

**HIV Testing in Antenatal Care Clinic:
The Experience of Burmese Migrant Women
in Northern Thailand**

By

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Abstract

The aims in this grounded theory qualitative study were to increase knowledge about Burmese migrant women accessing health care in pregnancy including HIV counselling and their subsequent decisions regarding HIV testing and treatments in the prevention of mother-to-child transmission of HIV programme. This study explored not only the women's own perspective and their decision-making but also learned about the experiences of the health professionals and how they interpret the current situation and the women's decision.

This study took a grounded theory approach. Individual interviews were conducted with 38 Burmese pregnant women and 26 health care workers who cared for these women in the Thailand-Burma border provinces in the northern parts of Thailand. Three focus groups were also conducted among health care workers. Data were analysed manually using a data driven analysis method that has been suggested by Charmaz. Member checking after each interview, interview recording, structural transcription and valid translation were used to ensure rigour.

The study found that entering into the antenatal care system meant that Burmese migrant women faced various difficulties and the health care workers who were caring for them also encountered many barriers. The findings also demonstrated the factors that influenced women's decision to have HIV screening including the influence of partners, health care workers and the fear for their unborn child. Interpretations of the women's decision to have the blood test came from women and health care workers' views of the processes involved. Health care workers suggested ways to develop people, networks and policies to increase the quality of screening and counselling for migrant pregnant women to participate in the Prevention of Mother-to-Child transmission of HIV programme.

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List of Abbreviations

AIDS	Acquired Immunodeficiency Syndrome
ANC	Antenatal Clinics
ARV	Antiretroviral
AZT	Ziduvudine
BATS	Bureau of AIDS, Tuberculosis and STI
DHSS	Department of Health Service Support
HIV	Human Immunodeficiency Virus
IOM	International Organisation for Migration
KWO	Karen Women's Organisation
MoPH	Ministry of Public Health
NGO	Non-Governmental Organisation
MTCT	Mother-to-child transmission of HIV
PBRI	Praboromarajchanok Institute
PCU	Primary care Unit
PHAMIT	Prevention of HIV/AIDS Among Migrant Worker
PMTCT	Prevention of Mother-to-Child transmission of HIV
SWAN	Shan Women's Action Network
UNDP	United Nation Development Programme
UNAIDS	United Nations Programme on HIV/AIDS
VCT	Voluntary counselling and HIV testing

Part 1: Background of the study

Chapter 1

Introduction

This chapter outlines historical background of the study. It aims to give an overview of situation of HIV infection in Thailand and it also encourages the understanding of the particular contexts of migration and pregnant migrant women in relation to HIV/AIDS.

1.1 HIV in Thailand

The Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS) epidemic is one of the greatest challenges facing mankind around the world today including Thailand. Thailand, a lower middle-income country in South East Asia, is situated in the heart of the Southeast Asian mainland and its population is approximately 63.4 million (WHO, 2008). It covers an area of 514,000 square kilometres and is bordered on the Northeast by Laos, on the North and West by Burma, on the East by Cambodia, and on the South by Malaysia (WHO, 2007b) (See Map1.1).

It is asserted that what was initially perceived to be 'a handful of infections' had developed into a HIV epidemic and 'a major national threat', with medical, social and economic consequences that were recognised as 'wide ranging' (Bloom and Godwin, 1997; East-West Center, 1995). In 2004, the HIV infection rate in Thailand had been the highest in the Asian Pacific region (Marlink and Kotin, 2004) and in Asia over the last decade (O'Keeffe et al, 2005).

The first case of AIDS in Thailand occurred in 1984 (Phanuphak et al, 1985). The initial epidemic started in injection drug users (WHO, 2005a) and then spread to

male and female commercial sex workers (Bloom and Godwin, 1997). Thereafter, infection among sex workers had been increased and resulted in following waves of the epidemic among their male clients and it quickly spread from them to their wives and children (Bloom and Godwin, 1997).



Map 1.1 Map of Thailand Borders (Source: United Nations Economic and Social Commission for Asia and the Pacific)

After the first case of HIV was notified, the Thai government responded immediately to prevent the spread of HIV as much as possible. The programmes put into place provided information and education to communicate their message to all people. They included the 'Condom Promotion' and the 'Condom 100%'

programmes, as well as the 'Prevention of Mother to Child HIV Transmission' programme, the 'Universal Screening for HIV in Blood Services' and many other programmes (Marlink and Kotin, 2004; Tancharoensathien et al, 2006: WHO, 2005a). These substantial programmes have decreased the prevalence and new infections dramatically by reducing visits to commercial sex workers by 50% and increased condom use (UNDP, 2004; Nelson et al, 1996: WHO, 2007a). Moreover, an evaluation model to demonstrate effectiveness of the programmes, by the Ministry of Public Health, has estimated that more than 6 million Thais have been protected from HIV infection during the past two decades (MoPH, 2007). However, due to the momentum of risk behaviours which was prevalent during the period, the number of people who had been infected with HIV had been tremendously high.

Currently, UNAIDS (2006) estimated that 580,000 (330,000 – 920,000) Thai adults and children were living with HIV at the end of 2005 and the number of new HIV infections was estimated to be around 18,000 cases with in 2005; among these the number of Thai women and girls living with HIV/AIDS is increasing remarkably, with more than one-third of the adults living with HIV/AIDS being women (UNAIDS, 2006). Surprisingly, a large proportion of new HIV infections in Thailand are in people who are considered to be at low risk of infection and about one third of new infections in 2005 were in married women who were probably infected by their partners (UNAIDS, 2006). This report related to a study by the Bureau of AIDS, TB and STIs in Thailand (2006) that the majority of new infections occurred among females contracting the HIV from their HIV infected husbands (38%) and HIV infection levels among pregnant women remain high in some parts of the country. UNFPA (2002) stated that women's lack of authority in sexual decision-making and the lack of female-controlled HIV prevention methods is one of the biggest reasons for increasing HIV prevalence among women.

1.2 Health Problems along the Thailand-Burma Border

It is difficult to exactly state a number of whole migrant populations in Thailand but it can be estimated that there are around 2.2 million illegal migrants living in the country, more than 80 per cent of whom are Burmese (UNDP, 2004). There are more than 100 different ethnic groups and sub-groups in Burma (Ekeh & Smith, 2007) and conflicts among the different ethnic groups. Moreover, ongoing conflicts between the Kareni and Shan State army and the Burmese [government] army are still continuing (Ekeh & Smith, 2007; Lall, 2009). These conflicts have forced Burmese to migrate to the bordering countries; India, Bangladesh, Malaysia, China and Thailand (Lall, 2009).



Map 1.2 Thailand – Burma Border Areas

The massive Burmese migration into Thailand is one of the largest migrations in the Southeast Asia Region, mainly due to the Thai-Burma border which is approximately 2,500 kilometres long with ten provinces bordering each other (UNDP, 2000) (See map 1.2). Moreover, Thailand is the only country in this region to have a border with Burma. Although the Thai government can control Burmese migration into Thailand among six official border-crossing points, there are unofficial points which are located in mountainous and heavily forested areas that are difficult to control (Isarabhakdi, 2004). The Women's Commission for Refugee Women and Children (WCRWC) (2006) estimated that some 2,000 to 3,000 Burmese continued to cross the border into Thailand each month. Currently, there are an estimated two million Burmese trying to increase their quality of life in Thailand (Refugee Studies Centre, 2008) and more than half of them are illegal. Importantly, this migration is expected to continue as long as the conflicts in Burma still continue.

There are many crucial problems among people living in the border-regions. Poverty and inadequate education prevent people from accessing useful resources (IIEP, 2008). Therefore, health issues are a major concern for migrants from Burma. Due to the situation in Burma, people have had very little health education and even less health care. Many undocumented migrants are less able to access health care services (Klin, 2000) and this creates a public health concern. HIV infection is one of the main health problems in the border regions (James, 2005; Celentano and Beyrer, 2008). It can be said that having various borders and population subgroups led to the spread of the HIV infection across Thailand.

Moreover, there is an association between people movement and risk of HIV transmission and borders are often considered as heightened HIV vulnerability areas (Shtarkshall and Soskolne, 2000). In Cambodia, Burma, and Thailand, HIV prevalence is higher among the provinces bordering with other countries (POLICY, 2003; WHO 2004). Since Thailand borders various countries, there are

many cross-border health issues, such as those relating to migrant populations (WHO, 2007b).

The Burmese who flee to Thailand are primarily Karen, Karenni, Mon and Shan people (Ekeh & Smith, 2007). The largest population of Burmese migrants usually lives in the upper north of Thailand (National Statistics Office, 1993). It is difficult to estimate how many Burmese migrant persons are living with HIV in Thailand. These migrant populations are at higher risk of contracting HIV because of their status. Their language barriers prevent them from getting information about HIV and AIDS. Many studies have reported that most immigrant workers live and work illegally and thus do not have access to basic health care services and most of HIV-positive Migrant workers have no access for treatment (Ekachai, 2003).

HIV prevalence among adult in Burma is between 1.3 and 2 percent and in a population of 47.3 million, there are up to 570,000 people who are infected with HIV (UNAIDS 2006). In Thailand, the HIV prevalence of migrant workers was revealed to be between 1.6 and 6.4 percent and among pregnant migrant women, HIV prevalence was very high in many regions, where it ranged between 2 – 6.7 percent (UNDP, 2004). However, there is no official report about the HIV prevalence among Burmese migrants both in Thailand itself and along the Thai-Burma border. However, a study by Plewes et al, (2008) showed that HIV infection rates among pregnant Karen refugee living in refugee camp in Tak Province, Thailand increased from 0.2% in 1997 to 0.4% in 2005. Similarly, the HIV prevalence among Burmese pregnant women attending Antenatal care in Mae Tao clinic located in Thailand near the Thai-Burma border also increased from 0.8% to 2.2 % during the same time (Muang, 2006).

Many factors – both direct and indirect – may have contributed to the migrants' vulnerability to HIV. Klin (2000) suggests that a lack of HIV information, an inability to negotiate safer sex and a lack of access to condoms have resulted in an increased vulnerability to HIV. These migrants also frequently lack access to

basic educational and health services due to language barriers, financial problem and illegal status. Most of the HIV education and information is provided in Thai. As second language speakers, education generally and HIV education in particular is therefore less accessible to Burmese. Moreover, in most health care services, the health care workers communicate only in the Thai language.

Although, the minimum wages for workers are between 148 and 203 Thai Baht (£2-3) per day (Office of Foreign Labour Migrant Commission, 2008), most migrants receive far less than this minimum wage. The necessity to work to earn money means that they are more likely to go to the hospital in an emergency rather than attend a health care service for health prevention or promotion programmes. There are studies of migrants' utilisation which founded that emergency services were more used than primary care services (Dias et al, 2008). Legal migrants have access to partial free health care, like the Thais, even if they do not access it for other reasons. Illegal migrants on the other hand do not have any free health care. They have to pay the full costs when they visit the hospital or health care service.

While HIV prevalence in this migrant group is very high, their knowledge about HIV transmission is very low. Importantly, most female immigrant workers were found to lack necessary access to family planning and safe sex services (IRIN, 2007) and many of them consequently suffer unplanned pregnancies and abortions.

Importantly, in the northern parts of Thailand, HIV prevalence among pregnant migrant women is approximately 2.5 % (UNDP, 2004). Nevertheless, HIV prevalence of Burmese women in refugee camps was lower than migrant women living outside the camp in Thailand or in Burma (Plewes et al, 2008). Although, some of the pregnant migrant women have the right to access public healthcare and Prevention of Mother-to-Child transmission of HIV (PMTCT) programmes, some of them tend not to take part in these programmes which are necessary to prevent transmission of the virus to their babies. Plewes et al (2008) pointed out,

that a lack of funding prevented the provision of HIV testing in ante-natal clinics for migrant women. Therefore, we need to find a way of targeting those most at need and identifying strategies to encourage them to accept testing and treatment aimed at preventing mother to child transmission.

1.3 The Thai Health Care System

Thailand has a well developed health care system with good financial and health resources and over the past 30 years, accessibility rates to essential health care has gradually increased (WHO, 2007). The government has universal healthcare coverage that means everyone has some form of health insurance to cover basic needs and emergencies (Wibulpolprasert et al, 2005; Wibulpolprasert et al, 2008). Currently, Thailand spends about 8 percent of the total government outlay on health care (WHO, 2007) and has made significant progress in reducing infant mortality, improving immunization rates and increasing life expectancy. However, the report of

Women's Commission for Refugee Women and Children (WCRWC) stated that more than one-third of the Thai population was reported to have inadequate access to health services due to inequities in health, especially between urban and rural areas (WCRWC, 2006). Health care in Thailand is organized and provided by both the private and public sectors. The Ministry of Public Health (MoPH) is the main organization to promote, support, control and coordinate all health services for the people.

Thailand is administratively divided into provinces, districts, and sub-districts. Health services in Thailand are classified into five levels including:

- self-care within the family,
- primary health care at village level in midwifery centres,
- primary care at Tambon (sub-district) level in health centres,
- secondary care at district level in community hospitals and

- tertiary care at provincial level in provincial or regional hospitals
(Wibulpolprasert et al, 2005).

All levels are linked together by a referral system.

At present, the Thai government is implementing a Universal Health Care Coverage Policy where every Thai citizen is covered by at least one health insurance scheme. State officials receive free treatment under the Medical Welfare Scheme while private employees paying are covered under the Social Security Scheme. Those Thais who are not government officials or have no social security insurance card must pay 30 Baht (about 50 pence) per visit when they receive care from government health facilities (Hughes and Leethongdee, 2007; WHO, 2007). Expensive treatments, including kidney dialysis and anti-retroviral drugs for HIV/AIDS sufferers are currently not being offered within this scheme. Other treatments under this universal healthcare include dental care.

Cross-border health is one of the major concerns of the Ministry of Public Health. The MoPH is the main institution currently working on cross-border health issues. The activities involve disease surveillance, research, financial support for public health projects, short course training and degree training for health workers or for migrant people (Wibulpolprasert et al, 2005).

Thai government health service centres provide health care for non-registered migrants based on humanitarian grounds. However, these migrants often do not seek government services due to the financial problem. Moreover, there are indirect costs including transportation and loss of working time. Their illegal status, communication difficulties and financial problem prevent them from accessing health care services.

1.4 Maternal (Antenatal) Care Service in Thailand

The majority of maternal and child health services are delivered throughout the country by government agencies at all levels of the health care system which are being provided by midwives at health centres or nurses at the hospitals. At village level there is a primary health care unit, where village health volunteers assist in providing advice and referring cases to health centres. The antenatal care services system at community level is complemented by the hospital component, made up of a network of community hospitals at district level, provincial, regional hospitals, Maternal and Child Health hospitals, and university hospitals (MoPH, 2006). All levels are linked together by an established referral system.

