3 Anxiety Provoking Incident

This section reports on whether respondents had experienced at least one actual anxiety provoking incident corresponding to their perceived fears. In all, 165 respondents did not experience any anxiety provoking incident. About 127 study participants experienced one anxiety provoking incident, while 41, eight, and two respondents experienced two, three and four anxiety provoking incidents respectively.

6.3.3.1 Prevalence of Anxiety Incidents

In total, 178 respondents had experienced between one and four anxiety provoking incident(s).

TABLE 21: ANXIETY INCIDENT WHEN TRAVELING TO OBTAIN MATERNAL HEALTH CARE

	STUDY POPULATION		BY DOCUMENTATION STATUS				BY ETHNICITY			
			Refugee		Asylum Seeker		Chin		Rohingya	
	n	%	n	Col %	n	Col %	n	Col %	n	Col %
N	343	100.0	219	100.0	124		201	100.0	142	100.0
No Anxiety Incident	165	48.0	102	46.6	63	50.8	84	41.8	81	57.0
Had Anxiety Incident	178	52.0	117	53.4	61	49.2	117	58.2	61	43.0

The actual occurrence of an anxiety provoking incident was higher among the Chins than the Rohingyas (58.2% versus 43.0%,p=0.006, two sided Fisher's exact test), whereas there was no difference in the experience of anxiety incidents between

refugees and asylum seekers (p=0.500, two sided Fisher's exact test). Further details are given in Table-21 below.

6.3.3.2. Types of Anxiety Incidents

FIGURE 10: ANXIETY INCIDENT WHEN TRAVELING TO OBTAIN MATERNAL HEALTH CARE: BY DOCUMENTATION STATUS & ETHNICITY

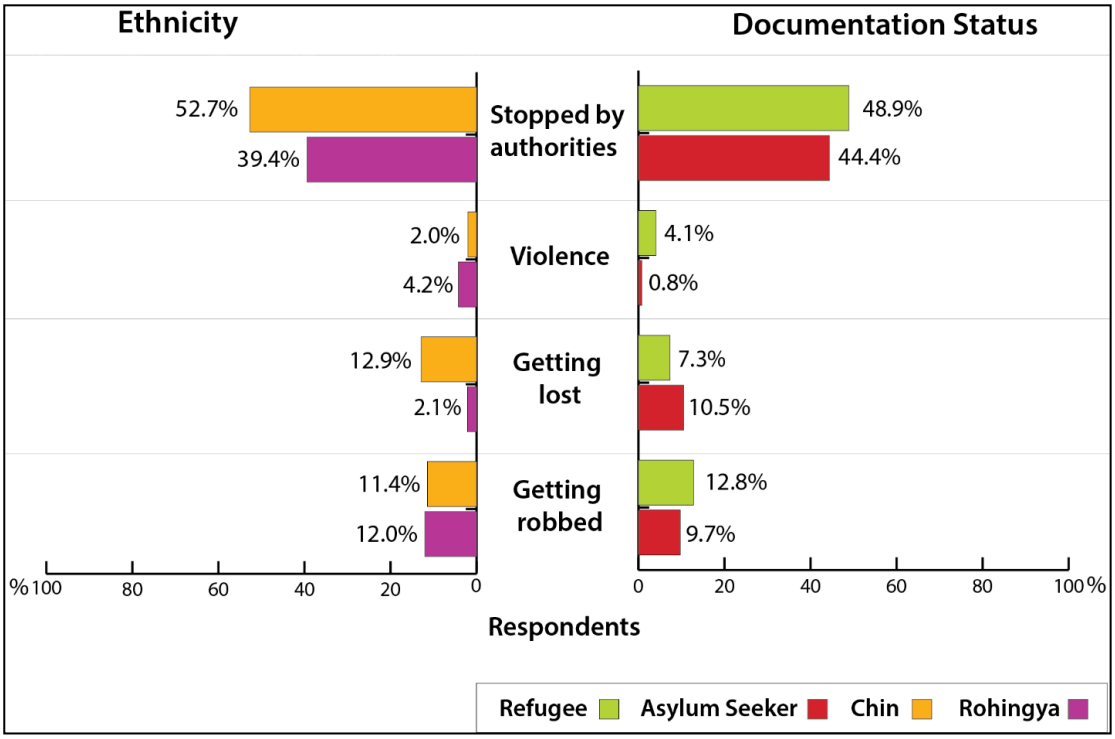


Figure-10 above and Table-69 in Appendix-6 provide details of anxiety incidents experienced by the respondents while traveling to obtain maternal health care. The highest proportion of anxiety provoking incidents for the study population (47.2%) was in relation to being stopped by enforcement authorities. Rohingyas had a lower proportion of cases of being stopped by enforcement authorities than Chins (39.4% versus 52.7%, p=0.016, two sided Fisher's exact test). There was no significant difference in the proportion of refugees and asylum seekers (44.4% versus 48.4%, p=0.433, two sided Fisher's exact test) who were stopped by authorities.

The next highest proportion of anxiety incident cases (11.7%) included getting robbed. However, neither documentation status (p=0.389, two sided Fisher's exact test), nor ethnicity (p=0.880, two sided Fisher's exact test) was significantly associated with this anxiety incident

A higher proportion of Chins than Rohingyas (12.9% versus 2.1%, p<0.001, two sided Fisher's exact test) reported getting lost. Documentation status (p=0.319, two sided Fisher's exact test) was not significantly associated with this event.

Given these results and the importance of safety in the definition of physical access in this study, logistic regression was used to ascertain the independent effects of documentation status and ethnicity on the likelihood that respondents would/would not experience an anxiety provoking incident. The logistic regression model was statistically significant $\chi 2(2) = 9..059$, p=0.011. The model explained 3.6% (Nagelkerke R^2) of the variance. Of the two independent variables, only ethnicity was statistically significant (as shown in Table-22 below). Rohingyas' odds of not having an anxiety provoking incident was 1.986 times more than the odds of Chins not experiencing an anxiety provoking incident. See Table-22.

TABLE 22: LOGISTIC REGRESSION ANALYSIS WITH DOCUMENTATION STATUS AND ETHNICITY AS INDEPENDENT VARIABLES AND ANXIETY PROVOKING INCIDENT AS THE DEPENDENT VARIABLE

n=331						
Independent Variables	**e^{β}(odds ratio)**	**β**	**SE β**	**Wald's χ^2**	**df**	**p**
Constant	0.625	-0.470	0.182	6.633	1	0.010
Documentation Status	1.386(0.865 - 2.223)	0.327	0.241	1.840	1	0.175
Ethnicity	1.968(1.245-3.110)	0.677	0.234	8.394	1	0.004

6.3.4 Fear Factor and Anxiety Provoking Incident(s) Combined

In the next step of the analysis, in order to determine the distribution of respondents who had experienced both feelings of fear and anxiety provoking incidents, a new variable was computed combining the variables which recorded feelings of fear and the occurrence of an anxiety provoking incident. This was to examine the objective dimension of the fear (anxiety provoking incident) with the subjective (fear).

The analysis showed that almost half the study population who had feelings of fear had experienced anxiety provoking incidents in the form of being stopped by enforcement personnel, getting robbed, getting lost and experiencing violence variously. Table-23 has more details.

A higher proportion of refugees did not have feelings of fear or experience an anxiety incident compared to asylum seekers (16.0% versus 4.0%; χ^2=15.659; df=3; p=0.001).

TABLE 23: EXPERIENCE OF FEELINGS OF FEAR AND ANXIETY INCIDENT

	STUDY POPULATION		BY DOCUMENTATION STATUS				BY ETHNICITY			
			Refugee		Asylum Seeker		Chin		Rohingya	
	n	%	n	Col %	n	Col %	n	Col %	n	Col %
N	343	100.0	219	100.0	124	100.0	201	100.0	142	100.0
No Anxiety Incident No Fear	40	11.7	35	16.0	5	4.0	30	14.9	10	7.0
No Anxiety Incident Had Fear	125	36.4	67	30.6	58	46.8	54	26.9	71	50.0
Had Anxiety Incident No Fear	9	2.6	6	2.7	3	2.4	3	1.5	6	4.2
Had Fear Had Anxiety Incident	169	49.3	111	50.7	58	46.8	114	56.7	55	38.7

Similarly, a lower proportion of Rohingyas did not experience feelings of fear or have an anxiety incident compared to Chins (7.0% versus 14.9%), while a higher proportion of Chins experienced both fear and anxiety incidents (56.7% versus 38.7%), (χ^2=24.485; df=3; p<0.001).

6.3.5 Travel Mode

Figure -11 and Table-70 in Appendix-6 show the modes of travel used by the respondents.

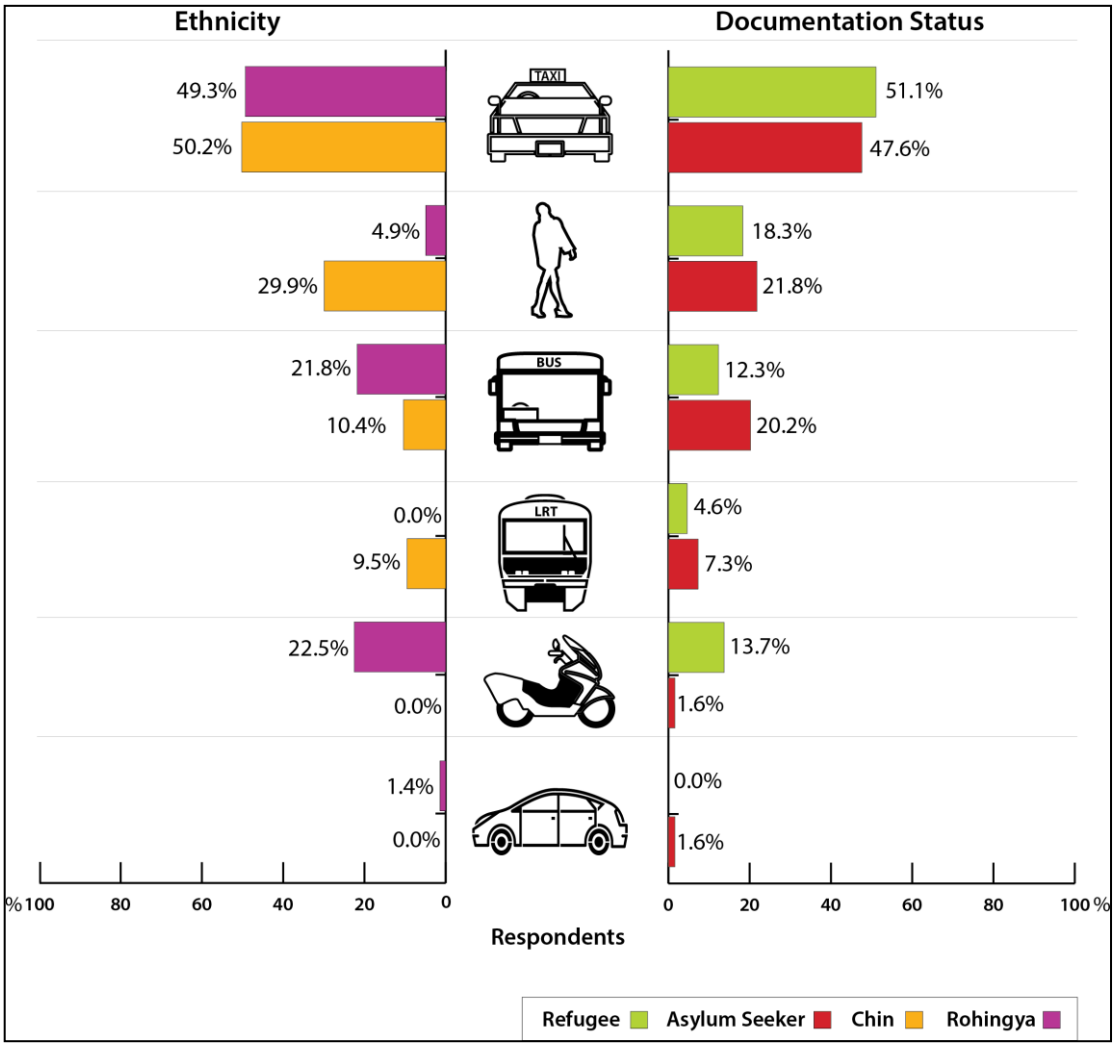
Taxis accounted for the main form of transportation for almost half the study population. About 1/5th of the population walked and another 15% took the bus. A higher proportion of asylum seekers than refugees (21.8% versus 18.3%), and Chin than Rohingya (29.9% versus 4.9%) walked. A higher proportion of refugees used taxis and had their own motorbikes. However, between Rohingyas and Chin, only Rohingya respondents used their personal motorbikes (n=32) while two used a car. Documentation status (χ^2=20.868; df=5; p=0.001) and ethnicity (χ^2=95.134; df=5; p<0.001) were associated with travel mode.

The relation between travel mode with feelings of fear, anxiety provoking incidents, and travel time were also explored.

In relation to travel mode and feelings of fear, the highest proportion of those who experienced fear (46.3%) used taxis as against 21.8% who walked, 15.6% who took the bus, 9.5% who used their personal motorbike, 6.1% who used the Light Rail Transit system (LRT), and 0.7% who used their own car (χ^2=22.722; df=5, p<0.001; Cramer's V =0.241).

In relation to travel mode and anxiety provoking incident too, the majority of those who had an anxiety provoking incident (47.8%) used a taxi, with another 25.3% who walked, 12.9% who took the bus, 7.3% who used their motorbike, 6.7% who used the LRT and none who used their own car (χ^2=17.040; df=5, p=0.004; Cramer's V =0.183).

FIGURE 11: TRAVEL MODES: BY DOCUMENTATION STATUS & ETHNICITY



Pearson's correlation applied to assess if there was a relationship between travel mode and travel time showed a very negligible correlation between ANC travel time and travel mode (r=-0.082,p=0.129, n=343), a weak correlation between delivery care travel time and travel mode (r=-0.229, p<0.001, n=343), and between PPC travel time and travel mode (r=-0.229,p<0.001, n=343), although the correlation with delivery care and PPC travel times was significant.

Travel mode was also associated with living below or above the poverty line income (PLI) of RM763 per month stipulated by the 10th Malaysia Plan for Peninsular Malaysia(χ^2=21.067; df=5, p=0.001). A higher proportion of those who lived below rather than above the PLI walked (22.3% versus 16.9%), used the bus (18.7% versus 11.9%), or the LRT (9.6% versus 1.7%). However, a higher proportion of those who lived above rather than below the PLI traveled by taxis (55.9% versus 43.4%) and used their own motorbike (13.0% versus 5.4%).

6.3.6. Relation between Travel Time and Documentation Status and Ethnicity

To examine if there was a relationship between travel time and documentation status and ethnicity, Pearson's correlation coefficients were computed and a regression analysis was performed. Table-24 has the results.

Examination of the distribution of travel time (for ANC, delivery care, and PPC) showed that the distribution was skewed. Thus, travel time was log-transformed to correct for skewness. Examination of the studentized residuals for log transformed travel time for ANC, for values greater than or equal to +/-3 revealed one outlier. The outlier took 180 minutes to travel for ANC. It was decided to exclude this case from the analysis. There were no outliers for log-transformed travel time for delivery care and PPC.

Having determined that the correlations between travel time and documentation status and ethnicity were significant, and having treated outliers and skewness in the distribution of travel time with a log-transformation, and accepting that the log transformed travel time was approximately normally distributed (in each group of the independent variables) for the purpose of the analysis, a regression analysis was carried out.

The relation between travel time and the independent variables was considered separately for ANC, delivery care, and PPC. In all three instances, the linear regression analysis obtained the best fit for the data with a logarithmic transformation. The regression analysis also analyzed the presence of interaction effects for documentation status and ethnicity on travel time.

ANC

The application of Pearson's correlation showed a very weak relationship between the log transformed travel time and ethnicity (r=0.133, p=0.016, n=331). There was no correlation between documentation status and the log transformed travel time for ANC (r=0.034, p=0.540, n=331).

The regression was a poor fit (R^2 = 2.2%) and revealed a significant model (adjusted R^2=0.016F (2,330)=3.673, p=0.026). Ethnicity was associated with travel time for ANC (β=0.148, p=0.009), not documentation status (β=0.067, p=0.234). Travel time for ANC was expected to increase by 0.188 units of the log transformed travel time for ANC when ethnic identity changes from Rohingya to Chin.

No significant interaction effect was found between documentation status and ethnicity for travel time for ANC, F(1, 327) = 0.950, p = 0.331.

Delivery Care

Pearson's correlation coefficient was statistically significant with regard to the log travel time for delivery and ethnicity albeit revealing a weak relationship (r=0.354, p<0.001, n=197). There was no correlation between documentation status and travel time for delivery care (r=-0.074, p=0.299, n=197).

The regression results showed a significant model (adjusted R^2=0.117, F(2,196)=14.004, $p<0.001$). The overall model fit was R^2 = 12.6%. Ethnicity was associated travel time for delivery care (β=0.350, p<0.001), not documentation status (β=-0.030, p=0.663). Travel time for delivery care was expected to increase by 0.475 units of the log transformed travel time for delivery when ethnic identity changes from Rohingya to Chin.

No significant interaction effect was found between documentation status and ethnicity for travel time for delivery care (1, 193) = 0.003, p = 0.954.

PPC

The correlation coefficients for log travel time for PPC and documentation status (r=-0.180, p=0.033, n=142) and ethnicity (r=0.197, p=0.019, n=142) respectively were very weak though significant.

The regression model yielded a significant model (adjusted R^2=0.049, F(2,141)=4.620, p=0.011). The overall model fit was R^2 = 6.2%. One again, ethnicity was significantly related to travel time for PPC (β=0.175, p=0.036), not documentation status (β=-0.154, p=0.065). Travel time for PPC was expected to increase by 0.208 log transformed travel time for PPC when ethnic identity changes from Rohingya to Chin.

No significant interaction effect was found between documentation status and ethnicity for travel time for PPC F(1, 138) = 0.087, p = 0.769.

TABLE 24: SUMMARY OF MULTIPLE REGRESSION RESULTS WITH DOCUMENTATION STATUS AND ETHNICITY AS INDEPENDENT VARIABLES AND LOG TRANSFORMED TRAVEL TIME FOR ANC, DELIVERY CARE, AND PPC AS DEPENDENT VARIABLES

Independent Variables	B	SE B	β	t	p
ANC					
Documentation Status	0.088	0.074	0.067	1.193	0.234
Ethnicity	0.188	0.071	0.148	2.639	0.009
Delivery Care					
Documentation Status	-0.050	0.115	-0.030	-0.437	0.663
Ethnicity	0.475	0.092	0.350	5.175	<0.001
PPC					
Documentation Status	-0.239	0.128	-0.154	-1.862	0.065
Ethnicity	0.208	0.099	0.175	2.112	0.036

B= unstandardized beta coeff.
SE B=standard error
β=standardized beta coeff
t=t-test statistic
P = significance value
Ethnicity = Ethnic group of respondent, Rohingya or Chin
Documentation Status = Documentation Status of respondent, Asylum Seeker or Refugee

6.3.6.1. Adjusting for Feelings of Fear

Considering that physical access includes the element of safety in physical mobility and the earlier results which showed that feelings of fear and anxiety incidents were associated with documentation status and ethnicity, it was decided to examine a new regression model that included feelings of fear as an additional independent variable. The variable, feelings of fear, was chosen over anxiety incident because feelings of fear reflect intrapersonal security issues that could influence physical mobility in populations with histories of trauma. Moreover, it had been previously established that the majority of those who experienced feelings of fear had also experienced anxiety incidents, the objective dimension of fear.

The regression analysis also analyzed the presence of interaction effects for: (i) documentation status and feelings of fear; and (ii) ethnicity and feelings of fear, on travel time for obtaining maternal health care.

Pearson's correlation applied to examine the correlation between feelings of fear and the log transformed travel time for ANC, delivery care and PPC did not reveal a significant correlation for ANC (r=-0.011, p=0.837, n=330), delivery care (r=-0.094, p=0.191, n=197), or PPC (r=0.068, p=0.421, n=141). However, as stated in the previous section, ethnicity was weakly but significantly correlated with the log transformed travel time for ANC (r=0.133, p=0.016, n=331), delivery care (r=0.354, p<0.001, n=197), and PPC (r=0.197, p=0.019, n=142). Ethnicity was also related to feelings of fear (p=0.211, two sided Fisher's exact test).

In order to examine the effect between ethnicity, documentation status, and the experience of feeling fear on travel time for maternal health care a multiple regression analysis was carried out.

The results of the regression did not reveal a significant model for travel time for ANC (adjusted R^2=0.013, $F(3, 329)=2.483$, $p=0.061$). The overall model fit was R^2 = 2.2%.

The regression analysis for travel time for delivery care (adjusted R^2=0.116, $F(3, 196)=9.576$, $p<0.001$) and PPC (adjusted R^2=0.043, $F(3, 141)=3.101$, $p=0.029$) showed a significant model. The overall model fit for delivery care and PPC

was13.0% and 8.6% respectively. Ethnicity was significantly related to travel time for delivery care and PPC (β=0.343, p<0.001 and β=0.224, p=0.010 respectively), not documentation status or feelings of fear. Please see Table-25 for more details.

TABLE 25: SUMMARY OF MULTIPLE REGRESSION RESULTS WITH DOCUMENTATION STATUS, ETHNICITY AND FEELINGS OF FEAR AS INDEPENDENT VARIABLES AND LOG TRANSFORMED TRAVEL TIME FOR ANC, DELIVERY CARE, AND PPC AS DEPENDENT VARIABLES

Independent Variables	B	SE B	β	t	p
ANC					
Documentation Status	0.107	0.074	0.083	1.451	0.148
Ethnicity	0.182	0.071	0.145	2.578	0.010
Feelings of Fear	0.018	0.098	0.010	0.187	0.851
Delivery Care					
Documentation Status	-0.062	0.116	-0.036	-0.532	0.595
Ethnicity	0.465	0.093	0.343	5.022	<0.001
Feelings of Fear	-0.105	0.120	-0.059	-0.869	0.386
PPC					
Documentation Status	-0.223	0.126	-0.150	-1.773	0.078
Ethnicity	0.257	0.098	0.224	2.625	0.010
Feelings of Fear	0.128	0.124	0.094	1.063	0.290

B= unstandardized beta coeff.
SE B=standard error
β=standardized beta coeff
t=t-test statistic
P = significance value
Ethnicity = Ethnic group of respondent, Rohingya or Chin
Documentation Status = Documentation Status of respondent, Asylum Seeker or Refugee

After excluding the outlier, relationships between documentation status and experiencing fear using the general linear model univariate analysis of variance (GLM UNIANOVA) did not reveal a significant interaction effect for travel time for ANC $F(1, 324) = 0.083$, $p = 0.774$), delivery care $F(1, 191) = 1.867$, $p = 0.173$), and PPC ($F(1, 136) = 0.130$, $p = 0.719$).

However, the GLM UNIANOVA analysis (after excluding outliers) revealed significant interaction effect between ethnicity and feeling fearful for travel time for ANC $F(1, 324) = 4.118$, $p = 0.043$), delivery care $F(1, 191) = 10.656$, $p = 0.001$), and PPC ($F(1, 135) = 10.765$, $p=0.001$).

The GLM UNIANOVA test showed a statistically significant difference in travel time for ANC between Rohingyas and Chins who experienced fear. Among those who felt fearful, Chins had a statistically significantly greater log transformed travel time

(M=3.108, SE=0.048) than Rohingyas (M=2.869, SE=0.048), F(1, 324) = 9.952, p = .002, partial η2 =0.003.

For travel time for delivery care, among those who felt fearful, Chins (M=3.463, SE=0.073) had a statistically significantly greater log transformed travel time than Rohingyas (M=2.864, SE=0.073), F(1, 191) = 36.621, p <0.001, partial η2 = 0.161.

For PPC travel time too, among those who felt fearful, Chins (M=3.243, SE=0.088) had a statistically significantly greater log transformed travel time than Rohingyas (M=2.821, SE=0.076), F(1, 135) = 15.317, p <0.001, partial η2 =0.102.

A cross-tabulation of travel mode by ethnicity and those who felt / did not feel fearful showed that a higher proportion of Rohingyas than Chins who felt fearful traveled by taxis (48.4% versus 44.6%), their own/their friend's car (1.6% versus 0.0%), and their own motorbike (22.2% versus 0.0%). On the other hand, a higher proportion of Chins than Rohingyas who were fearful walked (33.9% versus 5.6%), and used the LRT (100.0% versus 0.0%).

Further, a cross tabulation of travel mode by and those who lived below/above the poverty line income of RM 763 per month showed that a higher proportion of Chins than Rohingyas who walked lived below the poverty line income of RM 763 per month (30.0% versus 7.1%).

6.3.7 Physical Accessibility: Summary of Results and Conclusions

The variable to assess physical access is travel time. The examination of results related to the travel time considered the related difficulties of (i) the refugee protection environment and its ability to trigger anxiety provoking incidents; (ii) the intrapersonal dimension of negative emotions and fears of the respondent related to the unfavorable protection environment; and (iii) transportation.

Table-26 at the end of this section gives the summary of variables analyzed for the section on physical access and the significance of the independent variable in relation to physical access.

The analysis of physical access shows that ethnicity was significantly related to more dependent variables than documentation status. In six out of eight analyses, documentation status was significantly related to the dependent variables only when ethnicity was also significant. Only in two analyses was documentation status significantly related to the dependent variables independently of ethnicity. This indicates the importance of ethnicity and its predominance among the two independent variables in terms of physical access in general, and the specific influence of documentation status in terms of particular barriers to physical access.

Documentation status was particularly associated with feelings of fear, anxiety provoking incidents, and travel mode. A higher proportion of asylum seekers (than refugees) experienced fear when traveling to obtain maternal health care. Asylum seekers' odds of feeling fearful were 3.5 times greater than those of refugees. Conversely, a higher proportion of refugees did not have feelings of fear or experience an anxiety incident compared to asylum seekers.

Documentation status was also related to the transportation used while traveling to obtain maternal health care. A higher proportion of asylum seekers than refugees walked whereas a higher proportion of refugees used taxis and had their own motorbikes.

There was no significant difference in the travel time of refugees and asylum seekers for ANC, delivery care, and PPC.

This seems to suggest that asylum seekers experienced more barriers than refugees in terms of experiencing insecurity while traveling to obtain maternal health care and in the travel mode used.

In terms of ethnicity, a higher proportion of Rohingyas (than Chins) experienced fear when traveling to obtain maternal health care. However, an analysis of anxiety provoking incidents corresponding to the fears of the study population showed that a higher proportion of Chins (rather than Rohingyas) experienced being stopped by enforcement authorities and getting lost. Rohingyas' odds of not having anxiety provoking incidents (such as being stopped by enforcement authorities, getting lost, getting robbed and experiencing violence variously) was 1.9 times more than that of Chins. A lower proportion of Rohingyas did not experience feelings of fear or have

an anxiety provoking incident compared to Chins, while a higher proportion of Chins experienced both fear and anxiety incidents. This could be because, unlike the Rohingyas who have a much longer duration of residence in the country, ethnic Chins are wont to be more easily identifiable as "foreigners", are less proficient in Bahasa Malaysia, and do not share the same religion as the dominant population in Malaysia.

Chins seemed to experience other barriers to physical access. The mean travel time for ANC and delivery care was higher for Chins than for Rohingyas. Ethnicity was significantly related to travel time for delivery care and PPC. When a third independent variable, feelings of fear, was added to the list of independent variables, the analysis showed that ethnicity continued to be significantly related to travel time vis-à-vis documentation status. However, ethnicity was related to feelings of fear. Among those who felt fearful, Chins had a significantly greater travel time for ANC, delivery care and PPC.

This could be explained by the results which show that a higher proportion of Rohingyas than Chins who felt fearful traveled by taxis, their own/their friend's car, and their own motorbike. On the other hand, a higher proportion of Chins than Rohingyas who were fearful walked, and used the LRT. The analysis of travel mode also showed that a higher proportion of Chins than Rohingyas who walked lived below the poverty line income of RM 763 per month.

Although it may appear that only asylum seekers and Chins had difficulties with physical access in the form of travel time, feelings of fear, anxiety provoking incidents and modes of transportation, the results reveal that physical access was problematic for the study population in general. The experience of fear was quite pervasive with about 86.0% of the study population reporting feelings of fear while traveling to obtain maternal health care. Additionally, a little more than half the study population had experienced between one and four anxiety provoking incident(s). Close to half the study population reported the experience of being stopped by enforcement authorities.

The higher odds of asylum seekers experiencing feelings of fear and of Chins having an anxiety provoking incident exacerbates for these two sub-populations the

ongoing related difficulties of physical access encountered by the study population in general.

TABLE 26: SUMMARY OF PHYSICAL ACCESS AND SIGNIFICANCE OF INDEPENDENT VARIABLES

Dependent Variable	Higher Value of Dependent Variable and/or Higher Proportion of Study Population Sub-Groups	Analysis	Significance of Independent Variable	
			Documentation Status	Ethnicity
Travel time	Chins	Independent samples t-test	p=n.s.	✓
Feelings of fear	Asylum seekers & Rohingyas	Two sided Fisher's Exact Test	✓	✓
Reasons for fear-Stopped by authorities	Asylum seekers	Two sided Fisher's Exact Test	✓	p=n.s.
Reasons for fear-Getting robbed	Rohingyas	Two sided Fisher's Exact Test	p=n.s.	✓
Reasons for fear-Physical & sexual violence	Rohingyas	Two sided Fisher's Exact Test	p=n.s.	✓
Relation between documentation status and ethnicity with feelings of fear	Asylum seekers	Logistic regression	✓	p=n.s.
Relation between self-reported level of fear/anxiety regarding travel for maternal health care with documentation status and ethnicity	Asylum seekers odds of feeling fearful was 3.5 times greater than that of refugees	Chi sq.	✓	✓
Relation between anxiety incidents with documentation status and ethnicity		Two sided Fisher's Exact Test	p=n.s.	✓
Type of anxiety incident-Stopped by authorities	Chins	Two sided Fisher's Exact Test	p=n.s.	✓
Type of anxiety incident-Getting lost	Chins	Two sided Fisher's Exact Test	p=n.s.	✓
Relation between documentation status and ethnicity with anxiety incident	Rohingyas' odds of not having an anxiety provoking incidents was 1.9 times more than that of Chins	Logistic regression	p=n.s.	✓
Relation between documentation status and ethnicity with combined variable including feelings of fear and anxiety incident		Chi sq.	✓	✓
Relation between documentation status and ethnicity with travel mode		Chi sq.	✓	✓

Dependent Variable	Higher Value of Dependent Variable and/or Higher Proportion of Study Population Sub-Groups	Analysis	Significance of Independent Variable	
			Documentation Status	Ethnicity
Relation between travel mode and feelings of fear		Chi sq. & Cramer's V	✓	✓
Relation between travel mode and anxiety incidents		Chi sq. & Cramer's V	✓	✓
Relation between documentation status and ethnicity with travel time	Change of ethnic identity from Rohingya to Chin increased travel time	Multiple linear regression	p=n.s.	✓
Relation between documentation status, ethnicity, and feelings of fear with travel time	Change of ethnic identity from Rohingya to Chin increased travel time for delivery care and PPC	Multiple linear regression	Doc status	p=n.s
			Ethnicity	✓
			Feelings of fear	p=n.s
Interaction between documentation status, ethnicity, and feelings of fear in relation to travel time	Among those who felt fearful, Chins had a higher travel time for ANC, delivery care and PPC than Rohingyas	GLM UNIANOVA	Doc status*Ethnicity	p=n.s
			Doc status* Feelings of fear	p=n.s
			Ethnicity* Feelings of fear	✓

6.4 ECONOMIC ACCESSIBILITY

The variable to ascertain economic access in this study is *Maternal Health Expenditure Ratio*, represented as:

$$\frac{\text{Total Maternal Health Expenditure}}{\text{Total Annual Family Expenditure less Food Costs} \,/\, (A_h + 0.5K_h)^{0.75}} \times 100$$

Total Annual Family Expenditure Less Food Costs includes the non-discretionary expenses of the family in the corresponding year of total maternal health expenditure. Family per adult equivalent expenditure is adjusted using the adult equivalence scale,$(A_h+0.5K_h)^{0.75}$ where A_h is the number of adults in the family h, and K_h is the number of children 0–14 years old [462] (p.95).

6.4 1.Maternal Health Expenditure

Maternal health expenses are categorized and analyzed as: (i) direct, indirect and total maternal health expenditures; (ii) ANC, delivery care, and PPC expenditures; and (iii) maternal health expenditures in the government, private and NGO sectors.

6.4 1.1. Direct, Indirect and Total Maternal Health Expenditure

Total Maternal Health Expenditure in this study includes direct costs (consultation fees, user payments at public and private clinics and hospitals, costs of inpatient and outpatient care and of drugs) and indirect costs (transportation and food/water costs for the day for the respondent and her companion seeking outpatient care).

Table-27 gives the distribution of direct and indirect maternal health care expenditure by documentation status and ethnicity. ANC expenses were calculated by multiplying the cost per visit by the number of ANC visits recorded in the Rekod Kesihatan Ibu.

With the exception of direct maternal health care expenditure of the Rohingya, the mean was greater than the median values for the other distributions and there was considerable variation between the minimum and maximum values, signifying the asymmetrical distribution of the data, a feature that is characteristically seen in health expenditure distributions [488]. The median total maternal health expenditure of

refugees (RM 795.00) was higher than that of asylum seekers (RM 202.00), (U= 9133.500, Z=-4.843, p<0.001) with refugees having a mean rank of 190.29 and asylum seekers having a mean rank of 136.36. There was no significant difference in the medians of the total maternal health expenditure of Chins and Rohingyas, (U=13310.500, Z=-0.881, p=0.0.378).

TABLE 27: DIRECT & INDIRECT MATERNAL HEALTH CARE COSTS (IN RM)

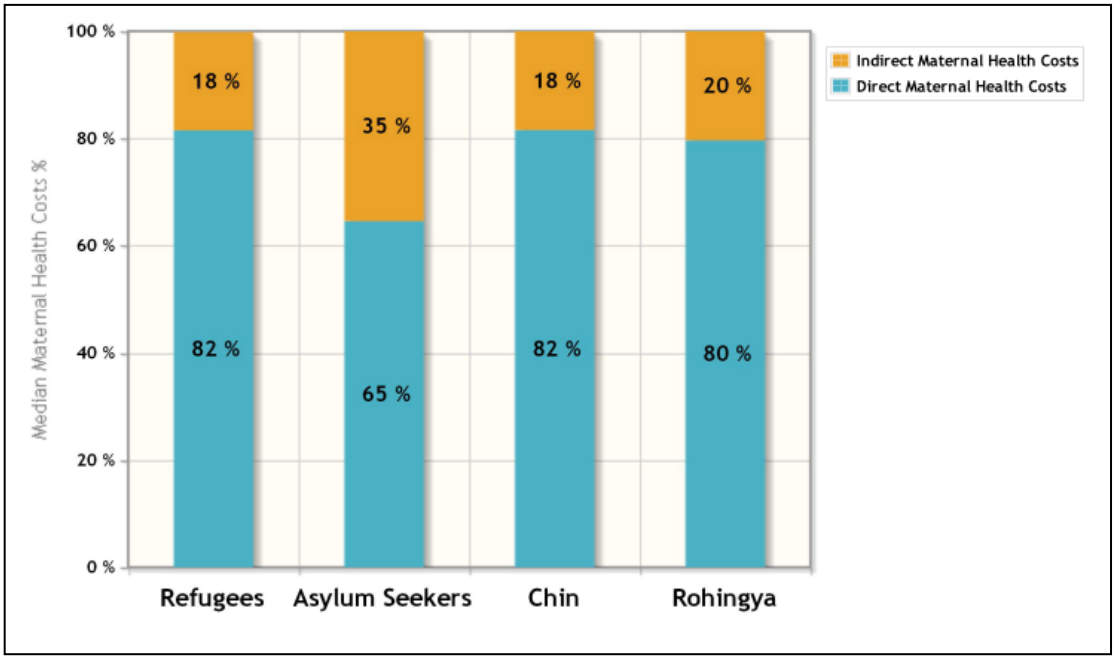
	STUDY POPULATION	BY DOCUMENTATION STATUS		BY ETHNICITY	
		Refugee	Asylum Seeker	Chin	Rohingya
N	343	219	124	201	142
Direct Maternal Health Expenditure					
Mean(SD)	587.00 (748.43)	656.00(764.94)	462.00 (704.00)	639.00(901.00)	513.00(445.00)
Median	515.00	595.00	95.00	444.0	570.00
Minimum	0.00	0.00	0.00	0.00	0.00
Maximum	7630.00	7630.00	3545.00	7630.00	2445.00
Indirect Maternal Health Expenditure					
Mean(SD)	271.00(440.00)	325.00(486.00)	175.00(321.00)	216.00(325.00)	349.00(555.00)
Median	105.00	135.00	52.00	100.00	145.00
Minimum	0.00	0.00	0.00	0.00	0.00
Maximum	4001.00	4001.00	2425.00	1894.00	4001.00
Total Maternal Health Expenditure					
Mean(SD)	858.00(972.00)	981.00(1014.00)	637.00(851.00)	854.00(1065.00)	862.00(706.00)
Median	655.00	795.00	202.00	632.50	705.90
Minimum	0.00	0.00	0.00	0.00	0.00
Maximum	9210.00	9210.00	3865.00	9210.00	5876.00

Based on median values, overall direct maternal health care costs comprised 83.06% of the total maternal health care costs. Direct maternal health expenditure was the largest contributor to total maternal health care expenditure. For refugees and asylum seekers, direct maternal health care costs comprised 81.50% and 64.62% respectively of their total maternal health care costs, while for Chins and Rohingyas the proportion of direct maternal health care expenditures to total maternal health care costs was 81.6% and 79.7% respectively. The median total direct maternal health expenditure of refugees (RM 595.00) was higher than that of asylum seekers (RM 95.00), (U=9678.000, Z=-4.220, p<0.001), with refugees having a mean rank of 187.81 and asylum seekers a mean rank of 140.83. There was no significant difference in the medians of the total maternal health expenditure of Chins and Rohingyas (U=13619.500, Z=-0.536, p=0.592),.

Total indirect maternal health care expenditure as a proportion of total maternal health care expenditure is the inverse of the direct maternal health care expenditure figures. Refugees again incurred higher median total indirect maternal health care expenditures (RM 135.00) than asylum seekers (RM 52.00), (U=9289.500, Z=-4.675, p<0.001), with refugees and asylum seekers having mean ranks of 189.58 and 137.64 respectively. The median total indirect maternal health care expenditure of the Rohingyas (RM 705.90) was higher than that of Chins (RM 632.50), (U=11665.500, Z=-2.722, p=0.006), with Rohingyas and Chins having mean ranks of 188.27 and 158.83 respectively.

Figure-12 shows the proportion of direct and indirect maternal health care expenditure for the study population, disaggregated by documentation status and ethnicity.

FIGURE 12: PROPORTION OF DIRECT & INDIRECT MATERNAL HEALTH CARE COSTS INCURRED: BY DOCUMENTATION STATUS & ETHNICITY (BASED ON MEDIAN DIRECT & INDIRECT MATERNAL HEALTH CARE VALUES)



Re-examining Differences in Maternal Health Expenditure

Although the examination of maternal health care costs showed that on the whole, refugees incurred higher costs than asylum seekers, data on utilization of services indicated that the majority of the refugees (72.6%) had delivered recently and had obtained adequate attendance in ANC (79.8%).

Given the possible influence of confounding covariates like delivery status and adequacy of care, total maternal health care expenditure was adjusted through stratification on confounders and re-examined. The results of the Mann-Whitney U test showed that after controlling for delivery status, there was no significant difference between the median maternal health care expenditures of refugees and asylum seekers, although their median maternal health care expenditures were RM 1069.00 and RM 1297.00 respectively, (U=2807.500, Z=-1.797, p=0.072).

However, after controlling for adequacy of care, asylum seekers had higher median maternal health care expenditures (RM =1375.25) than refugees (RM 1115.50), (U=1949.500, Z=-2.196, p=0.028) with refugees and asylum seekers having mean ranks of 85.23 and 106.35 respectively.

6.4 1.1. ANC, Delivery Care and PPC Costs

Table-28 provides the descriptive statistics for ANC, delivery care and PPC expenses. Median values are provided because of the considerable level of dispersion in data. In general, delivery costs exceeded ANC and PPC expenditures.

TABLE 28: ANC, DELIVERY, AND PPC COSTS (IN RM)

	STUDY POPULATION	BY DOCUMENTATION STATUS		BY ETHNICITY	
		Refugee	Asylum Seeker	Chin	Rohingya
ANC **Cost**					
N* [α]	331	214	117	194	137
Mean(SD)	304.00(404.00)	340.00(431.00)	238.00(342.00)	247.00(329.00)	384.00(482.00)
Median	150.00	161.25	120.00	122.50	215.00
Minimum	0.00	0.00	0.00	0.00	0.00
Maximum	2970.00	2970.00	2450.00	2160.00	2970.00
Delivery Cost					
N [β]	201	158	43	105	96
Mean(SD)	829.00(589.00)	757.00(508.00)	1095.00(772.00)	958.00(599.00)	689.00(546.00)
Median	660.00	620.00	1042.00	800.00	603.50
Minimum	0.00	0.00	0.00	0.00	0.00
Maximum	4816.00	4816.00	3580.00	3580.00	4816.00
PPC Cost					
N [δ]	140	116	24	53	87
Mean(SD)	67.00(181.00)	70.004(195.00)	53.00(89.00)	138.00(274.00)	24.00(48.00)
Median	15.00	15.00	19.00	25.00	13.00
Minimum	0.00	0.00	0.00	0.00	0.00
Maximum	1435.00	1435.00	425.00	1435.00	315.00

[α] Excluded those who did not have ANC

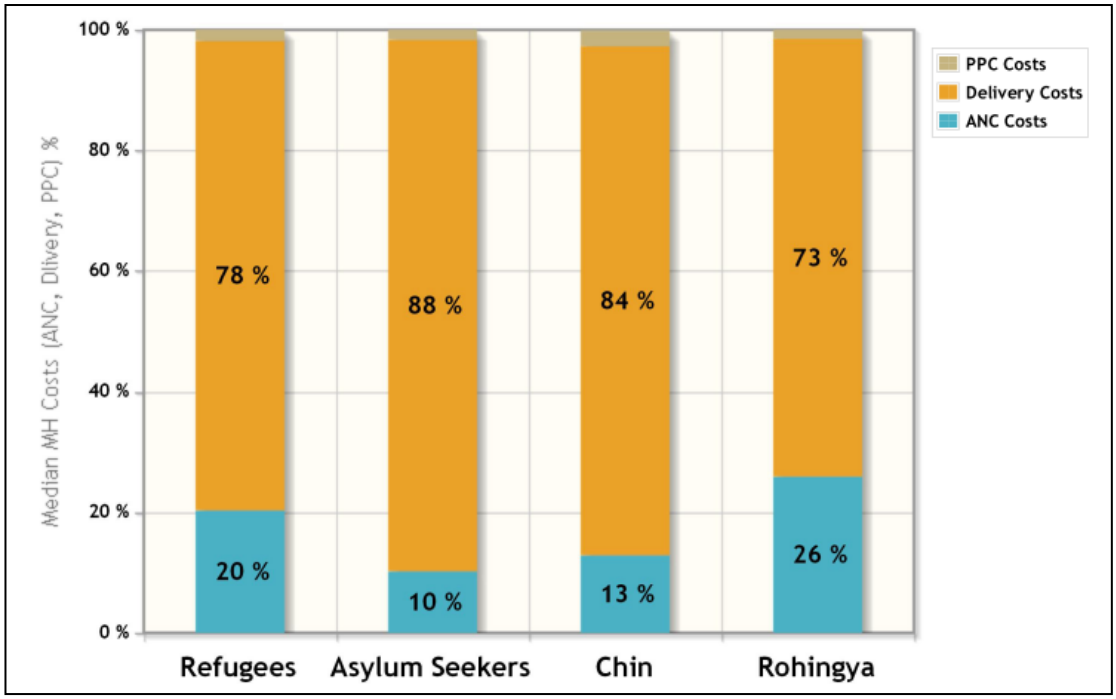
[β] Included those who delivered and excluded one case which included neonatal health costs in delivery costs

[δ] Included those who received PPC and excluded 5 cases which added neonatal health costs in PPC costs

The median total ANC expenditure of refugees was higher than that of the asylum seekers (U= 10068.000, Z=-2.945, p=0.003) with refugees having a mean rank of 177.45 and asylum seekers 145.05. The median total ANC expenditure for the Rohingyas was higher than that of the Chins (U=10770.000, Z=-2.938, p=0.003) with Rohingyas having a mean rank of 184.39 and Chins having a mean rank of 153.02.

Similarly, the median delivery expenditure of refugees was lower than that of the asylum seekers (U= 2199.500, Z=-3.541, p<0.001) with refugees having a mean rank of 93.42 and asylum seekers 128.85. The median delivery expenses of the Rohingyas was lower than that of the Chins (U=3320.000, Z=-4.176, p<0.000) with Rohingyas having a mean rank of 83.08 and Chins having a mean rank of 117.38.

FIGURE 13: PROPORTION SPENT ON ANC, DELIVERY & PPC MATERNAL HEALTH CARE COSTS BY DOCUMENTATION STATUS & ETHNICITY (BASED ON ANC, DELIVERY & PPC EXPENDITURE VALUES)



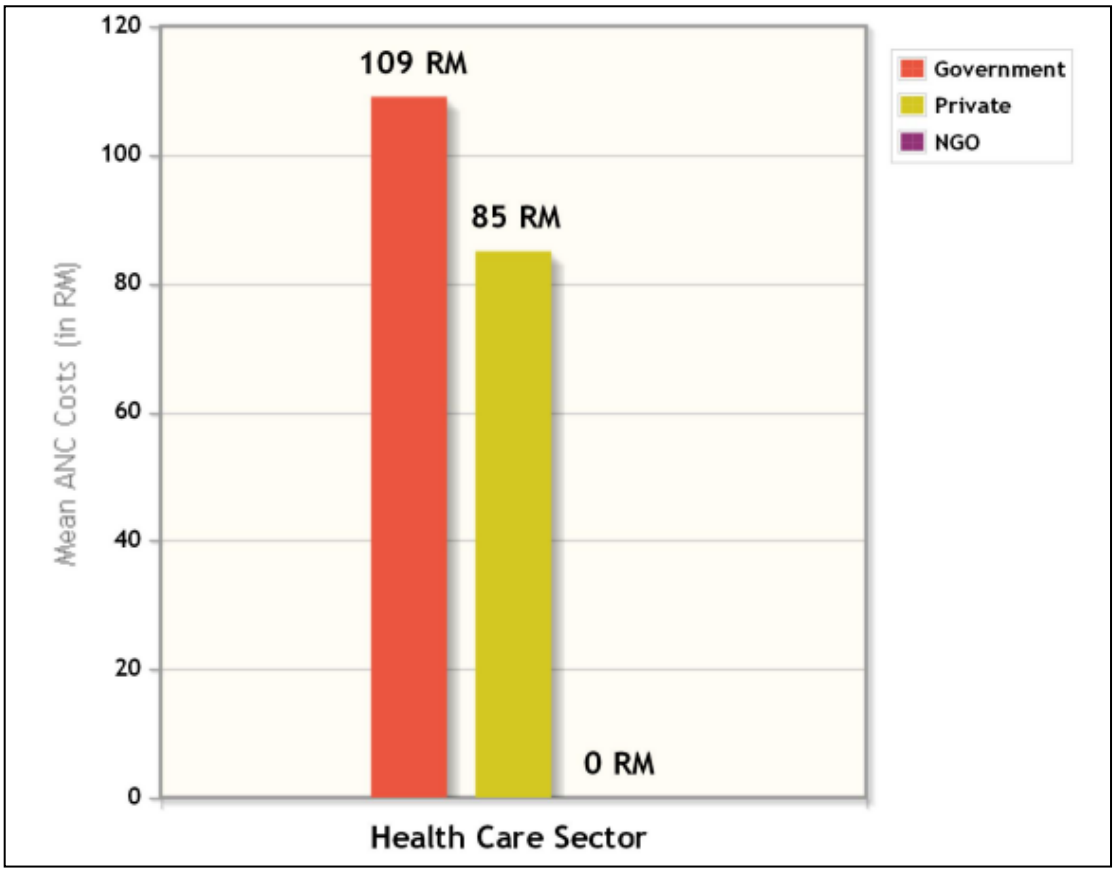
With regard to PPC costs, the median PPC expenses of the Rohingyas was lower than that of the Chins (U=1530.000, Z=-3.356, p=0.001) with Rohingyas having a mean rank of 61.59 and Chins having a mean rank of 85.13. The Mann Whitney U test did not show a significant difference between the median PPC costs of refugees and asylum seekers, (U=1204.000, Z=-1.047, p=0.295.

6.4.1.2. Maternal Health Expenditures in the Government, Private and NGO Health Sectors

Out of the 343 respondents, 259 obtained ANC in the government sector while 13 and five respondents sought ANC care in the private and NGO health sectors respectively. The remaining 54 sought a combination of care in the government, private and NGO sectors while 12 did not obtain ANC (see Section 6.6 on Utilization of Maternal Health Care for more details).

Of those who delivered, five delivered in a private hospital and there were five home deliveries; the rest (n=192) had an institutional delivery in a government hospital.

FIGURE 14: MATERNAL HEALTH CARE COSTS BY SECTOR (GOVERNMENT, PRIVATE, NGO)



The difference in the maternal health care expenditures in the government, private and NGO health care sectors are given in Figure 14 and Table-71 in Appendix -6.

Since the objective was to compare costs in the three sectors, only direct maternal health care costs (consultation fees, user payments at public and private clinics and

hospitals, costs of inpatient and outpatient care and of drugs) were included. Additionally, only respondents who had sought care exclusively in either the government, private and NGO sectors were included in the analysis. Those who had sought a combination of care in different sectors and who had not sought care were excluded from the analysis.

With regard to delivery, there were no deliveries in the NGO sector and home delivery costs were excluded from the analysis.

Maternal health costs in the private sector were lower than the government sector because women who lacked financial means could choose to not undergo various medical investigations. This helped them to contain their ANC costs.

6.4.2. Annual Family Expenditure Patterns

The items for the annual family expenditure were culled from the 12 main groups of goods and services in the Household Expenditure Survey Report 2009/10 of Malaysia [489], which were relevant to refugees and asylum seekers in Malaysia. These included: (i) housing; (ii) water; (iii) electricity; (iv) gas; (v) food; (vi) clothing and footwear; (vii) transport costs; (viii) communication costs (mobile phone); (ix) alcoholic beverages; (x) general health care costs; (xi) self-medication; (xii) education costs; and (xiii) recreation costs. Maternal health care expenditures were excluded from the annual family household expenditures. Respondents were asked to provide information on these expenditures incurred for the family unit per month. The annual family expenditure was computed by multiplying the monthly family expenditure by 12.

These family expenditure patterns are provided in Table-29. The contrasting annual income pattern is given in Table-30.

Tables 29 and 30 show that the median annual income exceeds median annual family expenditure. The median annual family expenditure of refugees (RM 9,780.00) was higher than that of the asylum seekers (RM 8,610.00), ($U= 10207.500$, $Z=-3.820$, $p<0.001$), with a refugees having a mean rank of 187.39 and the mean rank of asylum seekers being 144.82. In terms of ethnicity, Rohingyas (Median= RM 10,290.00; mean rank=195.58) had a higher median annual family

expenditure than Chins (Median=9,000.00; mean rank=155.34), (U=10923.000, Z=-3.702, p<0.001).

TABLE 29: ANNUAL FAMILY EXPENDITURE PATTERN (IN RM)

	STUDY POPULATION	BY DOCUMENTATION STATUS		BY ETHNICITY	
		Refugee	Asylum Seeker	Chin	Rohingya
Total Annual Family Expenditure					
N	343	219	124	201	142
Mean(SD)	10,208.00 (4392.00)	10,706.00 (4370.00)	9,328.00(4311.00)	9532.00 (3834.00)	11,165.00 (4936.00)
Median	9240.00	9780.00	8610.00	9000.00	10290.00
Minimum	0.00	0.00	0.00	0.00	0.00
Maximum	37,080.00	37,080.00	29400.00	27000.00	37080.00
Total Annual Family Expenditure Less Food Costs					
Mean(SD)	5,567.00 (2673.00)	5, 881.00 (2752.00)	6.5	5 486.00 (2395.00)	5,682.00 (3028.00)
Median	4920.00	5280.00	4560.00	5040.00	4620.00
Minimum	0.00	0.00	0.00	0.00	0.00
Maximum	21120.00	21120.00	15360.00	15360.00	21120.00

TABLE 30: ANNUAL FAMILY INCOME (IN RM)

	STUDY POPULATION	BY DOCUMENTATION STATUS		BY ETHNICITY	
		Refugee	Asylum Seeker	Chin	Rohingya
N	343	219	124	201	142
Mean(SD)	11,758.00(6378.00)	12,496.00(6465.00)	10,455.00(6028.00)	10,294.00(5460.00)	13,829.00(7001.00)
Median	10800.00	10800.00	9600.00	9600.00	12000.00
Minimum	0.00	0.00	0.00	0.00	0.00
Maximum	57600.00	57600.00	48000.00	48000.00	57600.00

Similarly, at the 0.05 level of significance there was evidence to prove that there is a difference in the median annual nonfood family expenditures between refugees (RM 5280.00; mean rank=185.38) and asylum seekers (RM 4560.00; mean rank=148.37), (U=10647.500, Z=-3.322, p=0.001). The data does not provide evidence that the difference in the median annual nonfood family expenditure of Rohingyas (RM 4620.00; mean rank=170.11) and Chins (RM 5040.00; mean rank=173.34), (U=14002, Z=-0.297, p=0.766) was statistically significant.

There was a significant difference between the median annual family income of refugees (RM 10,800.00) and asylum seekers (RM 9,600.00), (U=10001.500, Z=-4.073, p<0.001; refugee mean rank=188.33; asylum seeker mean rank=143.16). Chins (RM 9,600.00) had a lower median annual family income than Rohingyas (RM

12,000.00), (U=7624.500, Z=-7.383, p<0.001; Rohingya mean rank=218.81, Chin mean rank=138.93).

Re-examining Differences in Annual Family Expenditure, Annual Family Non Food Expenditure and Annual Family Income after Controlling for Family Size

The analysis of annual family expenditure and income showed a significant difference between Chins and Rohingyas, and refugees and asylum seekers. The higher annual family expenditure of Rohingyas and refugees suggests that Rohingya refugees had a higher annual family expenditure than others.

On the other hand, there was a significant difference only in the mean annual family non-food expenditure between refugees and asylum seekers.

There was also a significant difference in the mean annual family income between Chins and Rohingyas, and refugees and asylum seekers with refugees and Rohingyas having higher mean annual family incomes.

Given that the Rohingyas had a higher mean family size (mean=4) than Chins (mean=3), and that family size could impact annual family expenditures, a re-examination of annual family expenditure, annual family non-food expenditure, and annual family income was undertaken through the process of stratification on confounders [487] by controlling for family size of less than four members.

The results of this analysis showed that after controlling for family size, with regard to annual family expenditure, asylum seekers continued to have a lower median annual family expenditure (median= RM 8,100.00; mean rank=111.54) than refugees (median= RM 9,000.00; mean rank=141.61), (U=6104.000; Z=-3.145, p=0.002). Chins (median= RM 8,220.00; mean rank=155.34) too continued to have a lower median annual family expenditure than Rohingyas (median= RM 9,240.00; mean rank=195.58), (U=10923.000, Z=-3.702, p<0.001).