There should be at least four antenatal care visits and the first visit should take place within the first 6 months of pregnancy (MoPH, 2006). However, the number of antenatal visits varies depending on the woman and her health-care providers. In contrast, in the United Kingdom, the first appointment needs to be arranged before 12 weeks. In addition in the UK, a woman who is primigravid with a normal pregnancy is offered a schedule of ten appointments and for a woman who is multigravid without complications, a schedule of seven appointments (NICE, 2008). Currently, the Thai MoPH reports that more than ninety percent of pregnant women receive at least 4 antenatal care visits (MoPH, 2006). Commonly, a pregnant woman should seek to access an antenatal service to find out about her pregnancy (Liamputtong et al, 2005). The woman will attend antenatal check-ups every month until 28 weeks of gestation, then every fortnight from 28–36 weeks and every week after 36 weeks. Routine antenatal care services include taking medical history; physical examination; blood testing for anaemia, blood group, hepatitis B antigen, syphilis, and HIV; urinalysis; diagnosis, treatment, and referral of women with high-risk pregnancies; tetanus toxoid vaccination; provision of vitamins and iron; and education on health, nutrition, and self-care (WHO, 2005 and 2006).

All pregnant women in Thailand are given the Maternal and Child Health Booklet to record any antenatal and postpartum care they receive. Antenatal care is provided free of charge in public-health services excluding laboratory testing with costs approximately 100 - 300 Baht (£1.45-4.35).

The Roles of Midwife and Nurse-midwife

As nursing and midwifery are integrated in Thailand, all qualified nurses who finish a four-year professional nursing educational programme are awarded a bachelor's degree in nursing sciences or equivalent and are called 'nurse-midwife'. This programme includes full nursing training plus 18 months of midwifery training. Therefore, almost all Thai nurses have had midwifery experiences and have been qualified to act as a midwife within Thai law.

Care-giving, providing correct and up-to-date information, providing, alternatives, and listening to clients' suggestions about the services that they need are the responsibilities of nurse-midwives in Thailand. Therefore, throughout the thesis the term nurse may be used but refers to those who are qualified as a nurse midwife.

1.5 Prevention Mother-to-Child Transmission of HIV in Thailand

Before looking at how to increase the participation of these women, it is important to evaluate the quality and effectiveness of the programme. The Prevention of Mother to Child HIV Transmission (PMTCT) Programme was launched as one of the National HIV programmes in 2000 (Amornwichee et al, 2002; MoPH, 2007). It encourages early antenatal care and offers antiretroviral (ARV) therapy before, during and after the labour period.

Pre-and post-test counselling with a voluntary HIV blood-test is offered to pregnant women who come to attend the Ante-natal Clinic (ANC). Voluntary HIV testing with consent is performed usually at hospital laboratories, using either rapid HIV tests or enzyme immunosorbant assays. Women whose test results are repeatedly positive are given post-test counselling at hospitals, generally the week following testing. If the test is positive, it is repeated and if the second test is positive, the Western Blot (WB) test is performed. Pregnant women who are found to be HIV infected will be offered treatment for prevention of maternal to child HIV transmission at this stage (MoPH, 2007).

ARV therapy can be prescribed usually Ziduvudine (AZT), one of the modern antiretroviral drugs which are highly effective at preventing HIV transmission during pregnancy, labour and delivery. AZT is usually taken two or three times daily, starting after the first trimester sometime between 14 to 34 weeks of pregnancy until labour begins, as well as being taken during labour every 3 hours. After birth, all babies who are born from HIV infected mothers will receive AZT syrups initially. However, giving a single dose of Nevirapine to mother and baby can cut the risk of transmission in half (Lallemant et al, 2004).

As part as the PMTCT programme a caesarean section is recommended as a safe delivery method which is normally used in order to deliver a baby from an HIV infected mother, protecting the baby from direct contact with mother's blood and other bodily fluids that would occur during the vaginal delivery. Moreover, infected mothers will be advised not to breast feed their infants and milk powder substitution will be given to all babies who are born from HIV infected mothers (Kennedy, 2003). The effective treatments can slow the disease and reduce the rate of HIV transmission from mother to child in pregnancy.

As previously mentioned, HIV prevalence among pregnant migrant women is more than twice as high as the prevalence among pregnant Thai women. In the northern part of Thailand, HIV prevalence among pregnant migrant women is approximately 2.5 % (UNDP, 2004). Moreover, numbers of women found to be

HIV positive among the multigavida migrant pregnant women is higher than in multigravida Thais (Mae Sai Hospital, 2006). Similarly, in refugee camps women with HIV tend to be multigravid (Plewes et al, 2008). This raises the concern about what happened when they attended antenatal care clinic during their previous pregnancy.

Although, some pregnant migrant women have the right to access public healthcare and Prevention of Mother-to-Child transmission of HIV (PMTCT) programmes, they do not take part in these programmes, despite their importance in preventing transmission of the virus to their babies. Therefore, we need to find a way of targeting those most at need and identifying strategies to encourage them to accept testing and treatment aimed at preventing mother to child transmission. Moreover, understanding or clarifying these women's experiences in antenatal care service and HIV counselling is also required.

The next chapter will explain construction of a review literature. It aims to present what knowledge is already known in relation to HIV and pregnant women. It also aims to find a gap in the research.

Chapter 2

Literature Review

In the classic account of grounded theory (Glaser and Strauss, 1967; Glaser, 1978), it is considered good practice to delay the literature review till after the data analysis in order to avoid data contamination. However, others argue that a preliminary literature review early in the research process can help to identify the 'theoretical code' and to clarify the research question (Charmaz, 2006). It is from this perspective that this literature review has been undertaken. It aims to develop the research questions and to demonstrate the body of knowledge in relation to the research questions. After developing the categories through data analysis, the search terms were changed and a second literature search was carried out to obtain literature relevant to the results of my study. Further literature was accessed at the point of new categories emerging and will be discussed in the findings.

The literature in this review was identified through searches of electronic databases; AMED, CINAHL, EMBASE MEDLINE, PubMed and the Cochrane Library. Many other journals and books were also hand searched and relevant electronic sources such as electronic Journals were also included. Databases were searched by using the keywords HIV/AIDS, HIV mother-to-child transmission, HIV pregnancy, HIV mother, and HIV women. All databases were searched from 1995 onward and the most up to date data were selected. Each relevant article was reviewed, focussing on the major result, the subjects (participants), when and where it was conducted, and which method was used.

2.1. Knowledge, belief, and attitude towards HIV/AIDS among pregnant women

HIV knowledge, attitude or belief and prenatal voluntary counselling and HIV testing (VCT) are critical to prevent mother-to-child transmission of HIV (PMTCT). There are many studies which investigated the knowledge, beliefs and attitudes towards HIV/AIDS among pregnant women (Ho and Loke 2003; Adeneye et al 2006; Roger et al 2006; Abiodun et al 2007 and Kominami et al 2007). With sample sizes ranging from 162 to 804 participants, these researchers collected data from pregnant women who attended Antenatal Clinics (ANC) by using questionnaires. Their findings showed that the majority of these women had little knowledge about HIV in pregnancy and Mother-to-Child transmission of HIV while they had a good general knowledge of HIV/AIDS and its transmission.

In Nigeria, Abiodun et al (2007) highlighted a low level of awareness of mother-to-child transmission of HIV. Only 68% of 164 pregnant women demonstrated awareness of it and less than one-third could identify how to prevent it. Nevertheless, they found no difference of knowledge of MTCT of HIV among different levels of education. Adeneye et al (2006) carried out a cross-sectional survey of 804 women in Ogun State, South-West Nigeria. They reported that most respondents had heard of the disease and were highly aware of HIV/AIDS. However, only about less than one-third knew HIV could be transmitted from mother to child and more than 95% did not know that they were expected to take a HIV test in the antenatal clinic. Although the majority of these women were multigravidarum most of them had never received the HIV/AIDS information from health care workers. Moreover, the attitude towards knowing their HIV status was poor with more than half of them not understanding its importance. Adeneye et al also found that participants treated in public hospitals had some understanding and had received more HIV/AIDS knowledge than those from private hospitals.

According to Ho and Loke (2003), approximately 60% of Hong Kong pregnant women in their study (n= 406) believed that there was no chance that they could contract HIV, while only 23% would use a condom when having sexual contact. The general knowledge of HIV/AIDS was fairly good among these women, but their specific knowledge on mother-to-child HIV transmission was very poor. Ho and Loke's discussion is excellent as it included the comparison of their findings with the previous studies showing an improvement of HIV/AIDS knowledge among pregnant women in Hong Kong. Moreover, they clarified what was already known and what their study added to the body of knowledge on HIV in pregnant women.

In addition, Rogers et al (2006) surveyed 202 pregnant women who attended a rural antenatal clinic in Karnataka, India and found that most respondents had good knowledge pertaining to risk factors for HIV transmission but with great misconceptions about blood donation. However, nearly half of them did not know the possibility to prevent mother-to-child HIV transmission and less than 5% of them perceived themselves at risk for HIV. Moreover, 43% had refused an HIV test, but the researchers did not explore their reasons for refusal fully. The researchers stated that some of the reasons may be the concern for confidentiality and negative reactions if the participant had been asked to have a HIV test. Kominami et al (2007) also found that the majority of their 401 participants in Dar Es Salaam, Tanzania had little knowledge about HIV in pregnancy and mother-to-child transmission with less than half of these knowing about MTCT and less than 40% knowing about its prevention.

Countering the previous studies that presented the low levels of knowledge about mother-to-child transmission in pregnant women, Shrotri et al (2003) conducted structured interviews on 707 randomly selected pregnant women related to HIV/AIDS knowledge at an urban antenatal hospital clinic in Maharashtra, India. They reported that most of these women had knowledge of general transmission routes as well as knowledge of maternal to child transmission. However, the

majority of the group did not know any methods of prevention. Although originating from a variety of countries these studies may explain why some pregnant women refuse to take part in PMTCT programme.

Rogers et al (2006) and Shrotri et al (2003) conducted their studies in Karnataka and Maharashtra state which were classified as areas of high HIV prevalence in India (Ekstrand, 2003). There were different level of HIV/AIDS between Karnataka and Maharashtra state. The Karnataka study took place in a rural area and the majority of subjects had completed only a primary education while the study in Maharashtra was conducted in an urban area (Shrotri, 2003; Roger et al, 2006). But a more recent study (Rogers et al, 2006) showed a lower level knowledge of HIV/AIDS than the earlier study (Shrotri, 2003). Although it cannot be said with certainty due to the difference in the research setting [i.e. rural vs urban] it seems that there was no improvement of HIV/AIDS knowledge in India while there was an improvement of HIV/AIDS knowledge from studies in Hong Kong (Ho and Loke, 2003).

2.2 Knowledge, belief, and attitude towards HIV/AIDS among migrant women:

Migration and mobility within and across borders affects the growing prevalence of HIV. Research on HIV among migrant populations is quite limited. However, there are a few research studies on migrant workers that were related to HIV/AIDS which were carried out by Bandyopadhyay and Thomas (2002), Fitzgerald et al (2003), and Mullany et al (2003).

Bandyopadhyay and Thomas (2002) reported that migrant women workers in Hong Kong were lack of knowledge regarding HIV/AIDS and its transmission. While most women had intentions to use condoms during sexual experiences, only about a quarter of them had done so during their last sexual experience. However, the researchers did not explore why this had occurred. Moreover, the

study found that information about AIDS, education and communication were not enough for women migrant workers 'needs. In their introduction, the authors provided more information in a literature review about migration and vulnerability to HIV/AIDS not only in Hong Kong but also in many developing countries in Asia and Africa.

A survey study in Tak province, Thailand by Mullany et al (2003) showed that among 725 Burmese migrant workers in eight factories, women had less knowledge than men about the prevention and transmission of HIV. Although, a majority of these women (90%) had heard of HIV/AIDS, most of them misunderstood and lacked of awareness regarding HIV transmission, risk factors and prevention. Moreover, this study showed negligible experience with condoms, with those women who reported ever using a condom amounting to only 1.4%. This could be a reflection of the lack of control these women had and on the likelihood that they play a passive sexual role. We should try to examine the power dimensions of the decision-making and the social or cultural values that support this decision-making to promote safer sex and condom use.

Bandyopadhyay and Thomas (2002), Mullany et al (2003) and Ho and Loke (2003) demonstrated that there was very little condom use among Asian women. Traditionally in Asia, as in other parts of the world, men play a dominant role in most relationships. Moreover, women also have less access to education as well as the mass media. This and local culture may make women more vulnerable to HIV infection. Therefore, gender inequality still greatly affects HIV prevention efforts.

A survey questionnaire which was developed by Fitzgerald et al (2003) demonstrated that the vast majority of 106 female migrant farm workers in rural Northwest Ohio knew that there was no vaccine for HIV infection and that HIV was detected through a simple blood test. However, nearly half of them could not identify perinatal infection as a route of HIV transmission for babies and did not

know that treatment was available to successfully prevent it. This is a very worrying finding. If women do not understand the risk to their babies they will unintentionally neglect to prevent mother to child transmission.

Education is considered the most effective means of preventing HIV infection. Regarding the knowledge of HIV/AIDS, most studies indicated the improvement of the people's knowledge while the knowledge about mother-to-child transmission and its prevention remained quite limited. However, enhanced knowledge of HIV infection does not appear to prevent high risk behaviour.

2.3 Factors influencing the utilisation of PMTCT

Counselling, testing, antiretroviral drugs and infant formula for babies born to infected mothers are provided to pregnant women without any cost in many countries, but some women are unwilling to participate in Prevention of Mother-to-Child Transmission of HIV programmes (PMTCT). Therefore, factors that prevent pregnant women from participating must be identified. There are a number of studies (See table 2_1) that describe factors which hinder and facilitate pregnant women participating in PMTCT programmes.

A number of studies described factors preventing women from participating in PMTCT programmes. In Abidjan, Côte d'Ivoire, Painter et al (2004) used qualitative interviews to ask 27 HIV infected women about their reasons for not participating in antiretroviral prophylaxis for prevention of mother-to-child transmission of HIV. They found that the negative experiences with programme staff or the programme's process were the main reasons. Moreover, more than 50% of these women did not believe their HIV positive test and some participants also stated financial problems and stigma as the barriers for participating in programmes. Peltzer et al, (2005) identified influencing factors for the under utilisation of PMTCT by interviewing 186 pregnant women in a rural district in the Eastern Cape, South Africa. They stated that the majority of these women lacked

physical access to a health facility and faced stigmatisation due to their community's negative attitudes towards people living with HIV/AIDS.

An exploratory qualitative study conducted by Kebaabetswe (2007) aimed to explore the factors involved in decision making to participate in PMTCT programmes in Gaborone, Botswana. They used face-to-face interviews with forty participants including pregnant women who had accepted or rejected the programme, PMTCT health workers and key community members. The hindrance from participation in the programme included fear to know their own status; fear of stigmatisation when seen bottle feeding their infant; lack of support from spouse; and bad attitudes of health workers. With these varied participants, the findings provided rich data with a clear link to the original data which provides authenticity and enables the reader to have an insight into why women choose to accept or refuse to participate in these programmes.

Mitra et al, (2006) explored decision-making about voluntary counselling and testing for HIV by interviewing 12 voluntary counselling and testing providers and 8 migrant women from HIV endemic countries in Ottawa, Canada. Both participant groups identified characteristics of HIV stigmatisation and communication as barriers. However, results revealed the different points of view between both participant groups. The migrant women stated a lack of awareness of HIV screening and treatment services as well as the potential benefits of both to be the main reasons for not participating. On the other hand their health providers identified the women's lack of knowledge about transmission and prevention as a primary need. These different views on voluntary counselling and testing for HIV in health care workers and women could reduce the quality of the programme. These findings stress the need to adapt voluntary counselling and testing for HIV to the need of the target group. The study also asked for improved availability and access to health services, with particular attention to the provision of language services.

HIV stigma is considered a major barrier for prevention, risk reduction, testing, and treatment. Both women and men face stigmatisation for breaking sexual norms for their gender. However, with the gender imbalances, it is easier for women to be blamed if their babies are infected even though the father is often the first to be infected. Stigma does not just impact on individual women, it also obstructs prevention and care programmes.

Some studies state a strong association between acceptance of voluntary counselling and testing (VCT) and partner involvement (Semrau et al, 2005; Kakimoto et al, 2007; Kebaabetswe, 2007). With the aim to test whether a woman's acceptance of HIV testing in a PMTCT programme was influenced by whether she was counselled alone or as part of a couple, Semrau et al (2005), in Lusaka, Zambia found that the acceptance rate in pregnant women who came with partners was higher than that of pregnant women who came alone. Kakimoto et al (2007) evaluated the relationship between partner participation in the mother class and the PMTCT services. From 20,757 pregnant women attending for Antenatal care (ANC) in Phnom Penh, Cambodia, they found that 85.1% of women who attended the class with their partner accepted the pre-test counselling while only 18.7% of those who attended the class alone accepted it. Moreover, research carried out by Kebaabetswe (2007) in Botswana previously discussed also argued that lack of partners' support was one of the barriers to participation in PMTCT programme.

In China, Khoshnood et al (2006) investigated the Voluntary Counselling and Testing [VCT] efficacy and found that pregnant women who had HIV-related knowledge were more likely to accept the testing. In addition, the study of Adeneye et al (2006) previously discussed also indicated health education about VCT was the key facilitating factor for VCT acceptance.

However, it should be carefully noted that the acceptance rate of voluntary counselling and testing in the PMTCT services cannot be an indicator of the

quality of voluntary counselling and testing for HIV or PMTCT services. For example, Delva et al (2006) reported the ineffectiveness of PMTCT programmes in antenatal clinics of the Coast Province General Hospital in Mombasa, Kenya. They evaluated the counsellors' social and communicative skills, duration and topics covered during pre-test and post-test counselling by observing and assessing. The counsellors' skills were high while the duration of antenatal HIV counselling session was much shorter than the standard in developing countries with a mean of 6.6 minutes. This is a very short meeting and calls into question the quality of the counselling. Moreover, this study showed that hardly any effort was being made to prevent HIV infection in women who test negative; only 20% of HIV negative pregnant women were provided with further information about safer sex and condom use. Delva et al (2006) also found that there was a lack of partner involvement in antenatal voluntary counselling and testing for HIV with only one partner from both 66 pre-test counselling and 50 post-test counselling sessions was counselled along with his wife. This is clearly a missed opportunity for promoting HIV prevention among male partners. In addition, Kebaabetswe (2007) also stated that most likely the main factors that increased participation were the availability of free antiretroviral drugs and of free infant formula.

When the rate of mother to child HIV transmission has increased in many countries, there is much evidence about HIV testing and treatment refusal in pregnant women. The recent study of Sherr et al (2006) found that in a four month period in 2002 and a one-month period in 2004, 15% and 9% of pregnant women with an established risk for HIV in three London hospitals refused HIV test respectively. It is important that any HIV positive pregnant women start attending antenatal care and accessing PMTCT programme as soon as possible. With these high percentages of refusal, it is very important for health professionals to discover the reasons for refusal in order to target health messages and interventions effectively.

Table 2.1 Factors influencing the utilisation of PMTCT

Author and Year	Setting	Method	Findings	
			Hinder	Facilitate
Painter et al, 2004	Abidjan	Interview (HIV Infected women)	Negative experience from programme & staff, Disbelief in result & treatment , Costs, and Stigma	-
Peltzer et al, 2005	South Africa	Interview	Lacked of transport and communication to health facility, stigma	Family and community support,
Semrau et al , 2005	Zambia	Interview	-	Partner participation in pre-counselling
Adeneye et al, 2006	India	Survey	-	Health Education about VCT
Khoshnood et al, 2006	China	Survey	-	HIV-related knowledge
Mitra et al , 2006	Canada	Interview	Stigma, Communication, Lack of HIV& prevention knowledge, Inadequate awareness of HIV screening & treatment	-
Kakimoto et al , 2007	Cambodia	Retrospective study		Partner participation in mother class
Kebaabetswe, 2007	Botswana	Face-to-Face interview	Fear of testing and knowing the HIV status, Stigma with infant feeding, Lack of partner's support, and negative attitude of HCWs	Free treatment and infant formula
Kominami et al, 2007	Tanzania	Face-to-Face interview	Lack of family and social support	Knowledge of MTCT prevention

From the findings of this literature review it has become clear that we need to develop an understanding of why women refuse to participate in PMTCT programme and find how to increase level of trust in order to engage them in services.

From literature review, facilitate and hinder factors influencing the utilisation of PMTCT are concluded with a conceptual framework as below (see diagram 2.1 and 2.1).

Diagram 2.1 Conceptual framework of facilitate factors

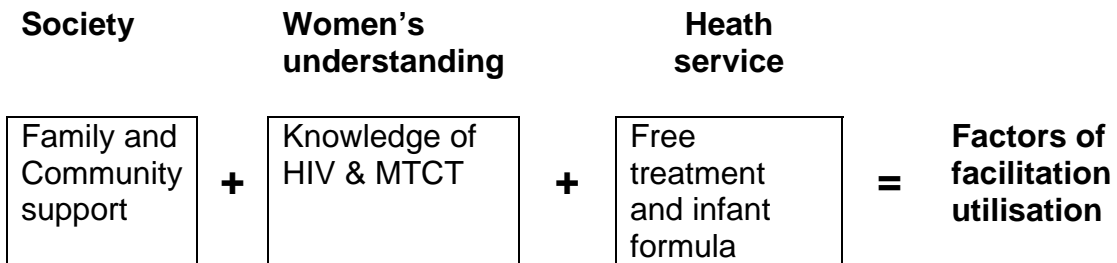
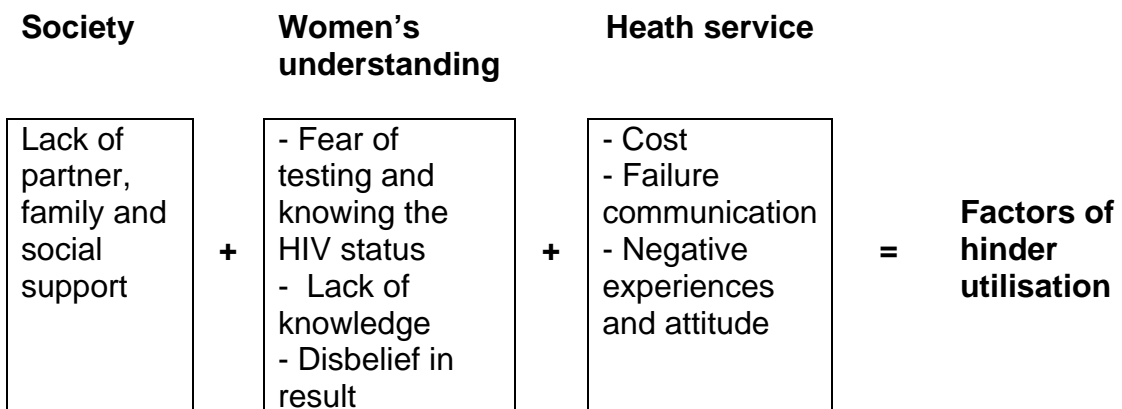


Diagram 2.2 Conceptual framework of hinder factors



2.4 Summary

In conclusion, the major reasons why women have refused to participate in HIV programme and treatment are identified as: stigma; lack of male partners' support; and negative experiences with the programme and programme staff. Therefore, to improve the participation of voluntary counselling and testing, prevention of mother to child transmission, PMTCT and HIV treatment, interventions to reduce HIV stigma, the quality of antenatal voluntary counselling and HIV testing services need to be developed. Moreover, we need to develop an understanding of women's perspective or experiences about voluntary counselling and testing for HIV.

In addition, the levels of understanding generally about HIV seem to be fairly high but women do not always have control to prevent themselves becoming infected. However with better education women have the opportunity to reduce the risk for their babies. Therefore, we need to find a way of targeting those most at need and identifying strategies to encourage them to accept testing and treatment aimed at preventing mother to child transmission. Although women had been under recognized in the literature on HIV/AIDS in the past, increasing numbers of studies have, more recently focused on the lives and experiences of women living with HIV/AIDS. Areas of research in which the study of women and HIV continues to be noticeably lacking include HIV and migrant women. There is a pressing need to identify and understand the socio-economic, cultural and structural factors that enhance and contribute towards HIV transmission in women in general and migrant women in particular, as migrant women face problems of women and problems of migrants.

The incidence of HIV/AIDS among minority or migrant women appears to be growing at an alarming rate, but there is little or no knowledge about how these women related with HIV, especially in relation to accessing HIV /PMTCT programmes when they are pregnant and their decision making to accept or

reject participation in prevention programmes of mother to child HIV transmission. Their knowledge about HIV testing and treatment in pregnancy should be used to influence the way in which health care workers individualise care to meet the needs of this vulnerable group.

Part 2: Methodology and Method

Chapter 3

Methodology and method

This chapter describes my selection of research methodology. It clarifies the choice of design and methods and identifies the research aims and research questions; data collection process including access to and recruitment of participants as well as the interview process. Ethical considerations are illustrated. It ends with an explanation of the process of data analysis.

This study aims to explore the experience of Burmese migrant pregnant women when accessing the Prevention of Mother to Child Transmission of HIV (PMTCT) programme and to investigate their decisions regarding HIV testing and treatment. With these aims, this study emphasises understanding the meaning of these women's experiences and their individual decision making. It is not only to hear these women's own perspective but also needs to explore how their experiences are interpreted according to the perspective of health care workers.

3.1 Selecting a qualitative research approach: Using a grounded theory approach

When exploring human experience, qualitative research is the preferred methodology, since the quantitative approach is unable to fully illustrate human experiences (Speziale and Carpenter, 2007). Qualitative research is able to

“provide an in-depth and interpreted understanding of the social world of research participants by learning about their social and material circumstance, their experience and histories” (Ritchie & Lewis, 2003, p.3).

Moreover, LoBiondo-Wood and Haber (2006) suggest that qualitative research is suitable when exploring the meaning of experience in human beings and is

particularly suitable for health issues. They also state that qualitative research is helpful for nurses to understand their clients. Therefore, a qualitative research method fits best with the aims and directions of this research.

Moreover, there is little or no knowledge of Burmese migrant women's experience. Many qualitative studies focus on phenomena about which little is known. LoBiondo-Wood and Haber (2006) stated that an exploratory design or a qualitative study is usually applied to exploring an area in which little or no literature.

Of the many different approaches of qualitative research, phenomenology, ethnography and grounded theory approaches are particularly influential in nursing (Polit and Beck, 2004). However, decisions about which is the best methodology to obtain and interpret the data depends on the particular experience that is studied and the research questions are as important as the discipline when choosing an approach (Nieswiadomy, 2008).

A phenomenological approach focuses on individuals' understanding of their experiences and how they express them (Munhall, 2007). The researcher's aim in phenomenology study is to gain understanding of the participants' world (Polit and Beck, 2006). Phenomenology is an approach which is used to explore the specific experience of individuals particularly during life changing events. However, the experience of the PMTCT programme by Burmese migrant women and their decisions is not all about an everyday life experience that can be explored and understood by the phenomenology approach (Polit and Beck, 2008) but is about accessing and decision-making of HIV programme. Moreover, with the nature of the participant group it would not be possible to ensure that the researcher was able to maintain contact over a period of time with migrant women because of their tendency to move frequently. Significantly, in term of flexibility, phenomenology method is not sufficiently flexible to explore new knowledge in multiple participant groups as my study need to investigate two

participant groups; Burmese women and health care workers as previously mentioned. Therefore, the phenomenological approach was discounted as an appropriate method to explore this experience.

The ethnographic approach focuses on how the people interact in their social group or setting and it is not about individuals (Roper and Shapira, 2000). In ethnography questions “are asked about life ways or particular patterns of behaviour within the social context of a culture or subculture” (LoBiondo-Wood and Haber, 2006: page 159). Furthermore, ethnography typically refers to fieldwork and the main method is participant observation (Polit and Beck, 2006). With the aims of this study, there were two key reasons for not adopting an ethnographic approach, one pragmatic, and the other ethical. If the ethnographic method was selected to explore the access experiences to the PMTCT programme the researcher would need to observe the whole process of the programme which would take a long time per participant. Although the observation takes place in the natural setting, observation by the researcher can change the real dynamic experience that occurs in a counselling room or in the antenatal service. Moreover, to understand the issues fully, observations would have to cover a much wider timeframe, possibly even going back into Burma to include the events that shaped their perceptions. It is practically impossible not only for the researcher due to time limitations within a PhD study, but also for these migrant women as in many cases they cannot go back to their home country. Importantly, in the counselling process the reaction, feeling and information given from both health care worker and pregnant women can be modified if the researcher appears during counselling time. Especially in post test counselling it may be inappropriate and unethical to observe when the participant is being given their HIV result.

Grounded theory approach allows discovery of the participants' points of view (Glaser, 1992) and all types of research questions can be addressed by it (Charmaz, 2003). Green et al (2007: Page 474) also state that the data

generated from grounded theory studies can develop not only theory but also a 'general abstract of people's interaction or action' including explanation of its process. There is little or no knowledge of these women in the Thailand-Burma border provinces regarding their access to the HIV programme and their decision-making to accept or reject HIV testing and/or ARV prophylaxis. Therefore, grounded theory is useful for areas of investigation where little is known or understood (Strauss & Corbin, 1998; Grbich, 2007; Munhall, 2007). Moreover, as a researcher, I was new to qualitative research and grounded theory has been recommended for the beginner qualitative researcher (Munhall, 2007). Therefore, a grounded theory approach was selected to underpin the design for this study.

3.2 Grounded Theory

Grounded Theory approach was initially developed by Glaser and Strauss (1967), its objective was to close the gap between theory and empirical research and to develop theory derived and based on data (Glaser and Strauss, 1967). They suggested that new concepts or theories should be developed from research data and the researchers should not attempt to fit the data into the established theories (Charmaz, 2006). Thus the grounded theory approach has been described as

'a qualitative research method that uses a systematic set of procedures to develop an inductively derived grounded theory about a phenomenon' (Strauss & Corbin, 1990: p 24).