With regard to annual family non-food expenditure, there was a significant difference in the median values between refugees (median= RM 4,800.00; mean rank=140.15) and asylum seekers (median= RM 4,400.00; mean rank=113.86), (U=6336.000, Z=-2.750, p=0.006), and no significant difference between Chins (median= RM 4,920.00) and Rohingyas (RM 4,260.00), just as before controlling for family size.

In relation to median annual family income too, there was a significant difference (U=6231.500, Z=-2.949, p=0.003) between refugees (median= RM 10,800.00; men rank=140.81) and asylum seekers (median= RM 9,600.00; mean rank=112.82),and between Rohingyas (median= RM 12,000.00; mean rank=218.81) and Chins (median= RM 9,600.00; mean rank=138.93), (U=7624.500, Z=-7.383, p<0.001), as before controlling for family size.

6.4.3. Maternal Health Expenditure Ratio

The *Maternal Health Expenditure Ratio* is represented as:

$$\frac{\text{Total Maternal Health Expenditure}}{\text{Total Annual Family Expenditure less Food Costs} \,/\, (A_h + 0.5K_h)^{0.75}} \times 100$$

The descriptive statistics for maternal health expenditure ratio are given in Table-31. Given the large standard deviations, median values have also been provided. In addition, seven respondents who were extreme outliers were excluded. Additionally, since payments made with support from extended family and others are to be treated as a form of insurance [490] and protection against reduced consumption of other goods and services in the short term [351], and thus, do not count as out of pocket payments for health care, respondents who received donations from family, friends and others were excluded from the analysis. Additionally, those who did not obtain care and those whose per anum family expenditure was zero were excluded from the analysis[356].

Refugees (median=34.98; mean rank=166.08) had a higher median maternal health expenditure ratio compared to asylum seekers (median=8.41; mean rank=118.67), (U=6919.500, Z=-4.568, p<0.001). There was also a difference between the median maternal health expenditure ratios of Rohingyas (median=22.99; mean rank=161.27) and Chins (median=22.99; mean rank=140.44), (U=9177.500,Z=-2.057, p=0.040). See Table-31.

TABLE 31: MATERNAL HEALTH EXPENDITURE RATIO

	STUDY POPULATION	BY DOCUMENTATION STATUS		BY ETHNICITY	
		Refugee	Asylum Seeker	Chin	Rohingya
N	297	190	107	175	122
Mean(SD)	35.53 (34.48)	39.88 (32.28)	27.80 (36.99)	33.06 (34.99)	39.07 (33.57)
Median	28.24	34.98	8.41	22.99	34.40
Minimum	0.38	0.38	0.00	0.00	0.00
Maximum	169.23	150.55	169.23	169.22	150.55

Since the results indicated that refugees had higher annual family expenditures and incomes, maternal health expenditures, and maternal health expenditure ratios, suggesting that they could be marginally better off than asylum seekers, a correlation and linear regression analysis was carried out to further explore if documentation status provided an advantage for better economic access.

6.4.4. Relation between Maternal Health Expenditure Ratio with Documentation Status and Ethnicity

To examine if there was any relationship between maternal health expenditure ratio and documentation status or ethnicity, Pearson's correlation was applied. The correlation revealed a weak relationship between documentation status and maternal health expenditure ratio ($r=0.168$, $p=0.004$, $n=297$). A weak negative correlation was revealed for maternal health expenditure ratio and ethnicity, but it was not statistically significant ($r= -0.086$, $p=0.139$, $n=297$).

Having established a significant though weak association between maternal health expenditure ratio and documentation status, an examination of the relationship between documentation status and maternal health expenditure ratio was undertaken. In like manner, though the association between maternal health expenditure ratio and ethnicity was weak and not significant, the relationship between ethnicity and maternal health expenditure ratio was explored as per the research questions set out in the study proposal.

Linear regression analysis was applied to the data to examine the effects of documentation status and ethnicity on maternal health expenditure ratio. Though the result of regression analysis of documentation status on maternal health expenditure ratio was significant at the $p < 0.05$ level, examination of the histogram and the p-p

plot of standardized residuals indicated that the residuals were not normally distributed. The regression analysis was therefore repeated after performing a log transformation of the maternal health expenditure ratio data. The histogram and the p-p plot of the standardized residuals after transformation of the data were fairly normally distributed (skewness= -0.591, kurtosis= -0.283).

The regression was a rather poor fit (R^2 = 9.0%), but the overall relationship between documentation status and maternal health expenditure was significant (F(2,291) = 14.216, p< 0.001). Documentation status was significantly related to maternal health expenditure ratio (β=0.260, p<0.001) while ethnicity (β=-0.095, p=-0.095) was not. A move from the status of asylum seeker to refugee was expected to increase the maternal health expenditure ratio by 0.758 units. See Table-32 for details.

This supports the earlier observation that refugees may be expected to spend more on maternal health than asylum seekers.

TABLE 32: SUMMARY OF MULTIPLE REGRESSION RESULTS WITH DOCUMENTATION STATUS AND ETHNICITY AS INDEPENDENT VARIABLES AND LOG TRANSFORMED MATERNAL HEALTH EXPENDITURE RATIO AS DEPENDENT VARIABLE

Independent Variables	B	SE B	β	t	p
Documentation Status	0.758	0.169	0.260	4.481	<0.001
Ethnicity	-0.270	0.165	-0.095	-1.639	0.102

B= unstandardized beta coeff.
SE B=standard error
β=standardized beta coeff
t=t-test statistic
P = significance value
Ethnicity = Ethnic group of respondent, Rohingya or Chin
Documentation Status = Documentation Status of respondent, Asylum Seeker or Refugee

The interaction between documentation status and ethnicity was examined by adding a product term, documentation status and ethnicity, to the regression model. No significant interaction effect was found F(1, 288) = 1.310, p = .253.

Given that there are various factors that influence the cost of maternal health care, e.g. if the respondent had delivered or was pregnant at the time of the interview, or if she had obtained adequate or inadequate attendance in ANC, an examination of the confounding effect of these factors was undertaken through the process of stratification of confounders[487].

6.4 4.1 Delivery Status as Possible Confounder

As those who had delivered recently would have incurred higher maternal health expenses than those who were only pregnant, linear regression analysis was applied to examine the effects of documentation status and ethnicity on the log transformed maternal health expenditure ratio while controlling for those who had delivered.

Using the enter method, a weak (R^2 = 3.5%) but significant model emerged (adjusted R^2=0.023, $F(2,169)=3.042$, p=0.05) which showed that documentation status (β=-0.187, p=-0.015) was still significantly related to maternal health expenditure ratio vis-à-vis ethnicity. See Table-33 for details.

TABLE 33: SUMMARY OF MULTIPLE REGRESSION RESULTS WITH DOCUMENTATION STATUS AND ETHNICITY AS INDEPENDENT VARIABLES AND LOG TRANSFORMED MATERNAL HEALTH EXPENDITURE RATIO AS DEPENDENT VARIABLE AFTER CONTROLLING FOR DELIVERY STATUS

Independent Variables	B	SE B	β	t	p
Documentation Status	-0.264	0.107	-0.187	-2.454	0.015
Ethnicity	-0.009	0.088	-0.008	-0.101	0.920

B= unstandardized beta coeff.
SE B=standard error
β=standardized beta coeff
t=t-test statistic
P = significance value
Ethnicity = Ethnic group of respondent, Rohingya or Chin
Documentation Status = Documentation Status of respondent, Asylum Seeker or Refugee

6.4 4.2 Medical Risk as a Possible Confounder

Given that the presence of medical risks during pregnancy might warrant an increase in the number of ANC visits and thus escalate maternal health costs, medical risks were controlled and a regression analysis was repeated to assess the relationship between maternal health expenditure ratio with documentation status and ethnicity.

The regression results showed that a significant model (adjusted R^2=0.055, $F(2,184)=6.417$, p=0.002). The overall model fit was R^2 = 6.5%. In this analysis, when controlling for medical risks, both documentation status (β=0.154, p=0.040)and ethnicity (β=-0.164, p=0.029) were significantly related to maternal health expenditure ratio. Table-34 has the details.

TABLE 34: SUMMARY OF MULTIPLE REGRESSION RESULTS WITH DOCUMENTATION STATUS AND ETHNICITY AS INDEPENDENT VARIABLES AND LOG TRANSFORMED MATERNAL HEALTH EXPENDITURE RATIO AS DEPENDENT VARIABLE AFTER CONTROLLING FOR MEDICAL RISKS

Independent Variables	B	SE B	β	t	p
Documentation Status	0.463	0.224	0.154	-2.068	0.040
Ethnicity	-0.463	0.210	-0.164	-2.204	0.029

B= unstandardized beta coeff.
SE B=standard error
β=standardized beta coeff
t=t-test statistic
P = significance value
Ethnicity = Ethnic group of respondent, Rohingya or Chin
Documentation Status = Documentation Status of respondent, Asylum Seeker or Refugee

A move in ethnicity status from Rohingya to Chin was expected to decrease the maternal health expenditure ratio by 0.463 units and a move in documentation status from asylum seeker to refugee is expected to increase the maternal health expenditure ratio by 0.463 units.

6.4 4.3. Adequacy of ANC Visits as Possible Confounder

TABLE 35: SUMMARY OF MULTIPLE REGRESSION RESULTS WITH DOCUMENTATION STATUS AND ETHNICITY AS INDEPENDENT VARIABLES AND LOG TRANSFORMED MATERNAL HEALTH EXPENDITURE RATIO AS DEPENDENT VARIABLE AFTER CONTROLLING FOR ADEQUACY OF VISITS

Independent Variables	B	SE B	β	t	p
Documentation Status	-0.185	0.108	-0.138	-21.707	0.090
Ethnicity	-0.086	0.089	-0.078	-0.966	0.335

B= unstandardized beta coeff.
SE B=standard error
β=standardized beta coeff
t=t-test statistic
P = significance value
Ethnicity = Ethnic group of respondent, Rohingya or Chin
Documentation Status = Documentation Status of respondent, Asylum Seeker or Refugee

After controlling for adequacy of ANC visits, multiple linear regression was used to test if documentation status and ethnicity were significantly related to maternal health expenditure ratio. The results of the regression did not reveal a significant model (adjusted R^2=0.009, $F(2,152)=1.738$, p=0.179). The overall model fit was R^2 = 2.2%. See Table-35 for details.

6.4.4.4 Annual Family Non-Food Expenditure Level as Possible Confounder

As explained previously annual family non-food expenditure includes the non-discretionary expenses of the family in the corresponding year of total maternal health care cost. Consumption expenditures are considered to be a better indicator of effective income or purchasing power. Given the wide variation in annual family non-food expenditure, study respondents were grouped into tertiles.

Since effective income (annual non-food expenditure) could influence economic access, each annual family non-food expenditure tertile (or income tertile) was controlled separately before a multiple linear regression was undertaken to assess the relationship with documentation status and ethnicity. The tertile cut-off points and mean annual family non-food expenditure of each tertile is given in Table-36.

TABLE 36: ANNUAL FAMILY NON-FOOD EXPENDITURE BY TERTILE(IN RM)

	N	Tertile Cut Off Levels	Mean Annual Family Non-Food Expenditure By Tertile
	(343)	(In RM)	(In RM)
Lowest Tertile	118	0.00-4,200.00	3,274.58
Middle Tertile @ 33.33%	112	4,201.00 - 5940.00	5,051.68
Highest Tertile@ 66.66%	113	5,941 – 21,120	8,472.42

The regression results comparing the economic access of the lowest, middle and highest tertiles are given in Table-37.

For those in the lowest annual non-food expenditure tertile, the regression results did not yield a significant model (adjusted R^2=0.063, F (2, 94) =4.236, p=0.017). The overall model fit was R^2 = 2.2%. Documentation status (β=0.154, p<0.019) and not ethnicity (β=-0.164, p<0.262) was significantly related to maternal health expenditure ratio.

For those in the middle annual non-food expenditure tertile, the regression analysis showed a significant model (adjusted R^2=0.119, F (2, 97) =7.665 p=0.001). The overall model fit was R^2 = 13.6%. Documentation status (β=0.375, p<0.001) was significantly related to maternal health expenditure ratio; ethnicity was not(β=-0.114, p<0.816).

For those in the highest annual non-food expenditure tertile, the regression analysis indicated a significant model (adjusted R^2=0.047, *F (*2, 92) =3.307, *p*=0.041). The overall model fit was R^2 = 27.2%. Neither documentation status (B=0.380, p=0.200) not ethnicity (B=-0.467, p=0.075) were significantly related to maternal health expenditure ratio.

TABLE 37: SUMMARY OF MULTIPLE REGRESSION RESULTS WITH DOCUMENTATION STATUS AND ETHNICITY AS INDEPENDENT VARIABLES AND LOG TRANSFORMED MATERNAL HEALTH EXPENDITURE RATIO AS DEPENDENT VARIABLE AFTER CONTROLLING FOR ANNUAL FAMILY NON-FOOD EXPENDITURE

Independent Variables	B	SE B	β	t	p
Lowest Tertile					
Documentation Status	0.463	0.224	0.154	-2.068	0.019
Ethnicity	-0.463	0.210	-0.164	-2.204	0.262
Middle Tertile					
Documentation Status	0.725	0.305	0.241	2.378	<0.001
Ethnicity	-0.338	0.300	-0.114	-1.129	0.816
Highest Tertile					
Documentation Status	0.380	0.294	0.135	1.291	0.200
Ethnicity	-0.467	0.260	-0.188	-1.798	0.075

B= unstandardized beta coeff.
SE B=standard error
β=standardized beta coeff
t=t-test statistic
P = significance value
Ethnicity = Ethnic group of respondent, Rohingya or Chin
Documentation Status = Documentation Status of respondent, Asylum Seeker or Refugee

6.4.6. Maternal Health Expenditure Ratio and "Catastrophic Maternal Health Expenditures"

The literature on equity in health financing generally regards the proportion of maternal health expenditure exceeding 40.0% of the annual family expenditure less food costs ("capacity to pay") as "catastrophic" [228].

Table-38 reveals that 48.9% refugees and 37.1% asylum seekers (p=0.042, two sided Fisher's exact test), whereas 40.8% Chins and 50.0% Rohingyas (p=0.099, two sided Fisher's exact test) had experienced *catastrophic maternal health expenditures*. On the whole 153(44.6%) of the study respondents had maternal health expenditures exceeding 40% of their annual family non-food expenditure. A higher proportion of refugees and Rohingyas had experienced catastrophic maternal health care expenditures.

TABLE 38: MATERNAL HEALTH EXPENDITURE AS CAPACITY TO PAY

	STUDY POPULATION		DOCUMENTATION STATUS				ETHNICITY			
			Refugee		Asylum Seeker		Chin		Rohingya	
	n	%	n	%	n	%	n	%	n	%
N	343		219		124		201		142	
Maternal health expenditure ratio <=40.0%	190	55.4	112	51.1	78	62.9	119	59.2	71	50.0
Maternal health expenditure ratio >40.0%	153	44.6	107	48.9	46	37.1	82	40.8	71	50.0

FIGURE 15: PREVALENCE OF CATASTROPHIC HEALTH EXPENDITURE: BY DOCUMENTATION STATUS & ETHNICITY

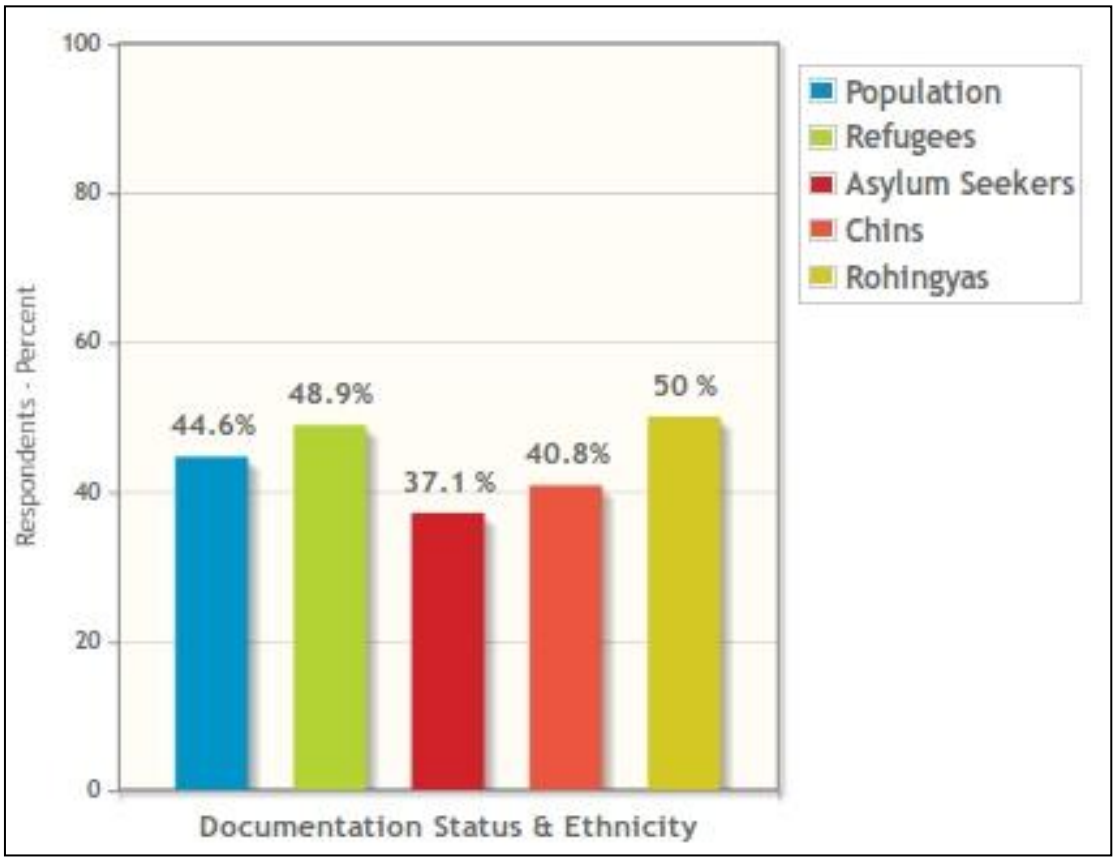
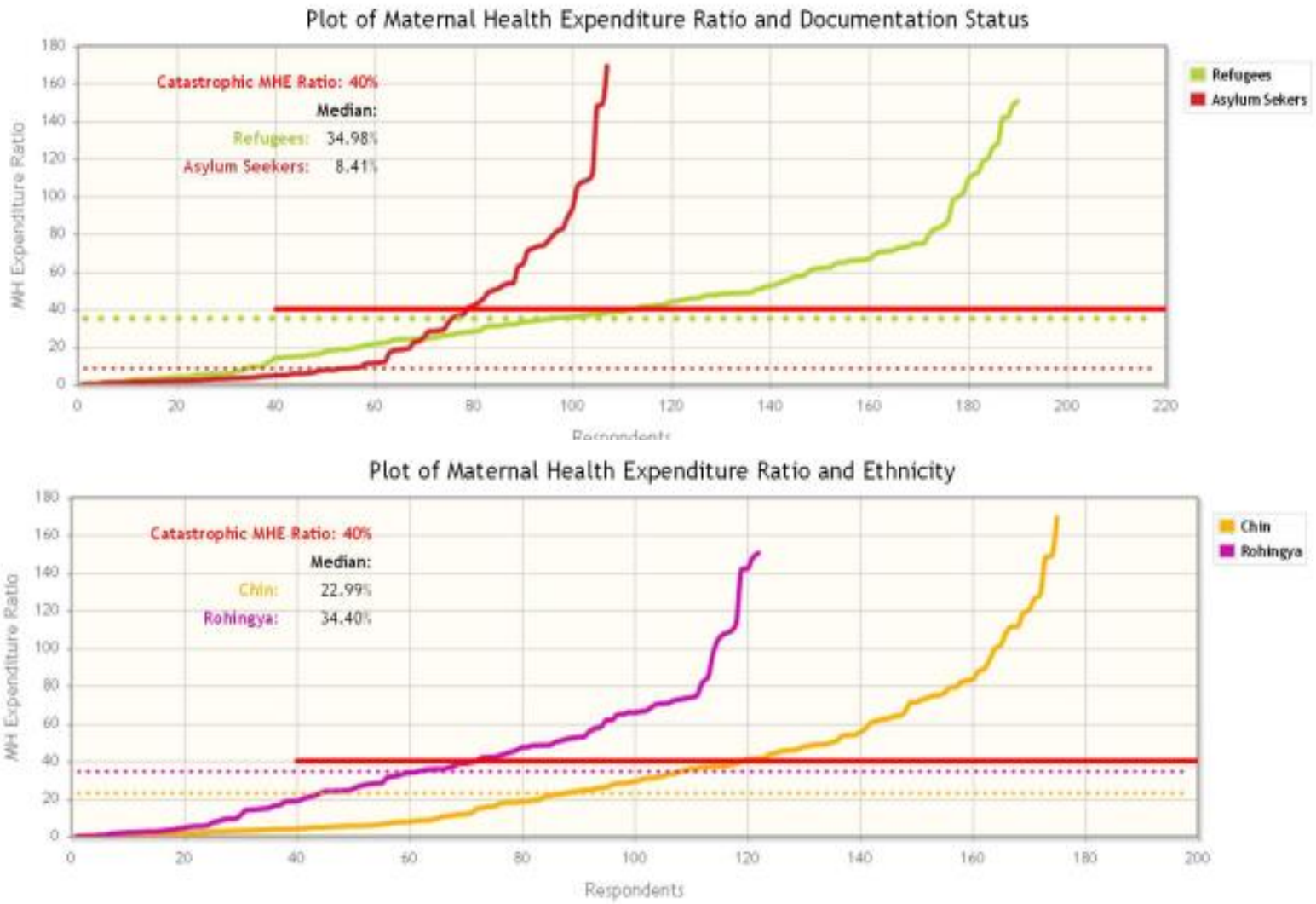


FIGURE 16: MATERNAL HEALTH EXPENDITURE RATIO: BY DOCUMENTATION STATUS & ETHNICITY



6.4.7. Maternal Health Expenditure and Poverty Head Count

Poverty head count refers to the proportion of individuals in a population living below the poverty line [491] or whose income or consumption is below the poverty line. It is a widely used measure of poverty developed by the World Bank. Using a poverty line income(PLI) of RM 763 per month defined by the 10th Malaysia Plan [492] (p.397) for Peninsular Malaysia the poverty head count was calculated before and after maternal health care expenses were deducted.

See Table-39. Prior to incurring an out of pocket maternal health expenditure, there were 91 and 75 refugees and asylum seekers respectively living below the PLI of RM 763 (and 128 and 49 refugees and asylum seekers respectively living above the RM7 63 PLI, a difference that was statistically significant (p=0.001, two sided Fisher's exact test)). After adjusting for maternal health expenses there were 130 and 92 refugees and asylum seekers respectively (p=0.002, two sided Fisher's exact test) living below the poverty line, leading to a 42.85%% and 22.67%% increase in the proportion of refugees and asylum seekers respectively living below the poverty line as a result of incurring the out of pocket maternal health expenditure.

FIGURE 17: PROPORTION OF THOSE IMPOVERISHED BEFORE AND AFTER MATERNAL HEALTH CARE EXPENDITURE WAS INCURRED (BASED ON POVERTY HEAD COUNT)

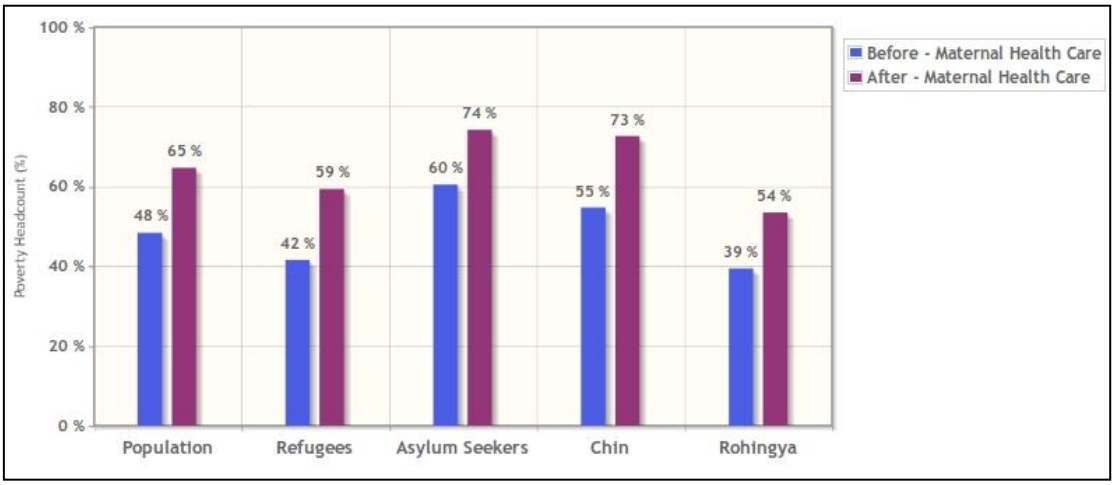


TABLE 39: POVERTY IMPACT POST MATERNAL HEALTH COST EXPENSES (PLI=RM763)

	Study Population	Refugee	Asylum Seeker	Chin	Rohingya
N	343	219	124	201	142
Below Poverty Line Head Count **BEFORE** Deduction of Maternal Health Cost	166	91	75	110	56
Below Poverty Line Head Count **AFTER** Deduction of Maternal Health Cost	222	130	92	146	76
POVERTY IMPACT Post Maternal Health Cost(% Change)	33.73	42.85	22.67	32.72	35.71

Similarly when disaggregated by ethnicity, there was a significant difference in the numbers of Chins and Rohingyas below the poverty line (110 and 56 respectively) and above the PLI of RM 763 (91 and 86 Chins and Rohingyas respectively), (p=0.004, two sided Fisher's exact test).After adjusting for maternal health expenses there were 146 and 76Chins and Rohingyas respectively (p=0.004, two sided Fisher's exact test), accounting for 32.72% and 35.71% increase in the proportion of Chins and Rohingyas respectively living below the RM 763 PLI. Figure-17 gives details of the proportions of the impoverished, before and after obtaining maternal health care.

6.4.8. Sources of Maternal Health Care Financing

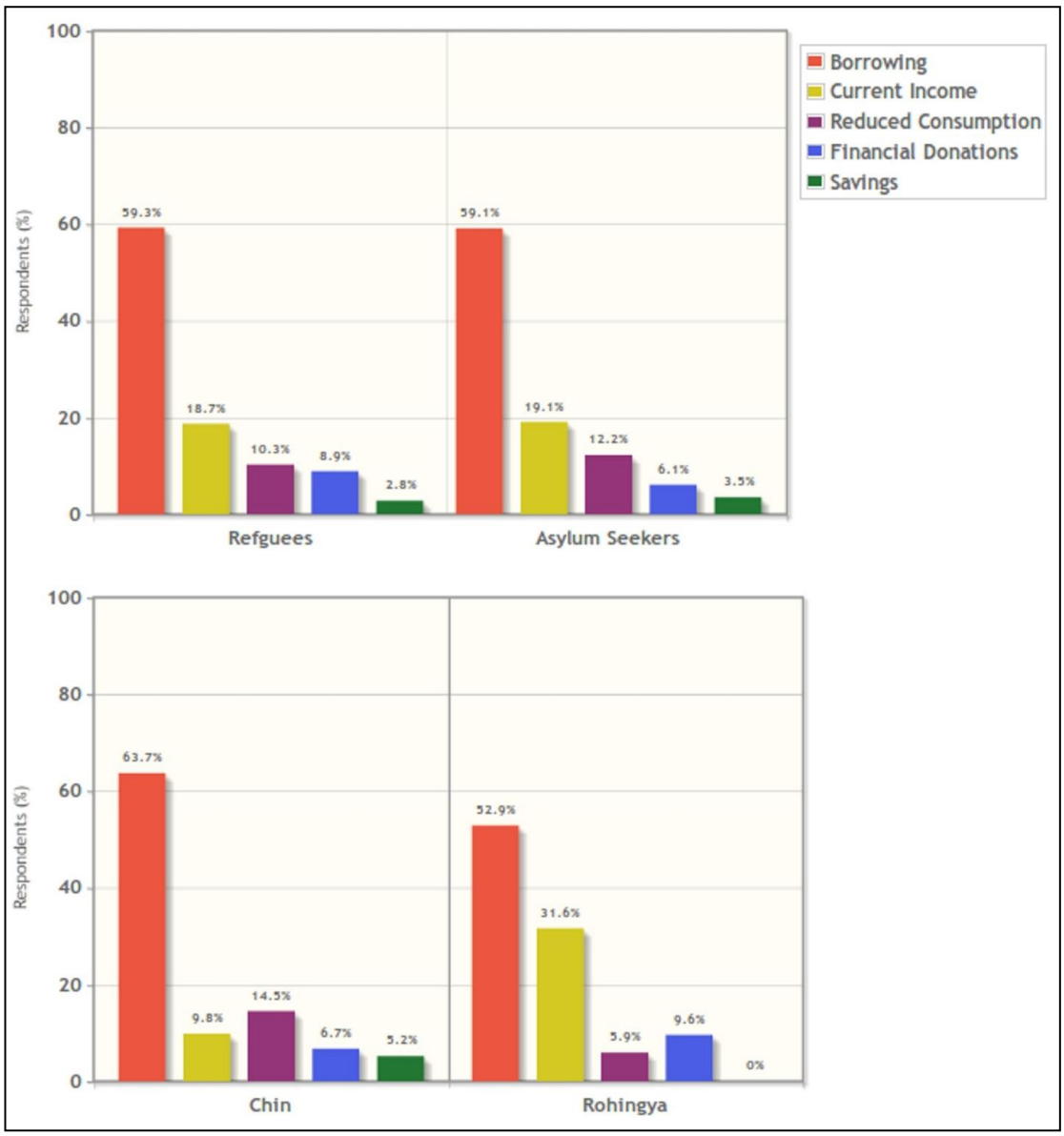
Respondents were asked about the sources of funding of their maternal health care expenses. These details are in Table-39.

TABLE 40: SOURCES OF MATERNAL HEALTH CARE FINANCING

	Study Population		Refugee		Asylum Seeker		Chin		Rohingya	
	n	%	n	%	n	%	n	%	n	%
N	329		214		115		193		129	
Borrowing	195	59.2	127	59.3	68	59.1	123	63.7	72	55.81
Current Income	62	18.8	40	18.7	22	19.1	19	9.8	43	31.6
Reduced Consumption	36	11.0	22	10.4	14	12.7	28	14.5	89	5.9
Financial Donations	26	7.9	19	9.0	7	6.4	13	6.7	13	9.6
Savings	10	3.03	6	2.8	4	3.5	10	5.2	10	0.0

As Table-40 and Figure-18 illustrate, “borrowing” was the primary source of financing of maternal health care expenditure for the majority of the respondents. A Chi Square test was performed to determine if the sources of maternal health care financing were distributed differently across the two documentation statuses and two ethnic groups. The test failed to indicate a significant difference in terms of documentation status, $\chi^2=1.310$; df=4; p=0.894. However there was a significant difference in the distribution of sources of maternal health care financing between the two ethnic groups, $\chi^2=30.483$; df=4; p<0.001.

FIGURE 18: SOURCES OF MATERNAL HEALTH CARE FINANCING



Family and friends accounted for the main source of borrowing. Of those who borrowed, about 22.8% and 33.3% refuges and 15.3% and 36.3% asylum seekers

borrowed from family and friends respectively. Similarly, 21.4% and 37.8% of Chins and 18.3% and 29.6% Rohingyas borrowed from family and friends respectively.

6.4.8. Economic Accessibility: Summary of Results and Conclusions

The variable to measure economic access, maternal health expenditure ratio, depends on the quantum of maternal health care expenditure and the annual family non-food expenditure.

Table-41 gives the summary of variables analyzed for the section on economic access and the statistical significance of the independent variable in relation to economic access.

The analysis of economic access shows that documentation status was significantly associated with more dependent variables than ethnicity. Ethnicity was significantly associated with the dependent variables only when documentation status was also significant, and not independently of documentation status.

This does indicate the importance of documentation status as the more significant of the two independent variables in terms of obtaining maternal health care. Refugees who had a valid UNHCR card incurred higher total maternal health expenditures than asylum seekers who were still awaiting the determination of their refugee status.

Asylum seekers, on the other hand, spent a higher proportion of their total maternal health care expenditure on direct costs whereas refugees spent a higher proportion than asylum seekers on indirect maternal health care expenses. This could be either (i) because refugees got a 50% discount off foreigner's rates at all State run hospitals and clinics, or (ii) because refugees having a higher annual family expenditure, annual family non-food expenditure, and annual family income than asylum seekers, had a little more capacity to pay for peripheral expenses once maternal health care costs had been met, or a combination of the two reasons. Total annual family non-food expenditure particularly, which indicates "capacity to pay" once non-discretionary items have been accounted for, was higher for refugees than asylum seekers.

The barriers that asylum seekers encountered in accessing maternal health care were also evidenced in the reversal of results, imputing higher maternal health expenditures to them, once the maternal health expenses were re-examined after controlling for factors like delivery status and adequacy of antenatal attendance which were in the favor of refugees. Delivery costs, which exceeded ANC and PPC expenditures and took the highest proportion of total maternal health expenses for all the sub-populations, were 1.45 times the amount for asylum seekers than for refugees. This could be because asylum seekers cannot avail the 50% discount off foreigner's rates at all State run hospitals.

However, it did not appear that refugees had better economic access to maternal health care than asylum seekers. As a result of incurring out-of-pocket maternal health expenses, a higher proportion of refugees (than asylum seekers) incurred catastrophic maternal health expenditures. Further, a higher proportion of refugees rather than asylum seekers fell below the poverty line income after incurring maternal health expenses.

Similarly, Rohingyas seemed to have better economic access than Chins. They had a higher annual family expenditure and annual family income in comparison to the Chins. Additionally, they incurred higher indirect maternal health expenses than Chins indicating possibly a greater ability to pay for secondary costs once maternal health care costs had been met. While this could be attributed to a high number of spouses of Rohingya respondents holding double jobs and engaging in retail and petty trade, just like refugees, a higher proportion of Rohingyas than Chins incurred catastrophic maternal health expenditures and dropped below the poverty line income after incurring maternal health expenses.

TABLE 41: SUMMARY OF ECONOMIC ACCESS AND SIGNIFICANCE OF INDEPENDENT VARIABLES

Dependent Variable	Higher Value of Dependent Variable	Analysis	Significance of Independent Variable	
			Documentation Status	Ethnicity
Direct maternal health expenditure	Refugees	Independent samples t-test	✓	p=n.s.
Indirect maternal health expenditure	Refugees & Rohingya	Independent samples t-test	✓	✓
Total maternal health expenditure	Refugees	Independent samples t-test	✓	p=n.s.
ANC expenses	Refugees & Rohingya	Independent samples t-test	✓	✓
Delivery expenses	Asylum seekers & Chin	Independent samples t-test	✓	✓
PPC expenses	Rohingya	Independent samples t-test	p=n.s.	✓
ANC expenses - government		Independent samples t-test	p=n.s.	p=n.s.
ANC expenses - private		Independent samples t-test	p=n.s.	p=n.s.
ANC expenses - NGO		Independent samples t-test	p=n.s.	p=n.s.
Delivery care expenses - government		Independent samples t-test	p=n.s.	p=n.s.
Delivery care expenses - private		Independent samples t-test	p=n.s.	p=n.s.
Total annual family expenditure	Refugees and Rohingya	Independent samples t-test	✓	✓
Total annual family nonfood expenditure	Refugees	Independent samples t-test	✓	p=n.s.
Annual Family Income	Refugees and Rohingya	Independent samples t-test	✓	✓
Relationship between documentation status and ethnicity with maternal health expenditure ratio (MH ratio)	Increase in MH Ratio with move from asylum seeker to refugee status	Multiple linear regression	✓	p=n.s.
Relationship between documentation status and ethnicity with maternal health expenditure ratio (MH ratio)	Increase in MH Ratio with move from asylum seeker to refugee status	Multiple linear regression After controlling for delivery status, lower and middle tertiles of annual non-food expenditure	✓	
Relationship between documentation status and ethnicity with maternal health expenditure ratio (MH ratio)	Increase in MH Ratio with move from asylum seeker to refugee status, and from Rohingya to Chin	Multiple linear regression after controlling for medical risk	✓	✓
Capacity to Pay		Chi Sq.	✓	p=n.s.
Poverty Head Count		Chi Sq.	✓	✓
Sources of maternal health care financing		Chi Sq.	✓	p=n.s.

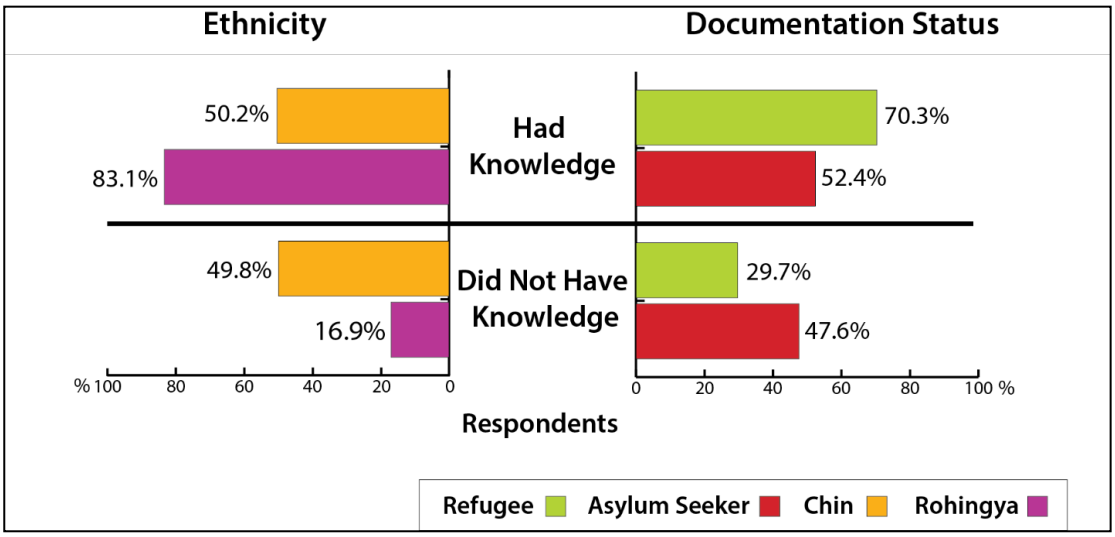
6.5 INFORMATION ACCESSIBILITY

The variable to measure information access is *Maternal Health Information* which comprises nine key maternal and child health information items provided to the respondent by the health care provider in relation to ANC, labor, and PPC.

6.5.1. Knowledge of Maternal Health Information Sources

To begin with, respondents' knowledge of maternal health information sources was examined in relationship to documentation status and ethnicity.

FIGURE 19: KNOWLEDGE OF MATERNAL HEALTH SOURCES: BY DOCUMENTATION STATUS & ETHNICITY



A higher proportion of refugees than asylum seekers had knowledge of the sources of maternal health information (70.3% versus 52.4%; p=0.001, two-sided Fisher's exact test). Similarly a higher proportion of Rohingyas than Chins had knowledge of the sources of maternal health information (83.1% versus 50.2%; p=0.001, two-sided Fisher's exact test). Figure-19 and Table-72 in Appendix - 6 have the details.

6.5.2. Knowledge Of Maternal Health Information

For all analyses from this point forward, those who did not receive ANC and one person who received ANC from an NGO clinic which does not provide the WHO recommended maternal health information (n=17), were excluded from the analysis.

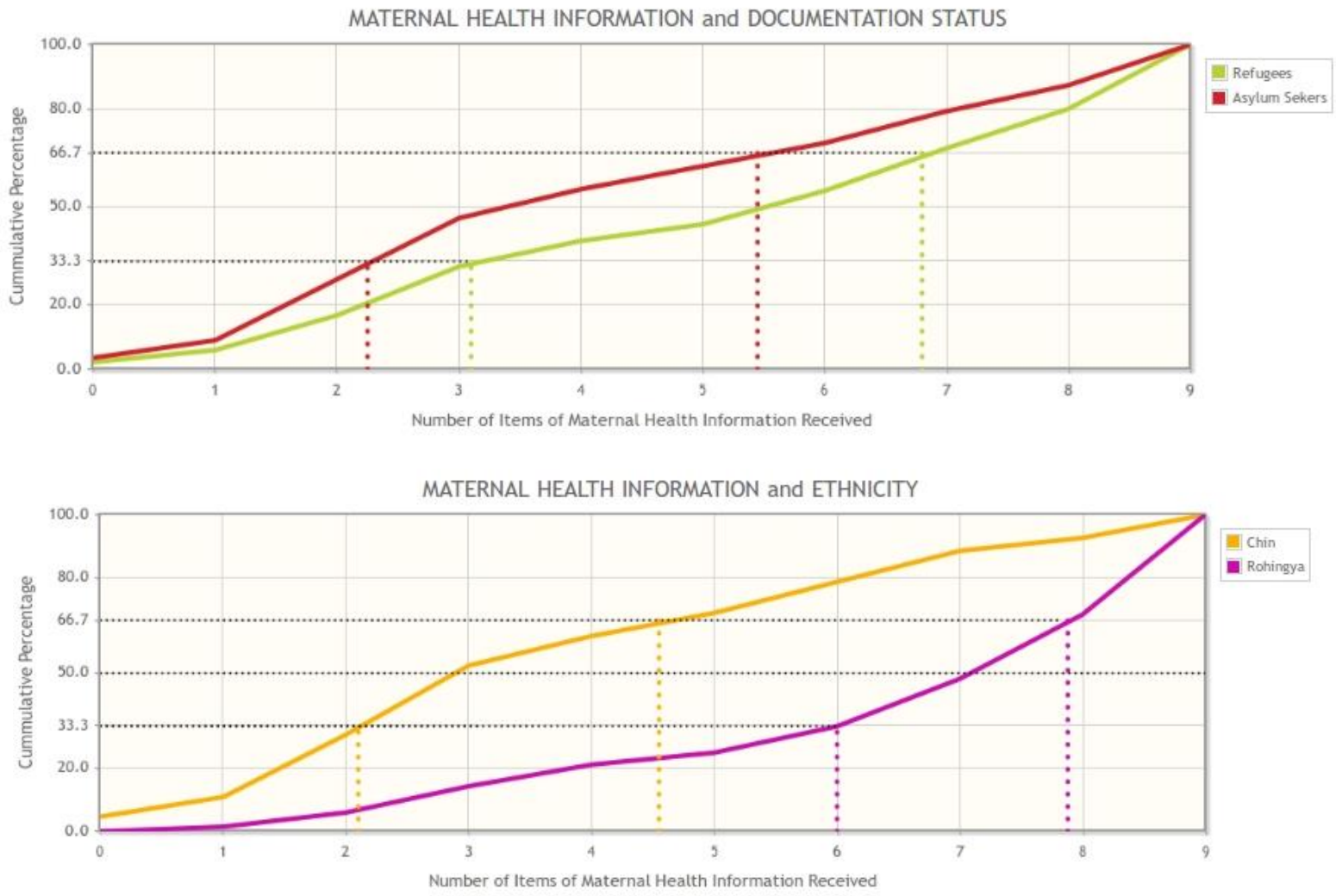
Only those who had sought care and received maternal health information at the health care facility (n=326) were considered for the analyses.

As a first approximation, ignoring the relative importance of the individual items of information, a simple count of the number of information items provided was examined. Of the nine items of maternal health information, 48.2% stated that information had been provided on one to five items with the rest (51.8%) confirming that information had been provided on more than five items. About 55.1% refugees and 37.5% asylum seekers (χ^2=10.360; df=9; p=0.322), and 31.1% Chins and 75.2% Rohingyas (χ^2=83.055; df=9; p<0.001) reported that maternal health information had been provided on more than five items. Details of the distribution of maternal health information disaggregated by documentation status and ethnicity are given in Table-42 and Figure 20.

TABLE 42: NUMBER OF ITEMS OF MATERNAL HEALTH INFORMATION

	STUDY POPULATION		BY DOCUMENTATION STATUS				BY ETHNICITY			
			Refugee		Asylum Seeker		Chin		Rohingya	
	n	Col %	n	Col %	n	Col %	n	Col %	n	Col %
N	326	100.0	214	100.0	112	100.0	193	100.0	133	100.0
0 Items	9	2.8	5	2.3	4	3.6	9	4.7	0	0.0
1Item	14	4.3	8	3.7	6	5.4	12	6.2	2	1.5
2 Items	44	13.5	23	10.7	21	18.8	38	19.7	6	4.5
3 Items	53	16.3	32	15.0	21	18.8	42	21.8	11	8.3
4 Items	27	8.3	17	7.9	10	8.9	18	9.3	9	6.8
5 Items	19	5.8	11	5.1	8	7.1	14	7.3	5	3.8
6 Items	30	9.2	22	10.3	8	7.1	19	9.8	11	8.3
7 Items	39	12.0	28	13.1	11	9.8	19	9.8	20	15.0
8 Items	35	10.7	26	12.1	9	8.0	8	4.1	27	20.3
9 Items	56	17.2	42	19.6	14	12.5	14	7.3	42	31.6

FIGURE 20: NUMBER OF ITEMS OF MATERNAL HEALTH INFORMATION RECEIVED: BY DOCUMENTATION STATUS & ETHNICITY



6.5.2.1. Distribution of Items of Maternal Health Information

The nine items in the *Maternal Health Information* measure ask whether health care staff: (i) asked about medical history; (ii) gave advice/information about diet and nutrition; (iii) discussed the place of birth; (iv) gave information about recognizing the danger signs during pregnancy; (v) advised what to do if there was a problem during pregnancy such as bleeding, convulsions and fits; (vi) discussed child spacing or family planning; (vii) talked about sexually transmitted diseases, HIV and AIDS; (viii) gave information or advice on how to take care of the baby; and (ix) discussed how to get to the health facility if there was an emergency.

Cronbach's alpha coefficient for the nine item measure of maternal health information was 0.839.

Figure-21 and Table-43 provide details of the distribution of the above nine items of maternal health information.

TABLE 43: DISTRIBUTION OF ITEMS OF MATERNAL HEALTH INFORMATION

	STUDY POPULATION		BY DOCUMENTATION STATUS				BY ETHNICITY			
			Refugee		Asylum Seeker		Chin		Rohingya	
	n	Col %	n	Col %	n	Col %	n	Col %	n	Col %
N	326	100.0	214	100.0	112	100.0	193	100.0	133	100.0
Medical History	301	92.3	198	92.5	103	92.0	173	89.6	128	96.2
Diet	251	77.0	167	78.0	84	75.0	128	66.3	123	92.5
Birth Place	248	76.1	175	81.8	73	65.2	129	66.8	119	89.5
Danger Signs	186	57.1	130	60.7	56	50.0	81	42.0	105	78.9
Bleeding	173	53.1	121	56.5	52	46.4	71	36.8	102	76.7
Child Spacing	125	38.3	97	45.3	28	25.0	46	23.8	79	59.4
STD&HIV	90	27.6	65	30.4	25	22.3	40	20.7	50	37.6
Care of Baby	146	44.8	108	50.5	38	33.9	49	25.4	97	72.9
Emergency	181	55.5	126	58.9	55	49.1	76	39.4	105	78.9

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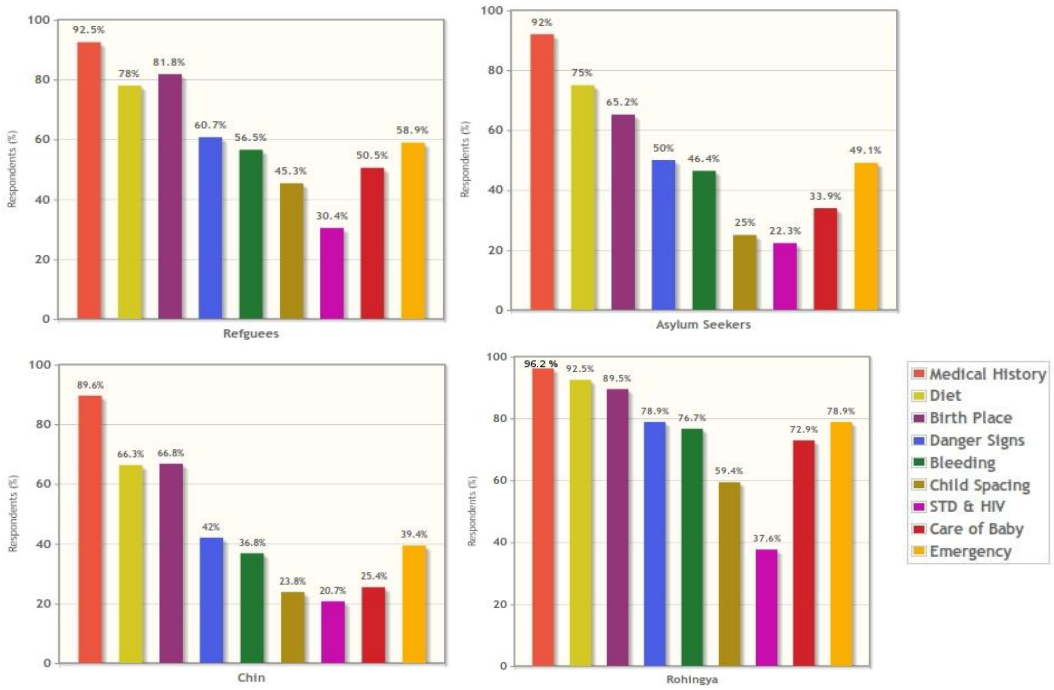
Overall, information elicited on medical history had the highest frequency (92.3%), followed by information provided on diet (77.0%) and the discussion on the place of birth (76.1%).

Three items of maternal health information related to complications/emergency preparedness were considered important to averting maternal morbidity and mortality. These items included information about (i) recognizing the danger signs during pregnancy, (ii) what to do if there was a problem during pregnancy such as bleeding, convulsions, and fits; and (iii) how to get to the health facility if there was an emergency.

FIGURE 21: DISTRIBUTION OF ITEMS OF MATERNAL HEALTH INFORMATION OBTAINED: BY DOCUMENTATION STATUS & ETHNICITY



Documentation status and being refugee and asylum seeker respectively was associated with information related to place of birth (81.8% versus 65.2%; p=0.002, two-sided Fisher's exact test), child spacing and family planning (45.3% versus 25.0%; p<0.001, two-sided Fisher's exact test), and taking care of the baby (50.5% versus 33.9%; p=0.005, two-sided Fisher's exact test). None of the items related to complications/emergency preparedness were related to documentation status.

However, ethnicity was associated with the provision of each of the nine items of maternal health information, including the items related to complications/emergency preparedness. In general, a higher proportion of Rohingyas than Chins reported that each of the nine maternal health information items had been provided including information on diet (92.5% versus 66.3%; p<0.001, two-sided Fisher's exact test), place of birth (89.5% versus 66.8%; p<0.001, two-sided Fisher's exact test),

recognizing danger signs during pregnancy (78.9% versus 42.0%; p<0.001, two-sided Fisher's exact test), advice regarding what to do if there is a problem such as bleeding, convulsions etc(76.7% versus 36.8%; p<0.001, two-sided Fisher's exact test), child spacing and family planning (59.4% versus 23.8%; p<0.001, two-sided Fisher's exact test), STDs, HIV and AIDS (37.6% versus 20.7%; p=0.001, two-sided Fisher's exact test), care of the baby (72.9% versus 25.4%; p<0.001, two-sided Fisher's exact test), how to get to a health facility in case of an emergency (78.9% versus 39.4%; p<0.001, two-sided Fisher's exact test).

6.5.3 Language Proficiency & Communication Issues

6.5.3 1.Language Competencies

Respondents were asked to rate their level of proficiency (i.e to speak and listen/understand) in Bahasa Malaysia and English along a scale of very well, well, satisfactory, not very well, and not at all.

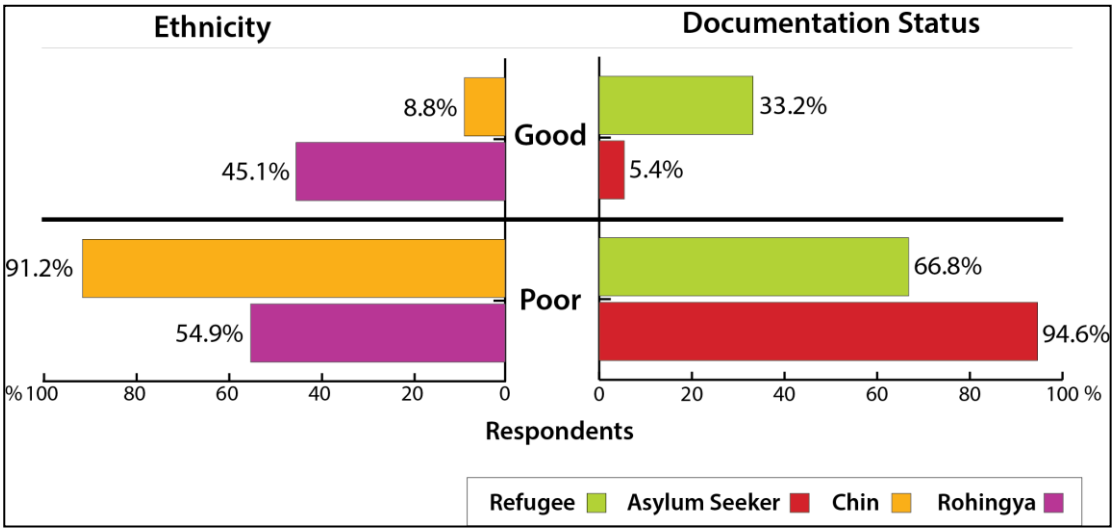
The distribution of self-reported levels of language proficiency in Bahasa Malaysia and English showed that a high majority reported “not very well”, and “not at all”. To overcome problems of skewness of distribution, this variable was recoded into dichotomous categories of “good” and “poor”. “Good” included those who had rated their language fluency as “very well”, “well”, and “satisfactory”, and “poor” included those who had rated their language fluency as “not very well”, and “not at all”.

Only 23.6% and 2.3% respondents rated their proficiency in Bahasa Malaysia and English respectively as “good”.

As shown in Figure-22 and Table-73 in Appendix - 6, a higher proportion of refugees than asylum seekers (33.2% versus 5.4%) rated their language proficiency in Bahasa Malaysia as good. However, a higher proportion of asylum seekers than refugees (94.6% versus 66.8%) rated their language proficiency in Bahasa Malaysia as poor, (p<0.001, two-sided Fisher's exact test). A higher proportion of Rohingyas than Chins (45.1% versus 8.8%) reported their proficiency in Bahasa Malaysia as “good”, whereas a higher proportion of Chins than Rohingyas (91.2% versus 54.9%) reported their proficiency in Bahasa Malaysia as “poor”, (p<0.001, two-sided Fisher's exact test).

Self-reported proficiency in English was not associated with documentation status or ethnicity.