Grounded theory has been explained as useful for developing new areas of knowledge both when nothing is already known and where a new conceptual knowledge is needed to answer a question.

After their original publication in 1967, Glaser and Strauss disagreed on practical aspects of grounded theory and developed different approaches to data analysis (Charmaz, 2006; Polit and Beck, 2006). The Glaser method uses the open-

ended initial and focused coding while the Strauss approach uses a three-stage coding process including axial coding (Charmaz, 2006). The Straussian coding process has been criticised for fragmenting data. Grbich (2007) argues persuasively, that this may lead to the loss of the bigger picture of the phenomenon. However, in exploring the experience of a small defined group, it is hoped that the big picture will remain in focus. Moreover, Strauss (1987) avoids reviewing the literature until categories have emerged while Glaser (1992) starts earlier when the first category has been identified.

Although there are many different processes between Glaserian and Straussian approach, the defining components or characteristics of grounded theory practice and method include

“simultaneous involvement in data collection and analysis, constructing analytic codes and categories from data not from preconceived logically deduced hypotheses, using the constant comparative method which involves making comparison during each stage of the analysis, and advancing theory development during each stage of data collection and analysis” (Charmaz, 2006: page 5).

Moreover, ‘delaying the literature review until after forming the analysis’ is also one of the characteristics of grounded theory (Charmaz, 2003: page 83). It is suggested that early engagement with subject literature may interfere with coding (Urquhart, 2007) as this process can be directed by previous knowledge (Backman and Kyngas, 1999). Glaser (1978) suggests that the researcher should have as few ‘preconceived ideas’ about the phenomenon of research as possible. This is a ‘valuable’ as well as a ‘problematic’ point (Charmaz, 2006: 165) when applied in a real research study which will be illuminated in the following section about theoretical sampling and coding and theoretical sensitivity.

The concept of avoiding a literature review was generally suggested by experienced researchers (Bryant and Charmaz, 2007) who have extensive knowledge. Their sophisticated knowledge and experiences are sufficient to

develop the proposal and to solve problems in the research field. Nevertheless, for the novice researcher, Backman and Kyngas (1999) argue that with the grounded theory approach, previous knowledge is required to outline the research phenomenon. Hutchison (1993) also coincides that for increasing awareness of the existing knowledge and identifying gaps, the literature should be initially reviewed. Moreover, to identify and to clarify the research question, a preliminary literature review in the early research process should be done (Charmaz, 2006). In addition to these arguments it is also important to consider the ethical implications. It would certainly be unethical to consider conducting health research in an area where it was not needed. Therefore the initial literature review literature review provided reassurance that this area had not been addressed in previous work in the Thai context. Therefore, I chose to review the literature in order to clarify the extent and level of existing knowledge relating specifically to the experiences of migrant women in Thailand.

3.3 Grounded theory for this study

I used the strategies of grounded theory modified by Charmaz (2006) to carry out this study. Unlike the classic grounded theory written by Glaser and Strauss (1967), Charmaz (2006) uses terms which are more straight forward and easy to understand. It also provides direction on how to apply grounded theory as a research process. Moreover, Charmaz (2001, 2005, 2006) demonstrates many examples of the data analysis processes, and this is useful for a novice researcher. She also emphasises the flexibility of the grounded theory approach and its systematic method including involvement in data collection and analysis (Charmaz, 2006).

In order to increase or aid understanding about Charmaz's developed strategies, a brief summary of them will be given. These strategies include data-gathering, data coding, memo-writing, theoretical sampling and reconstructing theory. Although these processes are not really linear, they usually begin with gathering

data and finish with writing up the analysis and reflection on the whole research process.

After defining the research problem and opening research questions, the decisions about how to start and how to choose the approaches to data-gathering are considered. Within Grounded Theory the researcher collects and analyses data simultaneously. Charmaz (2001) suggests that using early analysis when collecting data can help the researcher get detailed and full data by building further questions into the following interviews with later participants. Charmaz' approach to analysis consists of a two-step data coding process. The first step is line-by-line and the second step is focused coding. Researchers are encouraged to using action codes such as 'having', 'seeing' or 'avoiding'. Coding is a process to create the definition of the data which aims to identify and create categories while ensuring that the researcher does not close down the theoretical direction too early. She follows the Glaserian approach by keeping initial coding and does not use axial coding. The next strategy is memo-writing aimed at the construction of conceptual analysis, the necessary step between data collection and writing draft papers. After developing some categories, theoretical sampling is conducted to refine the researcher's emerging theoretical ideas. It can define the categories and their properties clearly by sampling to develop each category's properties until no new properties emerge. The last strategy is reconstructing theory with integration of the theoretical framework (Charmaz, 2006).

3.4 Design and method

Research Question

Grounded theory does not begin with research questions, but with a statement of purpose (Denzin & Lincoln, 2000), this statement should, as was noted by Glaser, ask 'What is going on here?' (Schreiber and Stern, 2001:13). Therefore

before moving on to develop research questions I developed a statement of purpose as follows.

This study aimed to explore the health care experiences of pregnant Burmese migrant women in the northern parts of Thailand, including their decision making about HIV testing and treatment.

The flexibility and freedom to explore the participant's experiences are the characteristics of grounded theory research questions (Chamaz, 2006).

Accordingly, three primary research questions were derived:

1. What are the experiences of Burmese pregnant women in Antenatal clinic and in HIV counselling section in the Thailand-Burma border provinces?
2. What makes Burmese pregnant women accept or refuse to participate in the PMTCT programme or HIV testing?
3. What might be the most appropriate way forward in the design of an intervention programme for screening and counselling for migrant pregnant women to participate in the PMTCT programme or HIV testing?

The experiences both in antenatal clinic and in HIV testing are the interactions between health care workers and pregnant women. The counsellor and information given in the counselling session have the potential to influence these women in their decision-making. Moreover, the ways to develop health care approaches concerning these issues rely heavily on the health care workers who care for the women. Therefore, this study needed not only to explore the women's own perspective but also had to learn about the experiences of the health professionals and how they interpret the current situation.

Researcher's personal stance within the research

I have grown up, studied, worked and lived in Thailand – Burma border provinces (for more than 30 years). Therefore, it is not only my life experiences but also my work experience that influence why I have an interest to study this topic. From my individual observation, there were many Burmese migrants in the northern part of Thailand. Almost all of them worked (illegally) as labourer in farms and factories and were poor. Burmese migrants especially woman had a particular style of makeup and dress that distinguished them from others.

I worked as a lecturer in Nursing Colleges in the northern part of Thailand for 12 years before commencing PhD studies. During supervising time as nursing instructor, I met many migrant women attending Antenatal care clinics, and admitting for labour delivery. Migrant clients had not been included as a case study for nursing students as they could not communicate sufficiently well. They had been excluded from normal group activities or health education. Therefore, how they solved their health problems and the quality of the health care they received had been questionable.

The research area and settings were all fairly familiar to me from my previous work as nurse-midwife and lecturer. This insider knowledge was helpful in gaining access to the areas, to the health care workers or staffs and to the women participants.

Setting, participants and methods

Setting: The settings for this study were antenatal care units in hospitals run by the Ministry of Public Health in Chiang Mai, Chiang Rai, Tak and Mae Hong Son, which are the Thailand-Burma border provinces in the northern parts of Thailand. The reasons for selecting these hospitals and provinces are that the HIV

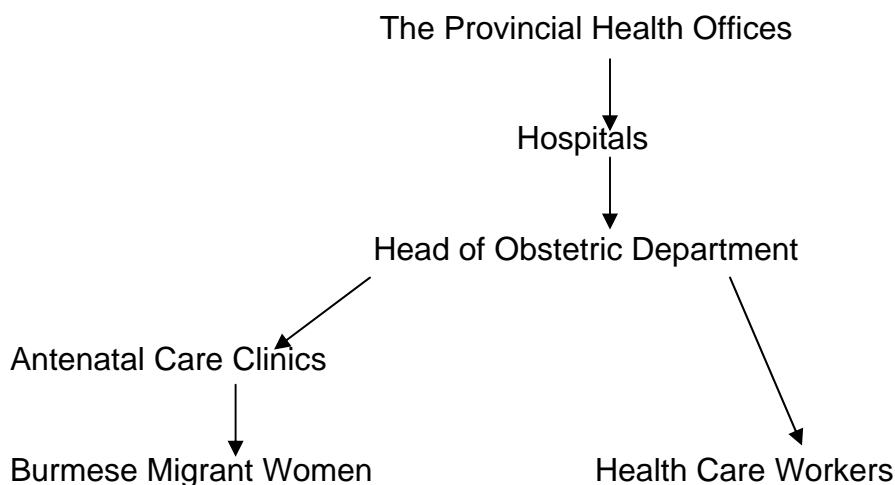
prevalence and/or the Burmese migrant population in these areas are extremely high.

Participants: Within grounded theory studies, sampling is purposive not random. The participants in this qualitative study were pregnant Burmese migrant women and the health care workers who care for them. The study was divided into two phases of data collection and began with pregnant women in phase I and followed by health care workers in phase II.

Access to the setting and participants

After gaining ethical approval from the Research Ethics Committee of the faculty of Health, University of East Anglia, the formal letter and research proposal were sent to Chiang Mai, Chiang Rai, Mae Hong Son, and Tak provincial health offices asking for Ethical Approval and permission to access staff and patients at the hospital. I then asked for co-operation from each hospital by sending a formal letter to the director of the hospital. Thereafter, I contacted the head of obstetric department in each hospital directly to explain the purpose and method, and clarify the timetable of work. Figure 1 shows the structure of the settings for the research.

Figure 3.1 The structure of the health care settings in the study



Meeting the nursing and health care staff of the obstetric departments was necessary to explain the research and its objectives to potential participants, to provide any additional information as requested and to recruit them to be participants. Moreover, in this meeting, the health care staffs of antenatal care units were asked for their co-operation in recruiting Burmese pregnant women during Phase I of the research and for their own participation in the interviews and focus group in Phase II. These health care staff cared for these women and my study had the potential to affect their service or routine work. Moreover, they were able to help me as the researcher to conduct the research in the field. Therefore, gaining their trust by stressing the significance of the potential research findings and demonstrating the significance of their participation and co-operation were an important part of the first meeting.

Recruitment Process

Accessing Burmese migrant women: participants in Phase I

Phase I of data collection took place in January – March 2008. Health care workers who have a duty to care for the pregnant migrant women were approached and asked to identify suitable women who could be approached by the researcher. The ANC record was used to confirm their compliance with the criteria for inclusion (see below) and the date to approach potential participants so that I could arrange the time to meet them during their next follow up date.

Only those who undoubtedly fulfilled the inclusion criteria and had no problems in terms of the exclusion criteria were approached by me and invited to participate in the study. These women lived either in refugee camps or settled in the community. For those living in a refugee camp, an additional letter asking for permission was sent to the director of refugee camp. According to the political and legal situation, refugees have hardly any rights to take part in outside activities by themselves (Jacobsen, 2003). Therefore, they needed to be

accompanied and permitted by the authorised person called a guardian. All participants in this group were asked to give their consent either in writing if they were literate or by thumb print, the normal way of giving a signature for illiterate people in Thailand.

Inclusion criteria

In order to be included in the study the women had to be

1. Burmese migrant women living in Thailand
2. Pregnant or had been pregnant and had either accepted or refused the HIV screening test and ARV prophylaxis in PMTCT (Prevention Mother-to-Child transmission of HIV) programme within the last year.
3. Able to speak Thai sufficiently well to communicate with the interviewer.
4. 20 years old and over (the legal age of consent in Thailand).
5. Volunteering to participate in this study

Exclusion criteria

Acutely ill women (physical as well as in terms of mental health) or women with increased levels of vulnerability were not be approached.

Once identified as a potential participant by the health care worker, I approached them and asked to give them information about the study. I explained who I was and what the study was about, using the participant information sheet (see appendix A).

I explained that their involvement in the study would include being interviewed by me in a quiet place, usually in the antenatal clinic. They were told that i wished to audio record the interview. They had some time to consider their involvement in the study and informed of their right to refuse to take part or withdraw if they so wished.

Those who agreed to be interviewed gave consent either in writing or by thumbprint. We arranged a date and time for interview.

Although none of the potential participants who met the inclusion criteria refused to participate in my study their reasons to accept were unclear. I had no idea of how many potential participants could speak Thai fluently. Therefore, the local health professionals who cared for them helped to screen who could speak Thai and introduced them to me. The reasons that they accepted involvement in my study might be because of the health care workers' direction. However, through the course of the interviews they willingly disclosed details of their lives and experiences. Therefore, it is clear from their interviews that they were voluntarily giving information.

Accessing health care workers: participants in Phase II

I approached the health care workers with responsibility for pregnant Burmese migrant women in their place of work and, if they expressed an interest, provided them with an overview of the study. They were also given an information leaflet. Following a period to consider their participation (not less than 72 hours) they had an opportunity to ask any questions and, if they agreed, to consent. Phase II took place during 15th November 2008 – 15 January 2009.

Although accessing health care workers was not complicated, consideration needed to be given to schedule their interview time so as not to interfere with their work load. Moreover, for the setting up of the focus group, careful timing was needed to include time slots when as many professionals as possible could attend between appointments or clinic times. This in practice proved to be very difficult.

I had expected to recruit health care workers (antenatal care nurses, HIV programme counsellors, and obstetric physicians) with not less than one year of experience of caring for these women within PMTCT programmes. I hoped to

include one member of each professional group in each setting. Although five doctors agreed to participate in my study only three doctors had time and could come for interview. This is due to their work load and the political situation in Thailand at that time. The international airport in Bangkok was blockaded by protestors who disagreed with the current government. One potential participant in the doctor group was obstructed in Bangkok and could not come back to the setting for our interview appointment.

Furthermore, there were no separate counsellors for pregnant women in the three hospitals because nurses in antenatal care clinics worked as counsellors. I did not plan to interview migrant volunteers who worked as translators or coordinators but many health care workers highlighted that these persons are the key informants linking between them and migrant women. So for this reason I included 3 migrant volunteers in the second phase.

3.5 Ethical considerations

The Burmese migrant women were at the centre of this study were doubly vulnerable, firstly for being women but also for being migrants. Moreover, when exploring the participant's feeling and reflection acting with sensitivity and diplomacy are required (Holloway and Wheeler, 2002). Therefore, not only regular ethical issues were considered but also an array of sensitive issues related to status of the women as refugees, some of whom were illegal. Formal ethical approval was sought from the Research Ethics Committee of the Faculty of Health, University of East Anglia and the Thai Ministry of Public Health (hospitals). The following ethical considerations were taken into account.

3.5.1 Information and consent

The research participants have the right to be informed about the study in which they are involved. Kylma (1999) states that the information sheet is suggested to be able to motivate, inform and welcome potential participants. Researchers

need to explain clearly the purpose of the research, who commissioned it, how the respondent was selected for the study, and what the methods are (Speziale and Carpenter, 2007), so that participants can make an informed choice about whether or not to take part.

The purpose of a consent form is to record what has been agreed between the researcher and participant (Speziale and Carpenter, 2007). Polit and Beck (2007, p 176) state that “Informed consent means that participants have adequate information regarding the research, are capable of comprehending the information and have the power of free choice”. As Marshall (2007) suggests, clear and simple language that can be easily understood must be used to enable informed consent. Moreover, around 50% of the Burmese women are illiterate. Therefore two versions of both the consent form and information sheet were prepared – one in Thai and another in Burmese. The language used was carefully considered to ensure that it was clear unambiguous and used simple terms. I also arranged a version for potential participants who could not read so that it could be read to them.

The information sheet, consent form and interview schedule were translated into Thai by myself and the translations were checked and verified by Arjan Sakorn Reunklai, a lecturer in Department of English at the Faculty of Humanities, Chiang Mai University. The information sheet and consent form for the Burmese women were translated into Burmese by a university lecturer who is a native Burmese speaker.

However, as the research progressed it gradually did become clear that only few women could read the Thai consent form and information sheet and none of the Burmese women could read written words in the Burmese version. This happened because the migrants were not Baman-Burmese which are the largest single ethnic group in Burma and whose language is the official Burmese

language. As a result, reading out the Thai information sheet and consent form to most women was the most practical way of giving information.

Theoretically, all participants were then given time at least 72 hours to consider whether they wished to participate and to ask any questions. However, as there were 6 settings in my study and they were all located far away from my base I had to ask local health care workers to introduce the study to potential participants and give them the information sheets to read within one week before I met the potential participants. Women were given the information sheets to take away with them to show to their husbands or employers so that they had the opportunity to discuss participation or otherwise if they wanted. One or two weeks later (depending on their gestation) I met the women when they came to attend the following antenatal care service, read the information sheet to them, asked them whether they wanted to participate in my study, emphasised their right not to participate or to withdraw from the study at any time, took their consent before I conducted the interview. The consent form was read to illiterate participants and all participants in this group were asked to give their consent either by signing their name if they were literate or thumb print as the normal way of giving a signature for illiterate people in Thailand.

The interviews were all planned to take place at a time when women would be attending for routine antenatal care therefore there was no need to consider payment of travelling expenses for them. Although they did have to extend their time away from work to be interviewed, the budgetary constraints of the PhD student meant it was not possible to offer them compensation for their time. Neither the women nor the health care workers asked about compensation for time spent taking part in the study. However, they were offered refreshments during the interview.

3.5.2 Anonymity and Confidentiality

The very nature of data collection in a qualitative investigation makes anonymity impossible. The personal one-to-one interaction during the interview process allows the researcher to know the participants (Speziale and Carpenter, 2007). Because of the sensitivity of HIV and AIDS in Thai society, all data produced for this study was anonymous and pseudonyms were used in the report of the findings. The identity of the participants was known only to myself and I kept these details in a password protected file on the central UEA computer hard drive. Moreover, for some participants, their identity as illegal immigrants is already known due to their registration with the Thai Health Service. Nevertheless, in terms of this research their identity and refugee status were protected by the same process as their participation in this study.

All data were kept in secure storage [UEA computer hard drive] when not in use, during the lifetime of the study. After analysis, report and acceptance of the thesis by the university, all tapes will be destroyed and all transcripts will be stored in electronic form for 5 years.

While research questions in other methods are fixed and prepared with ethical consideration before conducting data collection, most question in grounded theory approach are initially unknown. Olesen (2007: 425) recommends to consider ethical issues with 'unexpected interactions from data gathering and analysis'. As a result, ethical considerations should be thought out not only at the beginning but continue all over the data collection process and these are explained in the following section. They are raised to ensure that my participants would not be threatened with the possibly unexpected questions which might make them uncomfortable and unwilling to continue in the study.

3.5.3 Debriefing

Debriefing is the process of providing participants an opportunity to ask question and sharing participants' perception about involving in the study and also sharing

the result with participants after research session (Brockopp and Hastings-Tolsma, 2003). I gave information about research process to my participant by using information sheet before each interview and brief discussing about interview and giving them to ask question.

3.6 Data Collection

A grounded theory methodology was used to drive data collection. The data were derived from interviews, researcher field notes and the women's antenatal care record. Interviews and focus groups were used to collect data from health care workers.

Data were collected by the following strategies:

The first phase: January – March 2008

- Potential participants were identified by using outpatient cards and antenatal records.
- Potential participants were given all the necessary information, were invited to join the study by the researcher or health care workers and then were asked for consent
- Participants were asked about their access experience to HIV programmes and the reasons why they accepted or rejected testing and treatment for HIV when pregnant
- An interview took 30 to 45 minutes and all interviews were audio-recorded, transcribed verbatim and translated into English.
- The interview locations included antenatal care units or another mutually agreed locations such as a counselling room or a hospital's garden.

Non-participating women received healthcare in the same health-centre, therefore identifying them was not problem. However, three potential participants who refused to have HIV testing in one setting did not participate in my study as they were living in a refugee camp and their guardian did not give them

permission to participate in my study. Therefore, no women who had refused HIV testing took part in my study. Significantly, their refusals of HIV testing were also related with their guardian's authority as the interviews from health care workers in the second phase revealed that they did not make the decision by themselves (See section 6.2).

The second phase: November 2008 – January 2009

- The health care workers who work in the PMTCT programme and care for these migrant women were invited to be interviewed in an attempt to understand their interpretations of the reasons why the women accept or reject testing and treatment for HIV in pregnancy and to explore any problems the health care workers encounter when dealing with these women.
- An interview took approximately 30 - 60 minutes; they were audio-taped, transcribed verbatim and translated.
- All interview participants were invited to take part in focus group.
- The interviews and focus group took place in the hospitals where the participants work.

Any non-verbal data obtained during the data collection phase were included into the researcher's field notes.

3.6.1 Preparing for data collection

Before the interviews began, the question of how I dress when interviewing the participants had been considered because appearance can influence the first impression between interviewer and participant. The idea to dress neutrally in the way similar to that of the respondent was useful when interviewing health care workers. I decided to wear the familiar uniform of a nursing instructor. However, for the Burmese pregnant women this principle could not be applied because in a country such as Thailand, the people respect the health care personnel. There is a sense that the uniform engenders respect therefore it might be more appropriate to wear uniform. I could have worn informal dress in the way similar

to the women to make them feel comfortable and relaxed, but this could have raised doubts in the women's minds about who I was. They may not have considered me as a serious person with the qualifications to interview them. Therefore, the use of a uniform seemed to be appropriate in this circumstance.

I wore the health care uniform and was able to encourage and motivate the Burmese pregnant women to participate in the study without problems. Wearing the uniform helped me to project to these women a picture of myself as a serious researcher.

To ensure accuracy all interviews were audio-recorded. Before, during and after the interview I took field notes as a supplement to recordings. I used the different interview schedules between both participant groups, both in Thai but with a different level of language. The questions for the Burmese migrant pregnant women were more informal and easier to understand than those intended for the health care workers.

In addition, with my previous role as a lecturer in Nursing Colleges in the northern part of Thailand for 12 years, it could be predicted that some health care worker participants would be my former students. I needed to prepare for dealing with this issue to avoid misunderstanding of interview aims. My questions had the potential to make them and other health care workers feel that they are going to be checked or evaluated for the quality of their work or the services they provided or that their knowledge was being assessed. As a result, all research aims were explained to them before the interview process. I worked hard to gain their trust and to ensure that they felt at ease and able to talk openly about their experiences. This ensured that data was based on the real world of their working experiences and the audit trail demonstrates the authenticity of their experience.

Furthermore, as my findings relate to the services they provide, the health care workers were encouraged to ask for the results of my study and to use them to

improve their service delivery. However, to ensure data privacy and confidentiality and other ethical considerations, the research report to be shared with them in due course is fully anonymised.

3.6.2 Conducting Interviews

There are several interview methods in qualitative research. Hence, considering which type of interview fitted my study (grounded theory method) was important. Strauss, Glaser and Charmaz discuss the data analysis in a great deal of depth. Yet there is much less emphasis on the method of collecting the data. Therefore, the researcher needs to consider carefully the way in which data can be obtained. The way in which an interview is conducted can have a large impact on the quality of data. Although the interview method in grounded theory approach is not emphasised as much as data analysis (Wimpenny and Gass, 2000; Allan, 2003) there are a number of arguments.

Chenitz and Swanson (1986) suggest that grounded theory interviews are uncharacteristic and Duffy et al (2004) elaborates that for grounded theory research unstructured and semi-structured interviews are both well suited for data collection. She also argues that analysis of the data from unstructured interview offer additional direction more than data from semi-structured interview. Charmaz (2001) only states that the in-depth interview and open-ended questions are the most suitable techniques for grounded theory method. She advocates using qualitative interviews for addressing individual experiences in grounded theory studies as it provides an open-ended, in-depth exploration of the participants' experiences. With open-ended questions, the researcher can focus the interview to 'invite detailed discussion of topic' (Charmaz, 2006: page 26). However, she also outlines clearly how to frame and order the grounded theory interview questions (Charmaz, 2001; Charmaz, 2006). The range of interview topics is narrowed for gathering specific data. In this study, semi-structured interviews with in-depth and open-ended questions were used for

collecting the data and the interview questions enabled the researcher to focus on the women's experience and to explore their ideas.

Grounded theory questions need to define and explore the participants' experiences with the early questions attempting to encourage participants to tell their story (Charmaz, 2001). Therefore, my first questions asked about the participants' story of their experience in antenatal care and these were followed by the questions exploring their experiences in HIV counselling and testing section. The following questions would be adapted to fit with their individual experiences. The ongoing grounded theory data analysis influenced the process of data collection and subsequent questions.

3.6.3 The use of prompts

The advantage of grounded theory interview questions is that it can be adjusted to suit individual participants as they need to be adapted by following the previous answers revealed by participants themselves. However, there were practical problems which arose during interviewing my participants due to the grounded theory method itself and my participants' characteristics.

Interviewing in grounded theory study needs not only communication but also particularly needs theoretical sensitivity defined as 'the ability to immerse themselves in the data' (Cluett and Bluff, 2006; page 164). It includes the ability of the researcher in "seeing possibilities, establishing connection and asking questions" (Charmaz, 2006; page 135). This theoretical sensitivity can be enhanced from both knowledge and experience (Strauss and Corbin, 1998). Therefore, for me as a novice researcher a preliminary literature review was needed to provide insight for theoretical sensitivity.

The stimulation question is the main characteristic of grounded theory data collection. Additionally, my study is related with HIV/AIDS which was defined as a sensitive issue (Renzetti and Lee, 1993; Kylma et al, 1999). As a result, during

the interview, it was not only considering what the next prompt question would be, but also how to ask questions properly, especially the issues surrounding HIV/AIDS in the context of, for example marriage life, sexual behaviours or living with a HIV positive diagnosis.

I was able to use prompts to encourage the participants to continue with a story or explanation or additional questions to help them clarify their thinking and for me to understand fully their experiences. In the early stage of each interview, I as an interviewer, attempted to mainly listen to the participants' story as suggested by Glaser and Strauss (1967). Nevertheless, many of the Burmese women had language difficulties. This and a general lack of confidence in many of the women were the barriers to applying this strategy.

In my study, I faced the unexpected emotional responses which occurred when I needed to ask my participants questions regarding sensitive issues such as being HIV positive or women who had an HIV positive husband or who had more than one husband. For example, an HIV positive woman was crying when telling about her husband who left her after being informed her HIV positive result. Emotions occurred unexpectedly included sobbing, watery eyes, and silence.

Long pauses occurred to clarify questions and answers and this did limit the effective interview time set aside to conduct the interview and decrease these participants' confidence to reveal their data. This would influence the quantity and quality of the data collected. However, Renzetti and Lee (1993: page 168) emphasise that accepting them as 'peers' with their experiences can empower participant in research process. Therefore, giving the participants more time, as well as patiently explaining any questions and waiting for the answers helped to gain more significant data in greater depth and allowed experiences to be revealed by the women who had considerable communication limitations.

3.6.4 Doing sensitive research

My study is related with HIV/AIDS which was defined as a sensitive issue (Renzetti and Lee, 1993; Kylma et al, 1999). As a result, during the interview, it was important not only to consider what the next prompt question would be, but also how to ask questions properly, especially the issues surrounding HIV/AIDS in the context of, for example married life, sexual behaviours or living with an HIV positive diagnosis.

I faced the unexpected emotional responses which occurred when I needed to ask my participants questions regarding sensitive issues such as being HIV positive or women who had an HIV positive husband or who had more than one husband. For example, a woman was crying during interview when telling me about her husband who had left her after being informed of her HIV positive result. Emotions occurred unexpectedly included sobbing, watery eyes, and silence.

Long pauses occurred to clarify questions and answers and this did limit the effective interview time and decrease some of the participants' confidence to reveal their thoughts and feelings. This could have influenced the quantity and quality of the data collected. However, Renzetti and Lee (1993; page 168) emphasise that accepting them as 'peers' with their experiences can empower participants in the research process. Therefore, giving the participants more time, as well as patiently explaining any questions and waiting for the answers helped to gain more significant data in greater depth and allowed experiences to be revealed by the women who had considerable communication limitations.

3.6.5 Theoretical sampling and saturation for the study

Draucker et al (2007) indicate that sampling in grounded theory begins with purposive sampling and when concepts begin to emerge sampling will move into theoretical sampling. Similarly, Charmaz (1990, 2006) suggests researchers to begin theoretical sampling when they have initial categories to develop.

Theoretical sampling is a key strategy in grounded theory method. Charmaz (2006) indicates that obtaining data for explicating the categories is the purpose of theoretical sampling. Using theoretical sampling is suggested when using grounded theory as a research method and this offers the variety of research samples (Glaser, 1978; Backman and Kyngas, 1999). Glaser and Strauss (1967: page 45) clarify that theoretical sampling is

“the process of data collection for generating theory whereby the analyst jointly collects, codes, and analyses his data and decides what data to collect next and where to find them, in order to develop his theory as it emerges”.

In the early stages of my data collection, I used purposive sampling for the initial recruitment to identify the most appropriate participants according to the inclusion criteria and find participants who were available. Charmaz (2006) calls the sampling in this stage ‘initial sampling’ and states that initial sampling in grounded theory is ‘where you start’, whereas theoretical sampling directs ‘you where to go’ (Charmaz, 2006: page 100). Thereafter, for example, when I was analysing how these Burmese women experienced antenatal care clinic and HIV testing I got the first category ‘experiencing language difficulties’ from the women who had been in Thailand for a long time (more than 10 years). I attempted to find participants who had been in Thailand for varying durations to explore whether language difficulties was a true category. This is another form of theoretical sampling.