FIGURE 22: LANGUAGE COMPETENCY-BAHASA MALAYSIA: BY DOCUMENTATION STATUS & ETHNICITY



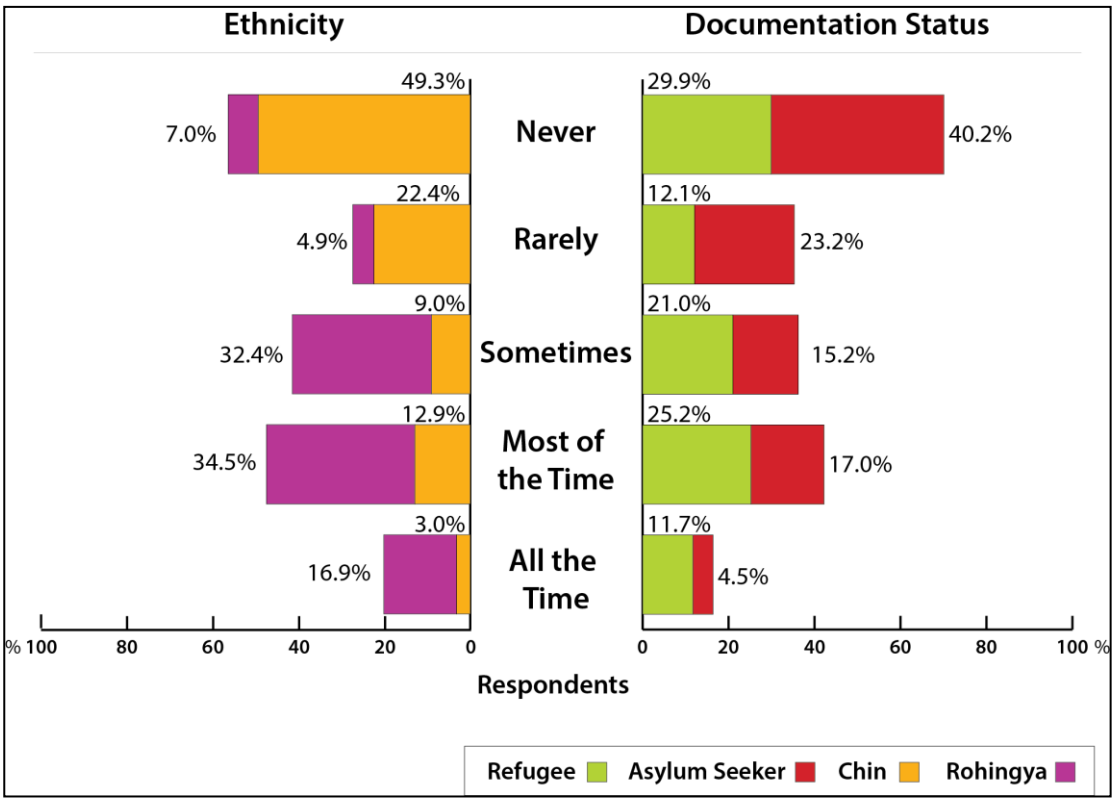
6.5.3.2. Frequency of Ability to Communicate in a Language They Understood

Overall only 9.2% of the study population reported being able to communicate all the time in a language that they understood well. See Figure-23 and Table-74 in Appendix - 6.

A higher proportion of asylum seekers than refugees were never (40.2% versus 29.9%) and rarely (23.2% versus 12.1%) able to communicate in a language that they understood well, while higher proportions of refugees than asylum seekers were sometimes (21.0% versus 15.2%), most of the time (25.2% versus 17.0%) and all the time (11.7% versus 4.5%) able to communicate in a language that they understood well, (χ^2=15.693; df=4; p=0.003).

Similarly, higher proportion of Chins than Rohingyas were never (49.3% versus 7.0%) and rarely (22.4% versus 4.9%) able to communicate in a language that they understood well, while higher proportions of Rohingyas than Chins were sometimes (32.4% versus 9.0%), most of the time (34.5% versus 12.9%) and all the time (16.9% versus 3.0%) able to communicate in a language that they understood well, (χ^2=15.693; df=4; p=0.003).

FIGURE 23: FREQUENCY OF ABILITY TO COMMUNICATE IN A LANGUAGE THEY UNDERSTOOD: BY DOCUMENTATION STATUS AND ETHNICITY



6.5.3 3 Ability to Communicate Independently at the Health Care Facility

Table 44 shows that about half the study population communicated via a Chin/Rohingya/Burmese speaking translator at the health care facility where they obtained ANC, delivery care, and PPC. Only a little over a quarter of the respondents had the ability to communicate independently in Bahasa Malaysia, and another one fifth of the study population was able to communicate independently in English with the health care providers.

In comparison to being able to communicate independently either in Bahasa Malaysia or in English, a sizeable proportion of refugees and asylum seekers (47.2% and 57.1%; χ^2=20.222; df=4; p<0.001) and of Chins and Rohingyas (54.9% and 44.4%; χ^2=18.003; df=4; p=0.001) required the help of a Chin/Rohingya/Burmese speaking translator at the health care facility where they obtained maternal health care. A small number of Rohingyas refugees reported seeking care in a private clinic where they could communicate with a Burmese doctor in Burmese.

TABLE 44: ABILITY TO COMMUNICATE INDEPENDENTLY AT THE HEALTH CARE FACILITY

	STUDY POPULATION		BY DOCUMENTATION STATUS				BY ETHNICITY			
			Refugee		Asylum Seeker		Chin		Rohingya	
	n	Col %	n	Col %	n	Col %	n	Col %	n	Col %
N	326	100.0	214	100.0	112	100.0	193	100.0	133	100.0
Bahasa Malaysia	87	26.7	72	33.6	15	13.4	38	19.7	49	36.8
English	70	21.5	38	17.8	32	28.6	48	24.9	22	16.5
Mandarin	1	0.3	0	0.0	1	0.9	1	0.5	0	0.0
Communicated through a Rohingya/Chin translator	165	50.6	101	47.2	64	57.1	106	54.9	59	44.4
Spoke in Burmese to a Burmese doctor	3	.9	3	1.4	0	0.0	0	0.0	3	2.3

Reliance on Translation Support

Of the 165 who communicated through a translator, a sizeable proportion (n=142, 86.0%) relied on their husbands to translate for them followed by dependence on a friend/relative/neighbor (n=77, 46.7%). A small minority (n=8, 4.8%) depended on fellow refugees in the health care facility to help translate for them.

A higher proportion of asylum seekers than refugees depended on their husbands (52.7% versus 38.8%), and a friend/relative/neighbor (27.7% versus 21.1%), (χ^2=17.808; df=4; p=0.001) for translation support. Similarly, a greater proportion of Chins than Rohingyas relied on their husbands (47.2% versus 38.3%), and a friend/relative/neighbor (25.4% versus 21.1%), (χ^2=17.808; df=4; p=0.0047) to help with translation at the health care facility.

6.5.3 4. Self-Reports on Adequacy of Maternal Health Information Obtained

Respondents were asked to report on the adequacy of maternal health information obtained on a scale of never, rarely, sometimes, most of the time, and all the time. Table-45 has the details.

Overall, only a third of the study population reported that the maternal health information they obtained was adequate most of the time.

A higher proportion of refugees than asylum seekers reported that the maternal health information they obtained was adequate all the time (10.3% versus 7.1%), most of the time (35.5% versus 28.6%), and sometimes (33.2% versus 31.3%); whereas a higher proportion of asylum seekers than refugees reported that the maternal health information they obtained was rarely (22.3% versus 9.3%) and never (11.7% versus 10.7%) adequate (χ^2=10.968; df=4; p=0.027).

Likewise, a higher proportion of Rohingyas than Chins reported that the maternal health information they obtained was adequate all the time (13.5% versus 6.2%), most of the time (43.6% versus 25.9%), and sometimes (37.6% versus 29.0%); whereas a higher proportion of Chins than Rohingyas reported that the maternal health information they obtained was rarely (22.8% versus 0.8%) and never (16.1% versus 4.5%) adequate (χ^2=50.791; df=4; p<0.001).

TABLE 45: SELF-REPORTED ADEQUACY OF MATERNAL HEALTH INFORMATION RECEIVED

	STUDY POPULATION		BY DOCUMENTATION STATUS				BY ETHNICITY			
			Refugee		Asylum Seeker		Chin		Rohingya	
	n	Col %	n	Col %	n	Col %	n	Col %	n	Col %
N	326	100.0	214	100.0	112	100.0	193	100.0	133	100.0
Never	37	11.3	25	11.7	12	10.7	31	16.1	6	4.5
Rarely	45	13.8	20	9.3	25	22.3	44	22.8	1	0.8
Sometimes	106	32.5	71	33.2	35	31.3	56	29.0	50	37.6
Most of the Time	108	33.1	76	35.5	32	28.6	50	25.9	58	43.6
All the Time	30	9.2	22	10.3	8	7.1	12	6.2	18	13.5

6.5.4. Relation between Maternal Health Information and Documentation Status and Ethnicity

A previous section had showed that ethnicity was associated with obtaining each of the items of maternal health information.

In order to explore further the nature of the relationship between ethnicity and access to maternal health information, a Mann-Whitney U test was conducted to determine differences in the number of information items received between Rohingyas and Chins. The Mann-Whitney test which was chosen because the count of perceived discrimination items was ordinal showed a statistically significant difference in the number of information items received between Rohingyas (median=7) and Chins (median=3), U=3996.500, Z=-6.908, *p*<0.001.

There was also a statistically significant difference in the number of information items received between asylum seekers (median=3) and refugees (median=5), U=6895.500, Z=-2.504, *p*=0.012.

Since nine items were used to assess access to maternal health Information, statistical procedures were attempted to reduce the data and obtain a single item or score for maternal health information, to be used in the linear regression analysis with the independent variables.

At first, tetrachoric correlation was applied between pairs of information item responses. Tetrachoric correlations were estimated using the program TETRA-COM. The tetrachoric correlations between the perceived discrimination items were found to be positively and significantly correlated (p<0.05). See Table-46 below for the tetrachoric correlation coefficient matrix.

TABLE 46: TETRACHORIC CORRELATIONS AMONG DISCRIMINATION IN HEALTH CARE ITEMS

	Medical History	Diet	Birth Place	Danger Signs	What to do – bleeding etc	Child spacing	STD & HIV	Care of Baby	Emergency preparedness
Medical History	1.000								
Diet	0.545	1.000							
Birth Place	0.520	0.335	1.000						
Danger Signs	0.401	0.750	0.559	1.000					
What to do – bleeding etc	0.512	0.535	0.705	0.875	1.000				
Child spacing	0.163	0.392	0.429	0.647	0.778	1.000			
STD&HIV	0.136	0.274	0.456	0.616	0.631	0.802	1.000		
Care of Baby	0.357	0.489	0.577	0.766	0.756	0.811	0.774	1.000	
Emergency preparedness	0.605	0.509	0.675	0.789	0.799	0.607	0.641	0.831	1.000

A Principal Component Analysis was conducted using the tetrachoric correlation coefficients matrix. An examination of the scree plot showed one dimension accounting for 45.7% of the variance. The factor score representing perceived discrimination was calculated from this.

The distribution of the perceived discrimination scores were negatively skewed with some outliers. A natural log transform was applied after making appropriate adjustments to avoid negative (non-transformable) values.

Pearson's correlation revealed a positive and very weak relationship between documentation status and information access scores (r=0.161, p=0.004, n=326). A negative and moderate correlation was revealed for information access scores and ethnicity(r=-0.471, p<0.001, n=326).

In the next step, documentation status and ethnicity were both included in the regression analysis. The regression results showed a significant model (adjusted R^2=0.219, $F(2,1\ 325)=46.562$, $p<0.001$). The overall model fit was R^2=22.4%. Ethnicity was found to be significantly associated (β=-0.459, $p<0.001$] while documentation status was not (β=0.048, p=0.345). A change in ethnic identity from Rohingya to Chin was expected to decrease access to the log transformed maternal health information factor score by 0.279 units. These results are provided in Table-47.

TABLE 47: SUMMARY OF MULTIPLE REGRESSION RESULTS WITH DOCUMENTATION STATUS AND ETHNICITY AS INDEPENDENT VARIABLES AND LOG TRANSFORMED MATERNAL HEALTH INFORMATION AS DEPENDENT VARIABLE

Independent Variables	B	SE B	β	t	p
Documentation Status	0.030	0.032	0.048	0.947	0.345
Ethnicity	-0.279	0.031	-0.549	-9.077	<0.001

B= unstandardized beta coeff.
SE B=standard error
β=standardized beta coeff
t=t-test statistic
P = significance value
Ethnicity = Ethnic group of respondent, Rohingya or Chin
Documentation Status = Documentation Status of respondent, Asylum Seeker or Refugee

Adjusting for Proficiency in Bahasa Malaysia

In an earlier section, language proficiency in Bahasa Malaysia was significantly related to both documentation status and ethnicity.

A simple linear regression established that proficiency in Bahasa Malaysia was a statistically associated with scores on information access, $F(1, 325)=29.352$, $p<0.001$, accounting for only 8.3% (R^2) of the explained variability in information access factor scores. The log transformed information access factor score increased by 0.203 units with a change in proficiency in Bahasa Malaysia from "poor" to "good".

Given the above results, other evidence showing that proficiency in the host country language in immigrant populations is associated with health literacy[493, 494], and the possible confounding effect of language proficiency in Bahasa Malaysia on access to maternal health information amongst the groups of interest in this study, the linear regression was repeated using the process of stratification of confounders[487]. As such, linear regression analysis was applied to examine the effects of documentation status and ethnicity on the log transformed maternal health information factor score while controlling for those who rated their language proficiency in Bahasa Malaysia as "good".

TABLE 48: SUMMARY OF MULTIPLE REGRESSION RESULTS WITH DOCUMENTATION STATUS AND ETHNICITY AS INDEPENDENT VARIABLES AND LOG TRANSFORMED MATERNAL HEALTH INFORMATION AS DEPENDENT VARIABLE AFTER CONTROLLING FOR PROFICIENCY IN BHASA MALAYSIA

Independent Variables	B	SE B	β	t	p
Documentation Status	0.152	0.103	0.167	1.479	0.143
Ethnicity	-0.133	0.066	-0.226	-2.004	0.049

B= unstandardized beta coeff.
SE B=standard error
β=standardized beta coeff
t=t-test statistic
P = significance value
Ethnicity = Ethnic group of respondent, Rohingya or Chin
Documentation Status = Documentation Status of respondent, Asylum Seeker or Refugee

A (R^2 = 9.4%) significant model emerged (adjusted $R^2=0.069$, $F(2,76)=3.827$, $p=0.026$) which showed that ethnicity (β=-0.226, $p=0.049$) was still significantly associated with the log transformed maternal health information factor score vis-à-vis documentation status(β=0.167, $p=0.143$). See Table-47.

Interaction Effect: Documentation Status, Ethnicity, and Language Proficiency in Bahasa Malaysia

Since the individual regression analysis with documentation status, ethnicity, and language proficiency in Bahasa Malaysia revealed significant outcomes in predicting access to information, and it being conceivable that acting together they could increase or decrease information access, a GLM UNIANOVA analysis (after excluding outliers) was applied to examine interaction effects between these three variables. The analysis did not show a significant interaction effect between documentation status and ethnicity $F(1, 319)=1.873$, $p=0.172$, between documentation status and language proficiency in Bahasa Malaysia $F(1, 319)=2.119$, $p=0.146$, and between ethnicity and language proficiency in Bahasa Malaysia $F(1, 319)=2.294$, $p=0.131$.

6.5.5 Information Accessibility: Summary of Results and Conclusions

The variable to measure information access is *Maternal Health Information* which comprises nine key maternal and child health information items provided to and obtained by the respondent from the health care provider in relation to pregnancy, labor, and post-delivery phases.

Table-50 gives the summary of variables analyzed for the section on information access and the significance of the independent variables in relation to information access.

The analysis of information access shows that ethnicity was significantly associated to more dependent variables than documentation status. Documentation status was significantly related to the dependent variables only when ethnicity was also significant, and not independently of documentation status. This does point to ethnicity as the more important of the two independent variables in terms of obtaining maternal health information.

Where documentation status was salient, refugees had an advantage over asylum seekers. For example, refugees had better knowledge of the sources of maternal health information. This could be because refugees' mean period of residence in Malaysia (5.45 years) was higher than that of asylum seekers (1.73 years), giving

them an advantage in terms of knowledge of health information sources. A higher proportion of refugees than asylum seekers also reported that the maternal health information they obtained was adequate most of the time. However, documentation status was associated with only obtaining maternal health information items that did not address complications/emergency preparedness. This indicates that documentation status alone does not provide the information required to avert risks related to maternal morbidity and mortality.

On the other hand, ethnicity was consistently related to all the variables associated with access to maternal health information. In terms of ethnicity, Rohingyas had a distinct advantage over Chins in relation to access to maternal health information. Rohingyas had better knowledge of the sources of maternal health information. Again, this could be because Rohingyas' mean period of residence in Malaysia (7.45 years) was higher than that of the Chins (1.8 years) giving them an advantage in terms of knowledge of heath information sources.

Ethnicity was associated with the provision of each of the nine items of maternal health information. The results indicate that a higher proportion of Rohingyas than Chins reported being provided with general maternal health information required to promote the health of the expectant mother and the child. A higher proportion of Rohingyas than Chins also reported being provided with maternal health information related to complications/emergency preparedness which could reduce the risks of maternal morbidity and mortality.

Although a higher proportion of Rohingyas than Chins reported being proficient in Bahasa Malaysia and being able to communicate independently and more frequently in a language they understood well, the analysis did not reveal a significant effect of language proficiency of the respondents or an interaction of language proficiency with the other independent variables. This could be because of other factors which were not considered in the analysis. For example, a sizeable proportion of the study population relied on their spouses for translation support. Several Rohingya spouses in this study depended on petty trade and retail trade for their livelihood. This would require significant interaction with the host country population, competency in the local language, and ability to navigate their way in the host country effectively. The language competency of their spouses could explain

the higher proportion of Rohingyas than Chins reporting that they were provided with maternal health information.

Although a higher proportion of Rohingyas than Chins reported being provided with the nine items of maternal health information, only a little over half the Rohingya study population reported that the maternal health information they had obtained was adequate. This was in contrast to a third of the Chin population which reported that the maternal health information they had obtained was sufficient. This could indicate that even in the best of circumstances where maternal health information is made available and provided as part of the routine content of care and there are family/community interlocutors to help them navigate information access, non-citizen populations such as refugees and asylum seekers might encounter unique barriers in accessing available care and/or may not be able to take advantage of available services even where they are accessible [270].

TABLE 49: SUMMARY OF INFORMATION ACCESS AND SIGNIFICANCE OF INDEPENDENT VARIABLES

Table : Summary of Information Access and Significance of Independent Variables				
Dependent Variable	**Higher Value of Dependent Variable and/or Higher Proportion of Study Population Sub-Groups**	**Analysis**	**Significance of Independent Variable**	
			Documentation Status	**Ethnicity**
Knowledge of maternal health information sources	Refugees & Rohingyas	Two sided Fisher's Exact Test	✓	✓
Knowledge: Number of items of maternal health information	Rohingyas	Chi Sq.	p=n.s	✓
Maternal Health Information: Medical history	Refugee & Rohingyas	Two sided Fisher's Exact	✓	✓
Maternal Health Information: Diet & nutrition	Rohingyas	Two sided Fisher's Exact	p=n.s	✓
Maternal Health Information: Place of birth	Rohingyas	Two sided Fisher's Exact	p=n.s	✓
Maternal Health Information: Danger signs during pregnancy	Rohingyas	Two sided Fisher's Exact	p=n.s	✓

Table : Summary of Information Access and Significance of Independent Variables				
Dependent Variable	**Higher Value of Dependent Variable and/or Higher Proportion of Study Population Sub-Groups**	**Analysis**	**Significance of Independent Variable**	
			Documentation Status	**Ethnicity**
Maternal Health Information: What to do if problem during pregnancy	Rohingyas	Two sided Fisher's Exact	p=n.s	✓
Maternal Health Information: Child spacing & family planning	Refugee & Rohingyas	Two sided Fisher's Exact	✓	✓
Maternal Health Information: Sexually transmitted diseases, HIV and AIDS	Rohingyas	Two sided Fisher's Exact	p=n.s	✓
Maternal Health Information: How to take care of baby	Refugee & Rohingyas	Two sided Fisher's Exact	✓	✓
Maternal Health Information: How to get to health facility if emergency	Rohingyas	Two sided Fisher's Exact	p=n.s	✓
Proficiency in Bahasa Malaysia	Refugee & Rohingyas	Two sided Fisher's Exact	✓	✓
Proficiency in English			p=n.s	p=n.s
Frequency of ability to communicate in a language they understood	Refugee & Rohingyas	Chi Sq.	✓	✓
Ability to communicate independently at the health care facility	Refugee & Rohingyas	Chi Sq.	✓	✓
Reliance on translation support	Asylum Seekers & Chins	Chi Sq.	✓	✓
Self-reports on adequacy of maternal health information obtained	Refugee & Rohingyas	Chi Sq.	✓	✓

Table : Summary of Information Access and Significance of Independent Variables				
Dependent Variable	**Higher Value of Dependent Variable and/or Higher Proportion of Study Population Sub-Groups**	**Analysis**	**Significance of Independent Variable**	
			Documentation Status	**Ethnicity**
Relationship between documentation status and ethnicity with maternal health information access	Decrease in access to maternal health information with change in ethnic identity from Rohingya to Chin	Multiple linear regression	p=n.s	✓
Relationship between documentation status and ethnicity with maternal health information access	Decrease in access to maternal health information with change in ethnic identity from Rohingya to Chin	Multiple linear regression after controlling for proficiency in Bahasa Malaysia	p=n.s	✓
Interaction between documentation status, ethnicity, and proficiency in Bahasa Malaysia in relation to maternal health information access		GLM UNIANOVA	Doc status*Ethnicity	p=n.s
			Doc status*Lang. Proficiency in Bahasa Malaysia	p=n.s
			Ethnicity*Lang. Proficiency in Bahasa Malaysia	p=n.s

6.6 UTILIZATION OF MATERNAL HEALTH CARE

This section is divided into two parts. In the first part, I provide contextual data on the study population's utilization of maternal health care in general. In the second part, I examine the relationship between the independent variables and the indicator chosen to measure utilization of care, namely, number of ANC visits (or adequacy of care).

I had initially chosen two indicators to measure utilization of maternal health care, namely, (i) number of ANC visits made; and (ii) whether an institutional delivery had been obtained. However, I was only able to examine only the relationship between documentation status and ethnicity with the number of ANC visits. I could not proceed with the analysis related to institutional delivery because of the small number of cases reported for those who had non-institutional (home) deliveries.

Nevertheless, utilization data related to delivery will be presented in the first part of this section.

All cases that did not receive ANC (n=12) were excluded from the analysis.

6.6.1. Part 1: Utilization of Maternal Health Care in General

6.6.1.1. Obtaining ANC Care

In all, 12 respondents did not seek ANC. Neither documentation status, nor ethnicity, was significantly associated with seeking/not seeking care (two sided Fisher's exact test). See Figure-24 and Table-75 in Appendix -6.

The reasons provided for not seeking ANC are given in Figure 25 and Table-76 in Appendix-6.

Fear of undocumented status and unaffordability were the two predominant reasons reported. A higher proportion of refugees (1.8%) cited unaffordability, whereas a higher proportion of asylum seekers (4.0%) cited fear due to undocumented status

(χ^2=11.821; df=4; p=0.019). Ethnicity was not related to these reasons (χ^2=8.725; df=4; p=0.068).

FIGURE 24: WHETHER ANC WAS SOUGHT: BY DOCUMENTATION STATUS & ETHNICITY

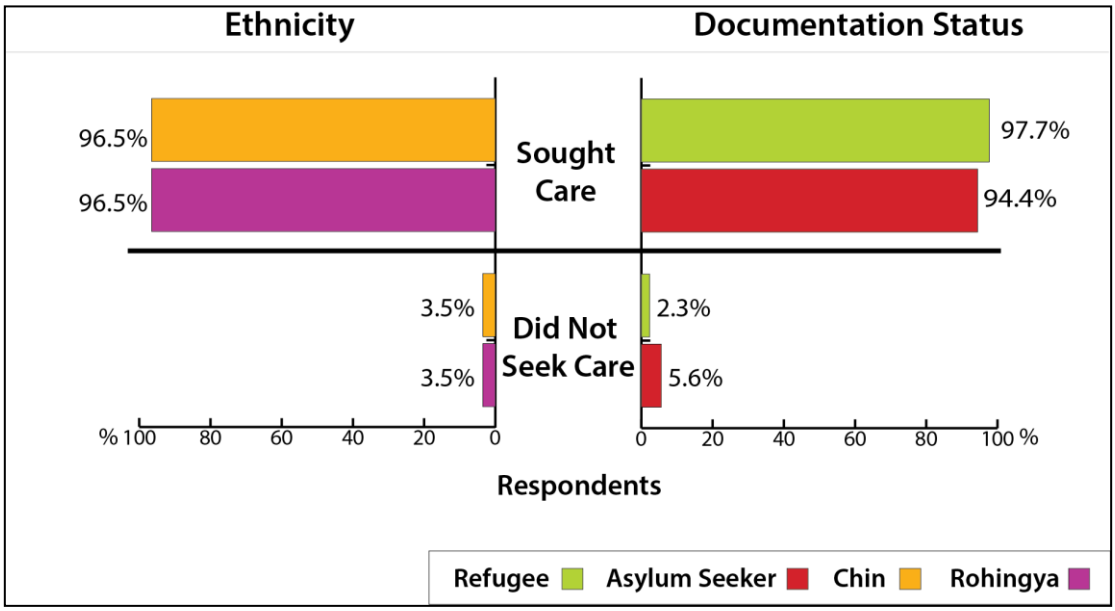
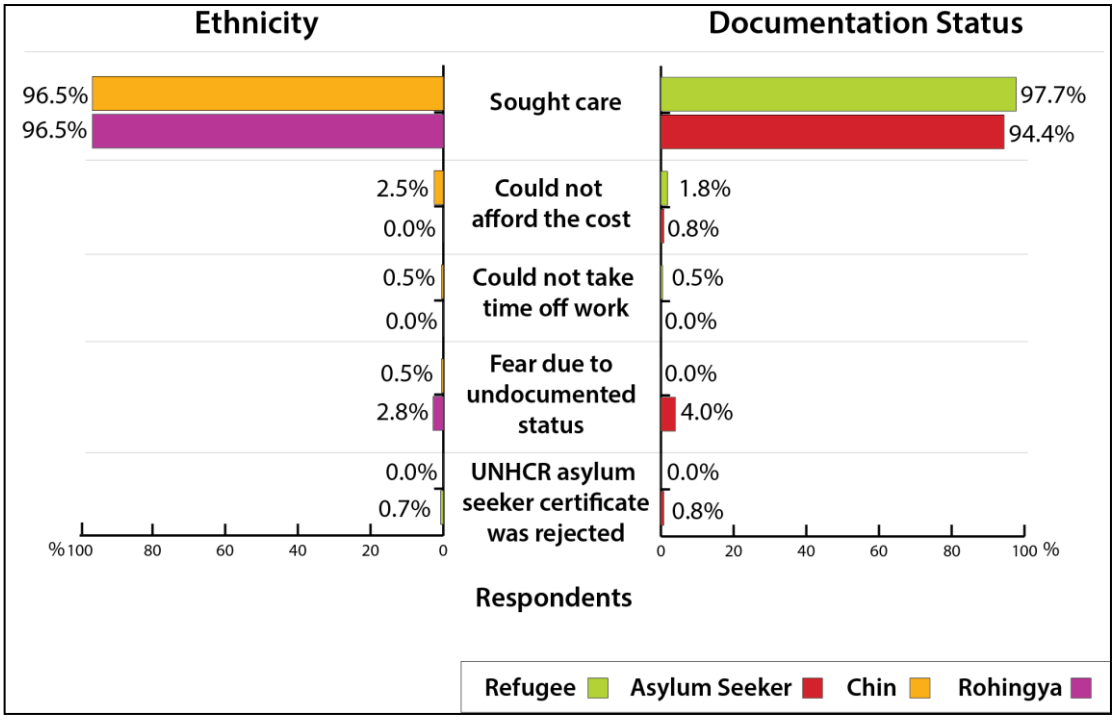


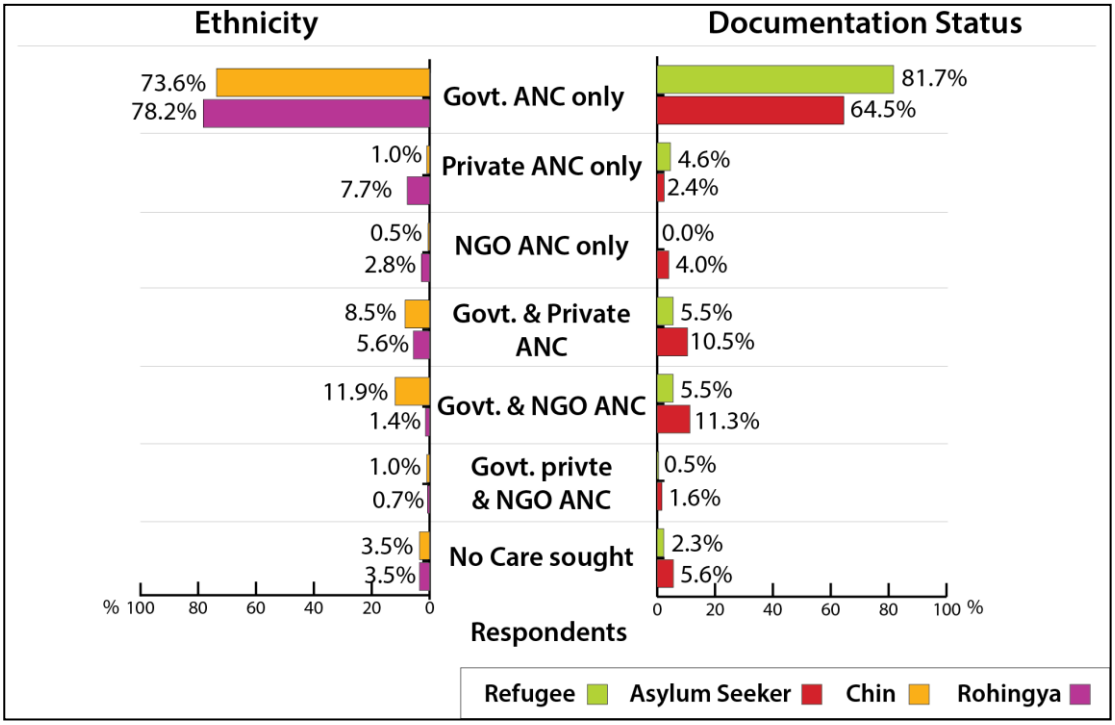
FIGURE 25: REASONS FOR NOT OBTAINING ANC: BY DOCUMENTATION STATUS & ETHNICITY



6.6.1.2 Sector Where ANC Care Was Sought

Out of the 331 respondents who sought ANC, 259 obtained it in the government sector while 13 and five respondents sought ANC in the private and NGO health sectors respectively. The remaining 54 sought a combination of care in the government, private and NGO sectors. The details are provided in Figure-26 and Tabl- 77 in Appendix-6.

FIGURE 26: SECTOR WHERE ANC WAS SOUGHT: BY DOCUMENTATION STATUS & ETHNICITY



A higher proportion of refugees than asylum seekers used ANC in the government (81.7% versus 64.5%) and private health care sectors (4.6% versus 2.4% respectively), whereas a higher proportion of asylum seekers than refugees sought mixed care in the government and private sectors (4.0% versus 0.0%), government and NGO sectors (11.3% versus 5.5%), and government, private and NGO sectors (5.6% versus 2.3%), (χ^2=22.918; df=6; p=0.001).

Similarly a higher proportion of Rohingyas than Chins used government ANC (78.2% versus 73.6%), private ANC (7.7% versus 1.0%), and government and private ANC (2.8% versus 0.5%), whereas a higher proportion of Chins than Rohingyas used care in the government and NGO ANC (11.9% versus 1.4%), and

government, private and NGO ANC (1.0% versus 0.7%), (χ^2=26.473; df=6; p<0.001).

6.6.1.3. Timing of Initiation of ANC

WHO [333] recommends the initiation of care preferably before week 12.

TABLE 50: TIMING OF INITIATION OF CARE

		BY DOCUMENTATION STATUS		BY ETHNICITY	
	Study Population	**Refugee**	**Asylum Seeker**	**Chin**	**Rohingya**
N	331	214	117	194	137
Mean (SD)	4.83 (1.47)	5.0 (1.44)	4.56 (1.50)	4.82 (1.42)	4.83 (1.54)
Median	5.0	5.0	5.0	5.0	5.0
Minimum	1.0	1.0	1.0	1.0	1.0
Maximum	9.0	9.0	8.0	9.0	9.0

Overall, the median was higher than the mean values and there was considerable variation between the minimum and maximum values, signifying an anticipated asymmetry in the utilization of health services [495]. The mean and median timing of initiation of ANC visits of all the population sub-groups in this study exceeded the WHO recommended initiation of ANC by the first trimester [333]. Asylum seekers had an earlier initiation of ANC than refugees (t(329)=-2.546, p=0.011). There was no difference in the timing of initiation of ANC between Chins and Rohingyas (t(329)=0.045, p=0.964). The details are given in Table-50.

6.6.1.4. Institutional Delivery

Study participants were asked to identify if they had delivered at a government hospital, private hospital, or if they had been delivered by traditional birth attendants, midwives or others at home.

Of those who delivered (n=202), five delivered at home. Of the rest (n=197), five had an institutional delivery in a private hospital and 192 had an institutional delivery in a government hospital. A higher proportion of refugees than asylum seekers (99.4% versus 90.7%; p=0.008, two-sided Fisher's exact test) and of Chins than Rohingyas (100% versus 94.8%; p=0.023, two-sided Fisher's exact test) had institutional deliveries. See Table-51 for details.

TABLE 51: INSTITUTIONAL OR HOME DELIVERY

	STUDY POPULATION		BY DOCUMENTATION STATUS				BY ETHNICITY			
			Refugee		Asylum Seeker		Chin		Rohingya	
	n	Col %	n	Col %	n	Col %	n	Col %	n	Col %
N	202	100.0	159	100.0	43	100.0	106	100.0	96	100.0
Hospital delivery	197	97.5	158	99.4	39	90.7	106	100.0	91	94.8
Home delivery	5	2.5	1	0.6	4	9.3	0	0.0	5	100.0

6.6 1 5 PPC Care

Of the 202 women who had delivered, 145 obtained PPC; 57 did not. See Table-52.

TABLE 52: POSTPARTUM CARE OBTAINED/NOT OBTAINED

	STUDY POPULATION		BY DOCUMENTATION STATUS				BY ETHNICITY			
			Refugee		Asylum Seeker		Chin		Rohingya	
	n	Col %	n	Col %	n	Col %	n	Col %	n	Col %
N	202	100.0	159	100.0	43	100.0	106	100.0	96	100.0
PPC obtained	145	71.8	120	75.5	25	58.1	57	53.8	88	91.7
PPC not obtained	57	28.2	39	24.5	18	41.9	49	46.2	8	8.3

A higher proportion of refugees than asylum seekers (75.5% versus 58.1%; p=0.035, two-sided Fisher's exact test), and Rohingyas than Chins (91.7% versus 8.3%; p<0.001, two-sided Fisher's exact test) obtained PPC.

Whereas, it is a standard practice for Malaysian women who deliver at government hospitals to receive a PPC visit from a midwife or a nurse, only 65 of the 145 respondents who obtained PPC received such a home visit. A higher proportion of Rohingyas than Chins (n=65[62.5%] versus n=5[4.7%]; p<0.001, two-sided Fisher's exact test) and refugees than asylum seekers (n=56[35.2] versus n=9[20.9%]; p<0.001, two-sided Fisher's exact test) obtained a home visit from a midwife/nurse post-delivery.

6.6.2. Part 2: Number of ANC Visits and Relation between Utilization of ANC and Documentation Status and Ethnicity

WHO[333] recommends a minimum of four ANC visits for normal pregnancies requiring routine care. Those with complications would require additional visits based on the appropriate clinical assessments. The recommended initiation of care and periodicity of visits recommended include that the first visit preferably take place before week 12, the second visit close to 26 weeks, third visit around week 32 and fourth visit between weeks 36-38. Additionally, the minimum prescribed examination and investigations include blood pressure measurement, testing of urine for bacteriuria and proteinuria, and blood tests to detect syphilis and severe anemia.

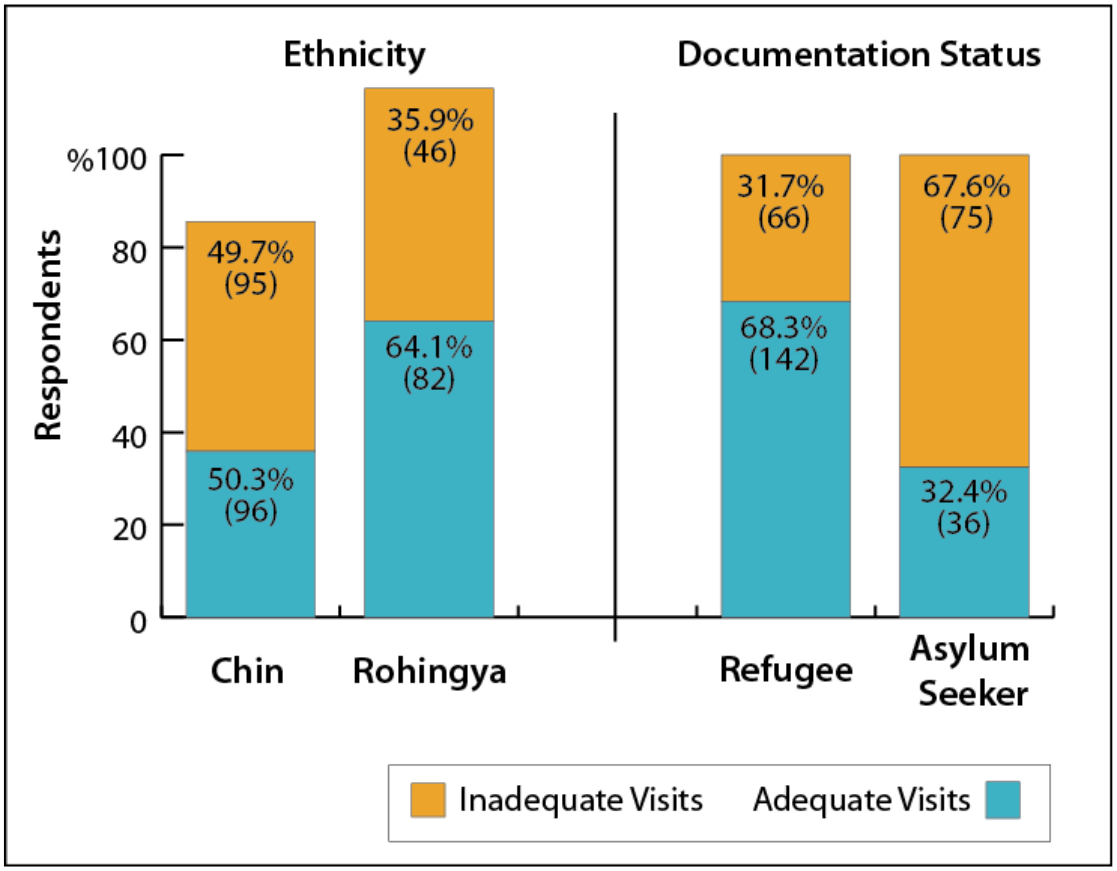
The data for the number of visits was acquired from the Rekod Kesihatan Ibu (RKI). Although there were color coded indicators on the RKI indicating pregnancy risks [496], further clinical data required to assess the adequacy of the number of visits for high risk pregnancies was lacking. Given these limitations, the adequacy of care for all cases was assessed on the basis of a minimum of four visits adjusted for length of gestation, regardless of whether it was a normal or a high risk pregnancy. Based on this computation, respondents were classified into those who had obtained an "inadequate number of visits" and those who obtained an "adequate number of visits". Figure-27 and Table-78 in Appendix-6 gives the distribution of adequate/inadequate care for the study population, based on the above classification.

For this section, in addition to those who did not obtain ANC (n=12), those respondents who obtained ANC but did get the minimum prescribed examination and investigations recommended by WHO (n=12) were also excluded from the analysis, based on the assumption that the visit did not offer care that could be counted as "adequate".

A higher proportion of refugees than asylum seekers (68.3% versus 32.4%; $p<0.001$, two-sided Fisher's exact test), and Rohingyas than Chins (64.1% versus 50.3%; $p=0.016$, two-sided Fisher's exact test) obtained an adequate number of ANC visits. Additionally, the strength of association measured by the Phi statistic for the association between documentation status and number of visits was 0.344

(p<0.001), and for the association between ethnicity and number of visits was -0.136 (p=0.016).

FIGURE 27: ADEQUACY OF ANC VISITS: BY DOCUMENTATION STATUS & ETHNICITY



6.6 2.1. Relation between Utilization of Care* (*Number of ANC Visits) and Documentation Status, Ethnicity

The previous section had shown that both documentation status and ethnicity were associated with obtaining an adequate number of ANC visits. As such, the statistical analysis continued with an examination of the relation between number of ANC visits, the variable to measure utilization of care, with documentation status and ethnicity.

Logistic regression analysis was performed to ascertain the effects of documentation status and ethnicity on the likelihood that respondents would/would not obtain adequate number of ANC.

A test of the full model against a constant only model was statistically significant χ2 (2) = 39.288, p<0.001.

The model explained 15.5% (NagelkerkeR^2) of the variance in obtaining adequate number of ANC visits. The Hosmer-Lemeshow test revealed goodness of fit of 1.217 (p=0.544). Of the two independent variables, only documentation status was significantly associated with adequate number of ANC visits (as shown in Table-53 below); not ethnicity. Refugees' odds of obtaining an adequate number of ANC visits were 4.2 times greater than that of asylum seekers. The details of this logistic regression analysis are given in Table-53.

TABLE 53: SUMMARY OF LOGISTIC REGRESSION ANALYSIS RESULTS WITH DOCUMENTATION STATUS AND ETHNICITY AS INDEPENDENT VARIABLES AND NUMBER OF ANC VISITS AS THE DEPENDENT VARIABLE

Independent Variables	e^{β}(odds ratio)	β	SE β	Wald's χ^2	df	p
Constant	0.588	-0.531	0.276	3.709	1	0.054
Documentation Status	4.220 (2.550-6.985)	1.440	0.257	31.380	1	<0.001
Ethnicity	0.762 (0.465-1.247)	-0.272	0.276	3.709	1	0.280

Given the substantial body of evidence on the association between various predictors of accessibility and utilization of maternal health care[497-503] and other relationships which had been identified between the independent variables and the four dimensions of access in this study, a full model was developed in the next stage, including the two independent variables (documentation status and ethnicity) and the four measures of access.

As such, the four measures of access, namely, (i) travel time; (ii) maternal health expenditure ratio; (iii) maternal health information; and (iv) perceived discrimination in health care were added to the independent variables in the study, namely, documentation status and ethnicity, in the multiple logistic regression model. The objective was to estimate the association between documentation status and utilization of maternal health care, after controlling for all other significant factors.

A test of the full model (see Table-54) against a constant only model was statistically significant χ2 (2) = 282.391, p<0.001. The model explained 84.0% (Nagelkerke*R2*)

of the variance in obtaining adequate number of ANC visits. The Hosmer-Lemeshow test revealed goodness of fit of 3.904 (p=0.866).

After controlling for all other factors, documentation status remained significantly related to utilization of maternal health care; not ethnicity. Refugees' odds of obtaining an adequate number of ANC visits were 4 times greater than that of asylum seekers. The accuracy of the model improved from 55.2% (null model) to 90.9%.

Although, after controlling for other factors, economic access emerged as a dimension that was significantly related to utilization of maternal health care, in keeping with the objectives of the study, the focus of this analysis was maintained on the independent variables, namely, documentation status and ethnicity.

TABLE 54: SUMMARY OF LOGISTIC REGRESSION ANALYSIS RESULTS WITH DOCUMENTATION STATUS AND ETHNICITY AS INDEPENDENT VARIABLES AND NUMBER OF ANC VISITS AS THE DEPENDENT VARIABLE AFTER CONTROLLING FOR THE FOUR MEASURES OF ACCESS

Independent Variables	e^{β}(odds ratio)	β	SE β	Wald's χ^2	df	p
Constant	.000	-16.748	3.286	25.983	1	.000
Documentation Status	4.008 (1.219-13.173)	1.388	.607	5.228	1	.022
Ethnicity	2.067 (0.465-9.188)	.726	.761	.909	1	.340
Economic Access	52.015 (15.877-170.409)	3.952	.605	42.595	1	.000
Physical Access	.672 (0.303-1.493)	-.397	.407	.952	1	.329
Information Access	5.079 (0.781-33.044)	1.625	.955	2.893	1	.089
Perceived Discrimination	6.501 (0.229-184.229)	1.872	1.706	1.204	1	.273

6.6.3. Utilization of Maternal Health Care: Summary of Results and Conclusions

The variable to measure utilization of maternal health care is number of ANC visits.

Table-55 gives the summary of variables analyzed for the section on maternal health care and the significance of the independent variables in relation to the dependent variable.

The analysis of utilization of maternal health care shows that documentation status was significantly associated with all the dependent variables. Ethnicity was related only when documentation status was significantly associated; not independently of documentation status. This indicates that documentation status was the more important of the two independent variables in the analysis of utilization of maternal health care.

A higher proportion of asylum seekers had an earlier initiation of ANC than refugees. However, this does not mean that they were better off because the initiation of care even for asylum seekers exceeded the WHO recommended cut off period of the first trimester, thereby conceivably qualifying as “delayed care”.

Although refugees had a later initiation of care than asylum seekers, a higher proportion of refugees than asylum seekers obtained an adequate number of ANC visits, had an institutional delivery, and obtained PPC. After controlling for all other factors, the multiple logistic regression analysis showed that documentation status was significantly associated with adequacy of number of ANC visits. Economic access also emerged as a significant variable independently of other factors. The importance of documentation status in relation to utilization of maternal health care could be because refugees got a 50% discount off foreigner’s rates at all State run hospitals and clinics, or because refugees had a higher maternal health expenditure ratio, annual family expenditure, annual family non-food expenditure, and annual family income than asylum seekers. Total annual family non-food expenditure particularly, which indicates “capacity to pay” once non-discretionary items have been accounted for, was also higher for refugees than asylum seekers. These results indicate the links between dimensions of accessibility and utilization of care and underscore the differences in the two concepts.

TABLE 55: SUMMARY OF UTILIZATION OF CARE AND SIGNIFICANCE OF INDEPENDENT VARIABLES

Dependent Variable	Higher Value of Dependent Variable and/or Higher Proportion of Study Population Sub-Groups	Analysis	Significance of Independent Variable	
			Documentation Status	Ethnicity
Obtained ANC care		Two sided Fisher's Exact	p=n.s	p=n.s
Reasons ANC was not sought		Chi Sq.	✓	
Sector where ANC care was sought		Chi Sq.	✓	✓

Dependent Variable	Higher Value of Dependent Variable and/or Higher Proportion of Study Population Sub-Groups	Analysis	Significance of Independent Variable	
			Documentation Status	Ethnicity
Timing of initiation of ANC	Asylum seekers	Independent samples t-test	✓	p=n.s
Institutional delivery	Refugees & Chins	Two sided Fisher's Exact	✓	✓
PPC	Refugees & Chins	Two sided Fisher's Exact	✓	✓
Number of ANC visits	Refugees & Rohingyas	Two sided Fisher's Exact	✓	✓
Relationship between documentation status and ethnicity with utilization of maternal health care	Refugees' odds of obtaining an adequate number of ANC visits were greater than that of asylum seekers	Multiple logistic regression	✓	p=n.s
Relationship between documentation status and ethnicity with utilization of maternal health care	Refugees' odds of obtaining an adequate number of ANC visits were greater than that of asylum seekers	Multiple logistic regression after controlling for four measures of access	✓	p=n.s
Interaction between documentation status, ethnicity, and four measures of access			Doc status*Ethnicity	p=n.s
			Doc status*economic access	p=n.s
			Doc status*physical access	p=n.s
			Doc status*info access	p=n.s
			Doc status*perceived discrimination	p=n.s
			Ethnicity* economic access	p=n.s
			Ethnicity* physical access	p=n.s
			Ethnicity*info access	p=n.s
			Ethnicity*perceived discrimination	p=n.s

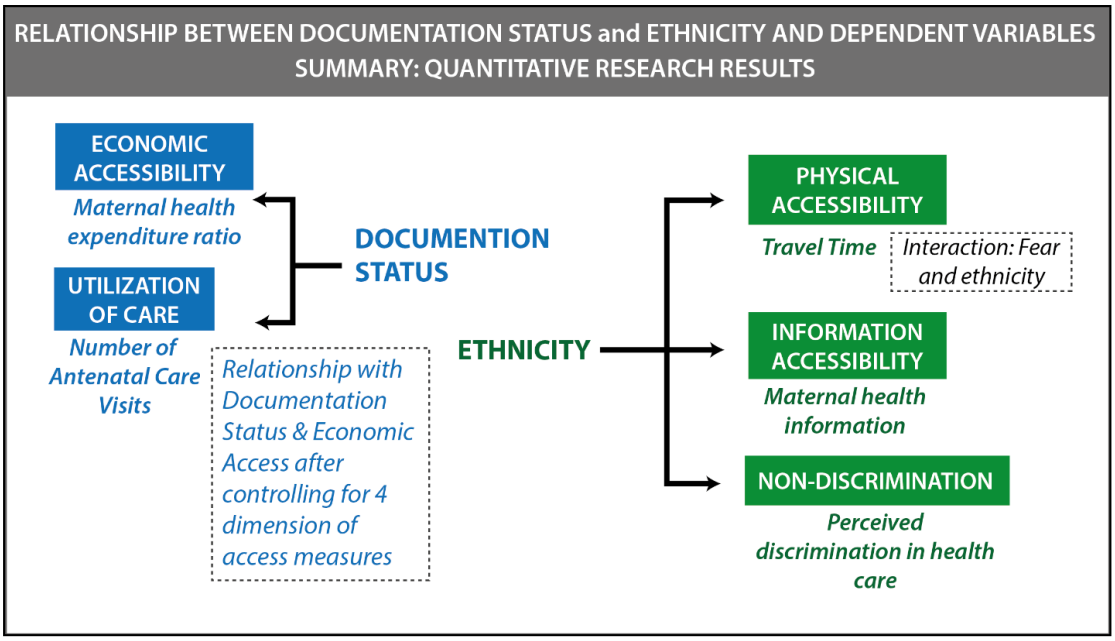
6.7. SUMMARY: QUANTITATIVE RESEARCH FINDINGS

This section summarizes the findings of the quantitative research using the two research questions of this study.

Q.1. What is the relationship of documentation status and ethnicity of Chin and Rohingya women refugees and asylum seekers in the Klang Valley to access to maternal health services in terms of (a) the dimensions of access, and, (b) utilization of maternal health services?

The summary of the results to this question is given in Figure-28 and shows that ethnicity was significantly related to physical accessibility, information accessibility, and non-discrimination. Documentation status on the other hand, was significantly related to economic accessibility and utilization of maternal health care.

FIGURE 28: SUMMARY OF FINDINGS-QUANTITATIVE RESEARCH



Non-Discrimination

Ethnicity was significantly related to non-discrimination measured via perceived discrimination in health care related to race.

Overall, only a third of the population did not perceive any form of discrimination in health care, although Rohingyas perceived fewer forms of discrimination.

Rohingyas' lower levels of perceived discrimination could be related to their higher mean period of residence in Malaysia (7.45 years vis-à-vis a mean residence period of 1.8 years for Chins) in addition to their greater proficiency in Bahasa Malaysia, and shared religion with the dominant population in Malaysia, which might offer better opportunities to assimilate into the local population.

Those who did experience discrimination accepted it as a fact of life. However, although a higher proportion of Chins perceived discrimination in health care, a higher proportion of Chins than Rohingyas also coped actively with the perceived discrimination in health care by complaining and asking for attention at the health facility, or talking about it to family and friends.

Physical Accessibility

Ethnicity was significantly related to physical accessibility. A change in ethnic identity from Chin to Rohingya was associated with shorter travel time to obtain maternal health care.

However, ethnicity was also related to feelings of fear. A higher proportion of Rohingyas (than Chins) experienced fear when traveling to obtain maternal health care. However, a higher proportion of Chins (rather than Rohingyas) experienced anxiety provoking incidents such as being stopped by enforcement authorities and getting lost. Among those who felt fearful, Chins (rather than Rohingyas) took a significantly higher travel time for ANC, delivery care, and PPC probably because a higher proportion of Chins than Rohingyas who were fearful walked and used the LRT, while a higher proportion of Rohingyas than Chins who felt fearful traveled by taxis, used their own/their friend's car and/or motorbike. A higher proportion of Chins than Rohingyas who walked lived below the poverty line income of RM 763 per month, reflecting the overlapping dimensions of physical and economic access in the study population.

Although it may appear that a higher proportion of Chins had difficulties with physical access in the form of travel time, feelings of fear, anxiety provoking incidents and modes of transportation, the results reveal that experience of fear was quite pervasive with about 86.0% of the study population reporting feelings of fear while

traveling to obtain maternal health care and close to half the study population reported the experience of being stopped by enforcement authorities.

Information Accessibility

Ethnicity was consistently related to all the variables associated with access to maternal health information. A change in ethnic identity from Chin to Rohingya was associated with better information access. This could be because Rohingyas' mean period of residence in Malaysia was higher than that of the Chins giving them an advantage in terms of linguistic capabilities and knowledge of health information sources.

Although a higher proportion of Rohingyas than Chins reported being provided with the nine items of maternal health information, only a little over half the Rohingya study population reported that the maternal health information they had obtained was adequate. This could indicate that even in the best of circumstances where maternal health information is made available and provided as part of the routine content of care and there are family/community interlocutors to help them navigate information access, non-citizen populations such as refugees and asylum seekers might encounter unique barriers in accessing care.

Economic Access

Documentation status on the other hand was significantly related to economic accessibility. Although refugees had higher annual family incomes and expenditures than asylum seekers, a higher proportion of refugees (than asylum seekers) incurred catastrophic maternal health expenditures and were impoverished after incurring maternal health expenses.

Although, a higher proportion of refugees fell below the poverty line income and incurred catastrophic maternal health expenditures, it cannot be concluded that they were worse off than asylum seekers. Catastrophic maternal health expenditures and poverty head counts adjusting for maternal health expenditures do not fully capture the consequences of out-of pocket medical expenditures, lack of access to risk pooling mechanisms and poverty because many poor families may elect to avoid health care utilization than obtain care and hazard impoverishment [350].

Utilization of Care

Documentation status was also significantly related to utilization of care. A higher proportion of refugees than asylum seekers obtained an adequate number of ANC visits, even after controlling for all four dimensions of accessibility.

Q.2. What are the differences in the patterns and levels of utilization of maternal health services of Chin and Rohingya women refugees and asylum seekers in the Klang Valley?

Overall, with regard to initiation of ANC, although a higher proportion of asylum seekers had an earlier initiation of ANC than refugees, their initiation of care exceeded the WHO recommended cut off period of the first trimester, thereby qualifying as “delayed care”. On the other hand, a higher proportion of refugees than asylum seekers obtained adequate number of ANC visits, had an institutional delivery, and obtained PPC.

Rohingyas accounted for the majority of non-institutional deliveries and non-utilization of ANC compared to the Chins. But overall, their utilization of adequate ANC exceeded that of the Chins. Additionally, a higher proportion of Rohingya women obtained PPC including a PPC home visit from a midwife/nurse after discharge from the hospital.

CHAPTER 7: RESULTS-QUALITATIVE

In Chapter 7, I describe the findings of the qualitative research which was undertaken to explore negative patterns of maternal health care utilization. The focus on this broad theme arose from the inability to quantitatively analyze factors influencing non-institutional (home) deliveries and non-utilization of ANC services. Given the importance of understanding such cases from the perspectives of human rights and research with hard to reach populations such as refugees, qualitative methods were pursued.

The findings highlight the *context* of accessibility to maternal health services experienced by the respondents. The challenges posed by contextual conditions to accessibility of care translated into avoidance of maternal health care, delays in seeking care, use of emergency care, use of sub-optimal care, and non-utilization of maternal health care for the respondents.

Although the qualitative results are based on a minority experience of extremely negative patterns of utilization of maternal health care, they point to social contexts that remain uncovered in traditional forms of inquiry using purely quantitative methods. Although qualitative research does not permit the generalizability of the findings, it adds unique perspective to the role of context in mediating accessibility, and the links between accessibility and utilization of maternal health care. It also provides insight into the non-utilization of maternal health care by a disadvantaged and hard-to-reach population such as refugees and asylum seekers. These findings would not have emerged from the data if they had not been purposively pursued.

A thematic case study approach was used to present the qualitative data findings. The key themes and main sub-themes resulting from the analysis are included in Table-56.

The three most commonly recurring themes across the entire data set related to life as a refugee, economic access, and physical access.

Throughout this chapter, themes have been highlighted in bold and sub-themes in italics.

TABLE 56: THEMES AND SUB-THEMES FROM THE THEMATIC ANALYSIS

KEY THEMES	SUBTHEMES
7.1. Life as a refugee	• *Life in Malaysia* • *Life in Burma* • *Life during flight*
7.2. Physical accessibility	• *Fear factor* • *Coping with fear* • *Distance and transport*
7.3 Economic accessibility	• *Living in poverty& unaffordable basic needs* • *Indebtedness and its social consequences* • *Coping with economic hardship*
7.4.Perceived discrimination	• *Perceived discrimination in everyday life* • *Perceived discrimination in health care* • *Coping with discrimination*
7.5.Information accessibility	• *Language barriers* • *Coping with language barriers*
7.6. Perceived availability of functional social support	• *Forms of functional social support & reciprocity* • *Factors influencing the absence of functional social support*
7.7. Private and NGO ANC	• *Underutilization of care and its links to economic and information access*

7.1. LIFE AS A REFUGEE

Life as a refugee was a key theme and highlighted risks to the sexual and reproductive health experienced of the women and deprivation of basic needs and of access to health care.

Life in Malaysia formed a key sub-theme of **life as a refugee**. Security fears of enforcement personnel and economic hardship punctuated the narratives of the respondents. Most of the respondents had been unaware of the situation in Malaysia prior to fleeing Burma. They were unaware about the lack of refugee protection in Malaysia, the absence of refugees' formal right to work and right to education for their children, and higher user fees (as foreigners) in public hospitals.

Recently arriving Rohingyas, like the asylum seeker IDI-7, thought that Malaysia would provide them a sanctuary from the ethnic and religious persecution they were experiencing in Burma:

> Staying in Myanmar was difficult. It was even difficult to pray… We Muslims cannot open mosques although there are some small mosques. Cannot pray loudly. They are like that…When I came to Malaysia, I thought, "Oh! Malaysia is an Islamic country. I am a Muslim. I can live here with ease, and pray." With such thoughts I came to Malaysia. But since coming here, there are so many raids. How to pray, how to earn money, how to take care of our children? Always, difficult and scared.

Being undocumented (awaiting registration with UNHCR) or being an asylum seeker brought additional hardships of being unable to secure work, being at greater risk of detention and deportation if arrested, and of being turned away by health care facilities.

> My UN card with bag was snatched. Robbed. Robbed. I cannot do anything. I went to the hospital. They said, if you do not have documents, we cannot accept you. If you have documents, we can accept you, [IDI-1, Rohingya]

Two women who engaged in paid employment stated that menial work was the only type of work available, that employers were verbally abusive, and did not pay them their overtime wages.

"It is very difficult" was a common refrain of the majority of the participants. "Yeah. It is very difficult. My husband earns RM 600 per month. We stay with his cousin. We had to pay the cousin RM 300 for room rent and food for my husband, son and myself. We also had to repay money that we had borrowed earlier. It cost me about RM 240 per month to go to the clinic and UNHCR office. So, we had to borrow again. So, it's very difficult', [IDI-8, Chin asylum seeker].

Life in Burma was always linked to factors triggering their forced migration. The reasons for the women to leave Burma were generally related to their spouses' need to flee the country and/or the inability of the spouses to return home because they had crossed national boundaries without the permission of their government. One

Rohingya woman, IDI-2, however, had to flee because she was involved in a motorcycle accident and motorcycles were banned in her home town. Another Rohingya woman, IDI-4, was forced to leave after the government confiscated their house. One Chin woman, IDI-9, had to flee after her husband was framed on trumped up charges at his work place where he was the only Chin person. Another Chin woman fled when the army came looking for her husband who was in Malaysia.

The ethnic violence that took place in the late seventies in Rakhine state influenced the *Life in Burma* experiences for Rohingyas. The long staying Rohingya respondents came to Malaysia at this time (late seventies, early eighties). Many families got separated at this time; one woman was even kidnapped at the age of ten by a human trafficker who sold her to a factory owner in Thailand, while forcing her into sex work simultaneously. She underwent one abortion during this time and was later sold to her husband in marriage by the trafficker for RM 3, 000 and 1 gram of gold which was kept by the trafficker. Rohingya women described their statelessness and absence of an Identity Card (I.C.) in Burma, specific restrictions on the movement of people living in Rakhine state, and inability to earn a livelihood, pray and to obtain tertiary education, as factors prompting their flight out of Burma.

Especially for recent arrivals, *Life during Flight* was perilous, marked by violence and rape for some, as they used smuggling/human trafficking routes to flee. One Rohingya woman (IDI-3) suffered a miscarriage and bled while waiting in the forest between Thailand and Malaysia for an opportune moment to cross over. She showed a blood stained *sarong*, her only piece of clothing during flight. She keeps the *sarong* to remind herself of the ordeal she survived. She dared not cry or grieve for her lost baby in front of the traffickers who were holding them in the forest. She stated that she was also traumatized by the regular screams of young women being raped by the armed human traffickers behind their hut in the forest.

Both, IDI-3 and IDI-7, who had been held by these traffickers in the no man's land between Thailand and Malaysia, reported that they were forced to squat throughout the time they were in the hut with the armed smugglers.

IDI-7, a young Rohingya respondent stated that she and her mother were the only two women in the hut of the armed human traffickers in the forest, when she was

"buang Thailand" (thrown into Thailand) after serving her term in an immigration detention centre in Malaysia in 2006. (A Report to the Committee on Foreign Relations United States Senate, One Hundred Eleventh Congress, and dated April 3, 2009 reported the involvement of Malaysian officials in the arrest, detention, and extortion of Burmese migrants and refugees, mistreatment including torture of detainees in detention facilities, and the transfer of Burmese migrants and refugees to human traffickers for payment)[504].The human traffickers told IDI-7 and her mother that they could be free if someone made a payment of RM 1,500. When they could not raise this money, even as a loan, from known sources, she accepted the offer of her husband (at that time, a total stranger to her) to secure their release for RM 1,500, in exchange for hand in marriage. She was 15 years of age at that time and he was already married with two wives and three children. At the time of the interview she was 18 years old; she had suffered a miscarriage, given birth to one baby and was pregnant with another child.

IDI-10, a Rohingya asylum seeker pending registration, described the difficult conditions in the refugee camps in Bangladesh, the country of first asylum for herself and her family, as lacking in sufficient food, security, and basic needs. She was one of the many young women I had interviewed, who were being brought to Malaysia to be married off to Rohingya men. She stated:

> Refugee life is not good…when I close my eyes I see many things but I cannot speak…very difficult…I see children go outside, no clothes. And women sit sadly, thinking; they do not share their sadness with another person … I also see men go out and walk up and down…They don't tell anybody what is in their heart…I used to work for a lawyer who helped undocumented Rohingyas in jail in Bangladesh. I saw Rohingya men remain in jail for years and years because they had no documents. I saw pregnant women give birth and raise their children in jail. They would cry when they saw me…I felt like crying too. I used to buy them biscuits and cigarettes because I felt very sorry for them.

7.2. PHYSICAL ACCESSIBILITY

The narratives categorized as physical accessibility revealed that greater than barriers of distance and transport, was the psychological factor of fear, which

impacted the mobility of almost all the respondents. It also showed that physical and economic accessibility were often co-prevailing factors influencing the utilization of maternal health care.

The *fear factor* was persistent in the narratives related to **physical accessibility,** especially in those who were undocumented and in three of the in-depth interview respondents who had been held in immigration detention in Malaysia with their children.

IDI-6, a Rohingya refugee with a valid UNHCR card, who had been in immigration detention stated:

> The first time I was arrested, in 2007. In March. I can still remember. They came in the early hours. It may have been about 3 a.m. They came pounding on the doors. We were all asleep. The RELA[3], they came. They were knocking hard on the door. I opened the door. My husband ran away from the back door. They said they were going to arrest us. I begged and cried and asked them to spare my children. But they dragged my sleeping children by the legs. We were in detention for 18 days… I am still very afraid. It is very difficult for me to sleep at night. I am afraid they will come again.

IDI-9, a Chin asylum seeker pending registration, who had delayed initiating ANC said:

> I don't go because I don't have any card like UNHCR card and I can't afford the charges. Also, I am new. I don't know where to go. All my friends are seeing doctors as they have cards …I'm afraid that I might be caught…I visit friends who stay on same floor with me…I don't go to church very often because it gets late and sometimes police are on the way to church. Yea, I have to be very alert; at every corner, to check the police…I'm scared of police all the time. So I did not go to the medical center.

[3]Ikatan Relawan Rakyat Malaysia or People's Volunteer Corps, a paramilitary civil volunteer corps under the Malaysian government

Coping with fear included many strategies. Respondents, both Chin and Rohingya, coped with fear by avoiding visits to the health care facility, staying indoors all day, and running in the opposite direction when they sighted enforcement personnel.

> When we see a policeman, as much as we can, we try to avoid them. If not, we just go through another way. And if we cannot run or we cannot avoid any more we just walk straight like this (nonverbal: puts palms together and walks straight) and they check everything. Some of them are very good. They just give us back our UNHCR card and they don't ask money. Some of them, they ask money. And then, er, it's very fearful. Now when I see a policeman, I am very fearful already. [IDI-8, Chin asylum seeker]

> Sometimes, I walk on the road in front of my house. If it is safe. It has become a habit to stay indoors at home all the time, [IDI-10, Rohingya, asylum seeker pending registration]

One Rohingya woman (IDI-1), a single mother, stated that every time there was a raid, she ran and hid in the forest close to her house with her children for a few days. Another undocumented Rohingya woman, (IDI-2) said that she hid in the house of a friend who lived far from her house every time there was word of an impending raid.

Distance and poor transport, although less cited by the respondents did pose some serious problems for two respondents who delivered on the road (birth before arrival).

In order to travel to the hospital,IDI-6, a 38 year old Rohingya refugee living on the periphery of the greater Kuala Lumpur area, needed to walk a dirt road to the nearest main road before waiting for a bus that came once every hour. The bus took approximately an hour to reach the hospital. For her first five deliveries, IDI-6 had depended on her husband for transportation to the hospital. However, he abandoned her during the fourth month of her last pregnancy to take the boat to Australia. She recounted the events of the delivery of her last child.

> The pain started increasing. I knew I could not delay any more. I had no money. I had no transport. The sun was very hot. I was in a lot of pain. Very difficult to walk. I did not know how long I might have to wait for the bus

at the main road. Suddenly, my water broke. I became terrified. I thought, am I going to deliver here on the road? I started crying loudly and shouting. One man who was driving a small lorry stopped and agreed to take me to the hospital. But the baby cannot wait. The lorry was moving from side to side. The road was bad. The baby already came out. It was the most terrifying day of my life. There was blood everywhere. I was bleeding profusely and was very weak; I could not move. As the lorry went from one side to the other, the baby swayed from side to side in the back of lorry. The cord got wound around the baby's neck, abdomen and legs. I was so terrified. I thought my baby would die. There was blood everywhere in the back of the lorry. But I was very weak. I could not move, I could not do anything. Finally, we reached the hospital. When we reached there, the hospital nurse came and shouted at me. She said, "You *bodoh** (*stupid). You refugee. Get up and walk by yourself". But the doctor was good. He told me to lie on the stretcher. There was blood everywhere. I was bleeding.

Physical accessibility was also related to economic accessibility as evidenced in the case of IDI-6 above. A Chin respondent, IDI-8, stated that she walked 30 minutes to the clinic to obtain ANC, even during full term pregnancy, because she lacked the financial resources to use public transport.

7.3. ECONOMIC ACCESSIBILITY

The narratives on economic accessibility revealed that although the women were aware of the need for maternal health care, their dire financial position created competing demands between survival needs and maternal health care and impeded their utilization of care. Additionally, the coping strategy of "borrowing" to finance maternal health expenses created embarrassment and impacted their social exchanges in the community.

As such, one of the significant sub-themes in the narratives of the women was,*living in poverty & unaffordable basic needs*. The spouses of most of the women were daily wage earners working in the informal sector, and/or men who worked double jobs to sustain their families. Three of the spouses and one of the respondents eked out a living by collecting scrap metal (besi buruk) from rubbish bins and the side of

the road, which they later sold to wholesalers. Such work helped them earn about RM 20-25 during a 12 hour working day.

IDI-7, a Rohingya asylum seeker, reported that she and her mother cleaned an apartment compound (from blocks A to H) and were jointly paid RM 400 per month. IDI-9's husband earned RM 500 per month. They paid RM 150 in rent and managed on RM 150 for food every month; there was no extra money for anything else, including maternal health care costs.

With narratives similar to IDI-9, the majority were unable to meet their basic daily needs. Three of the women reported that they were four to six months overdue in paying their house rent. A common coping strategy for many women in the study (including several women in the survey) was to reduce consumption by cutting back on food. IDI-8, a Chin asylum seeker, stated that she did not eat breakfast, drank one packet of soya milk three times a week at lunch time, and at night, ate the leftover food (rice and vegetables) that she had cooked for her husband for lunch before they had both left for work in the morning. She was the same woman who walked 30 minutes to obtain ANC checkups even when she was eight and nine months pregnant. She said:

> Yeah. I ate like that. Why? We because we are going to have a baby. We need baby cloth, powder, and white cloths to wipe. We don't have anything from the beginning, lah. So, we need to buy. And we need to repay back those from whom we borrowed money when we came to Malaysia first time.

In fact, ongoing *indebtedness and its social consequences*, was a significant sub-theme in the majority of the narratives. The indebtedness and repaying back of loans related to: (i) financing their flight from Burma; (ii) loans borrowed to rent a house and settle in when they first arrived in Malaysia; and (iii) lack of a steady job and income leading to borrowing for basic consumption needs. Consequently, the majority of the women also stated that they had always looked with longing at the food (especially fruits) being eaten by local and economically better-off refugee women in the ANC clinics.

The consequences of indebtedness extended to the social domain too impacting their relationships with family and friends. IDI-1 and IDI-2, both Rohingyas, had the

perception that others, including family members, looked upon them with contempt. IDI-4 and IDI-7 reported that they felt deep shame and embarrassment when they were unable to repay the money borrowed. IDI-7, a Rohingya asylum seeker, who had to borrow money from her friends each time she went for ANC said:

> If I am going to the clinic next week, today I look for money. But I am ashamed to even borrow. If s/he is not happy with me, s/he will not want to give me. I feel ashamed…Twice or thrice I will go and see. If people do not want to give me money, that day I will not go to the clinic…I do not want to go to friends' house.

Consequently, like other respondents, she skipped visits to the ANC clinic. Her embarrassment about having to borrow for maternal health care expenses also reduced her social interactions within the community.

In relation to utilization of maternal health care, c*oping with economic hardship* often included: (i) delay in initiating care as in the case of IDI-9; (ii) avoidance of ANC as in the case of IDI-7; and (iii) non-utilization of ANC as in the cases of IDI-1, IDI-2, and IDI-3.

IDI-2, a recently arrived undocumented Rohingya woman, who did not obtain ANC said:

> In Malaysia, I cannot go to the clinic for pregnancy checkups. I know, I should go to the clinic, get the appointment date for the next visit, take medicines, and I should eat well. I know all this, but I have no money.

For her first child, IDI-2 had attended ANC and had a nurse deliver her baby in Burma.

Coping with economic hardship also included non-utilization of institutional delivery care and opting for home delivery, as in the cases of IDI-1, IDI-2, and IDI-3. IDI-1, a Rohingya was a single mother, who earned her livelihood by searching for scrap metal in addition to cleaning houses and washing clothes for others. She delivered her baby at home and had this to say:

I want to go to hospital. But no money, nothing. From childhood till now, it is difficult. I search for scrap metal, I eat. If I want to go to the clinic, I must pay RM 15 or RM 20. If I want to deliver (in the hospital), they will take RM 2,000 or RM 3,000. This, I cannot pay. God helped me. I delivered at home. Friends came to help. But they did not know how to deliver a baby, did not know how to cut (umbilical cord). They said, go to the clinic. I said, how can I go to the clinic? If I want to go, I must have money. I have no money. At home only. I delivered. I ate a garlic. I pushed once, twice, then everything came out. I told my friends, "Cut!" But they were scared. Later, I wanted to cut, but I could not. I took the baby, wore my clothes. They took me to the clinic. The doctor wanted RM80 to cut the cord. I told him, I don't have RM 80. I paid RM 40. My friend gave me RM 10. One Malay lady in the clinic gave RM 10. Two Myanmar women at the clinic gave me RM 20. Total RM 40. They paid for me. I returned home. No medicine, nothing. I was aching all over. Soon after delivering, I started searching for scrap metal. I tied my baby to my back. My two older children are very beautiful. I was afraid that people would steal them. My luck was good, neighbors helped keep an eye on them.

7.4. INFORMATION ACCESSIBILITY

Being foreigners and being Chin/Rohingya in Malaysia included dealing with language barriers, especially for recent arrivals. It impeded their ability to communicate with health care personnel. It also impeded their ability to obtain critical information related to complications/emergency preparedness.

IDI-5, a recently arrived Rohingya refugee woman, reported the difficulties she had in communicating with nurses and doctors at the hospital where she also worked as a cleaner. She was unable to provide them information and was unable to comprehend the advice they gave. Her baby was born before arrival. She delivered by the road in the early hours of the morning when they failed to get a taxi to go to the hospital. She slowly walked back to her house with the support of a relative who held the baby's head. However, the placenta was not expelled and the umbilical cord had to be cut. The family did not know what to do. They later approached their Malaysian landlord for help. He called the ambulance. The nurses who came accused her of delivering at home to "save money" and threatened to have her prosecuted for delivering at home. She was terrified. When she arrived at the

hospital, the nurses again threatened to have her arrested and prosecuted. She stated that a doctor who recognized her as a cleaner in the hospital intervened and stopped them from calling the police.

IDI-8, was a Chin woman with tertiary education and was able to communicate in English with the nurses at the clinic. However, she stated that the information given was insufficient.

> Some nurses, they just tell us, “Eat properly”. Only that much. What I wanted to know is what ‘proper food’ is? Which one is proper food?

She stated that although she had told the doctor that she had bleeding and had a miscarriage prior to her last pregnancy, she had never been informed of the danger signs during pregnancy during her ANC visits. She also said that a biopsy had been done during the time of her pregnancy. At the time of delivery, the attending doctors, upon reading her Rekod Kesihatan Ibu, wanted to know the results. But she had never been informed of the results.

On the other hand, IDI -10, another young Rohingya who had arrived recently, was very appreciative of the nurses and doctors in the hospital she went to. She stated that they took time to explain and answer her doubts. Although, she could not speak Bahasa Malaysia, her husband who was born in Malaysia spoke the language fluently. He acted as translator, just as a significant number of spouses of women in the survey acted as translators at health care facilities.

For others, like IDI-5 who did not have a spouse who could speak Bahasa Malaysia, *coping with language barriers* included paying a local Malaysian or a refugee residing for a long time in Malaysia, to translate for her. IDI-5 whose birth before arrival experience was detailed in this section earlier, paid a long time residing refugee RM 20-RM 25 per visit, when the doctors at the hospital asked her to return for the ANC visit with a translator.

IDI-9’s *coping with language barriers* included avoiding going to the clinic and delaying the initiation of ANC out of fear; because she could not speak the language and because she had heard from friends that nurses at the maternal health clinic scolded those who could not speak Bahasa Malaysia.

7.5. PERCEIVED DISCRIMINATION

The narratives on perceived discrimination, a continuation of the respondents' being foreigners and being Chin/Rohingya in Malaysia, showed mixed support, with some citing discriminatory attitudes and behavior from health care personnel, and others citing non-discriminatory behavior. The respondents perceived the discriminatory behavior as being related to their (i) ethnicity (Chin/Rohingya); (ii) being foreigners in Malaysia; (iii) being refugees; and (iv) deficits in language competencies.

For those who perceived discrimination, there were again mixed consequences, with some delaying utilization of health care whereas the others continued to seek care after rationalizing this as "part of life".

Although the research focused on perceived discrimination in health care, the narratives of many of the women focused on *perceived discrimination in everyday life*.

IDI-6, the Rohingya woman, whose baby was born before arrival in the lorry and who was shouted at by the nurse and asked to get up and walk when she arrived at the hospital had this to say:

> This is not in the hospital alone. Wherever you go, there is no respect. They call, "Eh Burma", "Eh, Rohingya".

IDI-8, the educated Chin woman, described her perception of racial prejudice while using public transport and at the restaurant where she worked as:

> Because, um, we can see when we get on the bus or the monorail, the way they look at us…It is as if they don't like sitting near us. Like this (makes a gesture of moving away from her). Some of them act like this. It's very, very, how do you say, it's not good. We, in our mind, we feel very bad.
>
> We don't understand Melayu and Chinese. Then myself, my experience, I can understand English but I don't know Melayu and Chinese. When the customers come, they treat us like mad people. Even if they cannot speak much English. They shout and we are very shy *[embarrassed]*. We cannot

> do anything. The boss also, they shout at us in front of customers. We are always scared. We don't feel like going to work but without working, we cannot earn money also.

With regard to *perceived discrimination in* health care, both verbal and non-verbal forms of discrimination were reported. The narratives revealed the following forms of perceived discrimination by personnel in health care based on refugee and/or ethnic identification: (i) being shouted at for not knowing Bahasa Malaysia; (ii) locals being called before refugees for consultation although the latter had arrived before the former; (iii) disapproving and sarcastic looks; (iv) being ignored by health care personnel; and (v) being told, "you Myanmar people, disturbing us", "you refugee people not allowing us to do our work", "go back to your country", and "you Myanmar people don't know anything".

IDI-8 recounted that while she was experiencing labor pains at the time of delivery the nurse scolded her and said, "You refugee people cannot deliver here. You cannot deliver in a foreign country. Why do you deliver here?". IDI-8 said:

> I also in so much pain already, I don't know what to do. I am also afraid I may die. That time when she shouted at me, I also, I cannot bear any more, lah… They look down and make me sad because that time I was in so much pain, I did not know if I was going to live or die. That time they said such a thing to me; I felt very sad, they looked down on me…That time I miss my mother a lot, and our village. Because even if we don't know anything, even if we are unable to go to the doctor, at least when we are pain, if our mother and family is near, they give us strength. Here, there is no one.

She added that during ANC visits,

> …they used to check our stomach isn't it? So sometimes, the cloth also, like this they pull out roughly (gestures to the clothing over the lower half of the body being pulled roughly).

She however added that, not all health care personnel treated the refugees this way, "some of them, they treat us the same way they treat Malaysians, but some of them, they treat us differently… some of them are very good. They are all not the same".

The women' forms of *coping with discrimination* largely included ignoring such speech and action. IDI-8 said, "I, we cannot do anything. So, I don't say anything. I try to avoid them, avoid going near them. So, I just turn off like this", (makes a gesture of turning her head the other way). She also stated that although she did not feel like returning to the clinic because of the way some of the nurses and doctors treated refugees. However, she rationalized her next course of action in the following way: "In my mind I noted, '…this is not my own country.' That is why it is not so easy. I already noted this in my mind…So, I have to take some strength in my mind. I have to make myself to be brave. If I don't go, for my baby it is not good. I have to go and meet her, however they treat us. I have to bear it."

IDI-5, however, stated that the nurses and doctors at the hospital she went for ANC checkups and her delivery, were very polite, kind, and respectful.

7.6. PERCEIVED FUNCTIONAL SOCIAL SUPPORT

The issue of **perceived functional social support**, a significant theme in the narratives of the women emerged as a mediating factor of accessibility. Social support was related to their ethnic identity within the broader refugee community. In general, Chins had a positive perception of functional social support compared to the Rohingyas who perceived a lack of solidarity and mutual reciprocity within their ethnic group.

Functional support is a subjective measure of perceived social support, with the most commonly cited forms of functional support being: (i) emotional support; (ii) instrumental/tangible support; (iii) information support and guidance; (iv) appraisal support related to self-evaluation; and (v) social companionship.

Chin

Family, friends, church/fellowship members within the Chin community were cited as the main sources of support by the Chin respondents. IDI-8 stated that although she belonged to a refugee community organization, the organization's office was located far from her residence. As such, she did not turn to them for help. However, she stated that she was aware that she could go to the refugee organization for information about UNHCR.

With regard to *forms of functional social support*, the two Chin women, IDI-8 and IDI-9, identified the following forms of social support that could be expected and given in relation to maternal health from members of their ethnic community: (i) financial; (ii) care of the baby; (iii) visits from friends and relatives; (iv) body massage; (v) information on delivery, baby care, and registration with UNHCR; (vi) sharing experiences of discrimination and sad feelings with each other.

IDI-8 and her family had lived with fellow Chins for several months when her husband lost his job and she was pregnant. She stated that her friends were also struggling financially. However, they allowed IDI-8 and her family to sleep in the living room and shared their meal of rice and vegetables with them. When she developed pains and started to bleed heavily one day, her friends were at a loss regarding how to help her because they had just enough money to pay for food for everybody living in the house. Finally, they gave her the money they had set aside as "church tithe", which was just sufficient for her medical costs. She repaid them the amount when her husband found employment.

Both IDI-8 and IDI-9 attributed their health condition (being pregnant and/or suffering a medical problem during pregnancy) and their poor economic state as factors that motivated their friends to feel pity for them and help them.

> I am pregnant; they feel pity on me struggling here. So, they are willing to help me. (IDI-9)

> I was bleeding already. I was in so much pain. No money to go to clinic. I don't have any UNHCR card also that time. I cannot go to hospital also. So, it is very difficult. So, those who I stay with, er Chin people, my friends, they also don't have money actually. But when they look at me they feel pity on me…. So, they gave me the tithe money we used to give to the church. (IDI-8)

The social support cut across national boundaries. IDI-8 shared that if not for the help of her resettled sibling in the United States at the time of her delivery, she would never have been able to cope with hospital expenses. Her sibling had also paid for a termination of pregnancy for her previously.

Reciprocity included helping their friends in various ways when they needed help. IDI-9 said of the friends who helped her financially, “The help I give, it’s not too much. I take care of their clothes when it rains, while they are at work. That small help made good understanding among us, and we are close friends now. I was never able to help them in cash.”

Their shared ethnicity as Chin and status of being refugees were also cited as a factors that prompted mutual generosity and empathy in times of trouble. Both, IDI-8 and IDI-9 asserted that tribe and sub-tribe differences among the Chin were not a barrier to social support in the community. Speaking about the different sub-tribes and differences, IDI-9 said,

> …we all are Chin and they are human-beings…Chin help each other. We understand how we struggle here. We are under the same status, ‘refugee’.

Rohingya

With regard to *forms of functional social support*, immediate family was the main source of social support among the Rohingyas, but it received mixed support in terms of reliability of the support.

IDI-10, a recently arrived “bride”, who came to Malaysia to be married to a Rohingya man born in Malaysia said:

> My family supported me very much during my pregnancy and when I had a child. Or else I would have had a lot of trouble…His father looked after me, took very good care of me…whatever I need, I go to my family; information, money, anything.

IDI-2, a newly arrived Rohingya asylum seeker who delivered at home because she did not have money and was undocumented stated that she did not receive any support from her family.

Like IDI-2, all Rohingya respondents except IDI-10 asserted that it was very difficult to turn to fellow Rohingyas for financial help, including family.

> Rohingyas do not help each other. Nobody helps each other. [IDI-2]

> She said, “You cannot live here. If you work, you can eat. If you do not work, you cannot live here”. [IDI-1, of her married sister, when she went to the latter’s house for help. The respondent’s parents were divorced and she had not yet reached the age of majority at that time].

For most of the Rohingya respondents, the perception of non-availability of functional social support seemed to be in relation to financial help and meetings one’s most basic needs. Although her aunt had loaned her money when she first arrived, her sister-in-law helped her with house work when she had to take care of her baby, and her mother took her to UNHCR to register herself, IDI-2 did not perceive it as support. “Nobody helps me”, she replied in response to the question about her sources of functional social support, after she had talked about family members doing things for her. She reiterated that financial help could not be expected from her family including her aunt, her mother, or her sister who have been residing in Malaysia for a long time. The same pattern was seen in IDI-1’s narrative. In spite of sharing about neighbors and friends who had helped her in small ways, she maintained that she did not have anyone in her life who wanted to help her. She said, “No one wants to help me. Even if I want to call someone, there is no one to call*”.*

The Rohingya respondents were unanimous in their reasons for the absence of social support in their community. They perceived the rich-poor divide to be the main factor influencing the *absence of social support*.

> In Myanmar, we helped each other. But in Malaysia, after they reached here, I don't know why Rohingyas changed…Only the rich and wealthy care for each other. The poor are not cared for…In Myanmar, in my place, we loved each other. It did not depend on the possessions we owned…After arriving in Malaysia, they are different. I didn't get any help. After reaching Malaysia, I didn't get even five cents from another. There is nobody to help me…So many changes. My aunt lives here. When we lived at there, we loved each other but here, she didn't even want to greet me when she met me face to face…My sister did not lend me any money. [IDI-2]

> I am poor. I have also seen. Rich-poor. The poor person helps the poor person. The rich person does not want to help the poor person. I have seen a lot, [IDI-1].

IDI-7, in stating that she could not turn to her family in times of financial crisis, said this, which might explain the statements of IDI-2 and IDI-1 above.

> I don't have money, right? No person can help me. They have money. I am a person with no money. I cannot repay them. They are afraid of this. They cannot help me, [IDI-7]

IDI-1 also added that there was greater interaction between Rohingyas who hailed from the same hometown in Rakhine state. She was born and raised in Malaysia and could not understand the charged relations to a particular place and dynamics of relationships rooted in emplacement and affiliation to hometowns in Rakhine state in the older generation.

> Maungdaung, lah, Buthedaung, lah, I don't know. But people here talk to people from their own village/place. They don't want to talk to other people. They fight, fight, fight…Like that.

Linking the qualitative findings to the survey, interestingly, only two respondents in the survey stated that they belonged to a refugee community organization although the Rohingya community organization which had assisted me in identifying several respondents viewed them as their members.

With regard to social support, most of the Rohingya respondents held the view that the Chins received a lot of help from churches and UNHCR, and the Mon and the Shan received help from the Buddhists in Malaysia.

7.7. PRIVATE AND NGO ANC CARE (SUBOPTIMAL CARE)

In this thematic case study, the data reveals that contextual conditions of undocumented status, economic hardship, and linguistic deficits contributed to the use of private and/or NGO ANC which resulted in under-utilization of care.

The WHO ANC randomized trial recommending four ANC visits (with the first visit occurring in the first trimester)[505] provides opportunities to assess the mother's health status, detect and treat diseases, screen for anemia and HIV and AIDS, prevent low birth-weight, and provide counseling related to nutrition, STIs, HIV and AIDS, healthy pregnancy and safe delivery, provide tetanus immunization, malaria prophylaxis, iron and folic acid tablets, and help women select a trained birth attendant or institution to deliver their babies. Standardized risk assessments and health prevention and promotion including screening, testing, counseling, immunization, and preventive medication are key components of such a focused ANC model. As such, blood tests for blood group typing, syphilis, HIV and AIDS, hemoglobin level, and urine tests for bacteriuria and proteinurea, and urinary tract infections are important components of care.

The analysis of maternal health records of 18 respondents who attended ANC in private and NGO run clinics indicated that the hemoglobin test was performed for only one respondent. Neither was blood grouping indicated on the maternal health record for the remaining 17 respondents who confirmed that a blood test had not been performed, nor counseling related to HIV given. All respondents who did not take the blood tests confirmed that they had not been advised on the benefits and risks of taking (or not) these tests.

See Table-57. Of the 18, nine were refugees, three were asylum seekers, and six were undocumented asylum seekers pending registration with UNHCR. In terms of ethnicity, three respondents were Chin and 15 were Rohingya.

TABLE 57: ANC TESTS/EXAMINATIONS IN PRIVATE AND NGO ANC SECTORS

EXAMINATION/TEST	NUMBER
Period of Amenorrhea	18
Blood pressure	17
Sugar	17
Albumin	17
Uterine Height/fundus	16
Fetus Position	15
Age of Fetus	13
Fetal Heart	10
Movement of Fetus	9
Edema	18
Hemoglobin	1
Heart	0
Breast	0

The three main reasons cited for utilizing private and NGO care was: (i) undocumented status prompting fear of travelling far from their homes and detection by authorities if they used a government clinic; (ii) lack of finance and (iii) presence of a Burmese speaking doctor in a clinic attended by four respondents which enabled them to communicate with ease.

While the NGO clinic lacked the facilities and resources to provide the WHO recommended content of ANC, respondents who used private care because of financial constraints stated that the facility to opt out of medical tests to contain ANC costs prompted their choice of such care.

7.8 SUMMARY: QUALITATIVE RESEARCH

The qualitative research revealed the importance of *context*. The thematic case study approach detailing the qualitative results highlighted seven themes which revealed insights about the contextual conditions influencing the respondents' access to maternal health services. Figure-29 at the end of this section shows the summary of the findings of the qualitative research.

Being a refugee and asylum seeker first predisposed the respondents to sexual and reproductive health risks through exposure to contexts of conflict and displacement. Contextual conditions related to their documentation status of being a refugee/asylum seeker/undocumented asylum seeker pending registration with UNHCR in countries of asylum like Malaysia and countries of first asylum like Bangladesh included absence of formal rights to refugee recognition, work, health care and education. This brought about protection challenges related to physical security, livelihood, poverty, deprivation, and social exclusions which contributed to negative patterns of utilization of maternal health services.

Specifically, the greater risks of arrest, detention, and deportation and the lesser risk of distance and transportation barriers in this group of respondents brought about security challenges which impacted physical accessibility.

The absence of livelihood opportunities and ensuing indebtedness in tandem with the high cost of foreigner's rate of medical care impeded their economic accessibility. Even refugees who received a 50% discount off the foreigner's rate

found it difficult to re-distribute their meager resources between their survival needs and the costs of ANC and delivery care including the cost of the hospital card, ward fees, and transportation fees. Economic inaccessibility with challenges of undocumented status and linguistic barriers prompted some to seek sub-optimal care in the private/NGO sector.

Being Chin and Rohingya in Malaysia meant being non-citizens/foreigners and dealing with language deficits, racial prejudice, and unfamiliarity with sources of health care and of possible support. Consequently, this impacted their information accessibility and exposed them to discriminatory attitudes and behaviors in everyday life and in health care from the local population. The social exclusion experienced as such was exacerbated by embarrassment about inability to repay old loans and having to borrow money to finance maternal health care expenses, which negatively affected the social exchanges within their communities.

Being Chin and Rohingya within the broader "refugee community" meant a differential perception in access to functional social support. While Chin respondents had a positive perception of available functional social support, Rohingya respondents experienced the opposite. Perceived functional social support was discussed in relation to financial support and support to meet immediate basic needs.

The case studies related to the perceived availability of functional social support highlight the mediating effect of social support on accessibility to maternal health services and provide a different perspective from the quantitative results. Whereas, in the quantitative results, refugees and Rohingyas had obtained adequate care, the case studies related to functional social support revealed that Chin asylum seekers had been able to utilize ANC, albeit delayed, because of the financial support of their immediate friends and neighbors. On the other hand, Rohingya refugees in the case studies had not utilized ANC or had an institutional delivery, and had not been able to garner support from their ethnic group, even when they had actively sought (financial) help. Moreover, the two cases of birth before arrival leading to the women delivering on the road were of Rohingya women.

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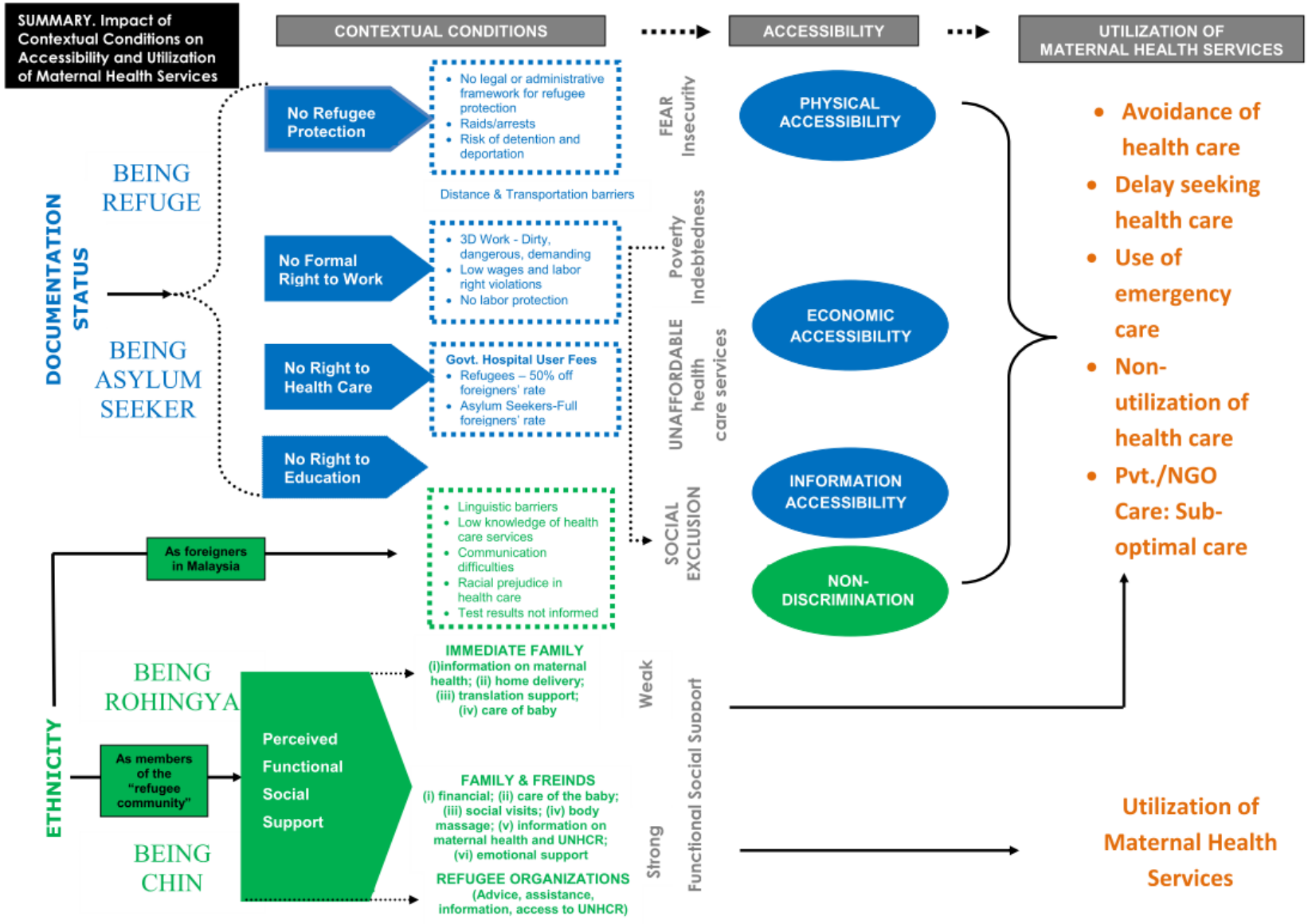
Figure 29: Summary of findings-qualitative research



CHAPTER 8: DISCUSSION

The purpose of this research project was to assess the accessibility of Chin and Rohingya refugees and asylum seekers in the Klang Valley to maternal health services. The study also aimed to assess difference in the patterns of their utilization of maternal health services. Toward this end I proposed that the right to health provided an appropriate framework of accessibility for this study. I then selected indicators from different domains of public health to measure accessibility according to the four dimensions of access in this framework. These indicators are not commonly used in empirical research on access. Clinical standards of care recommended by the WHO guided the use of the indicator related to maternal health care utilization. The qualitative research focused on the context of accessibility to and utilization of maternal health care. A mixed methods approach with contemporaneous use of quantitative and qualitative research methods and triangulation of methods and data sources was undertaken. The findings of this study will now be presented and discussed in this chapter.

In the first section (8.1), I summarize and discuss the findings within the broader discourses related to the accessibility of refugees and asylum seekers to health care and approaches to studying accessibility to health care of disadvantaged populations. In the second section (8.2), I discuss the limitations, strengths, and generalizability of findings. In section three (8.3) I draw out implications for policy and practice. Finally I make my conclusions in 8.4.

8.1. DISCUSSION OF RESEARCH FINDINGS

The major thematic topics arising from the findings of the study include: (i) the unique accessibility problems experienced by the study population because of their refugee status; (ii) the salience of legal status and citizenship in accessing health care; (iii) the role of social networks and social capital in refugees and asylum seekers' negotiation of accessibility to health care; and (iv) the appropriateness of

the right to health framework to examine accessibility of disadvantaged populations to health care.

8.1.1. Unique Accessibility Problems as Urban Refugees

Overall, the quantitative and qualitative findings show that the study population as a whole experienced many barriers in accessing maternal health services. The qualitative research provided insights into the contextual conditions creating the study population's exposure to reproductive health risks and experiences of exclusions that culminated in difficulties in accessing and utilizing maternal health care.

The distinctive nature of the accessibility problems of the study population because of their refugee status can only be established by comparing their experience of access to that of Malaysian citizens. This may not be a straight forward effort given the non-availability of comparable data. However, the uniqueness of the study participants' experiences of obtaining maternal health care can still be inferred through some available data related to general health care and maternal health care for the Malaysian population.

Economic Access

According to the Ministry of Health, Malaysia, the Malaysian population is reported to be protected against catastrophic health expenditures through policies of universal coverage [506]. Malaysia is frequently cited as an example of having the lowest burden of out-of-pocket payments for health care in Asia [488] and of catastrophic medical expenditure risk [507]. This corresponds to the underlying principle of the Malaysian health care system that accessibility to health care should not be determined by the ability to pay [463]. Despite this, the World Health Survey Report Malaysia 2003 (as cited in the 10th Malaysia Plan)[506], reports that about 4.0% of households were exposed to catastrophic spending and about 2.0% became impoverished. These figures contrast starkly with the 44.6% prevalence of catastrophic maternal health expenditure in the study population.

Other government estimates reveal that OOP spending increased from 32.0% in 2001 to 40.0% in 2006;and that OOP spending at hospitals was mainly at private

hospitals reaching 78.0% of total OOP payments in 2009 [508]. OOP health expenditure in the private sector is regarded by the government of Malaysia as indicative of "choice … preference of payers … and cost sharing by those who can afford" [506] (p.25). In the case of the study population however, the entire OOP maternal health expenditure was largely incurred at public hospitals with about 75.5% and 95.0% of the study population using public clinics/hospitals for ANC and delivery care respectively. Moreover, 48.4% of the study population had already been living under the poverty line before incurring maternal health care costs. Additionally, sources of maternal health care funding indicated that 59.3% of respondents resorted to borrowing to finance their health care expenditure.

Although the Malaysian OOP and catastrophic estimates are in relation to general health care and not maternal health care in particular, the prevalence of catastrophic health expenditures and the sector in which it occurred is different for the Malaysian and study populations.

The economic barriers experienced by the study population could be explained by various contributing factors. Both refugees and asylum seekers lack legal status in Malaysia under the Immigration Act 1959/63 (Act 155). They are denied the formal right to work and usually remain concentrated in low-level, underpaid informal sector work. Lacking in legal status, they are almost completely without the protection of the law, do not have access to grievance mechanisms and remedial procedures for violations of their labor rights, and are highly vulnerable to exploitation and forced labour [509].

However, they are subject to substantially higher non-citizen fees at public hospitals. Ward deposits and hospitals charges for citizens and non-citizens differ significantly. UNHCR recognized refugees obtain a 50% discount on fees charged to non-citizens for health care services at government hospitals; not asylum seekers. But, as the findings reveal, this is also unaffordable for a high number of refugees.

Utilization of Maternal Health Care

According to the WHO (2006)[510] Malaysia achieved 100.0% coverage of births by skilled health personnel. In the study population, 97.5% of the women had births attended by skilled health personnel. The high proportion of births attended by

skilled health personnel in the study population could be explained by the fact that issuance of birth certificates for refugee children requires proof of place of delivery through delivery records. Without a birth certificate, it would be very difficult for a refugee child to obtain immunization or treatment at any hospital. In the absence of legal status, the birth certificate is an important document for refugees. As such, an institutional delivery might be preferred because of its practical advantages, especially in acquiring identity documents.

The data with regard to ANC is a little more difficult to compare given the differences in the computation of adequacy of care. The World Bank (2009) reported that 91.0% of pregnant women received pre-natal care[511] (attended at least once during pregnancy by skilled health personnel for reasons related to pregnancy). For the study population, about 55.8% obtained the appropriate number of ANC visits (based on four visits at full term or number of visits adjusted appropriately for length of gestation).

In general, the results related to economic accessibility and maternal health care utilization align with the literature from countries in Africa and Asia showing the inverse relationship between user fee changes and utilization of maternal health care[499, 512-516]. However, they also indicate the possibility of distinct utilization problems related to the study population of urban refugees.

Physical Accessibility

Multiple regression analysis revealed that physical accessibility (travel time) was significantly related to ethnicity. Additionally, there was an interaction between ethnicity and fear. Among those who were fearful, Chins took a longer time to travel and experienced more anxiety provoking incidents during travel. Nevertheless, the experience of fear was quite pervasive with about 86.0% of the study population reporting feelings of fear while traveling to obtain maternal health care. More than half the study population had experienced between one and four anxiety provoking incident(s) and close to half the study population reported being stopped by enforcement authorities.

Hoffstaedter's research asking refugees in Malaysia for reasons for wanting to go to Australia found that "fear of enforcement personnel" and the desire "to move around

freely" were primary reasons cited by the majority of the respondents[517] (p.4). Hoffstaedter writes that as "illegal immigrants" and "transgressors of borders", refugees in Malaysia experience severe problems with spatial mobility. He links their challenges with spatial mobility to state policy which attempts to "contain and police those it cannot and does not wish to discipline into a category of state" and thus governs them through a "state of exception"[517] (p.11). He adds that while refugees elsewhere have been known to "shape, engage and remake place, [giving] them a sense of belonging as both in the here and now and the translocal ancestral home"[517](p.8), in Malaysia, this place making is denied and severely curtailed. These distinctive aspects of physical accessibility highlight the specific accessibility problems of the study population as urban refugees without legal status.

In general, the accessibility problems encountered by the study population are unique because they relate to their refugee status and/or "non-status" in the country. On the other hand, it also aligns with the health care accessibility and utilization experiences of others of similar status elsewhere. This will be discussed in the next section.

8.1.2. Salience of Legal Status and Citizenship in Accessing Health Care: Human Rights versus Citizenship Rights within Migration Regimes

In terms of findings on accessibility to maternal health care for the study population, it can be inferred that while ethnicity offered some advantages/disadvantages to navigate the environment and the health system, documentation status was moot to actually utilizing maternal health care. Economic accessibility was also related to being refugee or asylum seeker. Being a recognized refugee (versus an asylum seeker) increased fourfold the chances of obtaining maternal health care.

The study population's experiences of barriers in accessing maternal health care are consistent with the empirical studies reviewed in chapters 2 and 3 which attribute refugees/asylum seekers' accessibility problems to contextual conditions prevalent in countries of asylum. For asylum seekers, failed asylum seekers, stateless persons, and undocumented migrants specifically, besides poor language proficiency and communication problems, poor knowledge of the health care systems, and other cultural issues related to the acceptability of care[140, 142, 518], an additional determinant, namely legal status, has been found to significantly mediate

their ability to utilize maternal health care[140, 305, 316, 406, 407], even in countries with an egalitarian outlook toward health care distribution.

In this study too, documentation status was significantly related to utilization of care and asylum seekers fared worse than refugees in their use of maternal health care. About 67.6% asylum seekers obtained inadequate ANC visits compared to 31.7% refugees. This could be because vis-à-vis recognized refugees, asylum seekers had lower incomes (RM 9,600 median income of asylum seekers vis-à-vis RM 10,800 median income of refugees), which could be related to fewer opportunities to obtain work, and more exploitative and harsh work conditions than refugees[509]. It could also be because they do not get the 50% discount off non-citizens' rates in public hospitals that refugees are able to avail.

The higher rate charged to non-citizens at public hospitals reflects the co-option of health policy as an instrument of deterrence within migration regimes. It also reflects the notion of "undeservingness" of non-citizens to universal health coverage that defines the Malaysian health system.

According to Castañeda, *deservingness* discourses refer to "migrants' shifting and historically produced experiences of socio-political exclusion from their countries of residence, often leading them to be portrayed as unwanted, undesirable, and unworthy of services" [519](p.830). In contrast to *entitlement* from the human rights discourse which includes guarantees of equal opportunity to a system of health care, *deservingness* is a moral assessment which discriminates in the distribution of such an entitlement. Deservingness, which is frequently invoked in the case of non-citizens' access to health care[520], is relational and constructed by the appraisal of one's own deservingness and the social connection to the person being assessed[521]. Thus, while human rights have universal relevance based on shared humanity, deservingness is contextual and relative [519, 521] and defined by the frames[522] that are applied to the assessment.

The commonly used public health frames of *deservingness*[519, 522, 523] to justify accessibility to health care for non-citizens span a range of perspectives including: (i) a utilitarian outlook on the cost effectiveness of providing preventive and curative health interventions to non-citizens with the view that it will reduce higher future costs in the form of emergency care or transmission of disease to the host

population; (ii) worthiness of work which appreciates the position of hard working migrants who make fiscal contributions and contribute to the productivity of the country, yet experience poor work/life conditions and underutilize health services compared to host populations; (iii) calculations of providing benefits to future citizens, as in the case of providing ANC to non-citizen mothers in countries where the principle of *jus solis* operates, wherein babies born in a territory are conferred citizenship of that country; (iv) humanitarian and professional norms which require that care providers provide care regardless of status, a good example being the "*don't ask, don't tell, don't care*" health policy context regarding legal status in San Francisco [523]; and (v) imaging of non-citizens as victims and vulnerable toward whom policy makers have a moral obligation to alleviate their ordeals. The right to health perspective with its emphasis on entitlements anchored in universality and equality, regardless of status, is yet another frame. While the former set of frames and the right to health frame both align with the overarching public health frame which supports the provision of health interventions to undocumented non-citizens, the distinguishing characteristic is that the former fits the paradigm of "justified need"[522]. The right to health frame, on the contrary, is rooted in claims to rights that advance health.

Frames for *undeservingness* comprise of perspectives which cast non-citizens, especially undocumented non-citizens, as freeloaders, criminals, "bogus", unhygienic people, backward, threats to national stability/security/identity, and a burden on resources[521, 524-526], rendering them unfit to claim entitlements to health care[522] and to participate in the broader social and political community[527]. As such, discourses of undeservingness usually disregard structural inequalities and political, economic, social, and cultural contexts that spawn inequalities although indeterminate legal status is simultaneously a "juridical status, a socio-political condition, and mode of being in the world" [520] (p.813).

It can be argued that the relativity in moral assessments of deservingness discussed earlier can be found in the Malaysian health care policy on refugees and asylum seekers, where citizens who as bona fide members of the political community of the Malaysian nation are entitled to heavily subsidized rates, and recognized refugees who presumably have proved the authenticity of their asylum claim are viewed as *deserving* of the 50.0% discount off the non-citizens' rates in public hospitals. Asylum seekers on the other hand, who are in an indeterminate position and who

are subjected to a *culture of disbelief* regarding the legitimacy of their claims in most places[528, 529], are viewed as *undeserving* of the discount provided to recognized refugees.

Larchanché argues that frames of undeservingness are used to "apprehend undocumented individuals in moral terms, which then underlie therapeutic and administrative interventions"[526] (p.863). These include barring them from the "political … [and] moral community" through exclusionary citizenship and migration regimes[520] (p.806), where discourses of undeservingness reinforce migration strategies of deterrence and punishment especially in relation to undocumented non-citizens[524, 525], who include asylum seekers, failed asylum seekers, asylum seekers pending registration, and stateless persons. Referring to the citizenship-migration nexus, Dauvergne states that "citizenship law and migration law work together in creating the border of the nation" with the "messy policing of the national boundary by inquiring into debt and disease, criminality and qualifications" being left to migration law and a "rhetorical domain of formal equality and liberal ideals" taken up by citizenship law [530] (p. 119 and 123 respectively).

Thus, the contextual tensions creating exclusions for non-citizen populations like refugees and asylum seekers arise in the intersection between citizenship rights and human rights within migration regimes, where the asylum seeking process is increasingly criminalized and socially excluded refugees and asylum seekers live in "legal non-existence"[531] (p.55) or an ambiguous liminal "in-between status"[532] (p.1000), sometimes being neither documented or undocumented, and at other times having some of the characteristics of both forms of status, or a multiplicity of in-between forms[533].

The tension between the contemporary practice of citizenship rights and human rights arises partly from the common premise of equality that both concepts share. Further, in practice, both rights are exercised within the context of a political community. However, citizenship rights derive from exclusive national identity and exclusionary membership in a political community[534] whereas human rights are based on personhood and global notions of shared humanity offering internationally protected rights[535]. The current praxis of citizenship rights confers on a citizen: (i) political recognition; (ii) legal status; (iii) national identity; (iv) entitlements and freedoms; and (v) the ability to participate in political activities to enjoy their rights[536].

Thus, while the discourse on citizenship rights and the deservingness of entitlements concomitant with this status are actively used to address asymmetries in substantive citizenship and push for the rights of disenfranchised citizens, it is also used to create legal and socio-political exclusions for non-citizens who are not members of that political community[537]. These exclusions are implemented largely through (i) migration governance arrangements which Menjívar claims "actively irregularizes" people by making it impossible to retain legal status over time" [532] (p.1000) and (ii) state-centered discourses on civic deficits and undeservingness of entitlements that accompany it[525, 538-541]. Irregularity of status or undocumented status, which is further to non-citizen status, exacerbates the exclusions. In that sense, the rhetoric of deservingness-undeservingness straddling the discourses on citizenship rights and migration creates social exclusions for non-citizens and gnaws at the foundational principles of the human rights framework that are presumed to guarantee the enjoyment of rights, i.e. "equality of opportunity", "political participation", and "accountability".

In the context of maternal mortality, the former UN Special Rapporteur outlines accountability as including three elements: (i) monitoring; (ii) assessing if commitments have been kept: and (iii) redress/remedy if pledges/commitments have not been kept[542]. By virtue of being non-citizens and undeserving of the right to political participation and to the right to redress, both of which are associated with rights of national citizenship in many countries in Asia, refugees and asylum seekers cannot enjoy equality of opportunity, or participate in political processes, or hold the state accountable for the violation of their human rights.

The application of such a frame of contextual tensions emerging from the intersection of citizenship and human rights within migration regimes to refugees and asylum seekers in the Malaysian context could explain the operational problems of a rights based approach, and provide the legal and political context to the exclusions and barriers experienced by the study population in accessing and utilizing maternal health care.