I moved to the other setting after I felt I had reached the saturation point and employed initial sampling in each setting. However, my theoretical sensitivity was generated from the previous collected data. Although sampling in six different settings in my study is not conducting theoretical sampling it can “reflect empirical distributions or situations” (Charmaz, 2006: page 101).

Generating sufficient data that can clarify the research question is the key of grounded theory. Auerbach and Silverstein (2003) suggest that enough data will be generated by an appropriate sample size that 'needs to be representative' (Stern, 2007 page 117). For grounded theory study, many researchers discuss ending data collection at the point of achieving 'saturation'. This is the point when researcher discovers no new data from new interviewees. However, this is not always easy to identify and there is a temptation to continue in case new data will be discovered in the next interview.

Before conducting data collection, I expected 25 +/- 5 interviewees to reach the saturation point as this point is considered to occur between 10 and 30 interviews (Thomson, 2004). Nevertheless, collecting and analysing data simultaneously enables a clearer idea of when data saturation is reached (Hood, 2007). At last, I conducted 38 interviews with Burmese women group and 26 interviews with health care workers.

3.6.6 Focus group

A focus group is defined as a small group of 6 – 12 people who discuss a particular issue (Green and Thorogood, 2004) under the researcher's direction (Stewart et al, 2007). It is suggested that the suitable duration for conducting a focus group is one to two hours (Kitzinger, 2006; Stewart et al, 2007). In qualitative research, the discussion between research participants in focus groups are the data which can be generated by the questions from the researcher asking group members about attitude, opinion, perception, suggestions (Kitzinger, 2006). It can create the interaction not only between researcher and participants but also among the participants (Kitzinger and Barbour, 1999; Green and Thorogood, 2004) as participants are free to talk with each other.

The purpose of my focus group was to aid the design improvements for the screening and counselling for migrant pregnant women. Therefore, in conducting

focus groups nurses, counsellors and physicians who care for these Burmese women could raise and share their ideas together.

Focus groups should include at least 6 participants and last for 1-2 hours.

I had been concerned that the additional times were required from health care workers who were already interviewed. Hence, I encouraged them to involve themselves in the focus group by emphasising the opportunity to contribute to the development of their hospitals and their clients together. However, due to time limitations and high work load, many health care workers could not attend the group. Three focus groups were conducted and members of each group were categorised in table 3.1.

Table 3.1 Characteristics of participants in the focus group

Participant	Group I	Group II	Group III	Total
Nurse	2	4	2	8
Counsellor	1	0	2	3
Doctor	1	0	0	1
Volunteer	0	0	1	1
Total	4	4	5	13

I used my early results from Phase I to develop the scenario of the women's experiences. This could allow them to learn new information and raise their perspective and enable me to get their 'interpretation of results' (Bowser and Sieber, 1993; 166). It was not only data that I collected from the focus groups but the dynamic occurring in groups which was also observed.

There were power imbalances among nurses in Group II as the other nurses appeared to mainly listen and agree with their head nurse. Therefore, I needed to encourage them to discuss individually by calling their names. However, this situation had not occurred in the other group. The members of other two focus groups were varied and they appeared to talk independently and showed interest

in their group member's perspective as they worked in different areas and had differing responsibilities.

3.6.7 Triangulation of data collection

Triangulation is a methodological approach that contributes to the validity of research results (Farmer et al, 2006). It usually refers to the use of more than one method in a study with the goals of achieving confirmation and completeness. There are various types of triangulation, such as data, investigator, theoretical, and methodological triangulation (Tobin and Begley, 2004). It can be said that triangulation can occur in a kind of jigsaw where the researchers use multiple methods to show them various parts of the picture and they can put it together as a whole. Therefore, for my study, triangulation was used to demonstrate rigour. I used the two different methods of data collection (interviews and focus group) to collect data from two different participant groups (Burmese migrant women and health care workers) to achieve method and sample triangulation. The validity can be increased by using different methods and the trustworthiness can be pinpointed from different sources of data (Green and Thorogood, 2009).

3.7 Data synthesis and analysis

Charmaz (2005) provided a step by step guild for the novice researcher to follow when conducting grounded theory data analysis. Although this was useful to some extent it also created some problems.

My data was analysed throughout the process of data collection as this is a requirement and an advantage of grounded theory research (Charmaz, 2005, 2006). Coding and theorizing based on that coding was a simultaneous process that began immediately after the first interview, (Glaser, 1978; Glaser, 1992 and Clarke, 2005).

This study used a data driven analysis method that has allowed for an exploration from data collection. This method can provide both a description and explanation of the women's' experiences. In this study, the data analysis section has been written using Charmaz, 2006 for reference.

Generating codes

Parts of data were represented through coding which consisted of two main phases. The first coding is initial coding with line-by-line or open coding by naming each word, line or segment of data. These provisional codes were improved upon and reworded as the coding process evolved. The second coding is focused coding by using initial codes that reappear in the data frequently. Thus, this coding is more directed and more conceptual than line by line coding and account for most of the data that the researcher categorises more precisely. Eventually these initial codes were developed into categories. As a final step theoretical coding enabled me to specify the relationships between substantial categories and will lead to theory development.

The grounded theory techniques of open coding were conducted by hand. As grounded theory analysis contains multiple processes, this process consumed time to work. As coding need to begin immediately when data collection commences (Charmaz, 2006), doing data analysis, and preparing theoretical sampling and the questions for the next interview at the same time was difficult for a novice researcher. Therefore, I needed to limit the number of participants to no more than two cases per day. The early data analysis was conducted from Thai transcription with English coding words or phrases.

Using gerund words is suggested in the data analysis process (Charmaz, 2006) as they can refer to the action gathered in data. I had tried to use them but sometime it was difficult to create English words as the interview was in Thai. Therefore, I agree with Cluett and Bluff (2006) who point out that a good ability to use and know English effectively are needed for grounded theory researchers.

Writing memos

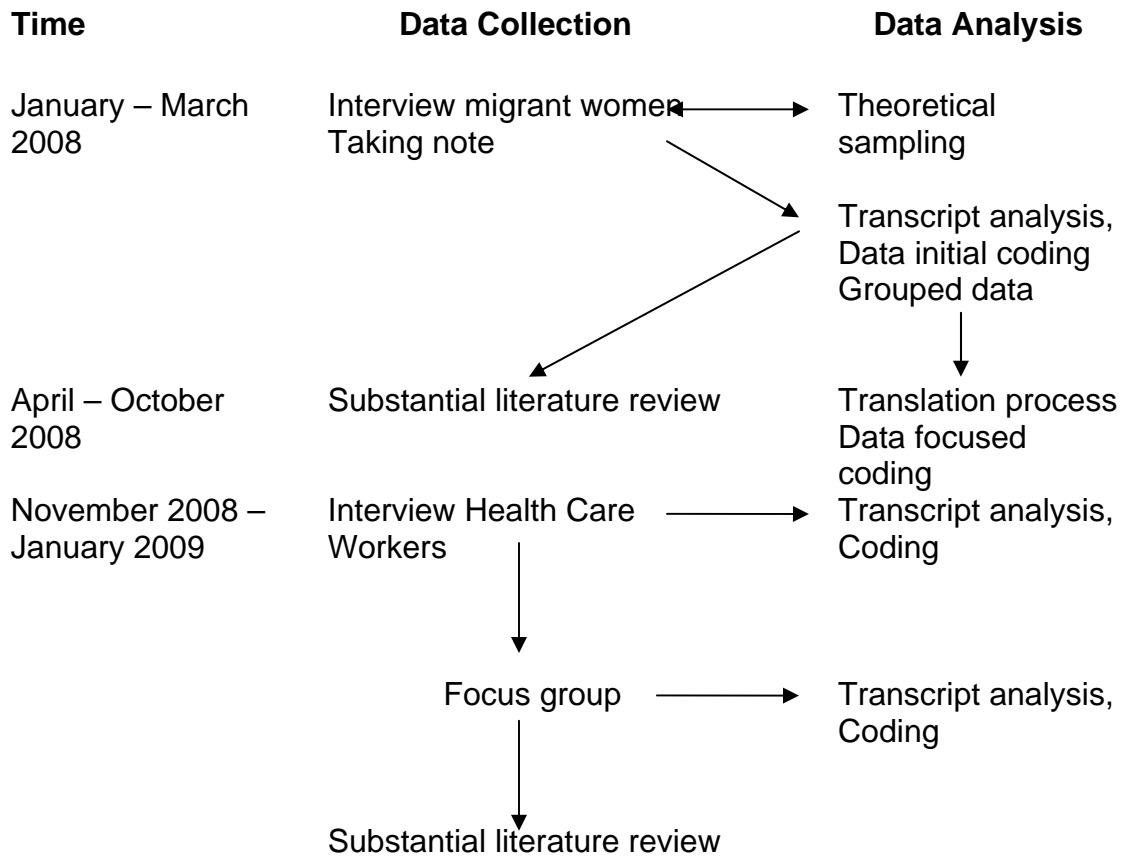
Memos were noted as memory aids and conceptual imagery tools that help in generating codes into categories during the moment of data analysis (Taylor and Kermode, 2006 and Charmaz, 2006; Stern, 2007). Writing a memo is an important step during the way from coding to writing (Charmaz, 2006). It served as the connection not only between data but also among data, codes, categories and concepts (Charmaz, 2006) and should be 'simple and straightforward' (Lempert, 2007). I made memo writing immediately after the first focused code emerged from initial code. It helped me to clarify my codes and categories as well as their 'properties'. Thereafter, I used and developed my memos to generate ideas and statements.

Constructing Theory in my grounded theory study

Before illustrating the other existing ideas, constructing grounded theory need to be started with our own thought (Charmaz, 2006). I therefore, clarified and wrote my core ideas developed from writing memos. Then, I reviewed literature to connect with the existing ideas and research. This review had an entirely different aim to that of the first literature review which was about exploring and understanding something of the subject. It aims to examine the previous studies and to identify how my grounded theory answers their ideas or theories (Charmaz, 2006). It also was used to make links between existing theories and the theory which I was generating from my own analysis of data.

Conclusion, the process and timeframe for data collection and data analysis are shown as below.

Diagram 3.1 Process and timeframe



3.8 Reflexivity

This section presents reflections on the uses of grounded theory in research. It includes additional approaches particularly in data collection and analysis as well as theoretical discussion.

There are various approaches and generations in grounded theory research. Selecting which version is suitable for researching on my topic had made me lack of confidence as I am a novice qualitative researcher. Therefore, I need to read and understand from root of grounded theory approach and its development. However, the more I read the more I have questions. I have found that after reading the original versions I could gain more understanding of them during reading the studies applied grounded theory as research methodology.

Grounded theory method allows me to collect more than one source of data. I could gain more experiences with interviewing and conducting focus group. However, the processes associated with data collection and analysis were time-consuming and not easy especially for researchers who have limited experiences.

The stimulation question is the main characteristic of grounded theory data collection. Its interview is not be conducted by using structured and formal schedule of questions. This helps to reduce inconvenient situation and to stimulate participants to response the questions as they were adjusted to suit individual participants. However, there were practical problems which arose during interviewing my participants.

Theoretical sampling is a key strategy in grounded theory method. It helped to direct me to identify further participants that can strengthen the findings. However, asking stimulation questions and theoretical sampling need theoretical sensitivity. It enables me to decide what to do about further data collection. Nevertheless, the effectiveness of this sensitivity depends on not only literature but also professional and personal experiences. I found that my theoretical sensitivity was increased case by case during data collection period.

My reflections provide insight for the novice researcher and illustrate the experiences in the use of grounded theory as research method for the first time. It can be submitted that grounded theory provides deep insights and understanding of participants' experiences and strengthen findings. However, applying grounded theory as research method can be complicated and time consuming. Therefore, fully understanding and training in using grounded theory is suggested

3.9 Summary

A qualitative grounded theory approach was undertaken to collect data by interview and focus group. It aimed to explore the migrant women's access to PMTCT programmes while pregnant, to investigate why they accepted or refused to participate in these programmes and to design an intervention programme for screening and counselling for migrant pregnant women to participating PMTCT programmes. The study was conducted among 38 Burmese migrant pregnant women in the Thai-Burmese border provinces in the northern part of Thailand during 2008 and 2009. It can be submitted that grounded theory provided the opportunity for deep insights and understanding of participants' experiences and strengthen findings.

Part 3: Findings

This section includes four results chapters including findings from the data collected from Burmese migrant women in Phase I and findings generated from health care workers in Phase II. The details are as below;

Chapter 4: The descriptions of the research settings and participants in both Burmese migrant women and health care workers groups.

Chapter 5: The findings related with experiences of these women when attending antenatal care and PMTCT programme and experiences of health care worker when dealing with these women.

Chapter 6: The findings related with women's decision to have the blood test including interpretations of the women's decision to have the blood test from women and health care workers' view.

Chapter 7: The finding related with how to design of an intervention programme for screening and counselling for migrant pregnant women to participate PMTCT programme.

Chapter 4

Research settings and participants

This chapter is the first of four findings chapters. It presents descriptions of the characteristics of the settings of the study and the participants. Overviews of personal data provide the details of who they were and the experiences they had.

4.1 The research settings

It was not easy to access the Burmese migrants when they were living in communities, due to their mobility and not least the fact that some of them were illegal immigrants. Therefore, to explore the experiences and decision-making of Burmese migrant pregnant women the appropriate place to access them was in the government hospitals, where most of them attended antenatal care clinics. Additional data was needed from the health care workers and the best place to access them was in their work places in the same hospitals.

All six hospitals in this study were run by the Thai Ministry of Public Health and located in the Thailand-Burma border provinces in the northern part of Thailand; three hospitals were general and/or provincial hospitals¹, two hospitals were community hospitals and one was a regional hospital. The antenatal care clinics and the prevention of mother-to-child transmission of HIV (PMTCT) programmes were organised following different procedures in each of the hospitals.

Hospital A was a regional hospital with 750 beds. It served patients in the northern region of Thailand. The antenatal care services were included in and administered by the Obstetrics and Gynaecology Department. Two clinics were

¹ Provincial hospitals serve the population covering all districts in the province while the smaller general hospitals serve people in only one district.

held each week and each of these was attended by 50 to 60 pregnant women. The antenatal care was provided by 3 nurses (nurse-midwives) who also counselled pregnant women in their clinic. HIV testing information was provided as part of group health education. Women who had been diagnosed as HIV-positive were offered individual counselling by a trained nurse. No translator was recruited to serve in the hospital services as there were few migrants who could not speak Thai.

Hospital B was a general and provincial hospital, where the antenatal care service was included in its Out - Patient Department with three nurses providing antenatal care each morning. There were 50 to 60 pregnant women attending each clinic, every day morning from Monday to Friday. Although the antenatal care clinics were included in the Out-Patient Department the counselling service in this hospital was managed by a different team based in the Psychology department. A trained counsellor provided the complete individual pre-test information for all pregnant women and post - test counselling for women who were diagnosed as HIV Positive. This service was provided in a private counselling room within the Psychology department. Women who received HIV negative results on the other hand, were given the result by a trained nurse who counselled them, in the antenatal care clinic. None of the nurses could speak any Burmese language and there was no translator employed in the hospital.