The Malaysian Immigration Act 1959/63 is meant to regulate the entry of foreigners and the Employment Restriction Act 1968 to regulate the employment of foreigners. Along with the provisions for nationality/citizenship in the Federal Constitution (Art.14), these two laws draw the boundary between citizen and non-citizen and who

can/cannot work in the country; with all three laws being implemented through a regime that emphasizes the salience of "documents" in validating status/identity. Thus, refugees/asylum seekers lacking such documents are unable to engage with legal processes to acquire legal status and the formal right to work.

The description of the refugee protection environment in Chapter 4 highlighted the contributing factors for refugees and asylum seekers having irregular status in Malaysia. These include the absence of a legislative/administrative framework of protection for refugees in the country, and the inability of UNHCR's refugee status determination process to confer legal status to this population. As such, UNHCR Malaysia's refugee protection mandate may be said to be located in a rather inconvenient position within the broader national context. It is allowed to operate in Malaysia by the Malaysian authorities. Yet the very nature of its operation can be viewed as impinging on the territorial sovereignty of the State, in which such Mandate operations are placed. The act of recognizing refugees under UNHCR's General Assembly Mandate serves to render refugees as the beneficiaries of international refugee protection, and thereby acquiring internationally protected rights that flow from such status. However, their legitimate acquisition of such rights is not reflected in national Malaysian legislation, leaving them in a state of liminality.

Malaysia is state party to only two of the core international human rights treaties: the 1989 United Nations Convention on the Rights of the Child (CRC), the 1979 United Nations Convention on the Elimination of All Forms of Discrimination against Women (CEDAW). It has also ratified the 1956 Supplementary Convention on the Abolition of Slavery, the Slave Trade and Institutions and Practices Similar to Slavery, and some International Labour Organization (ILO) Conventions (C29, 1930; C98, 1949; C100, 1951; C138, 1973; and C182, 1999).

The Malaysian government has the obligation, among others, under CEDAW, to ensure the application of substantive equality to all women regardless of legal status. As such, the provisions of CEDAW (Art 12.2)[86] and its General Recommendation No. 24 (paragraph 26)[323], related to the right to appropriate pregnancy, confinement, and post natal services, including free services where required would also apply to refugee women. However, implementation of international instruments, including CEDAW, requires the incorporation of the said international law(s) into a parliamentary act or a legislative measure to that effect.

To date, no domestic legislation has been passed for the incorporation of CEDAW in Malaysia. Moreover, although the CEDAW Committee recommended (in 2006 in response to Malaysia's combined first and second reports), "that the State party adopt laws and regulations relating to the status of asylum-seekers and refugees in Malaysia, in line with international standards, in order to ensure protection for asylum- seekers and refugee women and their children" [543] (paragraph 28), Malaysia has yet to report on its progress with regard to the Committee's recommendations through its third and fourth pending reports to the treaty body [544]. Instead, media reports in 2010 reported that the Deputy Foreign Minister had said that, "as there were no special laws for refugees in this country, issues involving them came under the Immigration Act 1959/63 and that refugees were considered as illegal immigrants." [545].

In fact, with regard to non-citizens, Malaysia has been known to counter the relevance of international law on the basis of[525]: (i) the salience of the Immigration Act 1959/63 which deems those without government issued documents as "illegal"; (ii) securitization of the migration discourse whereby migrants and refugees in Malaysia have been cast as "threats" to the national welfare/stability of the country via discourses pitching them as beggars, prostitutes, criminals, vectors of disease, urban squatters, and freeloaders manipulating the public services[546]; and (iii) the cultural relativism argument related to human rights.

As such, (i) discourses of undeservingness based on negative images of migrants/refugees; and (ii) a punitive immigration regime implemented through documents, deterrence, large scale crackdowns on undocumented non-citizens, whipping, and detention[547], coalesce to draw borders and obstruct entry and membership into the political/social community of the nation. Restricted as rights guaranteed to citizens are (because of the restrictive approach to judicial review, wide use of emergency powers, and use of restrictive legislation[525]), the distinction made under the Federal Constitution between rights of citizens and non-citizens seriously constricts the latter's space to assert their fundamental rights in the domestic sphere or to challenge laws/policies that violate them [548].

Thus, it may be argued that in the Malaysian situation too, refugees and asylum seekers caught in the intersection between citizenship rights and human rights within an (im)migration regime bolstered by discourses of undeservingness, find

themselves in a legal limbo where "actions are denied, relationships are discounted, identities are assumed, … events do not officially happen" [531](p. 54), and exclusions in terms of health care are justified and reinforced.

The above problems not only expose the weaknesses of a purely juridical approach to the practice of public health using the human rights framework; it brings again to the fore the salience of citizenship rights and their concomitant imperatives of a (i) national identity; (ii) legal status; and (iii) documents that attest to status and enable the use of services. In the absence of these imperatives and a migration regime that has little regard for the rights of non-citizens, "the clinical setting becomes a site of contention and negotiation of citizenship and care in social networks as well as pragmatic and discursive strategies" [549].

This is not to deny (i) the effectiveness (as discussed in the chapter on research methodology) of a rights based framework to investigate health care access, especially of disadvantaged populations; or (ii) the power of human rights norms in advocacy and mobilization efforts to demand attention and bring political visibility to issues of health care inequality and inequity.

Rather, it is to acknowledge the following in efforts to include non-citizens in strategies to realize universal access to health care (i) the highly complex terrain of migration including the migration-asylum nexus [550] which has not been discussed here; (ii) the overarching legal and political contexts within which rights based approaches to health are implemented and within which urban refugees and asylum seekers as non-citizens navigate political-legal-social-health systems, negotiate access, and utilize health care; and (iii) the significance of citizenship rights and their intersection with human rights within migration regimes.

Additionally, it is to affirm that the pursuit of rights based approaches to public health practice would require a multi-pronged strategy which among others includes (i) juridical approaches to enforcing entitlements; (ii) inter-disciplinary and multi-disciplinary scholarship examining problems and solutions related to the empirical aspects of accessibility and utilization of care; and (iii) socialization of norms that regard all human beings as equal and health care as a human right, to strengthen leverage for discourse building and norm and standard setting for health care as a human right for all.

8.1.3. Ethnicity and Social Support: Pathways to Agency or Coping?

The quantitative findings showed that ethnicity (being Rohingya/Chin) proffered advantages in terms of being able to better obtain maternal health information, perceive lesser discrimination in health care, and use lesser travel time to obtain maternal health care. As stated earlier, this could be related to the Rohingyas' length of residence in the country, competency in Bahasa Malaysia, and shared religion with the dominant population in Malaysia.

The survey also showed that 86.0% of China and Rohingya women who communicated through translators relied on their spouses for translation support. This pattern matches the findings of a systematic review by Boerleider et al on factors determining prenatal care by non-Western women in industrialized western countries, where "dependency on husband" was cited as a determining factor especially if the husband was fluent in the host country's official language[551] .

The qualitative findings however showed that in spite of lacking the advantages attributed to the Rohingyas, Chin respondents managed to achieve positive maternal health care utilization outcomes. The Chin case studies showed that social support contributed toward achieving these positive maternal health care utilization patterns. The qualitative results also showed that social support differed by ethnicity. The perception of functional social support was positive among the Chins and also included transnational forms of support from resettled family and friends. Although immediate family and friends were the main sources of support, the Chins had also organized themselves into community organizations who mediated between the community and UNHCR/the host population.

The reverse was true for the Rohingya respondents who seemed to share a sense of social isolation and low perceived functional social support. Only two Rohingya respondents in the survey saw themselves as members of a refugee community organization although the leaders of the community were of the view that substantial numbers who participated in the survey belonged to their organizations. The majority of the respondents attributed the fragmentation in their community to the class divide, and some put it down to affiliation to specific regions of Rakhine state from where the older generation hailed.

The case of the Chin concurs with studies that have identified social support as an important factor in achieving accessibility to health care[238] and to maternal health care[146, 498]. In the context of non-citizens, the role of social support in circumventing access barriers as evidenced in the Chin community in this study, was also reported by Derose in the case of Latina undocumented migrant populations in the United States[240], and may also be reflective of resilience in migrant populations like the Bedouin in accessing maternal health care[552]. Additionally, the social ties of the Chins in the study coheres with the literature on urban refugees which confirm their readiness/ability to solve their problems[27] and their reliance on social networks for their everyday survival which typically include relatives, friends and neighbors or people with shared characteristics[553].

Related to the perception of social support among the Chins was a shared sense of identity linked to being ethnic Chin and to being refugees, which prompted mutual generosity and empathy to help deal with shared life circumstances. The narratives stating, "…we all are Chin … We understand how we struggle here. We are under the same status, 'refugee'…", equates with evidence related to individuals who tend to seek support from others with whom they share cultural and situational similarities, because of the perception of "empathic understanding" from such individuals[554] (p.420). Simich and colleagues [555] reiterate this point in the context of refugees in stating that, "for refugees adapting to a new society, not only empathy and shared culture but also shared experience are important" and add that in addition to informational, instrumental, and emotional support, affirmational support of those who have successfully adapted is critical to developing social competency in the new place and coping with the challenges of migration.

Further, the Chin respondents' assertion of their shared ethnic identity and prevailing reciprocity in their community (when they said, "we all are Chin" and "Chin help each other"), may be related to the consciousness of a common identity that is able to withstand the onslaughts of conflict to the social fabric of the community. According to the Chin scholar Lian H Sakhlong, the common identity arises from the interlinked traditional Chin concepts of *Miphun* (race)*, Ram* (homeland) and *Phunglam* (ways of life). In his treatise, Sakhlong provides an in-depth analysis on Chin nationalism, the role of Christianity in preserving the identity of the Chin *nation*, and the inter-relationships between religion, ethnicity and nationalism and describes how *Miphun* (ethnicity) in its linkage to *Ram* (homeland) survives expulsion from home land and

displacement. Citing the sociologist Anthony Smith he says that for the Chin, *'ethnic homeland', refers not only to the territory in which they are residing, i.e. present Chinram, but also the 'original homeland' where their ancestors once lived as a people and a community. What matters most in terms of their association with the original homeland is that 'it has a symbolic geographical center, a sacred habitat, a "homeland", to which the people may symbolically return, even when its members are scattered ... and have lost their [physical] homeland centuries ago'* [556] (p.7). His book also describes how Christianity not only enabled Chins to maintain their identity but also became a creative force of national identity.

On the other hand, the dearth of literature on the Rohingya, on the issue of statelessness and health[557], and the limited scope of the qualitative component of this study, raises some questions and makes it difficult to draw comparisons with the Chins. For example, was the social support among the Chins truly reflective of social capital within their social networks or was it practical reciprocity associated with survival of those in a similar bad situation? Did the Rohingyas' better integration into Malaysian society preclude the need for practical reciprocity in this community? Could social and cultural constraints on women's mobility in the Rohingya community offer possible explanations for perceptions of social isolation and low social support within the community? It is also conceivable that the restrictive policies/contexts confronting this stateless population in Burma, like the ongoing lack of security and the need to acquire special permission to travel outside their village impeded their mobility and ability to interact/communicate as members of a community. Thus, could the absence of political/legal contextual pre-requisites to build social trust and its associated political trust[558], norms of reciprocity, networks of civic engagement, and successful cooperation[559] also explain the stateless Rohingyas' difficulties in developing sustainable social bonds and social cohesion? Although the experience of the Chins resonates with the increasing recognition of the significance of social networks in migrants' adaptation to the new environment[560, 561] and examples of agency demonstrated in undocumented migrants[78, 532], there is need for caution in the transposition of these constructs and concepts to the experiences of the study population.

Alternative debates challenging the celebratory discourses on the agency of the community manifested via their social networks state that such social capital may often be an "essentially defensive response in an environment of hostile immigration

policy … [and] contradictory policies"[562] (p.11 and 19), and is a *coping strategy* of the poor rather than an indicator of social capital[563, 564]. Referring to the reliance of the poor on family and friends for economic survival, Portes and Landolt add that, "There is considerable social capital in ghetto areas, but the assets obtainable through it seldom allow participants to rise above their poverty"[565] (p.20). This view augurs with the experience of the Chin who despite advantages of social ties which enabled them to overcome financial barriers and utilize care in the qualitative research findings, obtained inadequate ANC in comparison to the Rohingya in the survey.

Moreover, the analysis of identity, social cohesion, social networks, and social capital, whether for the Chin or the Rohingya, cannot ignore the following factors in the social construction of identity: the role of different statuses of gender, legal, length of residence[562]; the multidimensional nature of ethnic identity[566]; influences within and outside the country[567]; and "powers and regulations that the subject encounters"[568](p.63). Nevertheless, this is an idea for future research requiring critical conceptualization of social networks, social capital, agency, and empowerment in relation to migrants/refugees and health care accessibility.

8.1.4. Accessibility to Health Care Frameworks: Contribution of the Right to Health

A substantive theoretical framework on access needs to capture the complexities of the phenomenon and provide a lens to make meaningful interpretations of the multi-faceted findings. Given that it is usually disadvantaged and marginalized populations that encounter accessibility problems, a fundamental attribute of an access framework needs to be its sensitivity to issues of exclusion, which would increase the relevance of its empirical application.

This study had proposed that because of such attributes the right to health approach provided a sound conceptual and theoretical framework for examining accessibility to health care for the study population. This project has shown the fruitful applicability of this framework to refugees and asylum seekers which could be extended to other disadvantaged populations. Such a claim is based on the following reasons.

Stating that "observations are embedded and must be understood within a context"[569], Whetten argues that a good theoretical contribution incorporates flexible conceptual terms that can be modified and adapted to coherently understand and interpret different contexts, without contradicting the core rationale of the framework. In the right to health framework on accessibility, the rationale, *equality of opportunity to a system of health care*, grounded in the norms of equality and non-discrimination provides the stable foundation that permits the transposition of concepts across contexts.

Within the study population, the right to health framework allowed for the consideration of accessibility within different contexts. The contexts of documentation status and of ethnicity were effectively examined using this framework. The concept of *safety* in physical access allowed the consideration of the security context of refugees and asylum seekers where physical accessibility is linked to their status under the restrictive immigration law applicable to undocumented foreigners. Further, the concept of *non-discrimination* in the use of services allowed the consideration of perceived discrimination in health care based on racial identification. Concepts such as "fear" and "discrimination" are relevant to other disadvantaged populations like sex workers, drug users, and sexual minorities in several countries because of their specific stigmatizing characteristics. As such, these concepts may be adapted differently to diverse contexts and populations of exclusion in empirical research on access.

A major gap in access theories (seen in Chapter 3) is the absence of a theoretical impetus to examine non-utilization of care. With its "preoccupation with vulnerable and disadvantaged groups"[268] (p.7), the right to health framework provided the theoretical impetus in this study to pursue the in-depth examination of negative patterns of utilization of care including non-utilization of care, a dimension which is usually sequestered from and unraveled in studies on accessibility to health care.

This study has also confirmed the suitability of the AAAQ framework, particularly the definition of accessibility, for policy analysis[318]. The use of the right to health definition of accessibility (within the AAAQ framework) rather than the tripartite typology of State obligations to respect, protect, and fulfill the right to health care permitted the use of continuous quantitative measures of access as against purely qualitative, and/or dichotomous/ordinal quantitative measures which would have to

be used to assess accessibility using the "respect, protect, and fulfill" approach. The use of continuous measures allowed access to be understood as a continuum and reflecting different degrees of accessibility to health care with regard to the two study groups (of refugees and asylum seekers and Chins and Rohingyas), although together they belonged to a common disadvantaged sector. The differentiation in the degrees of accessibility enjoyed by the disadvantaged sub-groups facilitated the consideration of complex intersecting contextual factors that need to be factored into any policy analysis.

In addition, the study has shown that individual health approaches assessing the enjoyment of the right to health care can be fruitfully used to monitor their right to health. Since most population based measures are usually more appropriate for the majority population, do not usually show differences between groups, often ignores preventive aspects of health, and focuses on those who have accessed care within the system[328], such an approach also requires the analysis of disaggregated data. But disaggregated data might not always be collected, may be too expensive to undertake in terms of research costs, or may be inaccessible because of political and legal restrictions imposed by the state. In such situations where it may be difficult to use an obligations approach, an individual health/enjoyment of the right to health approach can still be used to monitor the right to health of disadvantaged groups. Such monitoring may utilize objective data (e.g. the maternal health records in this study) or subjective data of self-reports by the respondent.

Although the MDGs only represent a political consensus between states and not legal obligations, it serves as an example to assess another merit of the enjoyment of the right to health approach. Using an obligations approach, Malaysia's performance with regard to the MDGs shows that the Malaysian government had met its commitments with regard to maternal health in Goal 5. Yet the study shows that the achievement of targets did not extend to refugees and asylum seekers in the country. This could be partly due to the use of aggregates in the MDG process. Nevertheless, in spite of it not being a legal obligation, the example of Malaysia's achievement of MDG Goal-5 does point to the differences in the data that can be produced using an enjoyment of the right to health approach and an obligations approach.

Finally, the former UN Special Rapporteur on health, in developing a comprehensive framework to monitor the right to health had called for consideration in the choice of right to health indicators; specifically, drawing attention to the need for these indicators to embody right to health norms[268]. This might sometime prove challenging for conceptually complex phenomena like accessibility which in themselves defy quantification through single summary measures, let alone embodying a right to health norm. Where it may not be possible to develop composite measures, as this study has shown, methodological approaches combining quantitative and qualitative techniques and analytical approaches examining the effect of multiple variables representing risk exposures and human rights norms are possible ways to address such challenges. These can be combined with disaggregation of data and comparative analyses between different population groups, to produce evidence based arguments that uphold human rights norms.

8.2. LIMITATIONS, STRENGTHS AND GENERALIZABILITY OF FINDINGS

One of the limitations of this cross-sectional exploratory study is the use of non-probabilistic sampling owing to resource constraints and unavailability of a sampling frame including unregistered asylum seekers. This means that the results are indicative but not generalizable to the larger refugee population from Burma in Malaysia. However comparability of the reproductive age sub-groups of the Chin and Rohingya women in the study population to that of UNHCR statistics, and the congruity in the description of the context of refugee protection of the study with those of other international organizations would suggest that many of the implications outlined in 8.3 would also be relevant for other refugee and asylum seeking women accessing maternal health care in Malaysia. Moreover, this limitation needs to viewed in the context of the dearth of data on the important issue of maternal health care experiences of a hard to reach to reach disadvantaged population.

With regard to economic access, it is possible that there might be some under-reporting of household expenditures [490]. However, it is also acknowledged that the under-reporting is more in richer than poorer households [570], a point that is pertinent to this population whose mean annual expenditures and incomes are very close to the annual poverty line income of RM 9,156 based on the RM 763 per month

poverty line income for Peninsular Malaysia in the 10th Malaysia Plan[492]. Additionally, it is recognized that longitudinal rather than cross-sectional research designs are best placed to assess catastrophic health expenditures and the poverty impact of OOP health expenditures [490].

Recall bias reflects respondents' incorrect recall of particular events. This study has some potential for such a bias. For example, recall bias is known to accompany the elicitation of historical self-report information. As such, the maternal health information elicited from those who had already delivered could embody such a limitation. However, given that only 23.6% and 2.3% respondents rated their proficiency in Bahasa Malaysia and English respectively as "good" and only a little over a quarter of the respondents had the ability to communicate independently in Bahasa Malaysia in the health care facility, risk of such recall bias may be less important an issue than their inability to comprehend the information provided.

With regard to physical accessibility too, although there is potential for recall bias in the self-reported estimates of travel time to access maternal health care, the consistency in the reported travel time of the majority that lived in the same geographical area and obtained care from the same health care facility suggests that this might be a dispensable concern.

A further limitation is the under-representation of those who did not have an institutional delivery. This limitation was however addressed by purposively selecting such respondents for the qualitative research.

Given the complexity of this research topic, deliberate choices had to be made to exclude certain measurement approaches and analyses from the scope of the study to maintain focus and cohesiveness. As such, owing to (i) a large number of explanatory variables and given the small sample size; (ii) in keeping with the objectives of the study; and (iii) to maintain consistency of analyses, utilization of maternal health care was not analyzed with the usual covariates in the literature, namely, age, parity, education, socio-economic status (SES), family size, cultural maternity practices, household and family relations, and risk factors[497, 498, 571-574] although their importance is not discounted. In addition, health care seeking by migrant populations is also impacted by personal concepts of health and illness[142]. However, behavioral models focusing on intrapersonal and interpersonal health and

health care seeking behaviors were excluded from the research design although the significance of such dimensions are recognized in the overall understanding of obtaining and utilizing health care.

Notwithstanding the limitations, the strength of this research lies in its contribution to the under-developed body of knowledge related to urban refugees[72], and maternal health care accessibility of urban refugees. The uniqueness of the study design is also in using the human rights framework to measure accessibility through an individual health approach.

Additionally, the use of a mixed methods design allowed for the appropriate use of quantitative methods to measure accessibility and utilization of maternal health care while the qualitative research enabled the amplification of the experiences of non-utilization of care which most often remains uncovered in studies on accessibility. The following section discusses the implications of the research.

8.3. IMPLICATIONS FOR POLICY AND PRACTICE

The findings from this study have clear implications for policy and practice on maternal health at global and national levels.

8.3.1. Global Initiatives:

1. Post-2015 Health Agenda:

Most often the justification for accessibility to maternal health care is rightfully linked to maternal mortality because of the avoidability of maternal deaths. However, valuing accessibility to maternal health care in terms of maternal mortality alone obscures the monetary and real costs incurred when access difficulties do not lead to maternal mortality but other serious forms of deprivation. These deprivations constitute the denial of fundamental human rights.

For example, the study revealed the extremely difficult conditions under which the women accessed maternal health care. The use of maternal health care lead to greater impoverishment for an already poor population. The proportion of both refugees and asylum seekers living below the poverty line increased by 42.85% and 22.67%% respectively as a result of incurring the out of pocket maternal health

expenditure. Further, about 48.9% refugees and 37.1% asylum seekers had experienced *catastrophic maternal health expenditures* following the use of maternal health care. Additionally, they managed a range of stressful situations: (i) an environment fraught with security risks to their body, their possessions, and their liberty of movement; (ii) interpersonal stress related to perceived discrimination in health care; and (iii) intra-personal stress related to managing ongoing fears and anxieties of arrest, detention, and extortion.

Global initiatives to address maternal health, including the high profile Millennium Development Goals (MDGs) are regularly marked by the lack of references to refugees, asylum seekers, stateless persons, and migrant workers. This could be due to the presumption of nationality and citizenship in policy arenas. With regard to the MDGs, this exclusion was also exacerbated by the focus on national targets[575], which possibly pre-empted the need for disaggregating data that was reported. Non-citizen populations like refugees and asylum seekers living lives of liminality as in Malaysia, who experience exclusions and encounter constraints to participate politically because of the lack of formal and substantive citizenship in the countries where they reside, are routinely excluded from the ambit of such initiatives and national targets. As such, in keeping with calls for a focus on equity and disadvantaged populations in the post-2015 health goals[575], there is an urgent need for refugees, asylum seekers, stateless persons, migrants (documented and undocumented) to be specifically mentioned and included in population targets and accountability mechanisms of global initiatives including the post-2015 agenda. This requires disaggregation in the planning of targets and monitoring of progress, which is consistent with a human rights approach[576].

Further, given the low political commitment to non-citizen health issues nationally, transnational processes are imperative to socialize norms related to equality of opportunity to access maternal health care regardless of legal status. The rationale for such a strategy draws from previous experiences of low political support for maternal mortality in some countries and gains achieved from transnational processes promoting norms related to the unacceptability of maternal deaths[577]. Global processes being planned for the post-2015 Health Agenda provide such an opportunity for transnational norm building related to migrants/refugees' accessibility to maternal health care, on the basis of health care as a human right for all regardless of legal status.

2. Strengthening the Refugee Protection Environment-Transnational Dimensions:

The study revealed the complexities of global/national contexts in creating threats to the refugee protection environment which impacts refugees' access to services. Thus, increasing access to health care for this population is linked to broader issues of refugee protection. Expansion of protection space for urban refugees needs to be anchored in state responsibility and obligations for persons in need of international protection. This should include regional/global burden sharing mechanisms which go beyond the provision of financial aid by countries of the global North to developing countries hosting urban refugees. Expanding protection space thus includes (i) effective opportunities for identification of those in need of international protection including proper adjudication of refugee claims according to international standards with robust examinations of individual experiences; (ii) de-criminalizing the asylum seeking process; (iii) expansion of opportunities for permanent rather than temporary protection through expansion of resettlement programs and eschewing the use of policies of interdiction, people-smuggling disruption programs, and mandatory detention[578, 579] which contradict (i); (iv) a human rights and human security orientation in regional processes such as the Bali Process[580] examining the issue of refugees and asylum seekers.; and (v) review of the 2009 UNHCR urban refugee policy which tries to harmonize a context of legal/political/social exclusions with empowerment and self–reliance oriented actions and strategies for urban refugees' survival.

8.3.2. National Initiatives

1. *Refugee Protection*

Failure to share the burden of providing protection to internationally displaced populations, and/or failure to respect and protect their rights by states constitutes their participation in creating and/or exacerbating a humanitarian crisis. As the results of this study indicate, Malaysia's failure to create a protection space for refugees and asylum seekers is inadvertently or otherwise, contributing to serious humanitarian challenges. As a member of the UN Human Rights Council and a signatory to some key UN Conventions like the CEDAW, Malaysia needs to (i) recognize refugees and ratify the 1951 Refugee Convention and its 1967 Protocol; and (ii) grant refugees and asylum seekers the formal right work.

2. Provision of Maternal Health Care

Positively, the Ministry of Health has provided a 50% off foreigners' rates to refugees. Given the barriers to health care experienced by the study population including the magnitude of impoverishment as a result of incurring maternal health care costs, linguistic barriers, and communication difficulties, and Malaysia's obligations under CEDAW, the Ministry of Health (i) should extend its universal health coverage including access to contraception and family planning to refugees and asylum seekers; (ii) work closely with UNHCR, refugee organizations, and Malaysian civil society in providing translators at maternal health clinics and providing maternal health information in some of the main dialects of the refugees.

8.4 CONCLUSIONS

In conclusion, in this study, I aimed to assess the access of Chin and Rohingya refugees and asylum seekers to maternal health services, by (i) assessing the relationship between documentation status and ethnicity with the four dimensions of accessibility, (nondiscrimination, physical accessibility, economic accessibility, and information accessibility) and utilization of care (number of ANC visits); and (ii) evaluating the differences between the patterns and levels of utilization of care between China and Rohingya refugees and asylum seekers. Toward this end, I implemented a survey with 343 respondents and conducted ten qualitative in-depth interviews.

I argued that the right to health definition on accessibility provided an appropriate conceptual/theoretical framework for the study because of its sensitivity to issues of exclusion experienced by disadvantaged populations. The study does vindicate this claim and extends the empirical knowledge about the accessibility of urban refugees and asylum seekers to maternal health care within spaces and dimensions of complex intersecting factors.

The analysis revealed that the study population as a whole experienced many barriers in accessing maternal health care. From a right to health perspective, the reproductive and maternal health risks experienced by the study population were a consequence of human rights violations as the qualitative findings indicated. Health care policies restricting the study population's access to health care and the absence of a system to recognize the status and rights of refugees in Malaysia

contributed to further human rights violations and had the potential to create risks related to maternal morbidity and mortality.

The study results showed that ethnicity offered some leverage to navigate the environment and the health system, with Rohingyas faring better than the Chins in terms of physical accessibility, information accessibility and non-discrimination. However, when it came to the moot question of utilization of maternal health care, documentation status was salient. Documentation status was also moot to economic access. Refugees fared better than asylum seekers in terms of obtaining adequate ANC; although the utilization of care also contributed to increased impoverishment for refugees.

I argue that the importance of documentation status in navigating economic access and achieving utilization of care is linked to Malaysia's immigration regime. This regime is based on the salience of government issued documents and deterrence, and raises formidable barriers to the entry of refugees/asylum seekers as foreigners lacking documents into the political/social/economic community of the nation. As such, it sequesters citizens from non-citizens and riding on the rhetoric of undeservingness, undermines non-citizens' entitlements to health care rights and creates barriers to maternal health care accessibility for refugees/asylum seekers. Such a phenomenon aligns with the health care experiences of (urban) refugees and asylum seekers, stateless persons, and migrants in other parts of the world.

While there is some support in this study to consider the relationship between ethnicity and accessibility as one demonstrating the community's agency, derived from the social capital within their social networks, further research is required to establish whether the observed social support is indeed not a coping strategy or practical reciprocity within a hard-pressed community; and if the Rohingyas better assimilation in Malaysia precluded the need for such practical reciprocity. It is however possible that certain ethnic characteristics allowing for better integration into Malaysian society may have contributed to better accessibility outcomes for Rohingyas. Yet, a higher proportion of Rohingyas were also impoverished following better utilization rates of maternal health care.

This study has made an important contribution to a few bodies of literature: (i) to studies on accessibility by demonstrating the viability of the right to health framework

as a theoretically sound framework with consistent empirical groundedness especially with regard to disadvantaged populations; (ii) to the under-developed body of knowledge on urban refugees[72], especially urban refugee health; and (iii) to the literature on maternal health by substantiating the importance of context[498], specifically legal status and ethnicity in mediating women's accessibility to maternal health care.

There is however, a need for further research on the longitudinal impact of barriers to accessibility on urban refugees and asylum seekers, notably of OOP maternal health costs on utilization of care and impoverishment. There is also need for systematic and critical inquiry on the role of social networks, social cohesion, and social capital in refugees and asylum seekers' accessing of health care within the context of legal non-existence [531], liminal legality, and clandestiny.

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APPENDIX-1: ACCESS-CONCEPTUAL FRAMEWORKS

This section discusses some of the major theoretical frameworks on access to health services, namely, the Andersen and Aday Behavioral Model of Health Services Use, The Penchansky-Thomas FIT model, the IOM model, and the Livelihood Approach.

In addition, a broad link will be made between health utilization approaches to accessibility and the health seeking behavior approaches.

Except for the conceptual framework of the right to health which emerged in the last decade, all other theories of access were developed in the 1970's and the 1980's. The literature on access theories since then have sought to either synthesize [269] or provide commentaries on these theories.

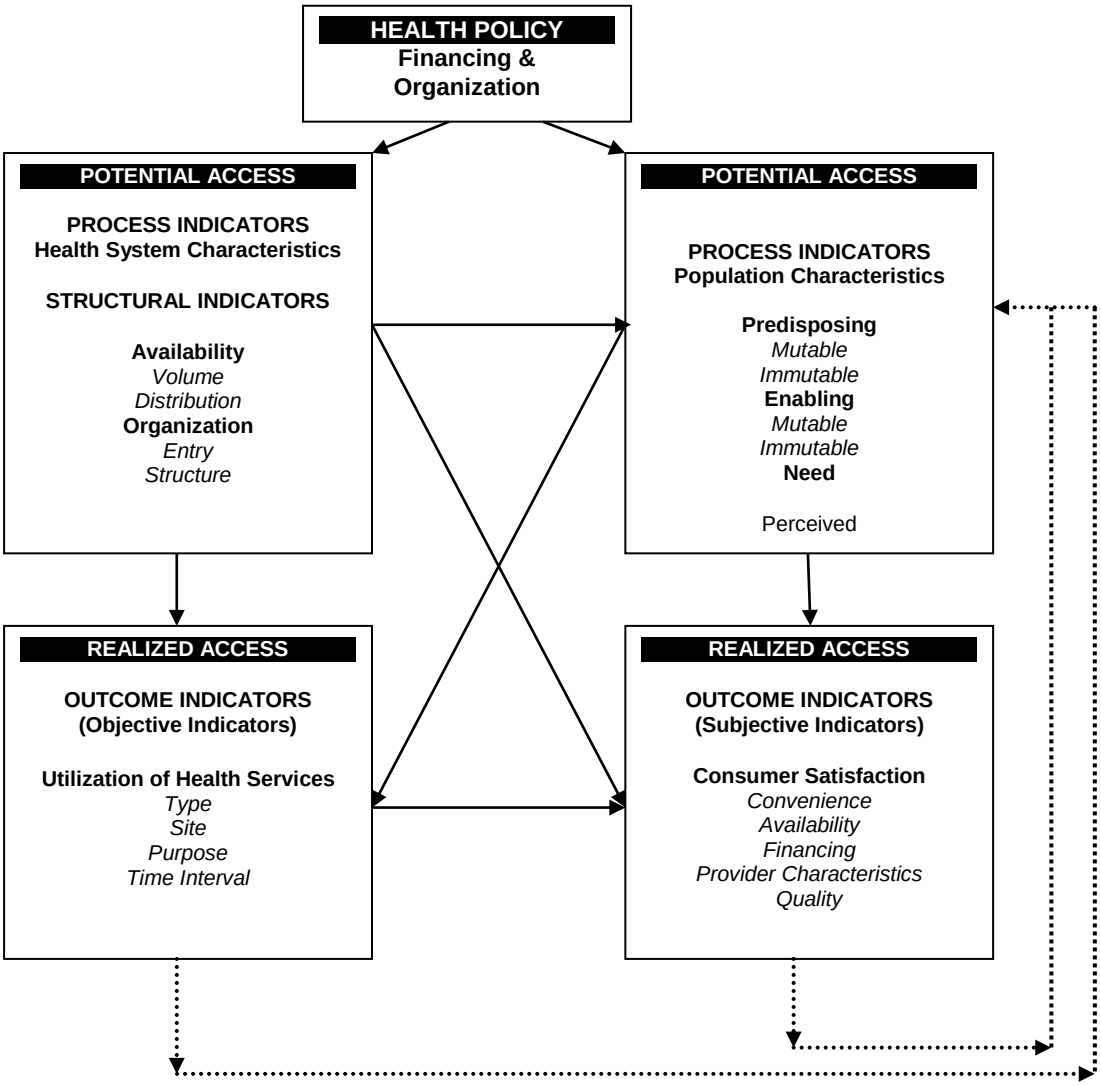
Behavioral Model of Health Services Use

A considerable body of knowledge on access and its related concepts evolved from the "Behavioral Model of Health Services Use" postulated by Ronald Andersen who worked on this model with John F Newman[192] and Lu Ann Aday among others[179, 189]. The Behavioral Model sought to predict and explain the use of health care services and to provide measures of accessibility to medical care [180]. The Behavioral Model went through six revisions [165].

It departed from previous theoretical constructs of access which binarily focused either on the health delivery system or on population characteristics alone. According to this model, access is a function of the characteristics of the health system (availability and organization of health services), and the characteristics of the population. Characteristics of the population include (i) perceived and evaluated need for health care; (ii) biological, genetic, psychological, and socio-demographic factors which determine the propensity to use services which Andersen called *predisposing characteristics*; and, (iii) individual and community resources like

income, medical insurance coverage, and other such factors which provide the means to access health care, also called *enabling characteristics*.

FIGURE 30: BEHAVIORAL MODEL OF HEALTH SERVICES USE



SOURCE: Adapted from:
Aday LA, Andersen RM. Equity of access to medical care: a conceptual and empirical overview. Medical Care. 1981 Dec 19(12 Supplement: Access to Medical Care: Progress, Problems and Prospects):4-27

The Behavioral Model distinguished between potential and realized access. Potential access is reflected in *structural* and *process indicators* related to the characteristics of the health system and the population and reflects resources that enable the utilization of health services. Realized access is reflected in *outcome indicators* like utilization rates of health care services and satisfaction with care. See Table-1 for some generic indicators of access suggested, used, and tested by the behavioral model. In a later dynamic and recursive version of this model, Andersen

suggested that outcome indicators could also transform into process indicators. For example, satisfaction with services (outcome indicator) could become a determinant (process indicator) of the continued use of services [180]. Figure-1 shows the behavioral model developed by Andersen and Aday[180, 189].

The behavioral model is the predominant theoretical framework that has been used in most empirical studies on access to health care. As such, most empirical research on access has been explained in terms of utilization rates and satisfaction with care. Additionally, many prominent population based surveys in the United States drew on the behavioral model for their assessments on access. Eden summarized the indicators of the behavioral model used in population based surveys under the broad topics of (i) usual source of care; (ii) barriers to care; (iii) physician and hospital use; (iv) satisfaction with health plan; (v) delays in obtaining care; (vi) preventive health services; and, (vii) satisfaction with care[581].

Goldsmith attributes the wide application of the behavioral model to: (i) the breadth of its framework which permits it to integrate any factor related to access; (ii) the complexities related to the concept of access which has precluded the development of better alternative paradigms even from the detractors of the behavioral model; and, (iii) the many operative variations of the model in this field of study which have not been questioned [165].

In spite of its wide application, the Behavioral Model has its limitations. Although it had a concern for *effective access* (an improvement in health status or satisfaction with services as a result of utilization of services), *efficient access* (increase in levels of health status and satisfaction with services relative to the quantity of health care obtained)[180], and *equity in access* (when need is a predictor of utilization of health services vis-à-vis demographic variables like race, ethnicity or family income)[180, 186, 189], the major empirical work in relation to this model focused only on the determinants of utilization rather than its outcomes [582].

Another criticism of the model relates to the limited usefulness and validity of its measures of access [331]. Goldsmith sums up these critiques which include: (i) the broad definition of access; (ii) the promotion of a fractured approach to the study on access; and, (iii) failure to incorporate the socio-cultural dimensions of access [165]. Pescosolido argued that this model should be discarded entirely for relying 'far too

greatly on the 'rational' decision-making ability of the individual' (cited by [165], p.85). The behavioral model is also said to lack relevance in contexts where the health financing is not based on a fee-for-service system and where people have special medical needs[328].

TABLE 58: INDICATORS: BEHAVIORAL MODEL OF HEALTH SERVICES USE

PROCESS INDICATORS					**OUTCOME INDICATORS**	
CHARACTERISTSICS OF THE ENVIRONEMENT: HEALTH DELIVERY SYSTEM		CHARACTERISTSICS OF THE POPULATION AT RISK			UTILIZATION OF HEALTH SERVICES	PATIENT/ CONSUMER SATISFACTION
RESOURCE	ORGANIZATION	PREDISPOSING FACTORS Propensity to Use Services	ENABLING FACTORS Individual Resources & Community Attributes	NEED	OBJECTIVE REPORTED RATES OF UTILIZATION	SUBJECTIVE DESCRIPTIONS OF CARE
• Number of physicians, hospital beds and ambulances per unit of population and per unit of geographical area	• Mean travel time • Mean appointment time and • Mean office waiting time • Mean response time from initial call for emergency service to ambulance arrival • Type of practice (solo, partnership) • Type of provider (GP, specialist, ancillary personnel etc), • Method of patient triage (numbers &kinds of encounter or admission forms, type of medical provider first seen etc	**MUTABLE** • General health care beliefs and attitudes • Knowledge and source of health care information • Stress and anxiety about health **IMMUTABLE** • Age • Sex • Race or ethnicity • Religion • Education • Marital status • Family size and composition	**MUTABLE** • Income and sources of income • Insurance coverage (type of payer extent of coverage, method of payment), • Regular source of care • Ease of getting care (mean travel time, appointment waiting time, office waiting time for given medical episode, etc.) **IMMUTABLE** • Residence groups or region of the country (rural-urban etc) • Residential mobility • Previous health behavior	**PERCEIVED NEED** • Perceived health status • Symptoms of illness • Disability (disability days and chronic activity limitation) **EVALUATED NEED** • Physician rated urgency of presenting condition, diagnosis and surgery	• Type of service used (e.g., hospital, physician, dentist, emergency care, home care) • Site at which care was rendered (home, office, clinic, inpatient hospital, etc.) • Purpose of the care received (preventive, curative, stabilizing, custodial) • Time interval involved (percent of population at risk who did and did not see a physician in a given time interval, mean number of visits to a physician in a given time interval) • Continuity as measured by number of different providers contacted for a given episode of illness • If care encompassed dental visits	Percentage of the study population who were satisfied or dissatisfied with: • Convenience of travel time, travel cost, appointment time, waiting time, visit cost • Provider behavior - Time with MD, information, MD courtesy, RN courtesy, Receptionist courtesy, MD concern, overall quality of care • Medical information • Overall Percentage who wanted medical care but did not get it, and why

Source: Aday LA, Andersen R. A framework for the study of access to medical care. Health Services Research. Fall 1974;9(3):208-20; Andersen RM, McCutcheon A, Aday LA, Chiu GY, Bell R. Exploring dimensions of access to medical care. Health Services Research. Spring 1983;18(1).

Further, although health policy and environmental factors are an integral part of the behavioral model these have not been the focus of inquiry for most empirical research on access using the behavioral model [583]. Reviewing the literature on applied studies on access, Goldsmith stated that the behavioral model failed to predict health care use, was unable to explain variations in use, and in some studies was unable to substantiate the conceptual core of the model; all of these factors which begged the question whether the core components of the model (enabling factors, predisposing factors and need) were too correlated with each other[165].

In spite of the criticisms leveled against it, the Behavioral Model made a distinction between availability and accessibility, recognized the presence of intervening variables between potential and realized access, and affirmed the multidimensionality of access.

The Penchansky-Thomas 'FIT' Model

At the same time that Aday, Andersen et al evolved the behavioral model of access in the University of Chicago, Donabedian, Penchansky and others developed other models and measures of access in the University of Michigan[582].

Penchansky and Thomas[174] defined access as the "consumers' ability or willingness to enter into the health care system" (p.128). They proposed a taxonomic definition of access as a measure of the "fit" between characteristics of providers and the health care system on the one hand and characteristics and expectations of clients on the other, which could be measured along five dimensions namely,

- Availability of services, reflected in the fit between the demand and supply of the type and volume of health services;
- Accessibility, in terms of the geographic relationship between service providers and the client, which needs to factor in client transportation resources and travel time, distance and cost;
- Accommodation, or the relationship between the way the services are organized and the client's ability to accommodate these arrangements;
- Affordability, or the financial ability of the client in relation to the prices of health services;
- Acceptability, which measures the fit between the attitudes of health care providers toward clients and vice versa. Attitudes often relate to patient and

provider attributes with regard to age, sex, gender, 'race' or ethnicity, language, cultural beliefs, and socio-economic status. In addition, acceptability of health services is also a function of expectations of providers and patients and their beliefs and perceptions

In this conceptual framework of access as a 'fit' between the characteristics and expectations of the provider and that of the client/patient, Penchansky and Thomas made certain departures from the behavioral model of access. For one, theirs was a more dynamic model than the revised recursive Andersen model of the nineties[313] which showed the feedback loops between utilization outcomes and the need for care. In the Penchansky-Thomas model, access is a direct function of the recursive interactions between the system's characteristics and the patient's needs, resources, and preferences along the different dimensions of access.

Further, there are inter-linkages between the dimensions of access. For example, the supply of services (availability) is linked to the convenience it offers patients in the way it is organized (accommodation) and its cultural acceptability (acceptability) [174]. Referring to these inter-linkages, Thomas and Penchansky cite studies of ethnic minorities and others who travel farther to receive culturally appropriate services[584, 585]. Also, the geographic mal-distribution of services (availability) would have consequences for affordability. Thus, they also showed the unsuitability of a 'one size fits all' approach to access because the interaction of diverse patients/users with the health system creates conditions within which access may be realized differently for different sub populations [586].

There was another important difference between the behavioral and the 'fit' model. While the behavioral model showed that indicators related to the characteristics of the health system and the individual were associated with utilization of health services and satisfaction with care, the 'fit' model helped explore 'to what extent' access was being realized[587].

In the paper that Penchansky and Thomas introduced the taxonomic definition of access, they report the successful testing of the discriminant and construct validity of the five access dimensions (availability, accessibility, affordability, accommodation, and acceptability) against measures related to satisfaction of services which brought out results that affirm the differentiation among the five dimensions and congruence

between the measures and the expected dimensions with which they were associated [174].

Given below are the predictors of satisfaction with care in terms of the different dimensions of access proposed by Penchansky and Thomas.

PREDICTORS: SATISFACTION WITH ACCESS TO CARE	
STRONG PREDICTOR	**WEAK / NEGATIVE PREDICTOR**
• Travel time - accessibility • Time to get an appointment – accommodation • Longer relationship with physician – availability and acceptability • Greater number of visits – availability, accessibility and accommodation • Less education of patient	• Longer wait in physician's office – availability and accommodation • Travel time, waiting time in physician's office together with opportunity cost of a visit – satisfaction with affordability • Having a private physician – less satisfied with affordability • Housewives are less satisfied with accessibility than are respondents in other occupational groups. • Persons with high health concerns, those who think about their health more than most other people, are shown to be less satisfied than other respondents with the accommodation dimension of access. (aspects of access-getting appointments, waiting in the office, telephone consultations)
Source: Adapted from Penchansky R, Thomas JW. The concept of access: definition and relationship to consumer satisfaction. Medical Care 1981 Feb 19(2):127-40.	

While Penchansky and Thomas were careful to state that their theory of access was not the same as Andersen's behavioral model[174], their own later research on access[584] departed from their theoretical model by failing to empirically establish a direct link between accessibility and utilization of care[165]. Instead, their research hypothesized that access influenced utilization through patient satisfaction, and variations in the relationship between patient satisfaction and accessibility/utilization of care could only be explained by socio-demographic characteristics of the population. It was also criticized for its failure to explain the nature and levels of interaction among the dimensions and for ignoring the important aspect of barriers to access in the framework[11].

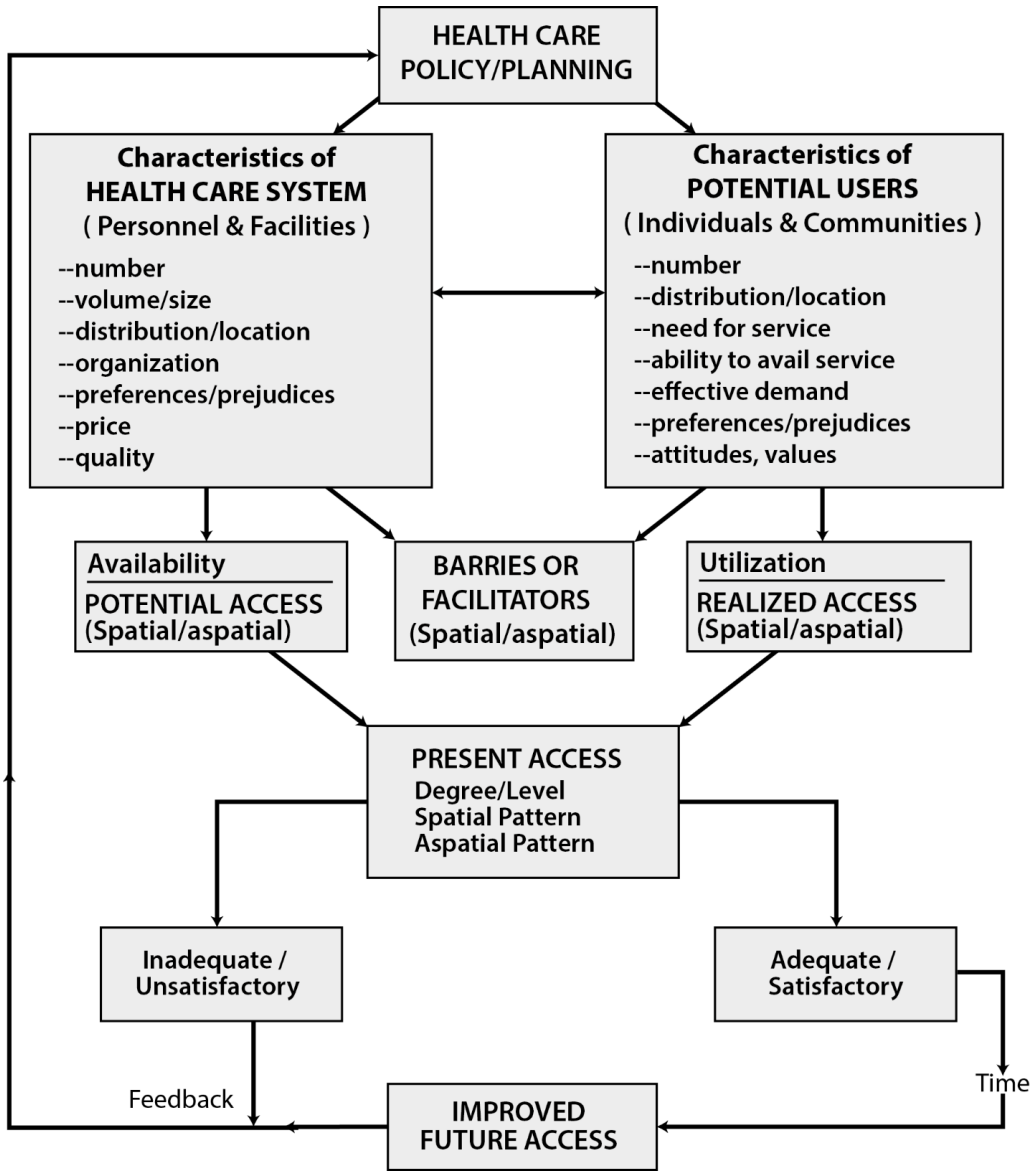
Through its strengths and deficits, this model reinforced the multidimensionality of access, and allowed the consideration of specific dimensions of access; although like the Behavioral model it reverted to utilization of care and satisfaction with care to validate access.

Khan and Bhardwaj Model

The Khan and Bharadwaj model[11, 588] of access adapted the Behavioral Model and included the following components from the latter model: (i) potential and realized access; (ii) the characteristics of the population; (iii) the characteristics of the health

system; and (iv) the indicator of service utilization. According to this model, the characteristics of the population and the health system influence *potential access* which in turn leads to *realized access* (or the use of services) through a phase where *facilitators/barriers* are negotiated. The model recognized both spatial (geographical) and aspatial (social, i.e. income, education, race and age) dimensions to potential and realized access. It also included an unidentified feedback loop between the characteristics of the population and realized access which was absent in the behavioral model. This model is shown in Figure-32.

FIGURE 31: KHAN AND BHARDWAJ MODEL



SOURCE: Khan AA, Bhardwaj SM. Access to health care: a conceptual framework and its relevance to health care planning. *Eval Health Prof* 1994 March 17(1):60-76.

Potential and realized access contributes to *present access* which can be categorized as *adequate* or *inadequate*. Feedback on inadequate access is transmitted to the health care policy and planning process while adequate access leads to improved future access.

Khan and Bhardwaj also created a typology of access by combining the two dichotomies, potential-realized access and spatial-aspatial/social access into a 2x2 matrix. They further divided each of the four cells into *opportunity* and *cost* to create another four pairs of access dimensions (see Tables 57 and 58); which indicated that access presented itself as an *opportunity* and as a *cost.* They stated that the breaking down of the access concept enabled focus on particular aspects of access which would allow the development of precise measures to evaluate health system performance.

TABLE 59: 2X2 MATRIX: SPATIAL-ASPATIAL ACCESS

ACCESS	**Spatial (Geographic)**	**Aspatial (Social)**
Potential	I Potential Spatial/ Geographic Access	II Potential Aspatial/ Social Access
Realized	III Realized Spatial/ Geographic Access	IV Realized Aspatial/ Social Access

TABLE 60: 2X2 MATRIX: OPPORTUNITIES-COST OF ACCESS

ACCESS	**Spatial (Geographic)**	**Aspatial (Social)**
Potential	Opportunities **Ia** / **Ib** / Costs	Opportunities**IIa** / **IIb** / Costs
Realized	Opportunities **IIIa** / **IIIb** / Costs	Opportunities**IVa** / **IVb** / Costs

Like the Andersen model, the Khan and Bhardwaj model reverted to utilization of care to validate achievement of access, and identified potential access only with the characteristics of the health system and not the users of care. However, the incorporation of 'barriers" within the theoretical construct was significant since it reflected the growing importance of barriers in empirical studies on accessing care.

Livelihood Approach to Access to Health Care

The livelihood approach[181] to access to health care services combines two traditional approaches to studying access, namely, the health seeking behavior approach which seeks to explain the relational and non-relational dimensions of why, when, and how individuals and groups seek health care services, and the health services utilization approach which focuses on improving the supply and delivery of health services.

FIGURE 32: LIVELIHOOD & INSECURITY FRAMEWORK

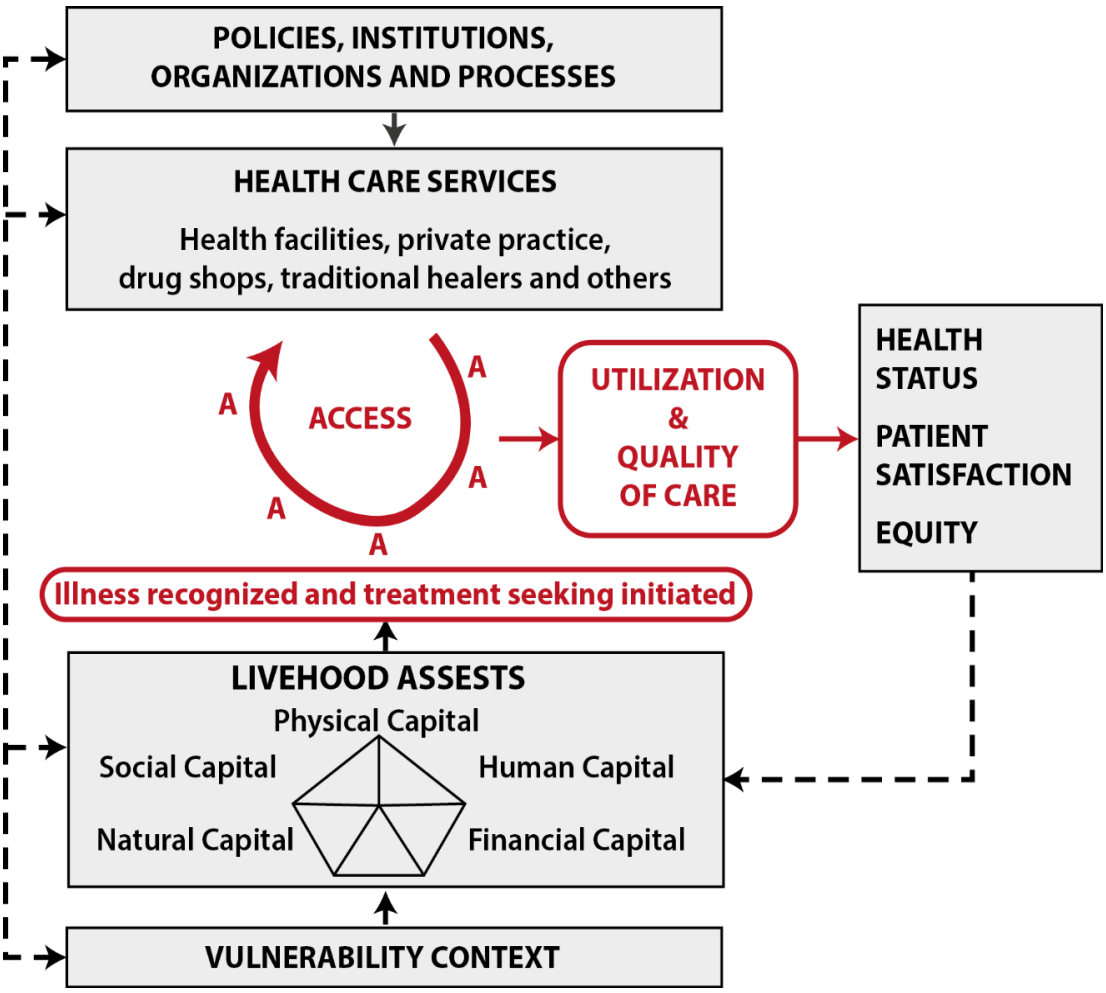


Fig 3 : Source: Obrist B, Iteba N, Lengeler C, Makemba A, Mshana C, Nathan R, et al. Access to Health Care in Contexts of Livelihood Insecurity: A Framework for Analysis and Action. PLoS Med. 2007;4(10):e308.