Hospital C was a general and provincial hospital with 160 beds where all antenatal care was included in an extra clinic of the Out - Patient Department. This extra clinic opened every day providing different services on each day including Antenatal care, side by side with HIV services, Diabetic, and Hypertension clinics. Antenatal care and counselling services were run by four nurses who also worked for all the other services in this extra clinic. They looked after 60 to 70 pregnant women attending their antenatal care clinic on two days a week. The clinic days were divided into a first pre-natal (booking) visit on one day and a separate day for follow -up visits. Information about HIV testing and

counselling were given in group health education sessions. Individual post test counselling was provided only to the women who were diagnosed HIV positive while HIV-negative women were given the result while they were being examined in the antenatal check-up room. There was no translator as most nurses in this clinic could speak Tai Yai, one of the Burmese languages.

Hospital D was a general hospital located in the Thai district sharing a border with Myawaddy, a Burma border town. It served not only the population in the local communities but also served the Burmese migrants from 3 refugee camps as well as Burmese patients who were referred from a Burmese private clinic located in Thailand and near the Burma border. This clinic was run by a Burmese Doctor and supported by various funds and donations. In this hospital, there were 45 pregnant women served by one nurse and one nurse aid every day. There was no pre-test counselling session as the information about HIV testing would be given at the screening desk in public view and could be heard by the other pregnant women who were waiting nearby. Individual counselling was provided if the women were HIV- Positive and they were counselled by a psychologist in the Psychology Department. One migrant worker had been recruited and trained by the hospital to serve as a translator.

Hospital E was a 90-bed community hospital. It is located in the Thai border district adjoining to Tachilek, a Burmese border town. It served the patients from both Thai and Burmese communities in the district and border areas. The antenatal care clinic was administered by the Health Promotion Department and was run by 5 nurses who also worked in all the other health promotion clinics. There were 120 to 150 pregnant women attending this antenatal care clinic one day per week on every Wednesday. It did not have pre-test counselling before HIV testing. Instead HIV testing was explained along with other blood tests during the first visit at the screening desk, again within earshot of the other waiting women. The result of the HIV test was given to women by nurses in the antenatal care clinic. No post test counselling service was offered formally. There

was one migrant health volunteer who worked as a translator for all the services in the hospital.

Finally, hospital F was a 60-bed community hospital, serving the Thai population of just one district and migrants who selected to register with its services. There were 80 to 100 pregnant women attending this clinic on each of the two days per week that it was open. Two nurses and one migrant health volunteer who also acted as a translator, managed the services to pregnant women during their day shift in labour ward. Although it is the smallest hospital in the research study it provided a complete individual pre and post test counselling service that was run by a trained nurse counsellor in a counselling room.

Hospital D and E were located within 3 and 6 kilometres respectively of the border. They therefore had many visiting migrants who crossed the border into Thailand only in order to receive health care. Consequently, 70 to 80% of the pregnant women in the antenatal care clinic in these hospitals were Burmese. The rest of the hospitals were located in city centres of big provinces and were much further away from the Thailand-Burma border.

Routine Antenatal care

In all six clinics the routine antenatal care services comprised taking a medical history and carrying out a physical examination, as well as the following:

- blood testing (blood group; anaemia and /or Thalassaemia; hepatitis B antigen, syphilis, and HIV),
- urinalysis,
- diagnosis, treatment and potentially referral of women with high-risk pregnancies,
- tetanus toxoid vaccination,
- provision of vitamin and iron supplements
- health education on general health, nutrition and self-care.

All pregnant women were also given the standard National Maternal and Child Health Booklet intended to record all the antenatal and postpartum care they received. Antenatal care is provided free of charge in public-health services if the women have health care insurance excluding laboratory testing which did cost approximately 100 to 300 Baht.²

According to the national guidelines for PMTCT, all pregnant women and their partners should be given group or individual pre-test counselling and offered voluntary HIV testing. If they are HIV-positive, they should be given post-test counselling to inform them of their test result, provided with psychological support and given an opportunity to discuss disclosure to partner or family. There should also be an offer of partner counselling with voluntary HIV testing. The counselling service should also enable discussion of reproductive options and advice on safer sex, as well as explaining and discussing the PMTCT intervention. If they are the women who were HIV-negative, post-test counselling included informing them of their test result, discussing window period, offering partner counselling with voluntary HIV testing, and providing HIV prevention information (MoPH, 2006).

In fact, for voluntary counselling and testing, there were only two settings which provided the complete individual pre and post test counselling service and testing, and these were run by trained counsellors in a separate counselling room. Two further settings provided pre-test counselling as a group education session, the blood test results were revealed in individual appointments as part of the normal antenatal care if the test was normal. Women were offered individual post test counselling if their HIV tests were positive. In the last two settings, the antenatal clinics did not have a pre-test counselling session at all. Nurses informed the women about blood testing during the first antenatal clinic visit at the screening desk.

² At the time of data collection in January to March 2008, the exchange rate was 70 Baht = 1 Pound. At the time of submission the exchange rate had dropped to 55 Baht = 1 Pound.

All hospitals are the registered place for migrants to attend. Compulsory health checks, including for women of child-bearing age a pregnancy test, are part of the registration process that migrants must undergo annually. The migrant women who have a positive pregnancy test are then invited to also attend an antenatal clinic. Four Hospitals, all of which were the small hospitals, had the highest proportions of migrant women in their antenatal clinics with a range from 70 to 80% of patients. In these hospitals, there were translators for Burmese migrants but only two hospitals provided an individual translator specifically in their antenatal clinics. There were nurses who could speak Tai Yai with Burmese women in only two of the hospitals. In contrast in the other two bigger hospitals there were no translators for these women at all. The health care workers could not speak any Burmese language and, when required, they would ask other people around their clinics such as women's husbands, friends or the other Burmese pregnant women who could speak Thai to translate for them.

When attending an antenatal care clinic, all pregnant women were given the maternal and child record booklet. Some of the migrant women were given the booklet in Thai, others in Burmese or the Tai Yai language, depending on the patient's ability to read Thai and availability of the booklet in these languages. There was only one setting which could reliably provide a suitable booklet in Tai Yai which was the native language of most Burmese patients there.

4.2 Description of the Burmese migrant women participants

The results presented here are those data that were collected from January, 2008 through March, 2008. The in-depth interviews were conducted among 38 Burmese migrant pregnant women who accepted the offer of a screening test for HIV and had been through the HIV screening and testing process at an ANC clinic.

Table 4.1: The demographic characteristics of Burmese migrant women

Participant	Age	Ethnic	Length of time in Thailand	Education
1	21	TaiYai	6	Primary
2	28	TaiYai	6	Secondary
3	25	TaiYai	5	Primary
4	24	TaiYai	3	Secondary
5	24	TaiYai	10	Primary
6	29	TaiYai	10	No
7	25	TaiYai	10	Primary
8	26	TaiYai	4	No
9	20	TaiYai	4	Primary
10	27	TaiYai	20	No
11	20	Bamar	10	No
12	26	Bamar	13	Secondary
13	28	Bamar	8	No
14	35	Bamar	10	Secondary
15	25	TaiYai	6	No
16	24	TaiYai	4	Primary [Thai]
17	28	TaiYai	3	No
18	28	TaiYai	12	Primary [Thai]
19	37	TaiYai	6	No
20	24	TaiYai	7	Primary
21	24	TaiYai	18	Secondary [Refugee camp]
22	28	Karen	14	No
23	27	TaiYai	18	No
24	34	TaiYai	20	No
25	27	TaiYai	10	No
26	25	TaiYai	16	No
27	20	TaiYai	13	Primary [Thai]
28	23	TaiYai	3	No
29	25	Bamar	20	Secondary [Thai]
30	29	Bamar	20	No
31	23	TaiYai	14	Primary [Thai]
32	22	TaiYai	5	Primary
33	24	TaiYai	5	Primary
34	29	TaiYai	7	Secondary
35	30	Bamar	10	Primary
36	22	TaiYai	4	No
37	29	TaiYai	7	No
38	24	TaiYai	7	Primary

The demographic characteristics of the participants are presented in Table 4.1. The average age of the Burmese women participants was 26 years, ranging from 20 to 37 years. Although all participants could be described as Burmese they were from a variety of ethnic backgrounds since there are more than 100 different ethnic groups and sub-groups in Burma (Ekeh & Smith, 2007).

Most of them (n=26/38) were Tai Yai-Burmese, the largest minority ethnic group of Burma, coming from Shan state which borders Thailand to the south and has a long border with the northern part of Thailand, the research area of this study. The rest of the participants were Baman-Burmese which are the largest single ethnic group in Burma and Karen. Participants had been in Thailand for between three and twenty years.

Half of them (n=19/38) had lived in Thailand more than 10 years. The women gave several reasons for migrating to Thailand such as social, economic, and political reasons. Most women (n=10/38) had come to Thailand when they were young with their parents and many of them had stayed in refugee camps along the Thailand-Burma border. Some of the women had migrated to Thailand with their husbands, siblings or friends. Achieving a better quality of life and having better income were the major reasons that they gave for moving to Thailand. In addition, some women mentioned that they followed their siblings or friends because they had known that they could earn much more money in Thailand. Only a small minority (n= 4) mentioned pressure from Burmese military as a factor that made them migrate to Thailand.

Nearly half of these women had not been educated in a formal school although a number had benefited from some education in the refugee camps. Most of the rest of the respondents who received some formal education graduated only at primary school level. There were some of them (n= 5) who had studied or

learned the Thai language in the private sector or at home.³ Therefore, most of the women were illiterate in both Thai and their own language. Only half of the ten participants, who were literate in Thai or could read Thai, were also literate in their own language.

All of the women had low incomes. Almost all of them had unstable jobs such as waitresses in restaurants, labourers in factories and shop workers. Three worked as housekeepers and nine were housewives. Four women worked as labourers on building sites and three of them were still working in these jobs while pregnant. Two reported having their own business; a laundry and a fruit shop respectively.

Five women had Thai husbands. The rest had husbands who had the same nationality or race and most of them had met their husbands after they moved to Thailand. While for half of the women this was their first pregnancy, one woman was pregnant for the fifth time and seven women reported that they had experienced previous miscarriages or abortions. Some of the women who already had a child or children were pregnant with their second husband. Four women [n=4/38] disclosed that they had more than one husband. Of these, some had already had a husband in Burma and when they moved to Thailand they had taken a new husband; either Thai or Burmese.

Migrants in Thailand who have a work permit or who are legal migrant workers can access the health insurance system. Their name would be sent to the health care system administration by their employer. The legal migrant workers and their families can then apply for a yearly health insurance for which they need to have an annual health assessment. They are required to renew both their work permit and their health insurance every year. The cost of applying for a work permit and health care insurance was 3,800 Baht including 600 Baht for the

³A UNICEF report shows that nearly 40 % of Burmese children had never been educated and only one-quarter of children who attend school succeed in completing primary school. Only 2% of Burmese children complete secondary school] (Thein Lwin, 2008)

physical examination by a doctor, 1,300 Baht for one-year health care insurance, 1,800 Baht for one –year work permit and a 100 Baht registration fee. Table 4.2 lists the details related with these women’s health containing gravidity⁴, result of HIV blood test and the category of their health insurance.

Table 4.2 Health-characteristics of the Burmese migrant women group

Participant	Gravidity	HIV result	Insurance
1	1	Negative	H
2	2	Negative	H
3	1	Negative	H
4	1	Negative	H
5	1	Negative	S
6	1	Negative	H
7	1	Negative	No
8	1	Negative	H
9	1	Negative	H
10	1	Positive	No
11	1	Negative	No
12	3	Negative	H
13	3	Negative	No
14	3	Negative	No
15	2	Negative	No
16	1	Negative	No
17	1	Negative	No
18	3	Negative	No
19	2	Negative	No
20	1	Negative	H
21	3	Negative	H
22	5	Negative	No
23	2	Negative	H
24	3	Negative	H
25	3	Negative	No
26	2	Negative	H
27	1	Negative	H
28	1	Negative	No
29	2	Positive	H
30	3	Negative	No
31	1	Negative	S

* H = Health Card, S = Social Scheme Insurance, No = No insurance

⁴ Gravidity refers to the number of time that a women has been pregnant

Table 4.2 Health-characteristics of the Burmese migrant women group (Con't)

Participant	Gravidity	HIV result	Insurance
32	1	Negative	H
33	1	Negative	H
34	2	Negative	H
35	1	Negative	H
36	1	Negative	H
37	4	Negative	H
38	2	Negative	H

* H = Health Card, S = Social Scheme Insurance, No = No insurance

Of the 38 women taking part in this study only two were HIV positive as well as involved in the PMTCT programme and receiving the treatment to prevent mother-to-child transmission of HIV. Their stories will be presented in the vignette section of chapter 5 (see page 94).

More than half of the women [n=24/38] had either government or private health insurance cover. There are three major sources of health insurance in Thailand. The largest scheme is the Health Card. It serves those Thai people who are not insured via any other health care insurance. The Health Card is also available for migrants who have a right to apply for it. Thai government officers are insured via the Civil Servant Medical Benefit scheme and workers in the private sector are covered by a compulsory Social Insurance scheme.

Most of the women without health care insurance were illegal and needed to pay the full cost of care or treatment in addition to the fees for any medication prescribed. Some of them, on the other hand, were legal immigrants and were officially permitted to get health care insurance cover but did not want to pay the advance payment [600 Baht for Physical examination and 1.300 Bahts for one-year health care insurance]. Another group of women [n= 5/38] who were legal immigrants without health care insurance revealed that they had never known about health care insurance. Finally, one participant who did not have health care

insurance revealed that she had known about health care insurance and but that she did not have a right to apply for it.

4.3 The description of health care worker participants [Phase II]

The second phase of this study collected data from health care workers who worked in the relevant clinics at the study hospitals in November and December 2008. The participants in this phase included 16 nurses, 4 counsellors, 3 doctors and 3 volunteers. The details of number and years of experience of participants in each professional group and each setting are shown in Table 4.3.

Table 4.3 Number and characteristics of participants of interviews

Interviewees	Hospital A	Hospital B	Hospital C	Hospital D	Hospital E	Hospital F	Total
Nurse	2	2	4	2	4	2	16
Years of Experience	1 – 4 [3]	3 – 4 [3.5]	3 – 7 [6]	5 – 7 [6]	3 – 18 [11.25]	2 – 12 [7]	
Counsellor	0	1	0	1	0	2	4
Years of Experience		10		13		9 – 10 [9.5]	
Doctor	0	1	0	1	0	1	3
Years of Experience		3		1		4	
Volunteer	0	0	0	1	1	1	3
Years of Experience				7	4	1	
Total	2	4	4	5	5	6	26

* Years of Experience = Years of experience with migrant women in ANC

I had expected to recruit health care workers (antenatal care nurses, HIV programme counsellors, and obstetric physicians) with not less than one year of experience of caring for these women within PMTCT programmes. I had also hoped to include one member of each professional group in each setting. This did not turn out to be possible. Although five doctors agreed to participate in my study only three of them did actually have the time necessary to come for an interview. This was due to their heavy work load and in one case by the political

situation in Thailand at that time. The international airport in Bangkok had been closed by protestors who disagreed with the Thai government of the time. One potential participant in the doctor group was obstructed in Bangkok and could not come back to the setting for our interview appointment. Moreover, I could not get the flight to one setting [MHS] in time and instead had to drive for 6 to 7 hours by car to get there which also disrupted the interview schedule considerably.