According to the livelihood approach, the mobilization of assets (both household and community) is a vital predictor of the ability of people to access health care and health related services. This approach considers five dimensions of access:

- Availability – volume, type and quality of services available including if these services match the needs of people; who is offering these services
- Accessibility – the geographic relationship between providers and users of care (distance) including availability of transportation and time to travel
- Affordability – Direct (cost of health care) and indirect costs (transportation costs, loss of income etc) of using health care services
- Adequacy – whether the way the services are organized match with the convenience and expectations of users intending to use the services
- Acceptability - cultural acceptability, trust of patients in the competency of the provider, and quality of interpersonal interactions between client and the provider

Thus, when people recognize the need for health services, the above five dimensions of access work on the health seeking behavior of people to determine accessibility to health services. However, the degree of access realized depends on the interplay between the health care services including the broader policies, institutions, organizations, and processes related to the services, and the livelihood assets that people can mobilize in particular vulnerability contexts. See Figure-3.

The vulnerability context refers to external factors that people have little control over – e.g. floods, draughts, armed conflicts or epidemics, and determines people's livelihood assets like human capital (local knowledge, education, skills), social capital (social networks and affiliations), natural capital (land, water, and livestock), physical capital (infrastructure, equipment, and means of transport) and financial capital (cash and credit). Their ability to mobilize these resources defines their capacities and strategies to deal with illness and disease in the context of the existing health care services including the quality of care and policies, institutions and governance frameworks in the particular geographic location.

Application of the livelihood framework to access to health care studies in Africa pointed to links between the vulnerability context and livelihood assets, and between livelihood assets and health care utilization, with those with fewer assets having lesser recourse to access to health care services[589].

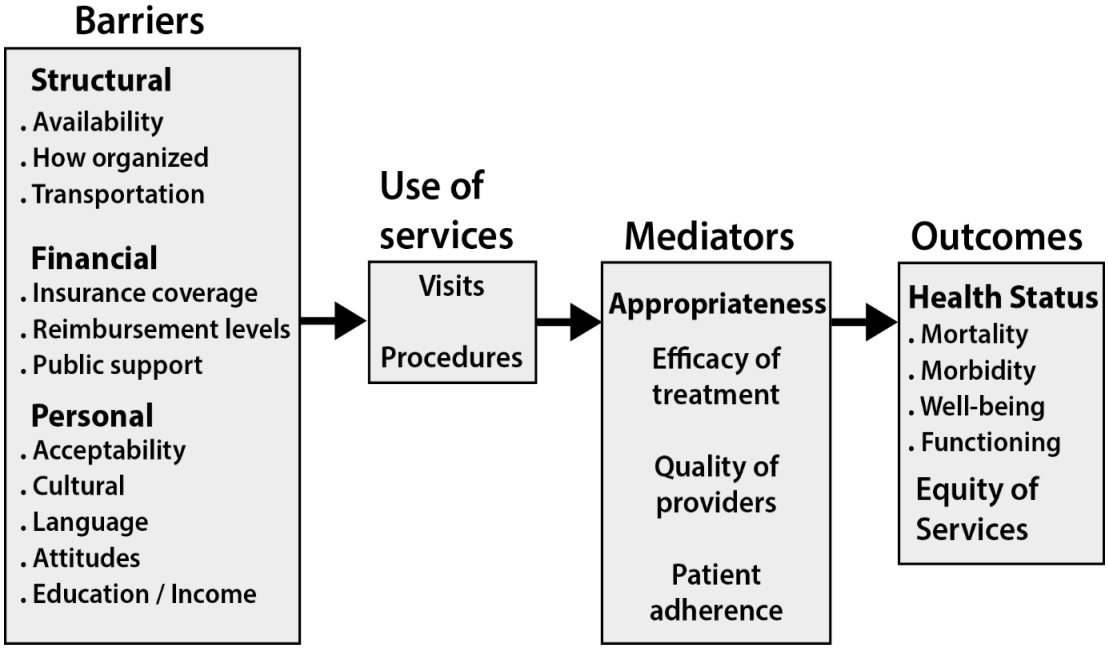
While this approach has not been widely adopted in concept or operation, it highlights the importance of contexts in influencing accessibility to health care and of

interdisciplinary approaches to examining the illness-poverty trap in relation to resource poor settings and the poor in general.

Institute of Medicine Framework

The Institute of Medicine (IOM) model was an outcome of the Institute of Medicine's Access Monitoring Project which sought to provide policy makers with a framework for monitoring access to health care services. Access to maternal care is one of the components of the framework.

FIGURE 33: IOM FRAMEWORK OF ACCESS



Source: Millman M, editor. Access to Health Care in America: Report of the Committee on Monitoring Access to Personal Health Care Services Institute of Medicine Washington, D.C.: NATIONAL ACADEMY PRESS; 1993.

The Institute of Medicine's (IOM) committee which was tasked with developing a set of indicators for monitoring access to personal health services at the national level carried an operational burden of translating broad policy goals of equitable access into the monitoring of access project.

The Institute of Medicine's (IOM) committee defined access as the 'timely use of personal health services to achieve the best possible health outcomes"[182] (p.33), thus focusing on both utilization and health outcomes in their definition of access. Like others who ascribed to a multidimensional view of access, the committee recognized that access was a "shorthand term used for a broad set of concerns that

center on the degree to which individuals and groups are able to obtain" needed medical services[182] (p.32).

The model was based on the premise that access problems are created when barriers cause under-use of services, which in turn leads to poor health outcomes. However, the model assumes that utilization in itself is not a very good proxy for access and has to be matched with need and appropriateness in order to qualify as a measure of access. Similarly, the model assumes that access to health care is but one mediating factor linking utilization of health care services with health outcomes. Nevertheless, the challenge for the committee was to find indicators of utilization and outcomes that corresponded to the hypothesized financial, structural, and personal barriers of access respectively.

The IOM Committee described *structural barriers* as 'impediments to medical care directly related to the number, type, concentration, location, or organizational configuration of health care providers'; ***financial barriers*** as barriers that 'restrict access either by inhibiting the ability of patients to pay for needed medical services or by discouraging physicians and hospitals from treating patients of limited means'; and p***ersonal and cultural barriers*** as barriers that 'inhibit people who need medical attention from seeking it or, once they obtain care, from following recommended post treatment guidelines'[182] (p.39). The Committee postulated that barriers were inter-related and that evidence indicates that structural barriers are often related to the way in which health care is financed. The Committee used personal and cultural barriers to expand on the notion of equity in access. They stated that, all things being equal, persistent under use of services by groups that were homogenous in terms of race, ethnicity, education, and attitudes among others indicated problems in equity of access.

Thus, the IOM framework's contribution to the discourse of "what is access" includes reinforcing the importance of barriers, the multi-dimensionality of access, and the access concerns of specific population groups based on their race, ethnicity, and education.

Health and Health Care Seeking Behavior Approach

Health and health care seeking behavior approaches from social psychology, medical sociology, and medical anthropology explain utilization of health services through health and health care seeking behaviors which involve intra-personal, interpersonal, and community dimensions. Thus, they complement the previous theoretical frameworks which consider structural issues in explaining "what is access".

Whereas *health care seeking behavior* refers specifically to the end-point of utilizing health care services, *health behavior* is the wider process of actions an individual takes to prevent illness, promote recovery and rehabilitation, and maintain/attain good health. Health seeking behavior can range from individual behavior to collective behavior. Behavioral approaches to health and health care integrate cognitive and affective processes in the decision making to utilize health care services[590] and are largely rooted in psychology[591]. Perceptual processes and attitudes are said to shape behaviors in relation to seeking health and accessing health care services [591-593] and includes steps taken by a sick person to recognize and identify illness and to seeking care and recovery. Examples include the illness behavior models developed by Suchman[594, 595], Fabrega, Dingwall and others[591]; and, intrapersonal behavioral models like Health Belief Model of Rosenstock[596], Becker[597], Consumer Information Processing Model of Bettman and Theory of Reasoned Action of Azjen[590, 591].

The health seeking behavior approach is useful in highlighting the intrapersonal (cognitive, affective) and interpersonal processes that mediate contextual factors in the utilization of health care services. Mackian's review of behavioral approaches used in studies related to maternal and child health indicate that 'women have much more subtle interpretations of health' that impacts their health seeking behavior. Varied cultural, social and structural contexts trigger equally varied health behaviors in women who follow quite different pathways for different conditions depending on the social networks they belong to, gender and power relations between the spouses, and cultural customs[598]. This approach also recognizes the dual and intermeshing biomedical and ethno-medical paradigms within which knowledge, beliefs, perceptions, and behaviors related to health are understood, given meaning, and played out by the patient within the formal health care system[589].

The criticism leveled against health seeking behavior approach to health care utilization is that they often tend to focus on the journey from illness to recovery and not illness prevention or maintenance of a compromised state of health[589], consider only the formal health care system in assessing access, fail to acknowledge multiple sources of care (even traditional) used by individuals, and fail to consider structural, socio-cultural, collective and dynamic processes that impact individual evaluations of perceptions of health risks and decision making to mitigate these risks[594].

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APPENDIX-2: ACCESS MEASURES

Two types of access measures will be discussed in this section: (i) utilization rates; and, (ii) satisfaction with care.

UTILIZATION RATES

1. **Use-Disability Ratio** - The use-disability ratio (U-D) measures rates of utilization of services in relation to need for those services and is defined as the ratio of physician visits to the days of disability, with disability days acting as a proxy for need for care reported in a given period. Disability days are defined as the number of days within a year which, because of illness or injury, the population reports being kept in bed, indoors, or away from usual activities. Use-disability days ratio is expressed as,

$$\frac{\frac{\sum_{i=1}^{n} MD_i}{n}}{\frac{\sum_{i=1}^{n} DD_i}{n}} (100) = \frac{\text{mean } MD_i}{\text{mean } DD_i} (100),$$

where MDi is the number of physician visits in a specified time period made by individual i in a group of n persons; DDi is the number of disability days in a specified time period by an individual i in a group of n persons[191].

The problem with the Use-Disability ratio is that both numerator and denominator are self-reported[332]. Other limitations include that (1) it does not reflect preventive health care needs like prenatal, child health services or dental services, (2) is not sensitive to factors like poor health benefits of workers that might prevent them from availing disability days in spite of need; the latter leading to under-estimation of need, and, (3) does not ascertain if the level of access is appropriate to need [329].

Chen critiqued the assumption implicit in the use-disability ratio that the worst case scenario reflected in a ratio value of zero and the best case scenario reflected in a ratio value of 100 may not necessarily correspond to effective utilization of care. He cites the example of physician visits for influenza where an arbitrary application of the use-disability ratio would lead to over-utilization of health services if the best case scenario of 100 were to be deployed [599].

2. **Symptoms-Response Ratio -(S-R ratio)** According to the S-R Ratio, first used bythe behavioral model [329], a panel of physicians determined if a visit to the physician was warranted for one or more in the checklist of 15 specific symptoms used in a national survey conducted by the Center for Health Administration Studies (CHAS) in 1964, 1971 and 1975-76. Respondents were first asked about the number of physician visits made upon recognition of symptoms in the checklist. The estimate of appropriate utilization was achieved by computing the difference between the actual number of symptoms for which a visit to the doctor was made and the physician estimates of the number of people with the symptom who should have seen the doctor for that symptom, and was represented by,

$$\text{symptoms-response ratio} = \frac{\text{A-E}}{\text{E}} \ (100),$$

where A represents the actual number of symptoms and E represents the estimates of the number of visits there should be for symptoms.

This measurement in contrast to the use-disability ratio which is totally based on self-reporting of the patient relied entirely on the professional judgment of the doctor for the need for care[332]. Andersen himself stated other limitations including the inability of this ratio to consider preventive care and revisits in an episode of illness, besides the dependence on the respondent to recognize the illness symptom [329]. Chen stated that it was unrealistic to assume that physicians would evaluate individual symptoms in isolation as the measure seemed to assume [599].

Andersen applied 3 measures of access to data collected from national surveys between 1964 and 975, namely, (1) mean number of physician visits (2) use-disability ratio (3) symptoms-response ratio and demonstrated how each of these

three measures generated variations in findings, thereby concluding that it was better to use multiple indicators rather than single measures to assess access to health care services.

3. **Episode of illness approach** - collects data during a specified period in relation to the number of days of disability following an episode of illness and includes questions about whether the patient/client sought care, the nature of the care sought and referrals made, the outcome of the illness and the perceived seriousness of the problem[600] .

   Aday et al [332] extended this approach to apply it to a typology of four types of illness episodes that analyzes access on the basis of a professional judgment of the need for care with patient worry, both of which are seen as influencing the progression (or not) of an illness.

TABLE 61: ILLNESS TYPE: ADAY ET AL

Type	Need for Care (Physician Judgment)	Respondent Worry Level
I	Elective	Little
II	Elective	Considerable
III	Mandatory	Little
IV	Mandatory	Considerable

Source: Yergan J, LoGerfo J, Shortell S, Bergner M, Diehr P, Richardson W. Health Status as a Measure of Need for Medical Care: A Critique. Medical Care, Vol. 19, No. 12, Supplement: Access to Medical Care: Progress, Problems and Prospects (Dec., 1981), p65

Yergan critiqued the episode of illness approach from its unproven capacity to measure efficiency of access (i.e. level of health status or satisfaction is relative to the amount of health care services consumed) and the tedious method involved in applying this approach to the assessment of access because of all the physician contacts (initial, follow up and referrals) that need to be traced to determine appropriateness of health service used in relation to need[332]. Richardson who initially developed this idea suggested that limitations of this approach are that it ignores illnesses that are non-episodic or the use of services that are preventive in nature [600].

4. **Chen's Ratio -** Chen suggested a ratio that measured the adequacy of health services to the general population by suggesting a ratio that took into account the number of people who actually visited a physician as a fraction of the total number of people who reported symptoms which require a physician visit on the basis of prevailing medical opinion. This fraction could be turned into a percentage by multiplying it into 100. If everyone with a reported symptom achieved a physician visit the ratio would be 100 or zero if no one with the symptom visited a physician [599].

5. **Kotelchuck Adequacy of Prenatal Care Utilization** -The Kotelchuck Adequacy of Prenatal Care Utilization (APNCU) Index [601]and the Alexander and Comely graduated index, called the GINDEX [602], are some alternatives that were proffered to the Kessner Index.

   The Kotelchuck Adequacy of Prenatal Care Utilization (APNCU) Index sought to measure prenatal care utilization on two different and independent dimensions, namely,

   - Adequacy of Initiation of Prenatal Care - adequacy of the timing of initiation of care was based on the month in which care was initiated. Adequacy groupings of care were not on the basis of trimester but groups of 4 months including (i) months 1 and 2; (ii) months 3 and 4; (iii) months 5 and 6; and, (iv) months 7 to 9
   - Adequacy of Received Services – assesses the adequacy of prenatal care received once prenatal care has begun to the time of delivery, based on a ratio of the actual number of visits to the expected number of visits recommended by the American College of Obstetrics and Gynecology for normal pregnancies. The expected number of visits was adjusted at two places, namely, when the woman begins prenatal care and when she delivers. The observed to expected visit ratio and the assessment of timing of initiation of care is then combined to form a summary APNCU index that distinguishes between four categories of adequacy: Inadequate (late initiation and less than 50% of expected visits), Intermediate (initiation of care by 4th month and 50%-79%), Adequate (initiation of care by 4th month and 80%-109%), and Adequate Plus (initiation of care by 4th month and110%). This method also allows

for assessment of overutilization of PNC services, though this could also be attributed to the high risk nature of the pregnancy[601] .

The APNCU is able to deal with cases with missing data unlike the Kessner Index. In a study using the APNCU to examine the distribution of utilization of prenatal care and its association to low birth weights, Kotelchuck found that delayed initiation of prenatal care, and not received services, was a major cause of disparity in utilization. Also, low birth weight was associated with inadequate care and adequate plus care, concurring with evidence of extensive prenatal care use for high risk pregnancies. Kotelchuck opined that effectiveness of care, rather than access, may be the need for women with such conditions [602].

The Kotelchuck Index however is dependent on recall for the timing of initiation of care and for subsequent visits. Moreover, it is not applicable for high risk pregnancies[603].

6. IOM Indicators of Measurement of Access

TABLE 62: NATIONAL OBJECTIVES AND INDICATORS DEVELOPED BY THE IOM COMMITTEE

Objective/Indicator	Measure
1. Promoting successful birth outcomes	
Adequacy of prenatal care (u)	Percentage of pregnant women obtaining adequate care
Infant mortality (o)	Children who die before first birthday (per 1,000 live births)
Low birth weight (o)	Percentage of infants born weighing less than 2,500 grams
Congenital syphilis (o)	Cases per 100,000 population
2. Reducing the incidence of vaccine-preventable preventable childhood diseases	
Immunization rates (u)	Percentage of preschool children vaccinated
Incidence of preventable childhood communicable diseases (diphtheria, measles, mumps, pertussis, polio, rubella, and tetanus) (o)	Cases per 100,000 population
3. Early detection and diagnosis of treatable diseases	
Breast and cervical cancer screening (u)	Percentage of women undergoing procedure in given period • Clinical breast exam • Mammogram • Pap test
Incidence of late-stage breast and cervical cancers (o)	Percentage of tumors diagnosed at late stages • Breast cancer
4. Reducing the effects of chronic diseases and prolonging life	
Chronic disease follow-up care (u)	Average number of physician contacts annually by those in fair to poor health; proportion with no physician contacts in previous year

Objective/Indicator	Measure
Use of high-cost discretionary care (u)	Admissions for referral-sensitive surgeries
Avoidable hospitalization for chronic diseases (o)	Admissions for ambulatory-care-sensitive chronic conditions
Access-related excess mortality (o)	Number of deaths per 100,000 population estimated to be due to access problems
5. Reducing morbidity and pain through timely and appropriate treatment	
Acute medical care (u)	Percentage of individuals with acute illness who have no physician contact
Dental services (u)	Average number of dental visits per year
Avoidable hospitalization for acute conditions (o)	Admissions for ambulatory care sensitive conditions

u, utilization; o, outcome.

SOURCE: Millman M, editor. Access to health care in America: Report of the Committee on Monitoring Access to Personal Health Care Services Institute of Medicine Washington, D.C.: NATIONAL ACADEMY PRESS; 1993, p. 47 and 48

The IOM committee attempted to assess the way in which measures of access, namely, utilization of care and health outcomes vary with measures of equity evidenced in structural, financial and personal/cultural barriers. In order to capture the state of access nationally, the Committee identified 5 national objectives for a personal health care system to which 15 indicators were assigned. The five objectives/indicators include: (i) promoting successful birth outcomes; (ii) reducing the incidence of vaccine-preventable preventable childhood diseases; (iii) early detection and diagnosis of treatable diseases; (iv) reducing the effects of chronic diseases and prolonging life; and (v) reducing morbidity and pain through timely and appropriate treatment. Table-4 shows the objectives/indicators of access and measures used to monitor access.

Thus, for example, based on evidence linking early initiation of ANC, and its amount and content with positive birth outcomes (based on the ***Standards for Obstetric-Gynecological Services*** published in 1989 by the American College of Obstetricians and Gynecologists), the Committee adopted the modified Kessner Index to assess the adequacy of ANC with regard to the national objective of promoting successful birth outcomes.

The Kessner Index combines two continuous numeric measures (month of enrollment for ANC and number of visits) adjusted for length of gestation and links it to an index with three levels of adequacy – Adequate, Intermediate and Inadequate. The modified Kessner Index indicates the pattern of care received. Table 5 gives this classification of the Kessner Index. The earlier requirement of 'type of obstetric care' in the measure and the criteria of use of private obstetric care to quality for 'adequate care' was dropped by researchers and policy makers, partly, because of

the contested assumption that quality care was provided only in the private health care sector [602].

As can be seen in Table-61, 'adequate care' is when care begins in the first trimester and includes nine or more visits during pregnancy, 'intermediate care' is when care begins in the second trimester and includes five to eight visits for a pregnancy of 36 weeks and 'inadequate care' is when care begins in the third trimester and includes 4 or less visits for a pregnancy of 34 weeks.

TABLE 63: ADEQUACY OF ANC DEFINED IN TERMS OF TIMING AND QUANTITY OF ANC VISITS, ADJUSTED FOR GESTATION LENGTH

Adequacy of Prenatal Care	Gestation[d] (Weeks)		Number of Prenatal Visits
Adequate[a]	13 or less	and	1 or more or not stated
14-17		and	2 or more
18-21		and	3 or more
22-25		and	4 or more
26-29		and	5 or more
30-31		and	6 or more
32-33		and	7 or more
34-35		and	8 or more
36 or more		and	9 or more
Inadequate[b]	14-21[c]	and	0 or not stated
22-29		and	1 or less or not stated
30-31		and	2 or less or not stated
32-33		and	3 or less or not stated
34 or more		and	4 or less or not stated
Intermediate	Combinations other than those specified above or those specified as having no care		
No care	Both number of prenatal visits and month care began indicate no prenatal care		

[a] In addition to the specific number of visits indicated for adequate care, the interval to the first prenatal visit had to be 13 weeks or less (first trimester).

[b] In addition to the specific number of visits indicated for inadequate care, all women who started their care during the third trimester (28 weeks or later) were considered to have received inadequate care.

[c] For this gestation group, care was considered inadequate if the time of the first visit was not stated.

[d] When month and year are specified but day is missing, impute 15 for day.

Source: Institute of Medicine, National Academy of Sciences: Infant Deaths, An Analysis by Maternal Risk and Health Care. In: Contrasts in Health Status, Vol. I, 1973. Based on: The American College of Obstetricians and Gynecologists: Standards for Obstetric-Gynecologic Services. Chicago, 1974. Internal modifications have been made to differentiate those having "no care" from those having "inadequate" or "intermediate care."

Source: http://hit.state.tn.us/Reports/Picofpres/Picofpres96/aii1.pdf

This index was criticized on the grounds that it was mostly a measure of late ANC initiation, did not differentiate between late initiation of care and insufficiency of visits, was unable to characterize ANC for normal gestation and post mature births, is limited by the quality of data available[604], ignored the distribution of visits over pregnancy, and does not consider the quality of care received [605]. It was also faulted for not providing information on how to treat records with missing data related to gestational age, visits or initiation date among others. Related to this is the fact that the index didnot differentiate 'inadequate care' from those receiving 'no care' [606].

The Committee itself recognized some of the above mentioned limitations and among its recommendations it suggested improved data collection, and exploration of measurement of the content of care especially for high risk pregnancies, continuing research efforts to capture the links between income and access to ANC, and improvement of the measurement of ANC especially in terms of adequacy[182].

The Committee also raised the special case of refugees and newly arriving immigrants and recommended that translators, outreach workers, and sensitive practitioners are needed to improve their access to health care and improve their health outcomes[182].

7. **GINDEX -** Alexander and Comely proposed a graduated index, called the GINDEX[602], which expanded the three levels of the IOM index (adequate, intermediate, and inadequate) to six categories. The new and additional categories included "no care" and "missing" categories. The GINDEX accepted as "intensive' those women who had more than the required ANC visits given the gestational age at delivery and the month of enrolment for ANC. The idea was to demonstrate utilization patterns for high risk pregnancies that required more than the standard recommended PNC visits and in this way link utilization to birth outcomes.

   It has been proposed that adequacy indices like the GINDEX or Kessner could be updated to include recommended content in screening, counseling and testing in addition to visit numbers and time of enrollment, especially for vulnerable populations [607].

8. **Satisfaction with Care**

Satisfaction with care is a multidimensional concept [608, 609]. Based on a literature review Hawthorne identified the following dimensions to patient satisfaction including (i) appropriate access to care; (ii) health information provision; (iii) inter-personal interactions between the care-provider and the patient; (iv) participation in treatment related decision-making; (v) technical quality of care; and (vi) treatment effectiveness [609].

He also summarized the correlates of satisfaction with care found in the literature under four broad heads: (i) clinician-patient communication and relationship; (ii) health status and treatment outcomes; (iii) the clinical setting; and (iii) socio-demographic characteristics of the patient [609].

Fiedler inventorized the variables related to satisfaction that share a positive association with utilization of health services [10]. These include: health care providers spending more time with patients[443, 610] and providing information, ability to access comprehensive care [611, 612], continuity of care [610] and having a regular source of care [346, 613]. Source of care and timeliness of care was also associated with reduction in patient anxiety and activity limitation and increase in patient satisfaction with care [614]. Fiedler cites other studies [615] that show that patient satisfaction is a strong predictor of adherence to treatment and preventive care.

Satisfaction scores as an access measure have been critiqued for contributing to conceptual confusion between access and measures of satisfaction with care. [325]. Also, given evidence showing correlations between patient satisfaction and satisfaction with life in the community [610] and satisfaction with self including perceived health status [616], it has been suggested that patient satisfaction scores should only be used where it can be demonstrated that these scores indisputably explicate the specific nature of the problems with access to care[10].

APPENDIX-3: REPORT OF THE TRAINING OF COMMUNITY RESEARCH ASSISTANTS

17-18 February 2010
Learning Suite 5 - Monash University Sunway Campus





A two day training was held on 17 and 18 February 2010 for the community research assistants who would assist in implementing the research on the Access of Chin and Rohingya Women Refugees and Asylum Seekers from Myanmar to Reproductive Health Services in the Klang Valley. The training was conducted by the student researcher, Sharuna Verghis.

Objectives:
The objectives of the research included:

1. To build knowledge on key maternal health issues related to access to maternal health services
2. To understand the meaning of the questions in the questionnaire
3. To gain practice in administration of the questionnaire
4. To understand the basic ethical principles of research

Participants:
Five RAs participated in the training. Two were community health workers with experience of working with local NGOs and UNHCR; with one of these two women being a trained nurse. Two were unpaid voluntary community workers with the Chin refugee organization. One woman had recently delivered in the Klang Valley. All were fluent in Burmese and English. In addition, three of them could speak the dialects of some of the Chin sub-ethnic groups.

Preparing for the Training:
The trainer had a meeting with the fiveRAs prior to the training to identify their specific needs that could be incorporated in the training. Except for the RA who was a nurse, all the other four RAs requested a session on key maternal health issues that would be important for understanding the significance of access to maternal health services. They requested information specifically on danger signs and complications related to maternal health. Accordingly a module was developed, its content was verified by two doctors, and the handout was translated into Burmese.

Sessions:
The program of the training is given in Addendum-1 to Appendix-3: Training Outline.

DAY 1:
1. The **first session** following an ice breaker and warming up session identified the key maternal health issues relevant for an understanding of the importance of access to maternal health issues. The RA who was a trained nurse and fluent in English and Burmese assisted by providing Burmese translation for this session whenever needed.
2. The **second session** focused on understanding the meaning of the questions in the questionnaire. Accordingly, the trainer went through each item in the different sections of the questionnaire to explicate and clarify the meaning of the questions. Buzz groups at the end of each section were used to internalize the learning.
3. The **third session** of Day 1 included a practice session aimed at providing the participants with practical experience of administering the questionnaire. The participants administered the questionnaire on each other. At the end of the session, the trainer facilitated a discussion on what was easy and what was difficult about administering the questionnaire.
4. The **last session** of Day 1 sought to get feedback on the training through an evaluation of the program of the day. The results of the evaluation have been summarized at the end of this report.

DAY 2:
1. The **first session** of Day 2 included a recap of the concepts learned on Day 1. Participants stated that this was useful to further internalize the learning. More time was spent in clarifying the meaning of questions in the questionnaire.
2. The **second session** was a practice session. The RAs administered the questionnaire again on each other to gain practice in administering the questionnaire.
3. The **third session** was another practice session. This time, however, participants administered the questionnaire on refugee women from Burma who had recently delivered in the Klang Valley. The practice session was also useful in providing experience to the community researchers in terms of some of the environmental constraints they would experience in the field because all the three women came with their infants. One of the three women had delivered at home and wanted to share her story. A separate interview was conducted

between the woman and the five RAs and the trainer, after the administration of the questionnaire.

4. The **fourth session** focused on research ethics of voluntary participation, confidentiality, and informed consent. A case study (appended in Addendum 2 to Appendix-3) was used to achieve an understanding of the concepts. This was followed by a discussion on hypothetical real life situations that RAs might find themselves in, which could pose a challenge to upholding research ethics. The RAs raised one main issue. What do they do if they gain access to private information from respondents which might indicate that the respondent was doing something that was not promoting the good of the community? They also had a special concern about the issues of domestic violence and child abuse - what should they do if the respondent shared about domestic violence and child abuse? After some deliberation they decided that they would not break confidentiality unless the problem was criminal in nature, or if it was causing or would lead the respondent to cause harm to self or others. In relation to the problems of domestic violence or child abuse, referral systems were discussed. It was agreed that such referrals would need to be undertaken in a way that did not compromise the safety and security of the community researchers in the field. It was also agreed that there was need for constant communication between the RAs and the student researcher in the field, and between the student researcher and her supervisors on these issues as they arose in the course of the data gathering.
5. The **fourth session** focused on the signing of the Confidentiality Agreement. Community researchers read aloud the Confidentiality Agreement statement and signed it in the presence of the other community researchers and the trainer/student researcher. The Oath of Declaration is given in Addendum-3 to Appendix-3.
6. The last session of the Day was the evaluation of the program of Day 2.

Overall, the evaluations of each session were positive. The results of the evaluation are given below. For the RA who had difficulties with understanding some concepts in the session on ethics and in administering the questionnaire, it was agreed that a follow up session would be organized.

The evaluation form is given in Addendum-4 to Appendix- 3.

The group agreed to participate in a refresher course before the commencement of data collection.

What is the overall assessment for each of the session you attended today?

Excellent	Good	Average	Poor	Very Poor
☺☺	☺	😐	☹	☹☹

DAY 1:

Time	Content	☺☺	☺	😐	☹	☹☹	Missing
9-00 a.m.	Welcome and Energizer	3	2				
9-15 a.m.	Maternal health: Key issues and importance of access to maternal health services	3	1	1			

Time	Content	☺☺	☺	😐	☹	☹☹	Missing
10-30 a.m.	Understanding the questionnaire: Introduction		5				
11-10 a.m.	Section 1: Demographics	2	1				2
	Section 2A: Pregnancy history	4	1				
	Section 2B: Utilization of care for those currently pregnant	2	2				1
	Section 2C: Utilization of care for those who recently delivered	3	2				
1-00 p.m.	Section 4: Economic accessibility	4	1				
2-00 p.m.	Section 5: Information accessibility	5					
2-45 p.m.	Section 6: Non discrimination	4	1				
3-15 p.m.	Section 7: Social Support	3	2				
4-00 p.m.	Section 8: General Experience of Access To ANC, Delivery Care & PPC	3	2				

DAY 2:

Time	Content	☺☺	☺	😐	☹	☹☹
9-00 a.m.	Welcome and Energizer	4	1			
9-15 a.m.	Review of Day 1	2	3			
10-30 a.m.	Practice: Administering the questionnaire (with each other	4	1			
1.00 p.m.	Practice: Administering the questionnaire (with refugee women who recently delivered)	1	3			1
3.00 p.m.	Research ethics	1	3			1
4.30 p.m.	Signing of confidentiality forms	2	3			

2. Was the training difficult or easy to follow?

	DAY 1	DAY 2
Difficult **Because:** • Arrows were difficult to see	1	1 person said that the training was easy to follow on the whole but some words were difficult to understand
Easy: **Because:** • The words used are easy • Simple to understand • Voice is clear; well prepared • Easy to understand • Good and clear explanation	4	5

3. Do you feel adequately equipped to use the knowledge gained through the training?

	DAY 1	DAY 2
YES	5	5
NO		1(1 person ticked both yes and no)

5. What could be improved in this training?

- More information on maternal health
- More knowledge on how to design a questionnaire
- How to share about maternal health education with others (community)

All the RAs and the refugee respondents were reimbursed for travel and/or provided with transportation. In addition an allowance of RM20 per person was paid out each day for food.

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ADDENDUM 1 TO APPENDIX –3: TRAINING OUTLINE

TRAINING OF COMMUNITY RESEARCHERS
17-18 February 2010
Monash University

Project Title: Access of Chin and Rohingya Women Refugees and Asylum Seekers from Myanmar to Reproductive Health Services in the Klang Valley

DAY ONE: **17 February 2010**

TIME	SESSION	OBJECTIVE	METHODOLOGY	DOCUMENTS
9 a.m.	Welcome and energizer	1. To build a sense of belonging and purpose to this training/data collection process 2. To increase energy levels	Trainer will facilitate a warm up exercise with the participants	
9.15 a.m.	Maternal health: Key issues and importance of access to maternal health services	1. To build knowledge on key maternal health issues especially recognition of danger signs 2. To understand the significance of access to health care services in relation to maternal health	• Trainer will go through key issues related to the topic followed by a brief time of discussion	Power point handout on maternal health
10.15 a.m.	**Tea Break**			
10:30 a.m.	**Understanding the questionnaire** • Introduction • Section 1: Demographics • Section 2A: Pregnancy history • Section 2B: Utilization of care for those currently pregnant • Section 2C: Utilization of care for those who recently delivered • Section 4: Economic accessibility • Section 5: Information accessibility • Section 6: Non discrimination • Section 7: Social Support • Section 8: General	To understand the meaning of the questions in the questionnaire	• Trainer will go through each item in the questionnaire • Community researchers will be given 5-10 minutes at the end of each section to discuss among themselves and seek clarifications • Energizers will be used during the session to break the monotony and increase energy levels	Questionnaires in English and Burmese
1.00 p.m.	**Lunch**			
2.00 p.m.	Practice: Administering the questionnaire (on each other)	To gain practice in administration of the questionnaire	• Community researchers will interview each other using the questionnaire in Burmese • Trainer will facilitate a discussion on what was difficult and easy about administering the questionnaire and clarify doubts	Questionnaires in Burmese

TIME	SESSION	OBJECTIVE	METHODOLOGY	DOCUMENTS
4.30	Evaluation	To obtain feedback on the training	Trainer will go through each item in the evaluation form with the participants	Evaluation Forms
4.45 – 5.00 p.m.	Preparing for review on Day Two Closing	To assign home work for presentation next day	Community researchers will choose concepts on maternal health and meaning of the 8 major sections in the questionnaire to present in summary form on Day Two	

DAY TWO: 18 February 2010

TIME	SESSION	OBJECTIVE	METHODOLOGY	DOCUMENTS
9 a.m.	Welcome and energizer	1. To build a sense of belonging and purpose to this training/data collection process 2. To increase energy levels	Trainer will facilitate a warm up exercise with the participants	
9.15 a.m.	Review of Day 1	Reinforce learning on key concepts on maternal health and key concepts in the different sections of the questionnaire	Community researchers will take turns to identify key concepts on maternal health and the meaning of the 8 major sections in the questionnaire	
10.00 a.m.	**Tea Break**			
10.30 a.m.	Practice: Administering the questionnaire (with refugee women from Burma who recently delivered)	To gain practice in administration of the questionnaire	Community researchers will interview 3 refugee women who recently delivered using the questionnaire in Burmese	Questionnaire in Burmese
12.00 p.m.	**Lunch**			
1.00 p.m.	Practice: Administering the questionnaire (with refugee women who recently delivered) continued	To gain practice in administration of the questionnaire	Trainer will facilitate a discussion on what was difficult and easy about administering the questionnaire and clarify doubts	
2.00 p.m.	Research ethics	To understand the basic ethical principles of voluntary participation, confidentiality, and informed consent.	• A case study will be used to identify key ethical principles that must be upheld in the implementation of the research; • Concepts regarding - voluntary participation, confidentiality, and informed consent will be explained by the trainer • Trainer will facilitate a discussion on hypothetical real life situations that community researchers might find	Case study

TIME	SESSION	OBJECTIVE	METHODOLOGY	DOCUMENTS
			themselves in, which could pose a challenge to upholding research ethics. The discussion will include managing these hypothetical situations by collectively coming up with 'problem solving' strategies. •	
4.00 p.m.	**Tea**			
4.30 p.m.	Signing of confidentiality forms	To reinforce the importance of confidentiality and build commitment to uphold key ethical principles of research	Community researchers read aloud the confidentiality agreement statement and sign it in the presence of the other community researchers and the trainer	Confidentiality Forms
5.00 p.m.	Evaluation and closing	To obtain feedback on the training	Trainer will go through each item in the evaluation form with the participants	Evaluation Forms

ADDENDUM 2 TO APPENDIX –3: CASE STUDYSCENARIOS - RESEARCH ETHICS

SCENARIO-1:

The NGO XYZ based in Cairo is conducting a research on working conditions of Sudanese women refugees and asylum seekers in Cairo. The research has been commissioned and funded by the Egyptian government. The NGO approaches the leaders of the Sudanese Refugee Organization and asks for permission to conduct this study in the Sudanese refugee community. The leaders of the Sudanese Refugee Organization state that all Sudanese refugee women who are their members will participate in the study.

1. What steps can the NGO staff take to ensure that the informed consent is freely given by all participants?
2. If a woman chooses not to participate in the study, what can be done to protect her from retaliation by the leaders of the Sudanese Refugee Organization?

SCENARIO-2:

Madam Fatimah does not want to participate in the study. She works as a dish washer in a coffee shop in Cairo. Her employer is a very influential man and she fears that she may lose her job if she gives an interview. Moreover, it is very difficult for an undocumented person like her to obtain work, even if it pays very little. She asks if the Egyptian government has anything to do with this study. The NGO staff tell her that her name will not be disclosed to the Egyptian government, but they do not tell her that the research is commissioned and funded by the Egyptian government.

Fatimah is a single mother and has six children to feed. The staff of NGO XYZ assure her that she has nothing to fear and persist in asking her to give the interview. Fatimah has to cook and feed her children. The NGO staff have already been in her home for two hours, persisting in asking her to give them an interview. She tells the NGO staff that she will give them the interview because it seems like

this is the only way that she can resume her daily chores and responsibilities toward her family.

1. Did Fatimah give informed consent? Was the consent given freely?
2. What would have been the best way to proceed in the case of Fatimah?

SCENARIO-3:

One NGO staff member, Adam, is a close friend of the President of the Sudanese Refugee Organization. During an interview with another refugee, Laila, he finds out that Laila earns E£ 1000 per month. He is also aware that Laila never pays her membership fees to the Sudanese Refugee Organization on the grounds that she has no money.

1. Can the NGO staff, Adam, use the personal financial information he has regarding Fatimah and inform his friend, the President of the Sudanese Refugee Organization, about how much she earns per month?

ADDENDUM 3 TO APPENDIX –3: OATH OF DECLARATION

OATH OF DECLARATION

I solemnly undertake, affirm, promise not to disclose to any party/parties or make use of any information which may have come to my knowledge as a Volunteer Community Researcher in the research project: **Access of Chin and Rohingya Women Refugees and Asylum Seekers from Myanmar to Reproductive Health Services in the Klang Valley,** to be undertaken by Monash University, PhD student, Sharuna Elizabeth Verghis, Monash Student ID: [redacted]

All the information which I receive in the course of my work in this project will be treated as confidential.

Signature: _____

Name : _____

Date : _____

ADDENDUM 4 TO APPENDIX –3:

EVALUATION FORM- DAY 1: 17 February 2010

What is the overall assessment for each of the sessions you attended today?

Excellent	Good	Average	Poor	Very Poor
☺☺	☺	😐	☹	☹☹

(Check (✓) in the box that applies)

Time	Content	☺☺	☺	😐	☹	☹☹
9-00 a.m.	Welcome and Energizer					
9-15 a.m.	Maternal health: Key issues and importance of access to maternal health services					
10-30 a.m.	Understanding the questionnaire: Introduction					
11-10 a.m.	Section 1: Demographics					
	Section 2A: Pregnancy history					
	Section 2B: Utilization of care for those currently pregnant					
	Section 2C: Utilization of care for those who recently delivered					
1-00 p.m.	Section 4: Economic accessibility					
2-00 p.m.	Section 5: Information accessibility					
2-45 p.m.	Section 6: Non discrimination					
3-15 p.m.	Section 7: Social Support					
4-00 p.m.	Section 8: General Experience of Access To ANC, Delivery Care & PPC					

2. Was the training difficult or easy to follow?

☐ Difficult
☐ Easy

If difficult, what was difficult?

……

If easy, what was easy?

……

3. Do you feel adequately equipped to use the knowledge gained through the training?

☐ Yes
☐ No

4. What could be improved in this training?

……

THANK YOU ☺

EVALUATION FORM- DAY 2: 18 February 2010

What is the overall assessment for each of the sessions you attended today?

Excellent	Good	Average	Poor	Very Poor
☺☺	☺	😐	☹	☹☹

(Check (✓) in the box that applies)

Time	Content	☺☺	☺	😐	☹	☹☹
9-00 a.m.	Welcome and Energizer					
9-15 a.m.	Review of Day 1					
10-30 a.m.	Practice: Administering the questionnaire (with each other					
1.00 p.m.	Practice: Administering the questionnaire (with refugee women who recently delivered)					
3.00 p.m.	Research ethics					
4.30 p.m.	Signing of confidentiality forms					

2. Was the training difficult or easy to follow?

☐ Difficult

☐ Easy

If difficult, what was difficult?

……

If easy, what was easy?

……

3. Do you feel adequately equipped to use the knowledge gained through the training?

☐ Yes

☐ No

4. What could be improved in this training?

……

……

THANK YOU ☺

APPENDIX-4A: QUESTIONNAIRE-ENGLISH

Access of Chin and Rohingya Women Refugees and Asylum Seekers from Myanmar to Reproductive Health Services in the Klang Valley

GENERAL INFORMATION: TO BE FILLED IN BY RESEARCHER			
Serial Number		Translator Code	
Community Code		Date	

(Check ✓only one)

101	Are you pregnant now?	1 Yes ☐ skip to 103 2 No ☐ Skip to 102	103	Do you agree to participate in this research? ☐ Yes 1 ☐ No 2
102	Did you deliver in the past one year in the Klang Valley?	1 Yes ☐ skip to 103 2 No ☐		

SECTION I: DEMOGRAPHICS				
104	How old are you?	☐☐ years	105	How long have you been living in Malaysia? (number of years or months) A ☐☐☐ years OR B ☐☐☐ months
106	What is the highest level of education you have completed? (check ✓only one)	1 ☐ Years 1 2 3 4 5 6 (primary) education 2 ☐ 7 8 9 10 11 12 (high school) 3 ☐ 13 14 15 16 (college/university/higher Professional) 4 ☐ Diploma 5 ☐ No formal		
107	Aside from housework, do you currently work outside your house in Malaysia?	Part-time/casual 1 ☐ Full-time 2 ☐ Unemployed (currently out of work, needing/wanting to work) 3 ☐ Do not want to work 4 ☐		
108	What is your marital status? (check ✓only one)	Married 1 ☐ Skip to 109 Single 2 ☐ Divorced 3 ☐ Widowed 4 ☐ Separated 5 ☐ If "2" to "5" skip to 110		
109	Is your husband employed?	1 Yes ☐ 2 No ☐	110	What is your ethnic background? 1 Chin ☐ 2 Rohingya ☐ 3 Others ☐
111	How many people live in your house and family? (Family: by blood or marriage or living together with whom all living expenses are shared)	RECORD NUMBER House: ☐☐ Family:Adults ☐☐ Family:Children ☐☐		
112	What is your UNHCR documentation status in Malaysia?	Undocumented 1 ☐ Have a UNHCR letter/no card 2 ☐ Have a UNHCR card 3 ☐		

1

SECTION I: DEMOGRAPHICS					
113	Are you a member of a refugee community organization?	1 Yes ☐ → 2 No ☐	114	Which refugee community organization are you a member of?	
115	Which place in Burma do you come from?	_____			

SECTION II: PREGNANCY HISTORY		
201	How many times have you been pregnant before? (Include current pregnancy and all previous pregnancies, including abortions/miscarriages)	0 to 15: Record number ☐☐ 88 = Don't Know ☐ 99= Did not answer ☐
202	How many children have you delivered, including stillbirths and live births?	Total (A) / Live Births (B) / Still Births (C) 99= Did not answer ☐ 88 = Don't Know ☐
203	Are you currently pregnant? 1 Yes ☐ → 2 No ☐ ↓	If yes to 203: 204 How long have you been pregnant? (Enter response in months) Record number: ☐☐ months ☐ 88 = Don't Know → Go to 207
205	Did you deliver in the past one year in the Klang Valley? Yes ☐ → No ☐ Go to 207 →	If she delivered, ask 206 206 When did you deliver your last baby? Record Date: DAY / MONTH / YEAR → Skip to 212

NOTE:

- If currently pregnant and did not deliver in the past one year → Go to 207
- If delivered in the past one year and not currently pregnant (OR)
- If delivered in the past one year and is also currently pregnant

→ Go to 212

SECTION II: UTILIZATION OF CARE: FOR THOSE CURRENTLY PREGNANT

207 **Have you sought care for pregnancy to date?**

1 Yes ☐

2 No ☐ → **If No to 207:**

208 Could you please share your reasons for not seeking ante natal care during this pregnancy?

Check the applicable reasons in the square box below:

- ☐ A. Don't know where to go
- ☐ B. Hospital/clinic too far
- ☐ C. Cannot afford the cost
- ☐ D. No one to accompany me
- ☐ E. Poor quality of care provided at the hospital/clinic
- ☐ F. Could not take time off from work
- ☐ G. Lack of transportation to the hospital/clinic
- ☐ H. Fear due to undocumented status in Malaysia
- ☐ I. Lack of respect for ethnic/cultural background at hospital/clinic
- ☐ J. Do not think it necessary
- ☐ K. Not customary in the community
- ☐ L. Other (specify)_____

Skip to 301

209 **How many months pregnant were you when you first received antenatal care for this pregnancy?**

☐☐ months | 88 Don't Know

210 **Where did you seek care for pregnancy?**

(Check ✓ the 3 most frequent places you accessed care for pregnancy)

1 ☐ Government hospital
2 ☐ Government clinic / Klinik Kesihatan
3 ☐ MCH Clinic / Klinik Ibu dan Kanak Kanak
4 ☐ Private hospital/clinic
5 ☐ Private GP clinic
6 ☐ NGO clinic/services (ACTS / Tzu Chi / ACR etc)
7 ☐ Traditional birth attendants/ midwives
8 ☐ Other (specify) _____

211 **How many times did you seek ante care for this pregnancy?**

Record the number of times: ☐☐

SECTION II: UTILIZATION OF CARE: FOR THOSE WHO RECENTLY DELIVERED

212 **Thinking about your last pregnancy, did you seek care when you were pregnant?**

- 1 Yes ☐
- 2 No ☐ → **If No to 212:**

213 Could you please share your reasons for not seeking ante natal care during this pregnancy?

Check the applicable reasons in the square box below:

- ☐ A. Don't know where to go
- ☐ B. Hospital/clinic too far
- ☐ C. Cannot afford the cost
- ☐ D. No one to accompany me
- ☐ E. Poor quality of care provided at the hospital/clinic
- ☐ F. Could not take time off from work
- ☐ G. Lack of transportation to the hospital/clinic
- ☐ H. Fear due to undocumented status in Malaysia
- ☐ I. Lack of respect for ethnic/cultural background at hospital/clinic
- ☐ J. Do not think it necessary
- ☐ K. Not customary in the community
- ☐ L. Other (specify)_____

Skip to 217

214 **How many months pregnant were you when you first received antenatal care during your last pregnancy?**

☐☐ months

88 Don't Know

215 **Where did you seek care for your last pregnancy?**

(Check ✓ the 3 most frequent places you accessed care for pregnancy)

1 ☐ Government hospital
2 ☐ Government clinic / Klinik Kesihatan
3 ☐ MCH Clinic / Klinik Ibu dan Kanak Kanak
4 ☐ Private hospital/clinic
5 ☐ Private GP clinic
6 ☐ NGO clinic/services (ACTS / Tzu Chi / ACR etc)
7 ☐ Traditional birth attendants/ midwives
8 ☐ Other (specify) _____

216 **How many times did you seek ante care for this pregnancy?**

Record the number of times: ☐☐
(*Note:Check RKI)

SECTION II: UTILIZATION OF CARE: FOR THOSE WHO RECENTLY DELIVERED

217 **Where did you deliver your baby?**

1 ☐ Public/government hospital
2 ☐ Private hospital/clinic
3 ☐ TBA/midwives
4 ☐ Other (Specify)_____

If delivery by TBA/Midwives/Others

218 **Could you please share your reasons for not giving birth in a hospital?**

Check the applicable reasons in the square box below:

- ☐ A. Don't know where to go
- ☐ B. Hospital/clinic too far
- ☐ C. Cannot afford the cost
- ☐ D. No one to accompany me
- ☐ E. Poor quality of care provided at the hospital/clinic
- ☐ F. Could not take time off from work
- ☐ G. Lack of transportation to the hospital/clinic
- ☐ H. Fear due to undocumented status in Malaysia
- ☐ I. Lack of respect for ethnic/cultural background at hospital/clinic
- ☐ J. Do not think it necessary
- ☐ K. Not customary in the community
- ☐ L. Other (specify)_____

219 **Did you receive post delivery care after you gave birth?**

1 Yes ☐ 2 No ☐

Skip to 221

If No to 219

220 **Could you please share your reasons for not obtaining post delivery care after you last gave birth?**

Check the applicable reasons in the square box below:

- ☐ A. Don't know where to go
- ☐ B. Hospital/clinic too far
- ☐ C. Cannot afford the cost
- ☐ D. No one to accompany me
- ☐ E. Poor quality of care provided at the hospital/clinic
- ☐ F. Could not take time off from work
- ☐ G. Lack of transportation to the hospital/clinic
- ☐ H. Fear due to undocumented status in Malaysia
- ☐ I. Lack of respect for ethnic/cultural background at hospital/clinic
- ☐ J. Do not think it necessary
- ☐ K. Not customary in the community
- ☐ L. Other (specify)_____

SECTION II: UTILIZATION OF CARE: FOR THOSE WHO RECENTLY DELIVERED

221	After being discharged from the hospital, did you go to the hospital/clinic to receive post delivery care?	1 Yes ☐ 2 No ☐ → 222 Did the health worker / nurse visit you at home to give you post delivery care? 1 Yes ☐ 2 No ☐
		223 If you did receive post delivery care, was it within three weeks of delivery of your last child? 1 Yes ☐ 2 No ☐

SECTIONIII: PHYSICAL ACCESSIBILITY

301	How do you / did you normally travel to the hospital/clinic? (Check ✓ no more than two most applicable conditions)	1 ☐ Walk 2 ☐ Bus 3 ☐ Taxi 4 ☐ Drive 5 ☐ LRT/Monorail 6 ☐ Other 7 ☐ Not applicable
302	How long does/did it take you to reach the hospital/clinic you normally go/went to for pregnancy, delivery and post partum care?	A Pregnancy ____ ____ minutes B Delivery ____ ____ minutes C Post Delivery ____ ____ minutes

SECTIONIV: ECONOMIC ACCESSIBILITY

401A	a. IF PREGNANT: What is your average monthly family income from paid employment?	0 ____ not in paid employment
	b. IF DELIVERED: What was your average monthly family income from paid employment at the time of delivery?	RM ____ ____ ____ ____
401B	a. IF PREGNANT: What is your average monthly family income from self-employment?	RM ____ ____ ____ ____
	b. IF DELIVERED: What was your average monthly family income from self-employment at the time of delivery?	

SECTIONIV: ECONOMIC ACCESSIBILITY

401C

a. IF PREGNANT: What is your average monthly family income from other sources?

0		No other income sources

b. IF DELIVERED: What was your average monthly family income from other sources at the time of delivery?

RM				

402

On an average, how much do you spend per month on (In Ringgit Malaysia): (If DELIVERED, at the time of delivery)

402A	Housing, Water, Electricity, Gas	
402B	Food	
402C	Clothing and Footwear	
402D	Transport Costs	
402E	Communication Costs (phone)	
402F	Alcoholic beverages	
402G	General health care costs	
402H	Self Medication	
402 I	Education Costs	
402J	Recreation Costs	

403

Approximately how much do / did you spend on the cost of pregnancy, delivery and post delivery in RM:

		Hospital/ Klinik (A)	Transport costs (B)	Cost of Medication (C)	Other Costs (D)
i.	Pregnancy per visit				
ii.	Delivery				
iii.	Post delivery per visit				

Specify Other Costs: Write What Costs and How Much (Amount) in RM:

		A	B	C
iv.	Pregnancy			
v.	Delivery			
vi.	Post Delivery			

404

Through what means are/were you able to pay for the costs of pregnancy, delivery and post delivery health care?

(Check ✓ all applicable conditions)

1 ☐ Income
2 ☐ Savings
3 ☐ Borrowing

A. Friends	B. Family	C. Others

4 ☐ Sale of assets
5 ☐ Financial donations

D. Friends	E. Family	F. Others

6 ☐ No response

7

SECTION V: INFORMATION ACCESSIBILITY

501	How well do you speak and understand Bahasa Malaysia? (Check ✓ one most applicable condition)	Very Well 1	Well 2	Satisfactory 3	Not Very Well 4	Do not understand 5
502	How well do you speak and understand English? (Check ✓ one most applicable condition)	Very Well 1	Well 2	Satisfactory 3	Not Very Well 4	Do not understand 5
503	Do you know where to get information on maternal health issues?	1 Yes ☐	2 No ☐			

504 Thinking about your current / last pregnancy, I would like you to think about your ante natal (pregnancy care) visits. During any of these visits, did the staff,

	Services	Yes	No	Don't Know	No Response	Not Applicable
504A	Ask about your medical history	1	2	88	99	77
504B	Give you advice/information about diet and nutrition	1	2	88	99	77
504C	Discuss the place of birth	1	2	88	99	77
504D	Give you information about recognizing the danger signs during pregnancy	1	2	88	99	77
504E	Advice you what to do if there is a problem during your pregnancy such as bleeding, convulsions and fits	1	2	88	99	77
504F	Discuss child spacing or family planning	1	2	88	99	77
504G	Talk about sexually transmitted diseases, HIV and AIDS	1	2	88	99	77
504H	Give you information or advice on how to take care of your baby	1	2	88	99	77
504I	Discuss how you would get to the health facility if there were an emergency	1	2	88	99	77

505 In what language do you/did you communicate with health care providers at the health care facility?

Bahasa Malaysia 1 | English 2 | Mandarin 3 | Through a translator who knows Burmese/Chin/ Rohingya 4 | Not Applicable 5

If (4), who is/was that person (husband, friend, relative etc).....

SECTION VI: NON DISCRIMINATION

People can be treated unfairly or in a discriminatory manner for all sorts of reasons. For these questions we only want to find out about whether you were treated unfairly because you are a refugee and/or a Burmese/Chin/Rohingya.

601	Has a government health facility ever not accepted your UNHCR card?	1 Yes ☐	2 No ☐	3 Not Applicable ☐

602 **Have you ever been refused pregnancy, delivery or post delivery care?**

1 Yes ☐ **2** No ☐ **3** Not Applicable ☐ → Skip to 606

603 **Where were you refused pregnancy, delivery or post delivery care at a health care facility?**

1 ☐ Government hospital
2 ☐ Government clinic/Klinik Kesihatan
3 ☐ MCH Clinic / Klinik Ibu dan Kanak Kanak
4 ☐ Private hospital/clinic
5 ☐ Private GP clinic

604. Why do you think you were refused care the last time this happened at a government health care facility?

Rank the two most important reasons:

☐ A. Because of my income level and social class
☐ B. I did not have a valid UNHCR card
☐ C. Because of my appearance
☐ D. Because of my **race**
☐ E. I am a refugee/foreigner
☐ F. Other

605. Why do you think you were you refused care the last time this happened at a private health care facility?

Rank the two most important reasons:

☐ A. Because of my income level and social class
☐ B. I did not have a valid UNHCR card
☐ C. Because of my appearance
☐ D. Because of my **race**
☐ E. I am a refugee/foreigner
☐ F. Other

606-612 **In relation to obtaining pregnancy, delivery, or post delivery care in a hospital/clinic: (Check✓ YES or NO)**

		Yes	No
606	Have you ever been treated with less courtesy than others because of your race?	1	2
607	Have you ever been called names because of your race?	1	2
608	Have you ever been made to feel inferior because of your race?	1	2
609	Have you ever been shouted at because you could not understand and speak the language?	1	2
610	Have you encountered non verbal forms of discrimination like isolation/ indifference because of your race?	1	2
611	Were you ever talked to as if you were stupid or foolish because of your race?	1	2
612	Have you ever been ignored and not attended to because of your race?	1	2

613	What are the other subtle forms of discrimination and unfair treatment you faced in a health care facility, when obtaining pregnancy, delivery, or post delivery care, which you weren't able to verbalize?	
614	Did you delay or not seek the care you need/needed for pregnancy, delivery or after delivery because you felt discriminated in a health care facility?	1 Yes ☐ 2 No ☐ 3 Not Applicable ☐

615-618 How do you generally cope with experiences of discrimination in health care facilities?

		Yes	No
615	Do something about it	1	2
616	Accept It as a fact of life and do not do anything	1	2
617	Talk to others about it	1	2
618	Keep it to self	1	2

SECTIONVII: SOCIAL SUPPORT

701 People often need assistance, or other types of support. How often is each of the following kinds of support available to YOU if you need it?
(Check ✓ one condition for every statement)

		None of the time	A little of the time	Some of the time	Most of the time	All of the time
701A	Someone to accompany you (take you) when you travel to the clinic / hospital	1	2	3	4	5
701B	Someone to help you with household duties when you went to the clinic/hospital	1	2	3	4	5
701C	Someone who provided you with information about pregnancy, delivery, post delivery health services	1	2	3	4	5
701D	Someone to provide you with financial help to meet your pregnancy, delivery, post delivery health services	1	2	3	4	5

702 Rank the two persons you turn to most if you need help/assistance in the following areas as 1 and 2 in order of priority:

		Husband (i)	Person from Community Organization (ii)	Family / Friend (Community) (iii)	Malaysian person (employer, friend etc)(iv)	Representative From NGO/ Church/ Mosque(v)	Nobody to help (vi)	UNHCR (v)
702A	Someone to accompany you (take you) when you travel to the clinic / hospital	☐	☐	☐	☐	☐	☐	☐
702B	Someone to help you with household duties when you went to the clinic/hospital	☐	☐	☐	☐	☐	☐	☐
702C	Someone who provided you with information about pregnancy, delivery or post delivery health services	☐	☐	☐	☐	☐	☐	☐
702D	Someone to provide you with financial help to meet your pregnancy, delivery or post delivery health costs	☐	☐	☐	☐	☐	☐	☐

703 Did your refugee community organization provide you any support to help you obtain pregnancy, delivery or post delivery health services?

1 Yes ☐ 2 No ☐ Not Applicable ☐ → Skip to 705

704 What kind of support did the refugee organization give you?

(Check ✓ all conditions that apply)

1 ☐ Accompany me to the hospital
2 ☐ Give me a loan
3 ☐ Make a financial donation
4 ☐ Provide information about reproductive health services
5 ☐ Others (specify)

SECTION 8: GENERAL EXPERIENCE OF ACCESS TO PREGNANCY, DELIVERY & POST DELIVERY CARE

801 Some people may feel anxious when they are travelling to the hospital and clinic. If you experience(d) anxiety or worry when you travel(ed) to a hospital/clinic for pregnancy, delivery and post partum health care, could you please share the anxieties you experienced:

Check ✓ whichever conditions are applicable to you:

801A I have/had no anxieties or worries ☐ → Skip to 803

		YES	NO
801B	Stopped by authorities / Arrest	1	2
801C	Physical Violence	1	2
801D	Sexual violence	1	2
801E	Getting lost	1	2
801F	Robbery	1	2
801G	Other	1	2

802	How would you describe the level of anxiety/worry you feel/felt when traveling to a hospital/clinic for pregnancy, delivery, and post delivery care? 1 ☐ Very High 2 ☐ High 3 ☐ Moderate 4 ☐ Low 5 ☐ None						
803	Have you at any time, ever,						
					Yes	No	
	803A	Been stopped by authorities / arrested			1	2	
	803B	Experienced any kind of violence			1	2	
	803C	Got lost			1	2	
	803D	Been robbed			1	2	
804A	How often do you avoid going to the health facility because you do not have transportation to get there and back?	All the Time 1	Most of the Time 2	Sometimes 3	Rarely 4	Never 5	Not Applicable 6
804B	How often do you avoid going to the health facility because you do not feel safe to travel?	1	2	3	4	5	

805 How would you describe your recent experience of obtaining pregnancy, delivery, and post delivery care, (Check ✓ one condition for every statement)

		Never	Rarely	Sometimes	Most of the time	All the Time	Not Applicable
805A	In general, I am / was able to afford the cost of pregnancy, delivery and post delivery care	1	2	3	4	5	6
805B	In general it is/was quite easy to get transport to travel to the doctor/clinic for obtaining pregnancy, delivery, and post delivery care	1	2	3	4	5	6
805C	In general, I am/was satisfied with the time taken to travel to the doctor/clinic or obtaining pregnancy, delivery, and post delivery care	1	2	3	4	5	6
805D	Health information related to pregnancy, delivery and post delivery care that I receive(d) is/was adequate	1	2	3	4	5	6
805E	Health information related to pregnancy, delivery and post delivery care that I receive(d) is/was normally in a language that I can understand well	1	2	3	4	5	6
805F	Health care professionals in Malaysia listen(ed) to and answer(ed) my questions and concerns.	1	2	3	4	5	6
805G	The reasons for my medical tests and/or treatment are/were explained to me in a way so that I understand.	1	2	3	4	5	6
805H	I am/was normally able to communicate with someone at the health care facility in a language that I understand	1	2	3	4	5	6
805I	Health care providers treat/treated me with respect and courtesy because I am a refugee	1	2	3	4	5	6
805J	I feel/felt comfortable to ask questions and raise concerns with health care providers	1	2	3	4	5	6

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This is the end of our interview. Thank you for your patience and for answering my questions. If you have any questions on any of the topics asked, I can try and answer them now. I would also like to leave these flyers/pamphlets that give information on some of the topics we talked about. I will also give you my name and phone number in case you wish to contact me about this interview. Kyay zue tin bade!

APPENDIX-4B: QUESTIONNAIRE-BURMESE

လေ့လာမှုစစ်တမ်းကောက်ယူခြင်း

ကလန်းဗေလီရှိမြန်မာပြည်မှချင်းအမျိုးသမီးဒုက္ခသည်များ နှင့်ဝိုလုံးခွင့်ရှာဖွေနေသူအမျိုးသမီးများ၏ မျိုးပွါးမှုပိုင်းဆိုင်ရာ ကျန်းမာရေးစောင့် ရှောက်မှုကိုရရှိနိုင်မှု

အထွေထွေ အချက်အလက် သုတေသနပြုသူ မှ ဖြည့်စွက်ရန်	
အမှတ်စဉ်	
လူထုအသိုင်းအဝန်းသင်္ကေတ	
ဘာသာပြန်သူ၏ သင်္ကေတ	
ရက်စွဲ	

(အမှန်ခြစ် တစ်ခုတည်းခြစ်ပါ။)

၁၀၁	သင့်မှာယခုကိုယ်ဝန်ရှိပါသလား	ရှိ ၁၀၃ သို့ကျော်ပါ။ မရှိ ၁၀၂သို့သွားပါ။	၁၀၃	ဤလေ့လာမှုတွင် ပါဝင်ရန် သဘောတူပါသလား	တူ မတူ
၁၀၂	ကလန်းဗေလီတွင် လွန်ခဲ့သော တစ်နှစ်အတွင်းသားဖွားခဲ့ပါသလား	ဖွား ၁၀၃သို့ကျော်ပါ။ မဖွား			

အပိုင်း(၁) လူဦးရေ စစ်တမ်းကောက်ယူခြင်း။			
၁၀၄	အသက်ဘယ်လောက်ရှိပြီလဲ နှစ်	၁၀၅	မလေးရှားတွင်နေထိုင်ခဲ့တာဘယ်လောက်ကြာပြီလဲ။ (နှစ်၊လ အရေအတွက်) နှစ် (သို့) လ
၁၀၆	ပြီးဆုံးအောင်သင်ကြားခဲ့သည့်အမြင့်ဆုံးပညာရေး။ (အမှန်တစ်ခုသာခြစ်ပါ)	၁ နှစ် ၁၂၃၄၅၆ (မူလတန်း) ၂ ၇၈၉၁၀၁၁ (အထက်တန်း) ၃ ၁၂၃၄၅၆၇၈၉၁၀(ကောလိပ်၊တက္ကသိုလ်) ၄ (ဒီပလိုမာ၊အသက်မွေးမှုပညာ) ၅ သင်ကြားမှုမရှိ	
၁၀၇	မလေးရှားတွင် အိမ်မှုကိစ္စ အလုပ် နှင့်အတူ အခြားအမြင် အလုပ်လုပ်နေပါသလား။	၁ အလုပ်မရှိ ၂ အချိန်ပြည့်အလုပ် ၃ အလုပ် မရှိ (အလုပ်မရ၊လုပ်ရန်လိုအပ်၊ဆန္ဒရှိ) ၄ အလုပ်လုပ်ရန်ဆန္ဒမရှိ	
၁၀၈	အိမ်ထောင်ရေးအခြေအနေ ဘယ်လိုရှိပါသလဲ။ (အမှန် တစ်ခုသာခြစ်ပါ)	၁ အိမ်ထောင်ရှိ ၂ အပျို ၃ ကွာရှင်းပြီး ၄ မုဆိုးမ ၅ ခွဲနေ ၁၁၀ သို့သွားပါ။ ၂ မှ ၅ အထိ ၁၀၉ သို့သွားပါ။	
၁၀၉	ခင်ပွန်းသည် အလုပ်ရှိပါသလား	ရှိ မရှိ ၁၁၀ တိုင်းရင်းသားနောက်ကြောင်း ၁ ချင်း ၂ ရိုဟင်ဂျာ ၃ အခြား	
၁၁၀	အိမ်(သို့)မိသားစုတွင်လူဦးရေမည်မျှနေထိုင်သနည်း။(အတူနေကုန်ကျစရိတ် ဝေမျှသုံးစွဲသည့် သွေးရင်းမိသားစု (သို့) လက်ထပ်ထားသူ (သို့) အတူနေသည့်သူများ	မှတ်ချက် နံပါတ် အိမ် မိသားစု (လင်ငှိန်း) မိသားစု(ကလေး)	
၁၁၂	သင့်တွင်မလေးရှားUNHCRe၏မည်သည့်အထောက်အထားရှိသနည်း။	မရှိ(စာရွက်၊ ကဒ် မရှိ) ၁ စာရွက်ရှိ/ ကဒ်မရသေး ၂ ကဒ်ရှိပြီး ၃	
၁၁၃	ဒုက္ခသည် အဖွဲ့မှ အဖွဲ့ဝင် တစ်ဦးဖြစ်ပါသလား	ဖြစ် မဖြစ် ၁၁၄ အဖွဲ့ဝင်ထားသောဒုက္ခသည်အဖွဲ့မှာမည်သည့်အဖွဲ့ဖြစ်ပါသနည်း။	
၁၁၅	မြန်မာနိုင်ငံ၏မည်သည့်အပိုင်းတွင်နေထိုင် ကြီးပြင်းခဲ့သနည်း။		

အပိုင်း(၂) လက်ရှိကိုယ်ဝန်ရှိသူအတွက် ကိုယ်ဝန်ဆောင်စောင့်ရှောက်ခြင်း ၊ စောင့်ရှောက်ခြင်းအားအသုံးပြုမှုနှိုင်းမှု

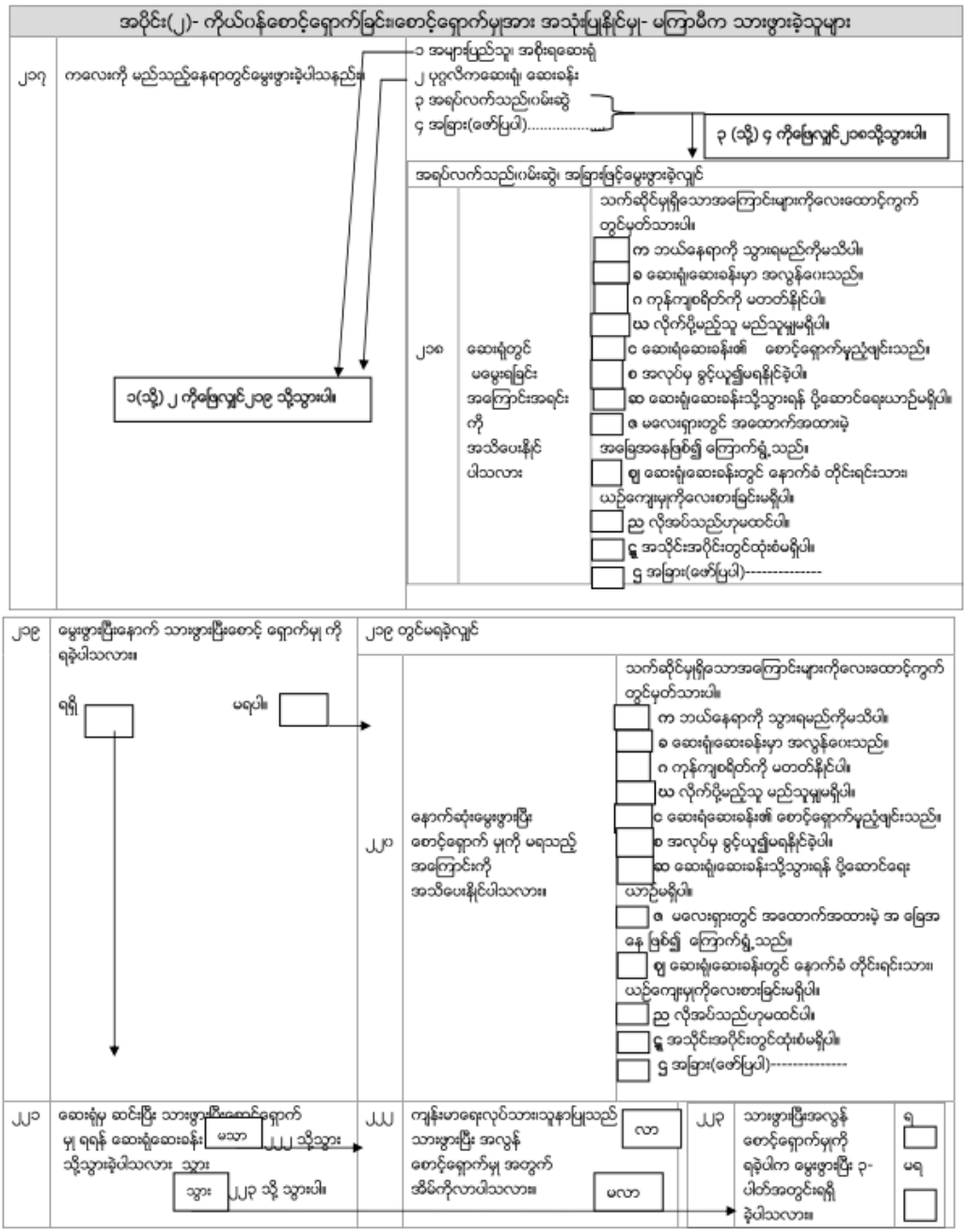
၂၀၁	ယခင်ကဘယ်နှစ်ကြိမ်ကိုယ်ဝန်ဆောင်ခဲ့ပါသလဲ။လက်ရှိကိုယ်ဝန်နှင့်သားလွှားခြင်း၊ ကိုယ်ဝန်ဖျက်ခြင်းအပါအဝင်အား၊လုံးသောကိုယ်ဝန်ဆောင်မှုများကိုထည့်သွင်းရေတွက်ပါ။	၀ မှ ၁၅ ကြိမ် အထိ အရေအတွက်မှတ်တမ်း	၈၈ မသိပါ	၉၉ မဖြေပါ
၂၀၂	အသေမွေးခြင်း၊အရွှင်မွေးခြင်းအပါအဝင်ကလေး အရေအတွက်မည်မျှမွေးဖွားခဲ့ပါသနည်း။	စုစု ပေါင်း ___ အရွှင် မွေး ___ အသေ မွေး ___	၈၈ မသိပါ	၉၉ မဖြေပါ

၂၀၃	ယခု ကိုယ်ဝန်ရှိနေပါသလား။ ☐ ရှိ ☐ မရှိ	၂၀၄	၂၀၃ တွင် ကိုယ်ဝန်ရှိခဲ့လျှင် ကိုယ်ဝန်ရှိတာဘယ်လောက်ကြာပြီလဲ (လ ဖြင့်ဖြေဆိုပါ)	မှတ်တမ်းအရေအတွက် ☐☐ လ ၈၈ မသိပါ။ ☐ ၂၀၇ သို့သွားပါ။
၂၀၅	လွန်ခဲ့သောတစ်နှစ်အတွင်း(ဧမလ ၂၀၁၉) နောက်ပိုင်းကလန်းဒေလီတွင်သားဖွားခဲ့ပါသလား။ မဖွားခဲ့ပါ။ ☐ ဖွားခဲ့ပါသည်။ ☐ ၂၀၇ သို့သွားပါ။	၂၀၅တွင်ဖွားခဲ့သည်ဆိုပါက	၂၀၆ နောက်ဆုံးကလေးကို မည်သည့်အချိန်က မွေးခဲ့ပါသနည်း။	မွေးသည့်ရက်စွဲ မှတ်တမ်း နေ့ လ နှစ် ၂၁၂ သို့သွားပါ။
•	ယခုကိုယ်ဝန်ဆောင်ပြီးလွန်ခဲ့သောနှစ်အတွင်းသားဖွားခဲ့လျှင် ၂၀၇သို့သွားပါ။	လွန်ခဲ့သည့်တစ်နှစ်အတွင်း သားဖွားခဲ့ပြီး ယခုကိုယ်ဝန်မရှိလျှင် (သို့မဟုတ်)လွန်ခဲ့သောတစ်နှစ်အတွင်းသားဖွားခဲ့ပြီး ယခုလည်းကိုယ်ဝန်ရှိနေခဲ့လျှင် ၂၁၂ သို့သွားပါ		

၂၀၇	ယခုအချိန်အထိ ကိုယ်ဝန်ဆောင်အတွက် စောင့် ရှောက်မှုအား ရှာဖွေထားပြီးပါပြီလား (ဆရာဝန်ဆီသွားရောက် အပ်နှံပြီးပါပြီလား)	၂၀၈	ဤကိုယ်ဝန်ဆောင်စဉ် အတွင်းစောင့်ရှောက်မှုအား အဘယ်ကြောင့် မရှာဖွေရခြင်းကို ကျေးဇူးပြု၍ အသိပေး ပြောပြနိုင်ပါသလား။	သက်ဆိုင်မှုရသောအကြောင်းများကိုလေးထောင့်ကွက်တွင် မှတ်သားပါ။ ☐ က- ဘယ်နေရာကို သွားရမည်မသိပါ။ ☐ ခ- ဆေးရုံဆေးခန်းမှာ အလွန်ဝေးသည်။ ☐ ဂ- ကုန်ကျစရိတ်ကို မတတ်နိုင်ပါ။ ☐ ဃ- လိုက်ပို့မည့်သူ မရှိပါ။ ☐ င-ဆေးရုံဆေးခန်း၏စောင့်ရှောက်မှုညံ့ဖျင်းသည်။ ☐ စ- အလုပ်မှ ခွင့်ယူ၍ မရပါ။ ☐ ဆ-ဆေးရုံဆေးခန်းသို့သွားရန်ပို့ဆောင်ရေးယာဉ်မရှိပါ။ ☐ ဇ- မလေးရှားတွင် အထောက်အထားမဲ့ ဖြစ်၍ ကြောက်ရွံ့သည်။ ☐ ဈ-ဆေးရုံဆေးခန်းတွင် နောက်ခံ တိုင်းရင်း သားယဉ်ကျေးမှုကို လေးစားခြင်းမရှိခဲ့ပါ။ ☐ ည-လိုအပ်သည် ဟုမထင်ပါ။ ☐ ဋ-အဝိုင်းအဝိုင်းတွင် ထုံးစံမရှိပါ။ ☐ ဌ- အခြား(ဖော်ပြပါ)----------
၂၀၉	ယခုကိုယ်ဝန်အတွက် ပထမဆုံး ကိုယ်ဝန်စောင့်ရှောက်မှု ကိုရသည့်အခါတွင် ကိုယ်ဝန်ဘယ်နှစ်လ ရှိနေပါပြီလဲ။		၃၀ သို့သွားပါ။ ☐☐ လ ၈၈ ☐☐ မသိပါ။	
၂၁၀	မည်သည့်နေရာတွင် ကိုယ်ဝန်အတွက် စောင့်ရှောက်ပေးမှုကို ရှာဖွေခဲ့ပါသနည်း။ (ကိုယ်ဝန်အတွက်စောင့်ရှောက်မှု ကို အကြိမ်ကြိမ် ရရှိခဲ့သည့် အများဆုံး ၃-နေရာကို အမှန်ခြစ်ပါ။)		၁ ☐ အစိုးရဆေးရုံ ၂ ☐ အစိုးရဆေးခန်း(ကာစီဟာတန် ဆေးခန်းများ) ၃ ☐ မိခင်နှင့်ကလေး ကျန်းမာရေးဆေးခန်းများ။ ၄ ☐ ပုဂ္ဂလိက ဆေးရုံဆေးခန်းများ ။ ၅ ☐ ပုဂ္ဂလိက အထွေထွေကုဆေးခန်းများ။ ၆ ☐ အစိုးရမဟုတ်သော အဖွဲ့အစည်းများ၏ ဆေး ခန်း၊ ဆောင်ရွက်ပေးမှုနေရာများ။(အေစီတီအက်စ်စက်ကြည်၊အေစီအာ..စသည့်နေရာများ) ၇ ☐ အရပ်လက်သည်၊ဟမ်းဆွဲ့၊သားဖွားဆရာမ ၈ ☐ အခြား(ဖော်ပြပါ)----------	
၂၁၁	ယခုကိုယ်ဝန်အတွက်ကိုယ်ဝန်ဆောင်စောင့်ရှောက်မှုကိုဘယ်နှစ်ကြိမ်ရှာဖွေခဲ့ပါသနည်း။			အကြိမ်အရေအတွက် မှတ်တမ်းမှုစုခဲ့သည်။ ☐☐

အပိုင်း(၂)- ကိုယ်ဝန်ဆောင်ရောက်ခြင်း၊ဆောင်ရောက်မှုအား အသုံးပြုနိုင်မှု- မကြာမီက သားဖွားခဲ့သူများ

၂၁	နောက်ဆုံးကိုယ်ဝန်ကိုစဉ်းစားပေးပါ။ကိုယ်ဝန်ရှိစဉ်က ဆောင်ရောက်မှုကို မြှုလုပ်ခဲ့ပါသလား။ မလုပ်ခဲ့ပါ။ ☐ → မြှုလုပ်ခဲ့ပါသည်။ ☐ ↓	၂၁၂ တွင် မမြှုလုပ်ခဲ့လျှင်
		၂၁၃ ဤကိုယ်ဝန်ဆောင်စဉ် အတွင်း ဆောင်ရောက်မှုအား အဘယ်ကြောင့် မရှာဖွေခြင်း အကြောင်းကို ကျေးဇူးပြု၍ အသိပေးပြောပြနိုင်ပါသလား။	သက်ဆိုင်မှုရှိသောအကြောင်းများကို လေးထောင့်ကွက်တွင် မှတ်သားပါ။ ☐ က ဘယ်နေရာကို သွားရမည်ကိုမသိပါ။ ☐ ခ ဆေးရုံဆေးခန်းမှာ အလွန်ဝေးသည်။ ☐ ဂ ကုန်ကျစရိတ်ကို မတတ်နိုင်ပါ။ ☐ ဃ လိုက်ပို့မည့်သူ မည်သူမျှမရှိပါ။ ☐ င ဆေးရုံဆေးခန်း၏ ဆောင်ရောက်မှုညံ့ဖျင်းသည်။ ☐ စ အလုပ်မှ ခွင့်ယူ၍မရနိုင်ခဲ့ပါ။ ☐ ဆ ဆေးရုံဆေးခန်းသို့သွားရန် ပို့ဆောင်ရေးယာဉ်မရှိပါ။ ☐ ဇ မလေးရွားတွင် အထောက်အထားမဲ့ အခြေအနေဖြစ်၍ ကြောက်ရွံ့သည်။ ☐ ဈ ဆေးရုံဆေးခန်းတွင် နောက်ခံ တိုင်းရင်းသား၊ ယဉ်ကျေးမှုကိုလေးစားခြင်းမရှိပါ။ ☐ ည လိုအပ်သည်ဟုမထင်ပါ။ ☐ ဋ အိုင်းအိုင်းတွင်ထုံးစံမရှိပါ။ ☐ ဌ အခြား(ဖော်ပြပါ)----------
		၂၁၄ သို့သွားပါ။
၂၁၄	သင့် နောက်ဆုံးကိုယ်ဝန်ဆောင်ချိန်၏ ပထမဆုံး ကိုယ်ဝန်ဆောင် ဆောင်ရောက်မှုကို သင်ရသည့်အခါ သင်၏ ကိုယ်ဝန်ဘယ်နှစ်လ ရှိပါပြီလဲ။	☐☐ လ မသိပါ။ ☐၈
၂၁၅	နောက်ဆုံးကိုယ်ဝန်အတွက် ဆောင်ရောက်မှုကို မည်သည့်နေရာတွင် ရှာဖွေခဲ့ပါသနည်း။ (ကိုယ်ဝန်အတွက်ဆောင်ရောက်မှု အကြိမ်ကြိမ် ရခဲ့သည့်အများဆုံး ၃-နေရာကို အမှန်ခြစ်ပါ။)	၁ ☐ အစိုးရဆေးရုံ ၂ ☐ အစိုးရဆေးခန်း(ကာစီဟာတန် ဆေးခန်းများ) ၃ ☐ မိခင်နှင့်ကလေး ကျန်းမာရေးဆေးခန်းများ ၄ ☐ ပုဂ္ဂလိက ဆေးရုံ၊ ဆေးခန်းများ ၅ ☐ ပုဂ္ဂလိက အထွေထွေ ဆေးကုခန်းများ ၆ ☐ အစိုးရမဟုတ်သော အဖွဲ့အစည်းများ ၏ ဆေးခန်းများ၊ဆောင်ရွက်ပေးမှုနေရာများ (အေစီတီအက်စ်၊စုကြည် စသည့်.....) ၇ ☐ အရပ်လက်သည်၊ဝမ်းဆွဲ၊သားဖွားဆရာမ ၈ ☐ အခြား (ဖော်ပြပါ။).....
၂၁၆	ဤကိုယ်ဝန်ဆောင် ဆောင်ရောက်မှုကို ဘယ်နှစ်ကြိမ်မြှုလုပ်ခဲ့ပါသနည်း။	အကြိမ် အရေ အတွက်မှတ်တမ်း ☐☐


အပိုင်း(၂)- ကိုယ်ပန်စောင့်ရှောက်ခြင်း၊စောင့်ရှောက်မှုအား အသုံးပြုနိုင်မှု- မကြာမီက သားဖွားခဲ့သူများ
၂၁၇
ကလေးကို မည်သည့်နေရာတွင်မွေးဖွားခဲ့ပါသနည်း။
၁ အများပြည်သူ၊ အစိုးရဆေးရုံ
၂ ပုဂ္ဂလိကဆေးရုံ၊ ဆေးခန်း
၃ အရေပ်လက်သည်၊ဂမ်းဆွဲ
၄ အခြား(ဖော်ပြပါ).....
၃ (သို့) ၄ ကိုဖြေလျှင် ၂၁၈ သို့သွားပါ။
၁(သို့) ၂ ကိုဖြေလျှင် ၂၁၉ သို့သွားပါ။
အရေပ်လက်သည်၊ဂမ်းဆွဲ၊ အခြားဖြင့်မွေးဖွားခဲ့လျှင်
၂၁၈ ဆေးရုံတွင် မမွေးရခြင်း အကြောင်းအရင်း ကို အသိပေးနိုင် ပါသလား
သက်ဆိုင်မှုရှိသောအကြောင်းများကိုလေးထောင့်ကွက်တွင်မှတ်သားပါ။
က ဘယ်နေရာကို သွားရမည်ကိုမသိပါ။
ခ ဆေးရုံဆေးခန်းမှာ အလွန်ဝေးသည်။
ဂ ကုန်ကျစရိတ်ကို မတတ်နိုင်ပါ။
ဃ လိုက်ပို့မည့်သူ မည်သူမျှမရှိပါ။
င ဆေးရုံဆေးခန်း၏ စောင့်ရှောက်မှုညံ့ဖျင်းသည်။
စ အလုပ်မှ ခွင့်ယူ၍မရနိုင်ခဲ့ပါ။
ဆ ဆေးရုံဆေးခန်းသို့သွားရန် ပို့ဆောင်ရေးယာဉ်မရှိပါ။
ဇ မလေးရှားတွင် အထောက်အထားမဲ့ အခြေအနေဖြစ်၍ ကြောက်ရွံ့သည်။
ဈ ဆေးရုံဆေးခန်းတွင် နောက်ခံ တိုင်းရင်းသား ယဉ်ကျေးမှုကိုလေးစားခြင်းမရှိပါ။
ည လိုအပ်သည်ဟုမထင်ပါ။
ဋ အသိုင်းအဝိုင်းတွင်ထုံးစံမရှိပါ။
ဌ အခြား(ဖော်ပြပါ)----------
၂၁၉ မွေးဖွားပြီးနောက် သားဖွားပြီးစောင့် ရှောက်မှု ကို ရခဲ့ပါသလား။
ရရှိ
မရပါ။
၂၁၉ တွင်မရခဲ့လျှင်
၂၂၀ နောက်ဆုံးမွေးဖွားပြီး စောင့်ရှောက် မှုကို မရသည့် အကြောင်းကို အသိပေးနိုင်ပါသလား။
သက်ဆိုင်မှုရှိသောအကြောင်းများကိုလေးထောင့်ကွက်တွင်မှတ်သားပါ။
က ဘယ်နေရာကို သွားရမည်ကိုမသိပါ။
ခ ဆေးရုံဆေးခန်းမှာ အလွန်ဝေးသည်။
ဂ ကုန်ကျစရိတ်ကို မတတ်နိုင်ပါ။
ဃ လိုက်ပို့မည့်သူ မည်သူမျှမရှိပါ။
င ဆေးရုံဆေးခန်း၏ စောင့်ရှောက်မှုညံ့ဖျင်းသည်။
စ အလုပ်မှ ခွင့်ယူ၍မရနိုင်ခဲ့ပါ။
ဆ ဆေးရုံဆေးခန်းသို့သွားရန် ပို့ဆောင်ရေးယာဉ်မရှိပါ။
ဇ မလေးရှားတွင် အထောက်အထားမဲ့ အ ခြေအနေ ဖြစ်၍ ကြောက်ရွံ့သည်။
ဈ ဆေးရုံဆေးခန်းတွင် နောက်ခံ တိုင်းရင်းသား ယဉ်ကျေးမှုကိုလေးစားခြင်းမရှိပါ။
ည လိုအပ်သည်ဟုမထင်ပါ။
ဋ အသိုင်းအဝိုင်းတွင်ထုံးစံမရှိပါ။
ဌ အခြား(ဖော်ပြပါ)----------
၂၂၁ ဆေးရုံမှ ဆင်းပြီး သားဖွားပြီးဆေးရုံ မှ ရရန် ဆေးရုံဆေးခန်း သို့သွားခဲ့ပါသလား
မသာ ၂၂၂ သို့သွား
သွား ၂၂၃ သို့ သွားပါ။
၂၂၂ ကျန်းမာရေးလုပ်သားသူနာပြုသည် သားဖွားပြီး အလွန် စောင့်ရှောက်မှု အတွက် အိမ်ကိုလာပါသလား။
လာ
မလာ
၂၂၃ သားဖွားပြီးအလွန် စောင့်ရှောက်မှုကို ရခဲ့ပါက မွေးဖွားပြီး ၃-ပါတ်အတွင်းရရှိခဲ့ပါသလား။
ရ
မရ

pg. 4

အပိုင်း-၃ ဆေးရုံဆေးခန်း သို့သွားရောက်နိုင်မှု								
၃၊၁၁	ဆေးရုံ/ဆေးခန်းသို့ပုံမှန်အားဖြင့်မည်သို့ သွားပါသလဲ။ သက်ဆိုင်သည့်အခြေအနေ အများဆုံး ၂ ချက်ကို အမှတ်ခြစ်ပါ။	၁ ☐ လမ်းလျှောက် ၂ ☐ ဘတ်စ်ကား ၃ ☐ တက္ကစီ ၄ ☐ ကိုယ်ပိုင်ကားမောင်း ၅ ☐ LRT/ရထား ၆ ☐ အခြား ၇ ☐ မသက်ဆိုင်ပါ။						
၃၊၂	ကိုယ်ဝန်ဆောင်ချိန် နှင့် သားဖွားပြီး အလွန်စောင့်ရှောက်မှု အတွက်ဆေးရုံ/ဆေးခန်းသွားရာတွင် ပုံမှန်အားဖြင့် အချိန်မည်မျှကြာသနည်း။	၁	ကိုယ်ဝန်ဆောင်အတွက်					မိနစ်
		၂	မွေးဖွားမှုအတွက်					မိနစ်
		၃	သားဖွားပြီးစောင့်ရှောက်မှုအတွက်					မိနစ်

အပိုင်း ၄- ကုန်ကျစရိတ် သုံးစွဲနိုင်မှု

၄၀၁ က	ကိုယ်ဝန်ဆောင်ဆိုလျှင်- အတူနေအိမ်သားများ၏ လစဉ်ပျမ်းမျှဝင်ငွေ မည်မျှနည်း။ မွေးဖွားပြီးလျှင်အတူနေအိမ်သားများ၏လစဉ်ပျမ်းမျှဝင်ငွေကိုသူဌေးမှမည်မျှထောက်ပံ့ပါသနည်း					အလုပ်ရှင်မှ မထောက်ပံ့ပါ။
		ရင်းဂစ်				
၄၀၁ ခ	ကိုယ်ဝန်ဆောင်ဆိုလျှင် - မိမိ၏ ကိုယ်ပိုင် လုပ်ငန်းမှဝင်ငွေမည်မျှရှိသနည်း။ မွေးပြီးပြီဆိုလျှင်-အတူနေအိမ်သားများ၏ ကိုယ်ပိုင်လုပ်ငန်းမှ လစဉ်ပျမ်းမျှ ဝင်ငွေမည်မျှနည်း။					ကိုယ်ပိုင်လုပ်ငန်း မဟုတ်ပါ။
		ရင်းဂစ်				
၄၀၁ ဂ	ကိုယ်ဝန်ဆောင်ဆိုလျှင်- နောက်ထပ် အခြားသော သင်၏မိသားစု လစဉ်ပျမ်းမျှ ဝင်ငွေ မည်မျှရှိသနည်း။ မွေးဖွားပြီးပြီဆိုလျှင်ထိုအချိန်တွင်နောက်ထပ်အခြားသောဝင်ငွေသင်၏မိသားစုတွင်ရှိပါသလား။					အခြားဝင်ငွေမရှိပါ။
		ရင်းဂစ်				

၄၀၂ ပျမ်းမျှအားဖြင့်အောက်ပါတို့အတွက်တစ်လလျှင်မည်မျှအသုံးပြုသနည်း။(ရင်းဂစ် မလေးရှားဖြင့်ပြပါ။)
(အကယ်၍ ကလေးမီးဖွားခဲ့သည်ဆိုပါလျှင် မီးဖွားချိန်ကုန်ကျစရိတ်)

၄၀၂ က	အိပ်ဌားရပ်ခ၊ရေခ၊ မီးဖိုး၊ ဂတ်စ်	
၄၀၂ ခ	အစားအသောက်	
၄၀၂ ဂ	အဂတ်အထည် နှင့် ဖိနပ်	
၄၀၂ ဃ	ခရီးသွားလာရေး စရိတ်	
၄၀၂ င	ဆက်သွယ်ရေး ကုန်ကျစရိတ်	
၄၀၂ စ	အရက်သေစာ သောက်စားခြင်း	
၄၀၂ ဆ	အဝေတွေ ကျန်းမာရေး ကုန်ကျစရိတ်(ဝီးဖွားမှုမပါ)	
၄၀၂ ဇ	ဆေးရုံဆေးခန်းမသွားဘဲ မိမိဘာသာ ဂယ်ယူသုံးစွဲသည့် ကျန်းမာရေးစရိတ်(ဥပမာ...ပါရာစီတမောလ်၊ချောင်းဆိုးဖျောက်ဆေး)	
၄၀၂ ဈ	ပညာရေး ကုန်ကျစရိတ်	
၄၀၂ ည	အပန်းဖြေ အနားယူခြင်းကုန်ကျစရိတ်	

၄၀၃ ခန့်မှန်းခြေ အားဖြင့် ကိုယ်ဝန်ဆောင်ခြင်းနှင့် သားဖွားပြီး စောင့်ရှောက်မှု ကုန်ကျစရိတ်အတွက် ရင်းဂစ်မည်မျှ သုံးစွဲပါသနည်း။

	ဆေးရုံ/ဆေးခန်း	သွားလာစရိတ်	ဆေးကုန်ကျစရိတ်	အခြားကုန်ကျစရိတ်
ကိုယ်ဝန်ပြဿ မှု တစ်ကြိမ်				
မွေးဖွားခြင်း				
သားဖွားပြီးစောင့်ရှောက်မှု တစ်ကြိမ်				

အခြားကုန်ကျစရိတ် ရင်းဂစ်ဖြင့် ဖော်ပြပါ။မည်သည့် အတွက် မည်မှုကုန်ကျသည်ကိုရေးသား ဖော်ပြပါ။

	(က)	(ခ)	(ဂ)
ကိုယ်ဝန်ဆောင်			
မွေးဖွားပြီး			
သားဖွားပြီး စောင့်ရှောက်မှု			

၄၀၄ မည်သို့သောနည်းလမ်းများဖြင့် ကိုယ်ဝန်ဆောင်ခြင်း၊မွေးဖွားခြင်းနှင့် မွေးဖွါးပြီးစောင့်ရှောက်မှ များ၏ကုန်ကျစရိတ်ကိုပေးနိုင်ခဲ့ပါသနည်း။ (သက်ဆိုင်သည့်အခြေအနေအား လုံးကိုအမှန်ခြစ်ပါ)

- ☐ ၁ ဝင်ငွေ
- ☐ ၂ စုဆောင်းထားသည့်ငွေ
- ☐ ၃ ချေးငှားခြင်း
- ☐ ၄ ပစ္စည်းများရောင်းချခြင်း
- ☐ ၅ လှူဒါန်းသောငွေကြေး
- ☐ ၆ တုံ့ပြန်ဖြေကြားခြင်းမရှိပါ။

အပိုင်း၅- လိုအပ်သော ဝဟုသုတ/သတင်းအချက်အလက် ရရှိနိုင်မှု						
၅၀၁	မလေးစကားကို သင်မည်မျှ နားလည်သနည်း ။(သက်ဆိုင်မှုအများဆုံး တစ်ခုကို အမှန်ခြစ်ပါ)	အလွန်ကောင်း ၁ ကောင်း ၂ သင့်တင့် ၃ သိပ်မကောင်း ၄ နားမလည် ၅				
၅၀၂	အင်္ဂလိပ်စကားကို သင်မည်မျှ နားလည်သနည်း။	အလွန်ကောင်း ၁ ကောင်း ၂ သင့်တင့် ၃ သိပ်မကောင်း ၄ နားမလည် ၅				
၅၀၃	မီးမွှားခင်အချိန်၊ကိုယ်ဝန်ဆောင်ချိန်နှင့်သားဖွားပြီး ချိန်ကျန်းမာရေးဟုသုတအချက်အလက်များ ကိုမည်သည့်နေရာမှရနိုင်မည်ကို သင်သိပါသလား	သိ ☐ မသိပါ ☐				
၅၀၄	လက်ရှိနောက်ဆုံး ကိုယ်ဝန်ဆောင်ထားရသည့် အချိန်တွင် ကိုယ်ဝန်ဆောင် စောင့်ရှောက်မှုအတွက် ဆေးရုံဆေးခန်း သို့သွားရောက်ခဲ့မှုများကို မြန်လည်စဉ်းစားစေချင်ပါသည်။ မည်သည့် သွားရောက်ခဲ့မှုတွင်မဆို ဆေးရုံဆေးခန်း ရှိ ဝန်ထမ်းသည်	ဝန်ဆောင်မှု		ရှိ	မရှိ	မသိ	မဖြေ
		၅၀၄ က	ဆေးနှင့်ပက်သက်သောနောက်ကြောင်းကိုမေးခြင်း	၁	၂	၈၈	၉၉
		၅၀၄ ခ	အစာအာဟာရအကြောင်း အကြံပေးခြင်း	၁	၂	၈၈	၉၉
		၅၀၄ ဂ	မွေးဖွားရန်နေရာ အတွက် ဆွေးနွေးခြင်း	၁	၂	၈၈	၉၉
		၅၀၄ဃ	ကိုယ်ဝန်ဆောင်နေစဉ် သိသင့်သည့် အန္တရာယ်ရှိသည့် လက္ခဏာများ အကြောင်း ရှင်းလင်းပြောပြခြင်း	၁	၂	၈၈	၉၉
		၅၀၄ င	ကိုယ်ဝန်ဆောင်စဉ် သွေးတက်ခြင်းတွက်ခြင်း စသည့် ပြဿနာများ ရှိလျှင် မည်သို့ပြုလုပ်ရမည်ကို အကြံပေးခြင်း။	၁	၂	၈၈	၉၉
		၅၀၄ စ	သားဆက်ခြားခြင်းနှင့် မိသားစုစီမံကိန်းကိုဆွေးနွေးခြင်း	၁	၂	၈၈	၉၉
		၅၀၄ ဆ	လိင်မှကူးစက်တတ်သောရောဂါများနှင့်HIV/AIDS အကြောင်းပြောပြခြင်း။	၁	၂	၈၈	၉၉
		၅၀၄ ဇ	သင့်ကလေးကို မည်သို့စောင့်ရှောက်ရမည်ကို အချက်အလက် (သို့) အကြံပေးခြင်း။	၁	၂	၈၈	၉၉
		၅၀၄ ဈ	အရေးပေါ်ဖြစ်လျှင်ကျန်းမာရေးစောင့်ရှောက်မှုရှိရာ နေရာသို့မည်သို့ရောက်ရှိနိုင်သည်ကိုဆွေးနွေးခြင်း	၁	၂	၈၈	၉၉
၅၀၅	ကျန်းမာရေး စောင့်ရှောက်ပေးသူများနှင့် ကျန်းမာရေး စောင့်ရှောက်ပေးသည့်နေရာများတွင် မည်သည့်ဘာသာစကားဖြင့် ပြောဆို ဆက်သွယ်ပါသနည်း	မလေး ☐ ၁	အင်္ဂလိပ် ☐ ၂	မန်ဒရင်း ☐ ၃	ဗမာ/ချင်း/ရိုဟင်ဂျာစကားပြော တတ်သည့် ဘာသာပြန်မှတဆင့် ☐ ၄	

အပိုင်း ၆- ခွဲခြားဆက်ဆံမှု မပြုခြင်း- ခွဲခြားဆက်ဆံခံရမှု

အကြောင်းပြချက် အမျိုးမျိုး အတွက် လူအများသည် မမျှတစွာ (သို့) ခွဲခြားသော အမူအကျင့် တစ်ခုခုဖြင့်ဆက်ဆံ ညှဉ်းဆဲခံနိုင်ပါသည်။ ဤမေးခွန်းများအတွက် ကျွန်ုပ်တို့ မှ သင်တို့သည် ဒုက္ခသည်ဖြစ်ခြင်း(နှင့်)သို့မဟုတ်)မြန်မာပြည်သား/ချင်း/ရိုဟင်ဂျာဖြစ်ခြင်းကြောင့် မမျှတစွာ ဆက်ဆံခံရပါသလား။ မခံရပါသလား ကို သာလျှင်ဖော်ထုတ်လိုပါသည်။

၆၀၁	သင့် ယူအန်ကဒ် ကို အစိုးရ ကျန်းမာရေးစောင့်ရှောက်သည့်နေရာမှ လက်ခံမှုရှိခဲ့ပါသလား	လက်ခံ / လက်မခံ / မသက်ဆိုင်ပါ
၆၀၂	သင်သည်ကိုယ်ဝန်ဆောင်မွေးဖွားခြင်းနှင့်သားဖွားပြီးစောင့်ရှောက်မှု အတွက် ခြင်းပယ်ခြင်းကို ခံခဲ့ရပါသလား။	ခြင်းပယ် / သို့သွားပါ / မခြင်းပယ် / မသက်ဆိုင် ၆၀၆
၆၀၃	ကိုယ်ဝန်ဆောင်မွေးဖွားခြင်းနှင့် သားဖွားပြီးစောင့်ရှောက်မှုအတွက် မည်သည့်နေရာတွင် ခြင်းပယ်ခြင်းခံခဲ့ရပါသနည်း။	အစိုးရဆေးရုံ / ပုဂ္ဂလိကဆေးရုံ၊ ဆေးရုံဆေးခန်း / အစိုးရဆေးခန်း / ပုဂ္ဂလိကအထွေထွေဆေးခန်းများ / မိခင်နှင့် ကလေးစောင့်ရှောက်ရေး / ၆၀၄ သို့သွားပါ။ / ၆၀၈ သို့ သွားပါ။
၆၀၄	အစိုးရကျန်းမာရေးစောင့်ရှောက်မှုနေရာများတွင်နောက်ဆုံးအကြိမ် တွင်စောင့်ရှောက်မှုကိုဘာကြောင့်ခြင်းဆန်ခြင်းခံရသည်ဟုထင်ပါသလဲ။ အရေးအကြီးဆုံး ၂-ချက်ကို သတ်မှတ်ပေးပါ။ က ဝင်ငွေအဆင့် နှင့် လူမှုရေး အဆင့်အတန်းကြောင့် ခ ကျွန်ုပ်တွင် တရားဝင် ယူအန်ကဒ်မရှိပါ။ ဂ ကျွန်ုပ်၏ ပုံပန်းဟန်ကြောင့် ဃ ကျွန်ုပ်၏ လူမျိုးကြောင့် င ကျွန်ုပ်သည် ဒုက္ခသည်နိုင်ငံခြားသား စ အခြား	၆၀၅	ပုဂ္ဂလိကကျန်းမာရေးစောင့်ရှောက်မှုနေရာများတွင်နောက်ဆုံး အကြိမ်တွင်စောင့်ရှောက်မှုကို ဘာကြောင့်ခြင်းဆန်ခြင်း ခံရသည်ဟု ထင်ပါသနည်း။ အရေးအကြီးဆုံး ၂-ချက်ကို သတ်မှတ်ပေးပါ။ က ဝင်ငွေအဆင့်နှင့်လူမှုရေး အဆင့်အတန်းကြောင့် ခ ကျွန်ုပ်တွင်တရားဝင်ယူအန်ကဒ် မရှိပါ။ ဂ ကျွန်ုပ်၏ ပုံပန်းဟန်ကြောင့် ဃ ကျွန်ုပ်၏ လူမျိုးကြောင့် င ကျွန်ုပ်သည် ဒုက္ခသည်နိုင်ငံခြားသား စ အခြား

ဆေးရုံ/ဆေးခန်းတွင် ကိုယ်ဝန်ဆောင်/မွေးဖွားခြင်းနှင့်သားဖွားပြီးစောင့်ရှောက်မှုများ ရရှိခြင်းနှင့် စပ်လျဉ်း၍ (✓)အမှန်ခြစ်ပါ။

၆၀၆ မှ ၆၁၂	၆၀၆ သင်၏ လူမျိုးရေး အခြေအနေကြောင့် လုပ်ငန်းခွင် ဆောင်ရွက်မှုများကို ကျော့ပါးစွာဖြင့် ဆက်ဆံခြင်းခံရဘူးပါသလား။	ရှိခဲ့	မရှိခဲ့
	၆၀၇ သင်၏ လူမျိုးအခြေအနေကြောင့် ဒုက္ခသည်ဟု အမည်တပ်၍ အခေါ်ခံခဲ့ရဘူးပါသလား	ရှိခဲ့	မရှိခဲ့
	၆၀၈ သင်၏ လူမျိုးအခြေအနေကြောင့် သိမ်ငယ်စွာခံစားရစေရန် ပြုလုပ်ခြင်းခံ ခဲ့ရဘူးပါသလား	ရှိခဲ့	မရှိခဲ့
	၆၀၉ ဘာသာစကားနားမလည်မပြောဆိုနိုင်ခြင်းကြောင့် အော်ဟစ်ခြင်း ခံခဲ့ရဘူးပါသလား။	ရှိခဲ့	မရှိခဲ့
	၆၁၀ သင်၏ လူမျိုးအခြေအနေကြောင့် နှုတ်မှထုတ်ဖော် ပြောဆိုခြင်း မပါသည့် သီးခြား တစ်ကိုယ်တည်းထားခြင်းခွဲခြားဆက်ဆံခြင်း တို့ကိုကြုံတွေ့ခဲ့ ဘူးပါသလား။	ရှိခဲ့	မရှိခဲ့
	၆၁၁ သင်၏ လူမျိုးအခြေအနေကြောင့် အသုံးမကျသူ(သို့) မိုက်မဲသူကဲ့သို့ ပြောဆို ခံရခြင်းများ ရှိပါသလား။	ရှိခဲ့	မရှိခဲ့
	၆၁၂ သင်၏ လူမျိုးအခြေအနေကြောင့် သင့်ကို လျစ်လျူရှုခြင်း(သို့) အာရုံစူးစိုက်မှု မရှိခြင်း တို့ကို ပြုလုပ်ခြင်း ခံခဲ့ရဘူးပါသလား။	ရှိခဲ့	မရှိခဲ့

၆၁၃	ကိုယ်ဝန်ဆောင်မွေးဖွားခြင်းနှင့်သားဖွားပြီးစောင့်ရှောက်မှုရပ္ပရာတွင်နှုတ်မှပြောမထွက်သောသင်ရင်ဆိုင်ခဲ့ရသည့်အခြားသိမ်မွေ့သည့်အသွင် ဖြင့်ခွဲခြား ဆက်ဆံခြင်းနှင့် မမျှတ သော ဆက်ဆံမှုများ က မည်သို့နည်း။	
၆၁၄	ကျန်းမာရေးစောင့်ရှောက်သည့်နေရာများတွင်ခွဲခြားဆက်ဆံခြင်းကြောင့်သင်လိုအပ်သည့်ကိုယ်ဝန်ဆောင်မွေးဖွားခြင်းနှင့် သားဖွားပြီးစောင့်ရှောက်မှုများကို ရရှိရန်နောင့်နေးခြင်း(သို့) ဂရုစိုက်မှုမရှိခြင်း (သို့)ကိုယ်ဝန်အတွက် လိုအပ်မှုများ မရရှိခြင်းများကို ခံစားခဲ့ရပါသလား။	ရရှိခဲ့သည် / မရရှိခဲ့ပါ။ / မသက်ဆိုင်ပါ။
၆၁၅ ၆၁၈	ဤ သို့ ကျန်းမာရေးဌာနများ၊ဆေးရုံဆေးခန်းများတွင်ခွဲခြားဆက်ဆံမှုအတွေ့အကြုံများကိုများသောအားဖြင့်မည်သို့ ရင်ဆိုင်ဖြေရှင်းပါသနည်း၊ ၆၁၅. တစုံတခု လုပ်ခဲ့သည်။ ၆၁၆. ဘဝဆိုးဖြစ်စဉ်ဘဲဟု သဘောထားလက်ခံ၍ ဘာမှမလုပ်ခဲ့ပါ။ ၆၁၇. အခြားသူများကို ပြောပြသည်။ ၆၁၈. မိမိဘာသာ နှုတ်ဆိတ်နေလိုက်သည်။	၁ / ၂ / ၃ / ၄

အပိုင်း ၇ - လူမှုရေးအထောက်အပံ့ရရှိနိုင်မှု

၇၀၁ လူအများသည် မကြာခဏ အကူအညီ (သို့) အခြားထောက်ပံ့မှုအမျိုးမျိုးကိုလိုအပ်ပါသည်။ သင်လိုအပ်သည့်အခါ အောက်ပါအထောက်အပံ့အမျိုးအစားများသည် သင့်အတွက်မကြာခဏမည်သို့ ရရှိနိုင်ပါသနည်း။
(ဇော်ပြချက်တိုင်းအတွါက်အခြေအနေတစ်ခုကို ✔ အမှန်ခြစ်ပါ။)

	တချိန် လုံးမရှိ	အချိန် အနည်း ငယ်	အချို့ သော အချိန်	များ သော အားဖြင့်	တချိန် လုံးရှိ
၇၀၁က သင့်ကိုဆေးခန်း၊ ဆေးရုံသို့လိုက်ပို့ရန်တစ်စုံတစ်ဦး	၁	၂	၃	၄	၅
၇၀၁ခ သင်ဆေးခန်း၊ ဆေးရုံ၊သို့သွားသည်အခါအိမ်တာဝန်များကိုကူညီမည့်တစ်စုံတစ်ဦး	၁	၂	၃	၄	၅
၇၀၁ဂ ကိုယ်ဝန်ဆောင်၊မွေးဖွားခြင်းနှင့် သားဖွားပြီးအလွန်ဝန်ဆောင်မှုများအကြောင်းအချက်အလက်စီမံပေးမည့်သူတစ်စုံတစ်ဦး	၁	၂	၃	၄	၅
၇၀၁ဃ ကိုယ်ဝန်ဆောင်၊ မွေးဖွားခြင်းနှင့် သားဖွားပြီးစောင့်ရှောက်မှုများကိုပြည့်ဆည်းပေးရန်ဌေကြေးကူညီမည့်သူတစ်စုံတစ်ဦး	၁	၂	၃	၄	၅

၇၀၂ အောက်ပါနေရာများအတွက်အကူအညီလိုသောအခါသင်အကူအညီရရန်သွားရောက်သည့်သူနှစ်ဦးကိုအဆင့်သတ်မှတ်ဖော်ပြပါ။

	၁ ယောကျ်ား	၂ အခွဲ့အစည်းမှလူ	၃ မိသားစု/မိတ်ဆွေ (အသိုင်းအဝန်းမှ)	၄ မလေးရှားနိုင်ငံသား (အလုပ်ရှင်၊ မိတ်ဆွေ)	၅ ဘုရားကျောင်းမှ လုယ်	၆ မည်သူမှ မရှိပါ။	၇ UNHCR
၇၀၂က ဆေးခန်း/ဆေးရုံသို့သွားသည့်အခါသင်နှင့်အတူအဖော်လိုက်(ခေါ်ဆောင်)မည့်သူ	၁	၂	၃	၄	၅	၆	၇
၇၀၂ခ ဆေးခန်း/ဆေးရုံသို့သွားချိန်တွင်အိမ်တာဝန်များကို ကူညီလုပ်ကိုင်ပေးမည့်သူ	၁	၂	၃	၄	၅	၆	၇
၇၀၂ဂ ကိုယ်ဝန်ဆောင်၊မွေးဖွားခြင်းနှင့်သားမွေးပြီးစောင့်ရှောက်မှုအကြောင်းအချက်အလက်များကိုစီမံပေးသူ	၁	၂	၃	၄	၅	၆	၇
၇၀၂ဃကိုယ်ဝန်ဆောင်၊မွေးဖွားခြင်းနှင့်ဗီးဖွားပြီးစောင့်ရှောက်မှုစရိတ် များပြည့် စုံရန်ဌေကြေးထောက်ပံ့ပေးမည့်သူ	၁	၂	၃	၄	၅	၆	၇

၇၀၃ သင်၏ဒုက္ခသည်အခွဲ့အစည်းသည် ကိုယ်ဝန်ဆောင်၊ မွေးဖွားခြင်းနှင့်ဗီးဖွားပြီးစောင့်ရှောက်မှုများရရှိရန်မည်သို့သောကူညီထောက်ပံ့မှုကိုမဆိုကူညီစီမံပေးပါသလား။

☐ ကူညီ ☐ မကူညီ
မသက်ဆိုင်ဘူး ▼ ၈၀၁ သို့သွားပါ။

၇၀၄ မည်သို့သောထောက်ပံ့ကူညီမှုကိုဒုက္ခသည်အခွဲ့အစည်းမှ ပေးခဲ့ပါသနည်း။
(သက်ဆိုင်သည့်အခြေအနေအားလုံးကို ✔ အမှန်ခြစ်ပါ။)

- ☐ ၁ ဆေးရုံသို့အဖော်လိုက်ပေးပါသည်။
- ☐ ၂ ချေးငွေထုတ်ပေးပါသည်။
- ☐ ၃ ငွေကြေးလူဝါန်းပါသည်။
- ☐ ၄ မျိုးပွားမှုပိုင်းဆိုင်ရာကျန်းမာဝန်ဆောင်မှုများအကြောင်းအချက်အလက်များစီမံကူညီပေးပါသည်။
- ☐ ၅ အခြား (ဖော်ပြပါ။)

အပိုင်း ၈ - ကိုယ်ဝန်ဆောင်ခြင်း၊ မွေးဖွားခြင်းနှင့် ပီးဈားပြီးစောင့်ရှောက်မှုများ၏အထွေထွေအတွေ့အကြုံ			
၈၀၁	အချို့သောသူများသည် ဆေးရုံနှင့်ဆေးခန်းသို့သွားသည့်အခါ သောကများခံစားကြရခဖလိမ့်မည်။ သင်သည် ကိုယ်ဝန်ဆောင်ချိန်၊မွေးဖွားခြင်းနှင့် ပီးဈားပြီးရက်ပိုင်းအတွင်းစောင့်ရှောက်မှုများအတွက် ဆေးရုံ/ဆေးခန်းသို့သွား(ခဲ့)သည့်အခါ သင်တွေ့ကြုံခဲ့ရသည့်ပိုးရိမ်မှုများ၊ သောကများကိုကျေးဇူးပြုပြီးသိခွင့်ပေးပါ။ မည်သည့်အခြေအနေမဆိုသင်နှင့်သက်ဆိုင်နေပါက အမှန် ✔ ခြစ်ပါ။			
	၈၀၁က ကျွန်ုပ်တွင်သောက၊ ပိုးရိမ်မှုများမရှိခဲ့ပါ	○	၈၀၃ သို့သွားပါ။ → (၈၀၃သို့မသွားမီသေချာစွာမေးမြန်းပါ။)
	၈၀၁ခ အာဏာပိုင်များ၏ရပ်တန့်စစ်ဆေးမှု/အဖမ်းအဆီး	○	☐
	၈၀၁ဂ ကိုယ်ကာယအပေါ်အကြမ်းဖက်မှု	○	☐
	၈၀၁ဃ လိင်ပိုင်းဆိုင်ရာအကြမ်းဖက်မှု	○	☐
	၈၀၁င လမ်းပျောက်ခြင်း	○	☐
	၈၀၁စ ဓားပြတိုက်ခြင်း	○	☐
	၈၀၁ဆ အခြား	○	☐
၈၀၂	သောက/ ခံစားရသည့်ပိုးရိမ်မှု/ကိုယ်ဝန်ဆောင်၊ မွေးဖွားခြင်းနှင့် ပီးဈားပြီးစောင့်ရှောက်မှုများအတွက်ဆေးရုံဆေးခန်းသို့သွားသည့်အခါခံစားခဲ့ရခြင်းများ၏အဆင့်ကို မည်ကဲ့သို့ဖော်ပြလိုပါသနည်း။ ☐ အလွန်မြင့်ပါသည် ☐ မြင့်ပါသည်။ ☐ အလယ်အလတ် ☐ နည်းပါသည်။ ☐ မရှိပါ။		
၈၀၃	ကိုယ်ဝန်ဆောင်၊ မွေးဖွားခြင်းနှင့် ပီးဈားပြီးစောင့်ရှောက်မှုများအတွက် ဆေးရုံ/ ဆေးခန်း သို့သွားရာတွင် အောက်ပါတို့ကို တွေ့ကြုံခဲ့ပါသလား။ ကြုံတွေ့ရသည်။ မကြုံတွေ့ရပါ။		
	၈၀၃က အာဏာပိုင်များ၏ရပ်တန့် စစ်ဆေးမှု၊ ဖမ်းဆီးခြင်း	☐	☐
	၈၀၃ခ မည်သည့်အကြမ်းဖက်မှုမျိုးမဆိုတွေ့ကြုံခဲ့ရပါသလား။	☐	☐
	၈၀၃ဂ လမ်းပျောက်ခြင်း	☐	☐
	၈၀၃ ဃ ဓါးျပ တိုက်ခံခြင်း	☐	☐
	၈၀၃င အခြားအချိန် များတွင်ကြုံတွေ့ခြင်း	☐	☐
၈၀၄	ယေဘုယျ အားဖြင့် သင်၏ ကျန်းမာရေး စောင့်ရှောက်မှုရရန် သွားသည့်အခါတိုင်း သင့်တွင်ခရီးသွားလာရန် အဆင်ပြေခြင်းမရှိ၍ သွားချိန်နှင့်ပြန်ချိန်တို့တွင် ဘယ်နှစ်ကြိမ် ရှောင်ရှား ခဲ့ရပါသနည်း။	အချိန်တိုင်း ☐	အချိန်တော်တော်များများ ☐ တခါတရံ ☐ ရှားပါး ☐ လုံးဝမရှိပါ။ ☐ မသက်ဆိုင်ပါ။ ☐

	မကြာသေးခင်က ကြုံတွေ့ခဲ့ရသည့် ကိုယ်ပန်ဆောင်မှုဆိုင်ရာ ကျန်းမာရေးစောင့်ရှောက်မှု ရရှိခြင်း ကို မည်ကဲ့သို့ ဖော်ပြလိုပါသနည်း။ (ဖော်ပြချက်တိုင်းအတွက် အခြေအနေတစ်ခု ကို အမှန် ✓ ခြစ်ပါ။)					
		ဘယ်တော့မှ	ရှားပါး	တခါတရံ	အချိန်များများ	တချိန်လုံး
၈၅၅	၈၅၅ က ယေဘူယျအားဖြင့် ကိုယ်ပန်ဆောင် ဓမ္မဗွားမှု နှင့် မီးဖွားပြီး စောင့်ရှောက်မှုများ အတွက် ကုန်ကျစရိတ်ကို တတ်နိုင်ခဲ့ပါသည်။	၁	၂	၃	၄	၅
	၈၅၅ ခ များသောအားဖြင့် ကိုယ်ပန်ဆောင်းဓမ္မဗွားမှု နှင့် မီးဖွားပြီး စောင့်ရှောက်မှု များရရှိရန် ဆရာဝန်၊ဆေးရုံဆေးခန်း သို့ သွားရာတွင် လွယ်ကူမှုရှိခဲ့ပါသည်။	၁	၂	၃	၄	၅
	၈၅၅ ဂ များသောအားဖြင့် ကိုယ်ပန်ဆောင်းဓမ္မဗွားမှု နှင့် မီးဖွားပြီး စောင့်ရှောက်မှု များရရှိရန် ဆရာဝန်၊ဆေးရုံဆေးခန်း သို့ သွားရာ လမ်းခရီးသည် ကျွန်ုပ်အတွက် စိတ်ကျေနပ်မှု ရှိခဲ့ပါသည်။	၁	၂	၃	၄	၅
	၈၅၅ ဃ များသောအားဖြင့် ကိုယ်ပန်ဆောင်းဓမ္မဗွားမှု နှင့် မီးဖွားပြီး စောင့်ရှောက်ခြင်းများနှင့် ပက်သက်၍ ရရှိခဲ့သောကျန်းမာရေး အချက်အလက်များသည်ပြည့်စုံလုံလောက်ခဲ့ပါသည်။	၁	၂	၃	၄	၅
	၈၅၅ င များသောအားဖြင့် ကိုယ်ပန်ဆောင်းဓမ္မဗွားမှု နှင့် မီးဖွားပြီး စောင့်ရှောက်ခြင်းများနှင့် ပက်သက်၍ ရရှိခဲ့သောကျန်းမာရေး အချက်အလက်များသည် ပုံမှန်အားဖြင့် ဂကောင်းမွန်စွာ နားလည်နိုင်သည့် ဘာသာစကား ဖြင့်ရေးသားထားခဲ့ပါသည်။	၁	၂	၃	၄	၅
	၈၅၅ စ မလေးရှားရှိ ကျန်းမာရေး ပညာရှင်များသည် ကျွန်ုပ်၏ဓမ္မဗွန်းများ နှင့် ဝိုးဝိုမ်မှုများကို နားထောင်ပြီးဖြေကြားခဲ့ပါသည်။	၁	၂	၃	၄	၅
	၈၅၅ ဆ ဆေးဘက်ဆိုင်ရာစစ်ဆေးမှုကုသမှုများ၏ အကြောင်းအရင်း ကို တစ်နည်းနည်းဖြင့် ကျွန်ုပ်နားလည် စေရန်ရှင်းပြ ပေးခဲ့ပါသည်။	၁	၂	၃	၄	၅
	၈၅၅ ဇ ပုံမှန်အားဖြင့် ကျန်းမာရေးစောင့်ရှောက်ပေးသည့်နေရာတွင် ကျွန်ုပ် နားလည်သည့် ဘာသာစကားဖြင့် စတ်ဦးပြီးကို ဆက်ဆံပြောဆိုနိုင်ခဲ့ပါသည်။	၁	၂	၃	၄	၅
	၈၅၅ဈ ကျွန်ုပ်သည် ဒုက္ခသည်ဖြစ်သောကြောင့် ကျန်းမာရေးစောင့်ရှောက် ပေးသည့်သူများသည် လေးစားမှုရှိပြီး ဂတ္တရားဓေကျွန်စွာ ဆက်ဆံခဲ့ပါသည်။	၁	၂	၃	၄	၅
	၈၅၅ ည ကျွန်ုပ်သည် စိတ်ချမ်းသာစွာဖြင့်ကျန်းမာရေး လုပ်သားထံသို့ ကျန်းမာရေးနှင့် ပက်သက်သည့် အကြောင်အရာများကို တင်ပြပြောဆို မေးမြန်းခဲ့ပါသည်။	၁	၂	၃	၄	၅

ဤတွင်ကျွန်ုပ်တို့၏ မေးမြန်းခန်းပြီးဆုံးပါပြီ။ သင်၏ စိတ်ရှည်စွာဖြေကြားပေးမှုအတွက် ကျေးဇူးတင်ပါသည်။

မေးမြန်းခဲ့သော မည်သည့်ခေါင်းစဉ်မဆို သင့်တွင်မေးခွန်းများ မေးရန်ရှိပါက ယခု ကြိုးစား၍ဖြေဆိုပေးနိုင်ပါသည်။ ကျွန်ုပ်တို့ပြောဆိုခဲ့သော ခေါင်းစဉ်များအတွက် အချက်အလက်များ ပေးထားသည့်ကြော်ငြာများ၊ လက်ကမ်းစာစောင်များကို သင်တို့အတွက် ထားခဲ့ပါမည်။ ယခုမေးမြန်းခြင်းနှင့်ပက်သက်ပြီး ဆက်သွယ်မေးမြန်းလိုပါက ဆက်သွယ်နိုင်ရန် ကျွန်ုပ်၏ နာမည်နှင့် ဖုန်းနံပါတ်ကိုလည်း ပေးထားခဲ့ပါမည်။ ကျေးဇူးတင်ပါသည်။

APPENDIX-5A: IN-DEPTH INTERVIEW GUIDE - ENGLISH

Access of Chin and Rohingya Women Refugees and Asylum Seekers from Myanmar to Reproductive Health Services in the Klang Valley

IN-DEPTH INTERVIEW GUIDE

(Note: Questions to be asked based on relevance).

1. Informed Consent Process (Refer to Consent Form)
2. Section 1: Introduction
3. Section 2: Demographic details
4. Section 3: Pregnancy history and pregnancy care - follow up from questionnaire
5. Section 4: Home delivery details
6. Section 5: Social support
7. Section 6: Coping
8. Section 7: Experience of health care system
9. Section 8: Closing

1. Section 1: Introduction:

Thank you very much for agreeing to do this interview today. This interview may take about an hour or a little more than an hour. This is a follow up to the questions I asked you earlier about your ability to access maternal health care services in Malaysia and your feelings about the medical care you received for your last pregnancy and delivery. I would like to understand in greater depth your experience of accessing health services for pregnancy, delivery and post delivery care.

There are no right and wrong answers. You may withdraw at any time during this interview if you so wish, with no consequences. As in the case of the questions we asked you earlier, your name will not be disclosed to anyone else and your participation and interview responses will be kept confidential unless there is a serious concern for your safety. Any information that I may include from this interview will not identify you as the respondent.

I would also like your permission to tape record this interview. Though I will be taking notes during the session, I may not be able to write fast enough and I do not wish to loose any information that you will share.

Do you have any questions about the interview and what I have just explained?

Are you willing to participate in this interview?

2. Section 2: Demographic details:

To supplement details elicited in the quantitative survey.

- Family/household details- Who are you living with / others members of the family-household
- Sub-ethnic group
- Place of birth and stay in Burma
- Reasons for migrating

3. **Section 3: Pregnancy History and Pregnancy Care**

- Confirm questionnaire details
- Family planning and contraception – Did you want to get pregnant? If no, do you use contraception?
- Reasons for not obtaining antenatal care
- Reasons for delaying initiation of care
- Reasons for choosing NGO or private sub-optimal care

4. **Section 4: Home delivery details**

- Can you share with me your experience of delivering your baby at home?
- Why did you deliver your baby at home? Why did you not go to a hospital?
- Probe: rejection by health care facility, economic circumstances, family circumstances
- In your opinion, is ANC necessary during pregnancy?
- What are the difficulties of trying to get care in the hospital as a person without documents?

5. **Section 5: Social support**

- Do you have friends or family here in Malaysia?
- Explore sources of social support – husband, family, friends, and community?
- Can you turn to them for help?
- What kind of help can you expect from them?

I have heard some women in this community say that pregnancy and childbirth is difficult in Malaysia because they are far away from their homes, mothers, and families. Other women in this community have said that even though they are far away from their families and the traditional support systems they used to have in their villages, they have found new friends and community here who have assisted them in their needs during pregnancy and child birth.

- What has been your experience? What are the good things and the hard things/difficulties about finding support for pregnancy and childbirth and post delivery as a refugee/asylum seeker in Malaysia?
- Did you have support for meeting your needs when you were pregnant, when you delivered and after your delivery?
- Who were your main sources of support?
- How important were these sources of support for your? Could you have managed on your own without these sources of support?

6. **Section 6: Coping**

A woman has several needs when it comes to accessing health care in relation to pregnancy, delivery and post delivery.

i. Could you share with me about some of the most important needs of a refugee/asylum seeking woman in Malaysia when she is pregnant, when she delivers and after delivery?
ii. Could you please explain what were some of your most significant needs when you were pregnant, when you gave birth to your last child and immediately after delivery?
(*Probe as relevant and appropriate* for:)

- *information about pregnancy, childbirth; post delivery*
- *financial support;*
- *someone to accompany her to hospital*
- *someone to cover her for her domestic responsibilities*

iii. How did you cope with these needs?

7. Section 7: Experience of Health Care System

- Now I would like to hear about your experiences of how people in general relate to (that is speak to and behave towards) refugees and asylum seekers.
- Do you think that refugees and asylum seekers are treated with respect?
- Could you please share your own experience of how you are usually treated as a refugee / asylum seeker by people in general?
- Could you please share how health professionals like doctors, nurses and medical assistants speak to and behave towards refugees and asylum seekers?
- What has been your experience of how you were treated as a refugee by doctors, nurses and medical assistants when you went to obtain health care for pregnancy, delivery and post delivery?
-
- How did you cope with the difficulties of relating to health professionals like doctors, nurses and medical assistants when you went to obtain services for pregnancy, delivery and post delivery?

8. Section 6: Closing

Is there anything else you would like to add?

Thank you very much for your time. You are welcome to see the transcript of this session. Please feel free to contact me at the numbers provided if you wish to see the transcript.

APPENDIX-5B: IN-DEPTH INTERVIEW GUIDE - BURMESE

ကလန်းဗေလီရှိမြန်မာပြည်မှချင်းဒုက္ခသည်ရိုဟင်ဂျာဒုက္ခသည်နှင့်ခိုလှုံခွင့်ရှာဖွေနေသူ အမျိုးသမီးများ၏မျိုးပွားမှုပိုင်းဆိုင်ရာကျန်းမာရေးဝန်ဆောင်မှုများကိုရရှိနိုင်မှု

အခြေအမြစ်ကျကျမေးမြန်းမှုလမ်းညွှန်

ရှင်းပြသိရှိပြီးသောသဘောတူညီမှုလုပ်ငန်းစဉ် (သဘောတူခြင်းပုံစံကိုကြည့်ပါ။)

- အပိုင်း ၁ - နိဒါန်းမိတ်ဆက်
- အပိုင်း ၂ - လူဦးရေစစ်တမ်းအသေးစိတ်များ
- အပိုင်း ၃ - ကိုယ်ဝန်ဆောင်ကာလနှင့် ကိုယ်ဝန်စောင့်ရှောက်မှု (မေးခွန်းများမှ ဆက်လက်ဆောင်ရွက်ခြင်း)
- အပိုင်း ၄ - အိမ်မှာမွေးခြင်းအကြောင်း အသေးစိတ်
- အပိုင်း ၅ - လူမှုရေးအထောက်အပံ့
- အပိုင်း ၆ - ကိုယ်တိုင်ဆောင်ရွက်ဖြေရှင်းနိုင်မှုခွန်အား
- အပိုင်း ၇ - ကျန်းမာရေးစောင့်ရှောက်မှု စနစ်အပေါ် တွေ့ကြုံခံစားရမှု
- အပိုင်း ၈ - နိဂုံးချုပ်ခြင်း

<u>အပိုင်း ၁ - နိဒါန်းမိတ်ဆက်</u>

ယနေ့စုံစမ်းမေးမြန်းမှုအား သဘောတူညီခြင်းအတွက် များစွာကျေးဇူးတင်ပါသည်။ ဤမေးမြန်းမှုသည်တစ်နာရီခန့် သို့မဟုတ် တစ်နာရီထက်အနည်းငယ်ပိုပါလိမ့်မည်။ ယခုမေးမြန်းခြင်းသည် အစောပိုင်းကမလေးရှားတွင် မိခင်ကျန်းမာရေး စောင့်ရှောက်ပေးမှုများကိုရရှိနိုင်မှု၊ နောက်ဆုံးအကြိမ်ကိုယ်ဝန်ဆောင်စဉ်နှင့် မွေးဖွားမှုအတွက်ရခဲ့သော ဆေးဘက် ဆိုင်ရာစောင့်ရှောက်မှုအပေါ် ခံစားချက်များနှင့် ပတ်သက်၍ဆက်လက် မေးမြန်းခြင်းဖြစ်ပါသည်။ ကျွန်ုပ်သည် ကိုယ်ဝန်ဆောင်မှု ၊ မွေးဖွားမှုနှင့်သားဖွားပြီးစောင့်ရှောက်မှုများအတွက် ကျန်းမာရေးဝန်ဆောင်မှုများကို လက်ခံရရှိမှုအတွက် သင့်အတွေ့အကြုံကိုပိုမိုကျယ်ပြန့်စွာ လေးလေးနက်နက်သိရှိနားလည်လိုပါသည်။

ဖြေကြားရာတွင်မှန်သောအဖြေ၊ မှားသောအဖြေများမရှိပါ။ သင့်ဆန္ဒအတိုင်း နောက်ဆက်ဆိုးကျိုးများမဖြစ်စေပဲ ယခု မေးမြန်းခြင်းအတွင်း မည်သည့်အချိန်တွင် မဆိုရုတ်သိမ်းနိုင်ပါသည်။ ယခင်အစောပိုင်းကမေးမြန်းခဲ့သော မေးခွန်းများကဲ့သို့ပင် သင့်အတွက်စိုးရိမ်ရသောပြင်းထန်သည့် လုံခြုံရေးအန္တရာယ်မဟုတ်မချင်း သင်၏နာမည်၊ သင်ပါဝင်ခြင်း နှင့်မေးမြန်းမှုများအတွက် ဖြေကြားမှုများအား မည်သူ့ကိုမျှဖွင့်ပြောဆိုမည်မဟုတ်ပဲ အတွင်းအရေးအဖြစ်သိမ်းဆည်း ထားမည်ဖြစ်ပါသည်။ ယခုမေးမြန်းခြင်းတွင်ပါဝင်သည့် မည်သို့သော အချက်အလက်မှမဆို သင်သည်ဖြေဆိုထားသူဖြစ်ကြောင်းဖော်ထုတ်သွားမည်မဟုတ်ပါ။

ကျွန်ုပ်သည်မေးမြန်းခြင်းအားအသံသွင်းရန် သင့်ထံမှခွင့်ပြုချက်အားမေတ္တာရပ်ခံလိုပါသည်။ မေးမြန်းမှုအချိန်ပိုင်းအတွင်းမှတ်ချက်များမှတ်သားမည်ဖြစ်သော်လည်း လျင်လျင်မြန်မြန်ရေးသားနိုင်မည်မဟုတ်ပါ။ ကျွန်ုပ်အနေဖြင့်လည်း သင်မျှဝေအသိပေးသည့်မည်သည့်အချက်အလက်ကိုမဆိုမဆုံးရှုံးလိုပါ။

ကျွန်ုပ်မှရှင်းပြခဲ့သော စုံစမ်းမေးမြန်းခြင်းအကြောင်းနှင့်ပတ်သက်၍သိရှိလိုသောမေးခွန်းများရှိပါသလား။

ယခုမေးမြန်းခြင်းတွင်ပါဝင်ရန်ဆန္ဒရှိနေပါပြီလား။

အပိုင်း ၂ - လူဦးရေစစ်တမ်းအသေးစိတ်များ

ထုတ်နုတ်ထားသောအသေးစိတ်များကိုချင့်ချိန်တိုင်းတာနိုင်သည့်စစ်တမ်းအတွင်ဖြည့်စွက်ရန်

၁။ မိသားစု (သို့) အိမ်သူအိမ်သား အသေးစိတ်အချက်အလက် (သင်သည်မည်သူ/ အခြားအိမ်သားများနှင့် အတူနေပါသလား)
၂။ တိုင်းရင်းသားအုပ်စုခွဲ
၃။ မြန်မာပြည်တွင်မွေးဖွားရာနေရာနှင့်နေထိုင်ရာအရပ်
၄။ ရွှေ့ပြောင်းလာရခြင်းအတွက်အကြောင်းရပ်

အပိုင်း ၃ - ကယ်ဝန်ဆောင်ကာလနှင့် ကိုယ်ဝန်စောင့်ရှောက်မှု

- မေးခွန်းများကို အသေးစိတ်အတည်ပြုခြင်း၊
- မိသားစုစီမံကိန်းနှင့် သားဆက်ခြားခြင်း(သင်ကိုယ်ဝန်လိုချင်ခဲ့ပါသလား၊ မလိုချင်ခဲ့လျှင် သင်ကိုယ်ဝန်တားဆီးခဲ့ပါသလား။)
- ကိုယ်ဝန်သည်စောင့်ရှောက်မှု မရရှိခြင်းအတွက် အကြောင်းပြချက်၊
- ကိုယ်ဝန်သည်စောင့်ရှောက်ခြင်း စတင်ရန် နောက်ကျခြင်းအတွက် အကြောင်းပြချက်၊
- အစိုးရမဟုတ်သောအဖွဲ့အစည်း (သို့) ကိုယ်ပိုင်စောင့်ရှောက်ခြင်း ကိုရွေးချယ်ရခြင်းအတွက် အကြောင်းပြချက်၊

အပိုင်း ၄ - အိမ်မှာမွေးခြင်းအကြောင်းအသေးစိတ်

- သင်အိမ်မှာကလေးမွေးခြင်း အတွေ့အကြုံကို ကျွန်ုပ်ကိုပြောပြပေးနိုင်မလား။
- သင့်ကလေးကို ဘာကြောင့်အိမ်မှာမွေးတာလဲ။ ဘာကြောင့်ဆေးရုံမသွားရသလဲ။
- ကျန်းမာရေးစောင့်ရှောက်ရေးဝန်ဆောင်မှုများမှ ငြင်းဆန်ခြင်း၊ စီးပွားရေးအခြေအနေ၊ မိသားစုအခြေအနေ။
- ကိုယ်ဝန်ဆောင်စဉ်အတောအတွင်း ကိုယ်ဝန်ဆောင်စောင့်ရှောက်မှုလိုအပ်တယ်လို့ သင်ထင်မြင်ပါသလား။
- အထောက်အထားမရှိသူတစ်ဦးအနေဖြင့် ဆေးရုံတွင်ကျန်းမာရေးစောင့်ရှောက်မှုရယူရန် ဘာတွေခက်ခဲမှုရှိပါသလဲ။

အပိုင်း ၅ - လူမှုရေးအထောက်အပံ့

မလေးရှားတွင်အမျိုးသမီးများသည်ကိုယ်ဝန်ဆောင်ရာတွင်၊ကလေးမီးဖွားရာတွင်မိမိတို့၏ အိမ် ၊ မိခင်နှင့် မိသားစုများသည်ဝေးကွာသောကြောင့် အခက်အခဲရှိသည်ကို ဤအသိုင်းအဝိုင်းရှိအချို့သောအမျိုးသမီးများထံမှကြားခဲ့ပြီးဖြစ်ပါသည်။ အခြားသောအမျိုးသမီးများသည်ငင်းတို့၏မိသားစုများနှင့်ရွာတွင်ရရှိနေကျဖြစ်သောတိုင်းရင်းဆေးနည်းများ အထောက်အပံ့နည်းစနစ်များနှင့်ဝေးကွာနေသည့်တိုင် ကိုယ်ဝန်ဆောင်ချိန်နှင့်မီးဖွားရန်လိုအပ်သည်များကိုကူညီပေးသည့်သူငယ်ချင်းမိတ်ဆွေသစ်များနှင့်အသိုင်းအဝိုင်းကိုတွေ့ရှိထားကြပါသည်။

၁။သင့်အတွေ့အကြုံမည်သို့ရှိခဲ့ပါသနည်း။မလေးရှားတွင်ဒုက္ခသည်/ခိုလှုံခွင့်ရှာဖွေနေသူတစ်ယောက်အနေဖြင့် ကိုယ်ဝန်ဆောင်၊မီးဖွားခြင်းနှင့်သားဖွားပြီးစောင့်ရှောက်မှုများအတွက်အကူအညီရှာဖွေရာတွင်ကောင်းသောအရာများနှင့်ခက်ခဲသည့်အရာများမှာမည်သို့ရှိပါသနည်း။
၂။ သင်ကိုယ်ဝန်ဆောင်ခဲ့စဉ် ၊ မွေးဖွားစဉ် နှင့်သားဖွားပြီးနောက်လိုအပ်ချက်များကိုပြည့်စုံရန်အတွက် အထောက်အပံ့များရရှိခဲ့ပါသလား။
၃။ မည်သို့သောသူများသည်အဓိကအထောက်အပံ့ပေးသောရင်းမြစ်များဖြစ်ကြသနည်း။

၄။ အထောက်အပရင်းမြစ်များသည်သင့်အတွက်မည်မျှလောက်အရေးကြီးပါသနည်း။ ဤအထောက်အပံ့ရင်းမြစ်များမရှိပဲ သင့်ဘာသာစီမံနိုင်ပါသလား။

အပိုင်း ၆ - ကိုယ်တိုင်ဆောင်ရွက်ဖြေရှင်းနိုင်မှုခွန်အား

အမျိုးသမီးတစ်ဦးသည် ကိုယ်ဝန်ဆောင်၊မီးဖွားခြင်းနှင့်သားဖွားပြီးကျန်းမာရေးစောင့်ရှောက်မှုများကိုလက်ခံရရှိရန် လိုအပ်ချက်များရှိပါသည်။

၁။မလေးရှားရှိဒုက္ခသည်/ ခိုလှုံခွင့်ရှာဖွေသူ အမျိုးသမီးတစ်ဦးအနေဖြင့ ကိုယ်ဝန်ရှိသည့်အခါ မီးဖွားသည့်အခါ၊ သားဖွားပြီးသည့်အခါများတွင် အရေးကြီးသည့်လိုအပ်ချက်များအချို့ကို အသိပေးနိုင်ပါသလား။
၂။ သင်ကိုယ်ဝန်ဆောင်ချိန်၊ နောက်ဆုံးကလေးမွေးချိန်နှင့်သားဖွားပြီးချက်ခြင်း အရေးပါသော သိသာသည့် အများဆုံးလိုအပ်ချက်များကိုကျေးလူပြုပြီးရှင်းပြပေးနိုင်ပါသလား။
(အောက်ပါတို့အတွက်သက်ဆိုင်လျောက်ပတ်သည်တို့ကိုစုံစမ်းပါ။)

- ကိုယ်ဝန်ဆောင်၊ကလေးမွေးဖွားမှု၊ သားဖားပြီးနောက် စောင့်ရှောက်မှုအကြောင်းအချက်အလက်
- ငွေကြေးအထောက်အပံ့
- ဆေးရုံသို့သွားရန်လိုက်ပါမည့်အဖော်တစ်စုံတစ်ဦး
- အိမ်မှုတာဝန်များကိုလုပ်ကိုင်ပေးမည့်တစ်စုံတစ်ယောက်

၃။ ဤလိုအပ်ချက်များကိုမည်ကဲ့သို့ကိုင်တွယ်ဖြေရှင်းခဲ့ပါသနည်း။

အပိုင်း ၇ - ကျန်းမာရေးစောင့်ရှောက်မှု စနစ်အပေါ် တွေ့ကြုံခံစားရမှု

၁။ ယခု ဒုက္ခသည်/ခိုလှုံခွင့်ရှာသူများနှင့်ပက်သက်ပြီးယေဘုယျအားဖြင့်လူအများသည်မည်ကဲ့သို့ (ပြောဆိုပြီးဆက်ဆံ) ကြသည့်အကြောင်းသင့်အတွေ့အကြုံများကိုကြားသိလိုပါသည်။

၂။ ဒုက္ခသည်နှင့်ခိုလှုံခွင့်ရှာသူများသည်လေးစားစွာဖြင့်ဆက်ဆံခြင်းခံရသည်ဟုထင်ပါသလား။

၃။ဒုက္ခသည်တစ်ယောက်အနေဖြင့်များသောအားဖြင့်လူအများ၏ဆက်ဆံမှုကိုပုံမှန်မည်ကဲ့သို့ဆက်ဆံခံခဲ့ရသည့်သင်၏ကိုယ်ပိုင်အတွေ့အကြုံကိုအသိပေးနိုင်ပါသလား။

၄။ဒုက္ခသည်နှင့်ခိုလှုံခွင့်ရှာဖွေသူများအားဆရာဝန်၊သူနာပြုများနှင့်ဆေးဘက်ဆိုင်ရာလက်ထောက်များမှမည်ကဲ့သို့ ပြုမူပြောဆိုဆက်ဆံသည်ကိုအသိပေးနိုင်ပါသလား။

၅။ကိုယ်ဝန်ဆောင်၊မွေးဖွားခြင်းနှင့်သားဖွားပြီးနောက်ကျန်းမာရေးစောင့်ရှောက်မှုများဒုက္ခသည်တစ်ယောက်အနေဖြင့်ဆရာဝန်၊သူနာပြုများနှင့်ဆေးဘက်ဆိုင်ရာလက်ထောက်များ၏ဆက်ဆံမှုသည်သင့်အပေါ် အတွင်မည်ကဲ့သို့ရှိ နေခဲ့ပါသနည်း။

(လိုအပ်၍ သကဆိုင်လျှင်အောက်ပါစုံစမ်းမှုများကိုအသုံးပြုပါမည်။)

- ကိုယ်ဝန်ဆောင်၊မွေးဖွားခြင်းနှင့်သားဖွားပြီးနောက်ကျန်းမာရေးစောင့်ရှောက်မှုများရရှိရန်သွားသည့်အခါ ဆရာဝန်၊သူနာပြုများနှင့်ဆေးဘက်ဆိုင်ရာလက်ထောက်များနှင့်ပက်သက်၍ခက်ခဲသောအရာများနှင့် ကောင်းသောအရာများမှာအဘယ်နည်း။

- ကိုယ်ဝန်ဆောင်၊မွေးဖွားခြင်းနှင့်သားဖွားပြီးနောက်ကျန်းမာရေးစောင့်ရှောက်မှုများရရန်လာသောမလေးနိုင်ငံသားအမျိုးသမီးများကဲ့သို့တူညီစွာလေးစားမှုနှင့်ဝတ်ကျေမှုများဖြင့်ဆက်ဆံခြင်းခံရသည်ဟုခံစားရပါသလား။

၆။ အောက်ပါတကိုခံစားခဲ့ရပါသလား။

က။ သင်၏လူမျိုး၊တိုင်းရင်းသား (သို့) ဒုက္ခသည်အခြေအနေကြောင့်အမည်နာမများတပ်၍ခေါ်ခံခဲ့ရပါသလား။
ခ။ သင်၏လူမျိုး၊တိုင်းရင်းသား (သို့) ဒုက္ခသည်အခြေအနေကြောင့်သိမ်ငယ်စေရန်ပြုလုပ်ခြင်း မျိုးခံခဲ့ရပါသလား။
ဂ။ သင်သည်ဘာသာစကာကိုနားမလည်၊မပြောတတ်သဖြင့်အမြဲတမ်းအော်ဟစ်ခြင်းခံရပါသလား။
ဃ။ သင်၏လူမျိုး၊တိုင်းရင်းသား (သို့) ဒုက္ခသည်အခြေအနေကြောင့်သီးသန့်ချန်ထားခြင်း၊ဥပေက္ခာပြုခြင်းအစရှိသောနှုတ်မှမပြောသောခွဲခြားသည်အသွင်များကိုတွေ့ကြုံခဲ့ပါသလား။
င။ သင်၏လူမျိုး၊တိုင်းရင်းသား (သို့)ဒုက္ခသည်အခြေအနေကြောင့်သင်သည်အသုံးမကျသောသူ အဖြစ်ပြောဆိုခြင်း ခံခဲ့ရပါသလား။

သင်တွေ့ကြုံခဲ့ပြီးသောဤအတွေ့အကြုံများမှဥပမာများကိုမျှဝေအသိပေးနိုင်ပါသလား။

၇။ ကိုယ်ဝန်ဆောင်၊မွေးဖွားခြင်းနှင့်သားဖွားပြီးနောက်ကျန်းမာရေးစောင့်ရှောက်မှုများရရှိရန်သွားသည့်အခါဆရာဝန်၊သူနာပြုများနှင့်ဆေးဘက်ဆိုင်ရာလက်ထောက်များနှင့်ပက်သက်၍အခက်အခဲများကိုမည်သို့ရင်ဆိုင်ဖြတ်သန်းခဲ့ပါသနည်း။

၈။သင်သည်မိခင်ကျန်းမာရေးစောင့်ရှောက်ရေးဝန်ဆောင်မှုများရရှိရန်သွားခဲ့သည့်အခါလေးစားမှုနှင့်ဝတ်ကျေစွာဆက်ဆံခြင်းမခံရသဖြင့်စောင့်ရှောက်မှုရရန်သင်သည်အမြဲတမ်းနှောင့်နှေးနေခဲ့ရပါသလား။

<u>အပိုင်း ၈ - နိဂုံးချုပ်ခြင်း</u>

သင့်အနေဖြင့် အခြားမည်သို့သောအကြောင်းများထပ်မံဖြည့်စွက်လိုပါသနည်း။

သင့်၏အချိန်များအတွက်ကျေးဇူးများစွာတင်ပါသည်။ ယခုပြုလုပ်သောအချိန်ပိုင်းမှရေးသားချက်ကိုကြည့်ရှုရန်ကြိုဆိုပါသည်။ ရေးသားချက်ကိုကြည့်ရှုရန်ဆန္ဒရှိပါလျှင်ပေးခဲ့သည်နံပါတ်ဖြင့်ကျွန်ုပ်အားလွှဲလပ်စွာဆက်သွယ်နိုင်ပါသည်။

APPENDIX-6: TABLES

TABLE 64 : MATERNAL CHARACTERISTICS (N=343)

	STUDY POPULATION	DOCUMENTATION STATUS				ETHNICITY			
		Refugee		Asylum Seeker		Chin		Rohingya	
		n	Col %	n	Col %	n	Col %	n	Col %
N	343	219		124		201		142	
MATERNAL AGE									
14-19 (Teenage pregnancy)	50	32	14.6	18	14.5	18	9.0	32	22.5
20-29	220	136	62.1	84	67.7	145	72.1	75	52.8
30-35	56	37	16.9	19	15.3	30	14.9	26	18.3
36-44(Advanced maternal age)	17	14	6.4	3	2.4	8	4.0	9	6.3
GRAVIDITY									
Primigravida	146	74	33.8	72	58.1	107	53.2	39	27.5
Multigravida	154	110	50.2	44	35.5	80	39.8	74	52.1
Grand Multigravida	43	35	16.0	8	6.5	14	7.0	29	20.4
PARITY									
Nulliparous	82	31	14.2	51	41.1	61	30.3	21	14.8
Primiparous	108	68	31.1	40	32.3	74	36.8	34	23.9
Multiparous	132	101	46.1	31	25.0	56	27.9	76	53.5
Grand multipara	17	16	7.3	1	0.8	9	4.5	8	5.6
Great grand multipara	4	3	1.4	1	0.8	1	0.5	3	2.1
PREGNANT OR DELIVERED AT THE TIME OF THE INTERVIEW									
Pregnant	141	60	27.4	81	65.3	95	47.3	46	32.4
Delivered	202	159	72.6	43	34.7	106	52.7	96	67.6

TABLE 65: DISTRIBUTION OF SEVEN ITEMS OF PERCEIVED DISCRIMINATION IN HEALTH CARE

	STUDY POPULATION		BY DOCUMENTATION STATUS				BY ETHNICITY			
			Refugee		Asylum Seeker		Chin		Rohingya	
	n	Col %	n	Col %	n	Col %	n	Col %	n	Col %
N	331	100.0	214	100.0	117	100.0	194	100.0	137	100.0
Treated with less courtesy	113	34.1	70	32.7	43	36.8	98	50.5	15	10.9
Called names	66	19.9	41	19.2	25	21.4	51	26.3	15	10.9
Made to feel inferior	150	45.3	92	43.0	58	49.6	134	69.1	16	11.7
Shouted at	145	43.8	91	42.5	54	46.2	111	57.2	34	24.8
Nonverbal discrimination	107	32.3	67	31.3	40	34.2	99	51.0	8	5.8
Talked to as stupid / foolish	63	19.0	38	17.8	25	21.4	47	24.2	16	11.7
Ignored / not attended	108	32.6	70	32.7	38	32.5	92	47.4	16	11.7

TABLE 66: COPING: DELAY IN SEEKING MATERNAL HEALTH CARE

	STUDY POPULATION		BY DOCUMENTATION STATUS				BY ETHNICITY			
			Refugee		Asylum Seeker		Chin		Rohingya	
	n	Col %	n	Col %	n	Col %	n	Col %	n	Col %
N	331	100.0	214	100.0	117	100.0	194	100.0	137	100.0
Delayed seeking care	24	7.3	14	6.5	10	8.5	21	10.8	3	2.2
Did not delay seeking care	201	60.7	126	58.9	75	64.1	155	79.9	46	33.6
Not applicable-did not perceive discrimination	106	32.0	74	34.6	32	27.4	18	9.3	88	64.2

TABLE 67: COPING: OTHER FORMS

	STUDY POPULATION		BY DOCUMENTATION STATUS				BY ETHNICITY			
			Refugee		Asylum Seeker		Chin		Rohingya	
	n	Col %	n	Col %	n	Col %	n	Col %	n	Col %
N	331	100.0	214	100.0	117	100.0	194	100.0	137	100.0
Took action	16	4.8	13	6.1	3	2.6	10	5.2	6	4.4
Accepted as fact of life	209	63.1	131	61.2	78	66.7	165	85.1	44	32.1
Talked to others	122	36.9	76	35.5	46	39.3	100	51.5	22	16.1

TABLE 68: REASONS FOR FEAR WHILE TRAVELING TO OBTAIN MATERNAL HEALTH CARE

	STUDY POPULATION		BY DOCUMENTATION STATUS				BY ETHNICITY			
			Refugee		Asylum Seeker		Chin		Rohingya	
	n	(%)	n	(Col %)	n	(Col %)	n	(Col %)	n	(Col %)
N										
Stopped by authorities	278	81.0	168	76.7	110	88.7	158	84.5	120	78.6
Physical Violence	182	53.1	111	50.7	71	57.3	73	36.3	109	71.8
Sexual Violence	174	50.7	105	47.9	69	55.6	72	35.8	102	75.8
Getting lost	196	57.1	115	52.5	81	65.3	97	48.3	99	69.7
Getting robbed	197	57.4	118	53.9	79	63.7	88	43.8	109	76.8

TABLE 69: TYPE OF ANXIETY INCIDENT

	STUDY POPULATION		BY DOCUMENTATION STATUS				BY ETHNICITY			
	Study Population		Refugee		Asylum Seeker		Chin		Rohingya	
	n	Col %	n	Col %	n	Col %	n	Col %	n	Col %
N	343		219		124		201		142	
Stopped by authorities	162	47.2	107	48.9	55	44.4	106	52.7	56	39.4
Violence	10	2.9	9	4.1	1	0.8	4	2.0	6	4.2
Getting lost	29	8.5	16	7.3	13	10.5	26	12.9	3	2.1
Getting robbed	40	11.7	28	12.8	12	9.7	23	11.4	17	12.0

TABLE 70: TRAVEL MODE

	STUDY POPULATION		BY DOCUMENTATION STATUS				BY ETHNICITY			
	Study Population		Refugee		Asylum Seeker		Chin		Rohingya	
	n	Col %	n	Col %	n	Col %	n	Col %	n	Col %
N	343		219		124		201		142	
Taxi	171	49.9	112	51.1	59	47.6	101	50.2	70	49.3
Walk	67	19.5	40	18.3	27	21.8	60	29.9	7	4.9
Bus	52	15.2	27	12.3	25	20.2	21	10.4	31	21.8
LRT	19	5.5	10	4.6	9	7.3	19	9.5	0	0.0
Motorbike	32	9.3	30	13.7	2	1.6	0	0.0	32	22.5
Car(Friend/Own)	2	0.6	0	0.0	2	1.6	0	0.0	2	1.4

TABLE 71: TOTAL MATERNAL HEALTH CARE COSTS IN GOVERNMENT, PRIVATE AND NGO HEALTH CARE SECTORS (IN RM)

	Government Health Care Sector	Private Health Care Sector	NGO Health Care Sector
ANC Expenditure: Ω			
N	259	13	5
Mean(SD)	109.00(166.00)	85.00(126.20)	1.00(2.00)
Median	75.00	0.00	0.00
Minimum	0.00	0.00	0.00
Maximum	2070.00	330.00	5.00
Delivery Healthcare Expenditure: Ł			
N	191	5	No Delivery in the NGO Sector
Mean(SD)	719.00(442.32)	1878.00(1179.58)	
Median	600.00	2000.00	
Minimum	0.00	350.00	
Maximum	3000.00	3500.00	

TABLE 72: KNOWLEDGE OF MATERNAL HEALTH INFORMATION SOURCES

	STUDY POPULATION		BY DOCUMENTATION STATUS				BY ETHNICITY			
			Refugee		Asylum Seeker		Chin		Rohingya	
	n	Col %	n	Col %	n	Col %	n	Col %	n	Col %
N	343	100.0	219	100.0	124	100.0	201	100.0	142	100.0
Had Knowledge	219	63.8	154	70.3	65	52.4	101	50.2	118	83.1
Did Not Have Knowledge	124	36.2	65	29.7	59	47.6	100	49.8	24	16.9

TABLE 73: SELF-REPORTED PROFICIENCY IN BAHASA MALAYSIA

	STUDY POPULATION		BY DOCUMENTATION STATUS				BY ETHNICITY			
			Refugee		Asylum Seeker		Chin		Rohingya	
	n	Col %	n	Col %	n	Col %	n	Col %	n	Col %
N	326	100.0	214	100.0	112	100.0	193	100.0	133	100.0
Good	77	23.6	71	33.2	6	5.4	17	8.8	60	45.1
Poor	249	76.4	143	66.8	106	94.6	176	91.2	73	54.9

TABLE 74: FREQUENCY OF ABILITY TO COMMUNICATE IN A LANGUAGE THEY UNDERSTOOD

	STUDY POPULATION		BY DOCUMENTATION STATUS				BY ETHNICITY			
			Refugee		Asylum Seeker		Chin		Rohingya	
	n	Col %	n	Col %	n	Col %	n	Col %	n	Col %
N	326	100.0	214	100.0	112	100.0	193	100.0	133	100.0
Never	109	33.4	64	29.9	45	40.2	99	49.3	10	7.0
Rarely	52	16.0	26	12.1	26	23.2	45	22.4	7	4.9
Sometimes	62	19.0	45	21.0	17	15.2	17	9.0	45	32.4
Most of the Time	73	22.4	54	25.2	19	17.0	26	12.9	47	34.5
All the Time	30	9.2	25	11.7	5	4.5	6	3.0	24	16.9

TABLE 75: WHETHER ANC WAS SOUGHT

	STUDY POPULATION		BY DOCUMENTATION STATUS				BY ETHNICITY			
			Refugee		Asylum Seeker		Chin		Rohingya	
	n	Col %	n	Col %	n	Col %	n	Col %	n	Col %
N	343	100.0	219	100.0	124	100.0	201	100.0	142	100.0
Sought care	331	96.5	214	97.7	117	94.4	194	96.5	137	96.5
Did not seek care	12	3.5	5	2.3	7	5.6	7	3.5	5	3.5

TABLE 76: REASONS FOR NOT OBTAINING ANC

	STUDY POPULATION		BY DOCUMENTATION STATUS				BY ETHNICITY			
			Refugee		Asylum Seeker		Chin		Rohingya	
	n	Col %	n	Col %	n	Col %	n	Col %	n	Col %
N	343	100.0	219	100.0	124	100.0	201	100.0	142	100.0
Sought care	331	96.5	214	97.7	117	94.4	194	96.5	137	96.5
Could not afford the cost	5	1.5	4	1.8	1	0.8	5	2.5	0	0.0
Could not take time off work	1	0.3	1	0.5	0	0.0	1	0.5	0	0.0
Fear due to undocumented status	5	1.5	0	0.0	5	4.0	1	0.5	4	2.8
UNHCR asylum seeker certificate was rejected	1	0.3	0	0.0	1	0.8	0	0.0	1	0.7

TABLE 77: SECTOR WHERE ANC WAS SOUGHT

	STUDY POPULATION		BY DOCUMENTATION STATUS				BY ETHNICITY			
			Refugee		Asylum Seeker		Chin		Rohingya	
	n	Col %	n	Col %	n	Col %	n	Col %	n	Col %
N	343	100.0	219	100.0	124	100.0	201	100.0	142	100.0
Govt. ANC only	259	75.5	179	81.7	80	64.5	148	73.6	111	78.2
Private ANC only	13	3.8	10	4.6	3	2.4	2	1.0	11	7.7
NGO ANC only	5	1.5	0	0.0	5	4.0	1	0.5	4	2.8
Govt. & private ANC	25	7.3	12	5.5	13	10.5	17	8.5	8	5.6
Govt. & NGO ANC	26	7.6	12	5.5	14	11.3	24	11.9	2	1.4
Govt. private and NGO ANC	03	0.9	1	0.5	2	1.6	2	1.0	1	0.7
No care sought	12	3.5	5	2.3	7	5.6	7	3.5	5	3.5

TABLE 78: NUMBER OF ANC VISITS

	STUDY POPULATION		BY DOCUMENTATION STATUS				BY ETHNICITY			
			Refugee		Asylum Seeker		Chin		Rohingya	
	n	Col %	n	Col %	n	Col %	n	Col %	n	Col %
N	319	100.0	208	100.0	111	100.0	191	100.0	128	100.0
Inadequate Visits	141	44.2	66	31.7	75	67.6	95	49.7	96	50.3
Adequate Visits	178	55.8	142	68.3	36	32.4	46	50.3	82	64.1

APPENDIX-7A: ALLIANCE OF CHIN REFUGEES

The Alliance of Chin Refugees in Malaysia was formed on the 14th May 2005 in Kuala Lumpur:Falam, Hakha, Kanpelet, Lautu, Mara, Matu, Mindat, Paletwa, Tedim, Tonzang, Zo, Zophei, and Zotung.

The organization is committed to equal rights and opportunities for the diverse groups of refugees espousing unity between the leadership team.

Aims and Objectives:

- To create an avenue for the various Chin ethnic communities to work together for their immediate well being, security and continued development as persons.
- To seek from among Malaysian individuals and groups various forms of assistance to carry out the above objectives and to coordinate with them to ensure their continued support and cooperation.
- To establish and administer a community centre to serve as a point from where all Chin refugees seeking assistance of any sort can come and have their problems attended to immediately.
- To liaise with the UNHCR and provide assistance to locate any Chin refugee who needs to attend appointments or interviews and provide the necessary assistance to see them through.
- To engage the assistance of local NGOs and support groups to organize health clinics enabling refugee communities to access healthcare and education for the prevention of illness especially HIV/AIDS and TB and to educate women on how to care for their children.
- To organize where possible, learning centres where children can receive some basic education to prepare them for school in the future.
- To create opportunities for women to engage in training and production of handicrafts which can be made at home and seek assistance in the marketing of such items.
- To organize various activities from time to time to cater for the social, cultural and spiritual needs of the Chin refugees in Malaysia.

Activities of ACR

Education

The children of the school of Chin refugees are taught by volunteer parents and teachers from the International schools and also Chin teachers among the refugee adults. The school commenced with a few children in one of the rooms at ACR in mid 2005 and is now catering for 130 children. This has necessitated renting additional larger premises in November 2008 in close proximity to the ACR office. Due to some additional fundraising and donations from overseas visitors, amenities have been improved. The children now have access to computers and they wear school uniform.

Health

ACR clinic is headed by Dr. Amelia Simon and assisted by experienced volunteer nurses from Europe, Canada and USA with Chin nurses also assisting when possible. The clinic opens every Thursday and also once a month with help from the Asian Outreach Church. ACR provides access to special medical services when necessary for example - Private clinics, General hospitals, and the medical services provided by ACTS and Welcome Community Homes at Batu Arang.

Women's Income Generating Project

'Mang Tha' – translated in English as 'Sweet dreams' – is the name given to the project to uplift the status of refugee women. The women are trained in the production of handicraft products which are marketed both in Malaysia and abroad with the purpose of generating income for the women.. All money raised through the sale of handicrafts goes directly to the women involved.

Administration

ACR liaises with Police and Rela so that these departments can better understand the conditions of the asylum seekers and refugees in Malaysia leading to more lenient actions on their behalf. ACR works closely with the office of UNHCR, Kuala

Lumpur cooperating with them in regards to registrations, resettlement and other concerns of refugees and also assisting UNHCR when requested.

ACR has links to a number of NGOs who assist in various ways when possible.
The establishment of ACR has attracted the attention of the International and expat communities resulting in the active involvement of overseas visitors and advisers many who give their leisure time or holiday weeks to involve themselves in various activities on a voluntary basis.

Income

Approximately 95% of the total income comes from the fee levied for an individual ACR membership card issued to the refugees. Membership has increased since 2005 from several hundred to 20,865 as of November 2008 from all the ethnic groups mentioned above.

Additional funds are donated from Baptist World Aid Australia and various other NGO's, churches and individuals. These include Malaysian nationals, ex pats, overseas visitors and several overseas contributors.

The leaders at ACR maintain strict financial balance sheets in accordance with recognized accounting practices overseen by Asian Outreach in Kuala Lumpur.The treasurer produces an annual audit report which is distributed to financially interested parties and also displayed publically on the wall of the office. It is available for any member on request.

Training

Under the auspices of UNHCR, ACR is working in coordination with local firms to train refugees to become skilled workers so that when they are resettled in a third country they will be able to earn a living and support their families. Meanwhile, in Malaysia, they are earning some money from their trainers sufficient for their own support.

APPENDIX-7B: ROHINGYA SOCIETY IN MALAYSIA

Rohingya Society in Malaysia (RSM) was formed in 2010 to advocate for the needs of Rohingya refugees and asylum seekers in Malaysia following discussions among the leaders of community based organizations, students, and respected individuals living in Malaysia.

The deprivation of basic human rights of Rohingyas in their home country, Burma which has contributed to their low levels of educational and economic attainment, and massive displacement across South and South East Asia, and the poor protection environment in Malaysia for refuges and asylum seekers guides the twin broad organizational goals: (i) Rohingya nation building; and (ii) provision of services to the community.

As such, the activities of RSM include:

1. Primary education for Rohingya children

Refugee children have limited access to informal education in Malaysia through education projects run by UNHCR, NGOs, and INGOs. Since 2005, the schools that were opened by UNHCR with the cooperation of Tzu Chi (a Buddhist NGO from Taiwan) were not sufficient for refugee children; thus, RSM has opened a school since 2008 for Rohingya children. The curriculums of the school are: Al-Quran, Mathematics, English, Science, and Bahasa Malaysia. RSM runs this program with very limited resources. The condition of the school is under resourced.

2. Health care for Rohingya Refugees

Rohingya refugees have been facing a lot of problems to get other basic services such as health care and legal services. In principle, government hospitals in Malaysia are open and available to refugees and asylum seekers, but evidence shows that refugees and asylum seekers experience substantial barriers accessing health care in Malaysia such as the cost of treatment, fear of arrest, and language barriers.

For above mentioned reasons, United Nation High Commissioner for Refugees (UNHCR) works closely with partner organizations who implement health programs. ACTS clinic is one of them. Our organization works with ACTS clinic. RSM's Deputy President, Abdul Ghani Bin Abdul Rahman is health coordinator for ACTS. He received training as well. Every month RSM has to take care of at least four-six patients.

Other activities include:

3. Issuance of recommendation letters to asylum seekers as a means of protection

4. Regularly organize interview sessions at RSM's office for human rights activists, journalists, reporters, and NGOs with asylum seekers and refugees in order to highlight the human rights violation in Arakan

5. Distributing alms to needy families during month of Ramadhan, RSM organize with the collaboration of local donors and NGOs to distribute alms to poor families.

Write-up provided by Dr. Abdul Hamid Musa Ali, President of Rohingya Society in Malaysia