In addition, in three hospitals there were no separate counsellors for pregnant women because nurses in the antenatal care clinics carried out the counselling. I also had not planned to interview migrant volunteers who worked as translators or co-ordinators but many health care workers highlighted that these persons are the key informants linking between them and migrant women. So for this reason I included 3 migrant volunteers in the second phase.

Table 4.4 provides an overview of the nurse participants, showing who they were, their level of experience, how long they had worked with Burmese migrant women and what tasks they actually performed.

The nurse group comprised fifteen females and one male; their experiences in their field were varied with a range from 16 to 32 years. Their experience of working with Burmese migrant pregnant women ranged from 1 to 18 years. Their duties and responsibilities in caring for the Burmese migrant women were also different. More than half of them worked as counsellors but some of them had never attended any training course for counselling or PMTCT programme. Many revealed that they had learned to counsel and to provide information about HIV from their senior colleagues and had read the guidelines book provided.

Table 4.4 Characteristics of nurse's roles of Phase II Interview

Nurse	Experience in nursing in years	Worked with Burmese women	Pre-test	Post-test	Trained as a Counsellor	Only ANC	ANC & Other Maternal & Child	ANC & Other Clinics	ANC cases per clinic day
			counselling						
1	20	12				✓ [LR]			80 – 100 2 Nurses, 1 Volunteer
2	18	2				✓ [LR]			
3	24	20	✓	✓	2 days Provincial Public Health office Training		✓		120 – 150 5 Nurses
4	31	3	✓	✓				✓	
5	17	9	✓	✓				✓	
6	19	18	✓	✓				✓	
7	16	4	✓	✓	3 days Region Training		✓		50 – 60 2 -3 Nurses
8	15	1	✓	✓				✓	
9	21	4				✓			50 - 60 3 Nurses
10	20	3		✓ Only Nega tive	1 week Coun-selling & 1 week TOT	✓			
11	22	5				✓ [PP]			45 [Fixed] Nurse & Nurse Aid
12	23	7	✓	✓ Only Nega tive	Project Training	✓ [FP]			
13	19	3	✓	✓	Basic coun- selling			✓	60 - 70 4 Nurses
14	33	7	✓	✓	PMTCT coun-selling			✓	
15	32	5	✓	✓	2 days Training			✓	
16	16	3	✓	✓	3 days Training			✓	

There was only one hospital where the nurses worked exclusively in the antenatal clinic and all pregnant women in this hospital were seen by the doctor at every visit. In the other hospitals the nurses also worked in the well-baby clinic and the family planning clinic as well as in the delivery and postpartum rooms. Some nurses were required to work in specialist clinics such as diabetes, hypertension or HIV clinics due to the nurse shortages at the time. The numbers

of pregnant women served by these nurses among their clinics varied with a range from 45 to 150 cases per day.

Table 4.5 Characteristics [of works] of counsellor of Phase II Interview

Inter- viewees	Experience work as nurse	Experience & Migrant women	Pre – coun- selling	Post – coun- selling	Training	Only Coun- seller	Nurse & Coun- seller
Counsellor 1 [N]	11	9	✓	✓	Basic Counselling		✓
Counsellor 2 [N]	13	10	✓	✓ Positive	1 week Counselling & 1 week TOT & PMTCT	✓	
Counsellor 3 [N]	26	20	✓	✓	1 week Counselling & 1 week TOT		✓
Counsellor 4 Psychologist	13	13		✓ Positive	Psychology	✓	

Three of the counsellors had previously worked as nurses with experience of two to six years and had been practising as nurse-counsellors for 9 to 20 years. All of the nurse counsellors had been trained in a basic counselling programme and two of them had also attended and passed the Training of Trainers in Counselling Skills. This training-of-trainers (TOT) programme aims to train experienced counsellors to serve as resource persons to train others in voluntary counselling and HIV testing (VCT) in their workplace. The remaining counsellor was a psychologist and counsellor with 13 years experience.

Two of the counsellors talked to Burmese women in both pre and post test counselling sessions even if these women received HIV negative results. The psychologist counsellor provided only in post test counselling for HIV positive women and another counsellor provided pre test counselling for all women and post test counselling only to the HIV positive women.

The counselling duration which was suggested by these counsellors was 30 to 45 minutes. The counselling of migrant women should really take more time than for Thais, but in reality they were able to spend only 10 to 15 minutes with these women due to the quantity of their clients and patients. Some counsellors expressed a lack of confidence in the quality of their counselling to these women due to language and communication problems and time limitation. The numbers of their clients for counselling were 8 to 40 women per day.

The length of professional experience in the doctor's group varied from 1 to 25 years and their experience with Burmese migrant pregnant women were 1 to 4 years. All doctors stated that they were not able to spend as much time with these women as nurses did. Two of them were obstetric doctors who worked only in obstetric clinics and one of them was a General Practitioner who worked in obstetric clinics and outpatient and general clinics. They only met these women on their first visit for checking their heart and lungs, when they needed advice or treatment for a complication and when they already knew their positive blood test result and needed to take AZT.

There were the three volunteer participants. The first had worked as a co-ordinator between a government hospital (one setting) and a Burmese private clinic which is run by a Burmese Doctor and supported by various funds and donations. This volunteer was Karen (one of the Burmese subgroups) and was paid by the private clinic. The second volunteer was employed by a project of the International Organization for Migration to educate migrants in communities and in factories. He was also employed by the hospital to work as a translator for every department in the hospital. The last volunteer worked as a nurse's assistant and translator for migrant women in the antenatal care clinic and in the community. She was employed by the International Rescue Committee, a global network which works in areas of crisis or extreme need to provide aid and support). Their work helps people to survive and rebuild their lives. The

volunteers' work experiences as migrant health volunteers were seven, four and one year[s] respectively.

4.4 Summary

The research settings included 6 government hospitals located in four northern Thai border provinces. In the first phase of data collection, there were the thirty-eight Burmese migrant interviewees. They were aged between 20 and 37 years and had been in Thailand between 3 and 20 years. Nearly two thirds of them had some kind of Thai health care insurance cover. Two participants were HIV-positive. Of the twenty-six health care worker participants in the second phase of this research sixteen were nurses, four were counsellors, three were doctors and three were volunteers. Their experience with Burmese migrant pregnant women ranged from one year to eighteen years.

The next chapter will present the thematic findings related to the experiences of these women when attending the antenatal care clinics and PMTCT programme and the experiences of the health care workers when dealing with these women.

Chapter 5

Experiences of the women and health care workers

In two separate sections, this chapter consists of presentation of themes emerging from data collected in Phase I and Phase II respectively. These two sections deal with the experiences of Burmese Migrant women when attending antenatal care clinics and the Prevention of mother-to-child transmission of HIV (PMTCT) programme and experiences of health care workers when dealing with these women.

5.1 Emerging themes: Experience of women

The themes presented here are those data that were collected from January 2008 through March 2008. In-depth interviews were conducted among 38 Burmese migrant pregnant women who accepted to take the blood test for HIV and had been through the HIV screening and testing process at an ANC clinic. The main 5 themes that arose from the interviews revealed their experiences when attending ANC clinic and Prevention of mother-to-child transmission of HIV programme. The details of these five generated themes are presented in Table 5.1 and each theme will be analysed in depth in the following subsections.

Table 5.1 Theme emergence and coding in Phase I

Theme	Category/Coding
Lack of effective counselling	Lack of knowledge
	Missing the important information or step
Implications of migrant status	Facing financial hardships
	Limited health insurance
Barriers to gaining information	Avoiding shame
	Feeling uncomfortable
	Experiencing language difficulties
Social comparison	Comparing with Thai experience
	Comparing with Burmese
Self efficacy	Seeking information
	Learning to survive

5.1.1 Lack of effective counselling

One of the project aims was to explore the experiences of women in the prevention of mother-to-child transmission of HIV programme. The data explored participant experiences and feelings about AIDS, HIV, counselling, the blood test, mother-to-child transmission of HIV and the prevention programme.

Most of the women had heard about AIDS from the media and friends, but few of them mentioned health care workers as the informants. A few women mentioned that they had read a leaflet given to them by the health care worker in the antenatal clinic and less than half knew the HIV transmission routes when asked.

For most women, the offer of the test was accompanied by little information about the reason for testing. Even those who had accepted the offer of testing could not articulate why it was important to take the test. They were unclear on how HIV was transmitted particularly between mother and baby. Only four women knew that HIV could be spread from a pregnant woman to her baby. According to their ability to catch all the words of counselling, many of them could not remember or understand the details and revealed a lack of knowledge or completely wrong assumptions when we discussed this during the interview. Significantly, many women (n=8/38) highlighted that they had not received any information and did not know or had never heard about AIDS.

From the below quotations, it seems that some were given a lot of general information but were not able to recall this. Some participants stated that they were given a lot of information and details about the testing but they were not able to retain or recall any or all of it. These women confirmed that they were given information about the diseases the blood test were intended to screen for but they could not recall the details in their entirety.

*P1: The nurse told that I would be tested for AIDS and
Err...what is disease which TAI YAI people usually have and
have paleface and yellow eyes? [Thalassemia] That disease*

and other diseases... there are 4 diseases. I cannot remember, may be leprosy or

P24: They told me that I would be tested for 4-5 diseases. I could not remember. They told about Anaemia... about AIDS. I could not remember the details.

P26: The nurse told me to take a blood test. She told me that it could prevent many diseases but I could not remember their names.

This last quotation demonstrates a lack of comprehension in that she believed taking the blood test prevented diseases. This lack of understanding is potentially dangerous to mother and baby. These quotations demonstrated that health care workers provided too much information and were not able to communicate the meaning of diseases to the women. Moreover, using more technical terms without clarification could make these women confused.

Education seems to be an influential factor related with the ability to capture the information or to recall it, as one participant stated her own perception was that being uneducated was the main barrier for remembering the information received.

P16: I have never been educated so it was difficult to remember.

Moreover, a few participants declared themselves incapable of remembering the details of information they had been given. Some were also confused with the information they received. One woman who had undergone antenatal blood tests in three previous pregnancies still demonstrated misunderstandings about the diseases which were being checked in this pregnancy.

P22: Many diseases could be checked with this blood test such as Cancer, AIDS and Umm...I could not remember.

The above statements show that these women lack the ability not only to grasp the information at the time that it is given but also to retain and recall it. However, recollection also depends on the time gap between when they received the

information and when they are asked to recall it. Many of participants were interviewed several months after they had attended the counselling or health education. Remarkably, among participants who were offered and informed about the antenatal blood tests, AIDS was the only disease often recalled by these women's memory. Nevertheless, this is not sufficient for the effective counselling or health education for this migrant group as the results show that they did not have adequate understanding of the information about AIDS, mother-to-child transmission and PMTCT and lack of the ability to retain it.

Notably, many of them appeared not to have been given any information about mother-to-child transmission and the PMTCT programme. They did not know neither why nor for what they had been tested.

P4: The nurse in the counselling room told me that the details about the blood test were in the book [ANC booklet]. She never told me why I need to take the test.

P21: I understood only some details. Sometimes, I could not understand what they said. They never told why they tested my blood. I did not know what diseases they tested for.

P23: I did not know whatever she [health care worker] tested. She did not tell me anything. She said "come here and go to take the blood test".

Although all the women took a test with nearly half of them (n=17/38) having attended the individual and group counselling; many of them claimed never to have known or heard about mother-to-child transmission and its prevention. For those who stated that they were familiar with 'mother-to-child transmission of HIV' (n=14/38), four of them (n=4/14) misunderstood about the effect of HIV infection on pregnancy and many of them had never known what HIV is.

P6: If we took the blood test and had been infected we could not have a baby. They never told me about prevention or treatment.

It would seem normal to expect that the women who had previous experiences with taking an HIV test should be informed and know about AIDS or mother-to-

child transmission of HIV. Significantly, the participant who had been pregnant previously and had taken the HIV blood test three times before revealed that she had never known anything about 'mother-to-child transmission'.

P14: I had taken a blood test when I had been pregnant for three times. I have known (only) that it could check for many diseases. I have heard of AIDS but I do not know what it is. I never heard the words "mother-to-child transmission".

The only women who could explain about mother-to-child transmission and the prevention programme were those who were infected and attended the National Access to Antiretroviral Program for People Living with HIV/AIDS programme.

In conclusion, these Burmese migrant pregnant women had insufficient knowledge related with the PMTCT of HIV programme due in part to their own inability to understand the information provided and also to the ineffectiveness of antenatal blood test counselling.

5.1.2. Implications of migrant status

Being pregnant, attending antenatal care and participating in the PMTCT of HIV programme meant that these women had to come to hospital to be provided with health care services. This involved the women in a process of accessing health care involving finding, obtaining and paying for the appropriate care (Chesney, 2008). Therefore their migrant status had implications for the method they used to access the health service, the direct or indirect cost they paid for the services and treatment and the rights they got from health care insurance. As migrants whether legal or illegal, many of the participants faced difficulties with financial hardship, limitations with their health insurance and their dependence on others.

Nevertheless their major concerns focused around the cost of health care services as they had to pay directly for antenatal care services and the costs related to their antenatal care (ANC) visits. Chesney (2008 : page 5) states that 'direct cost are the dollars spent by health care facilities to provide care' and 'indirect cost are losses resulting from decreased patient productivity (e.g.,

absenteeism)'. Both direct costs in accessing facilities and paying for services and indirect costs in relation to time taken off from work to attend and transport costs occupied the minds of participants.

Normally, migrants who have health insurance need to pre-pay 3,800 Thai Baht⁵ per year and have to pay a reduced rate of 30 Baht per visit to a health care facility. Those migrants who did not have any health insurance had to pay the full amount for each visit to the antenatal care clinic. This amount depended on the services that they required such as 300 Baht for taking a blood test or 500 Baht for an ultrasound examination. The cost of medication varied for each visit between 30 and 200 Baht.

With humanitarian aid, all migrants in Thailand can access the health care system and the Thai government also offers the legal migrant the possibility to apply for health care insurance which can help them to reduce the cost. There were national mass-media campaigns encouraging migrants to register for being legal and apply for health care insurance. Although health insurance was offered for migrants for several years some of them revealed that they had never heard of health care insurance for migrants. Without health care insurance, they had to pay the full cost of health services including additional drug and treatment fees. With health care insurance, they pay only 30 Baht per visit, but although the women had applied for it or intended to do so, some of them were not entitled to it.

P7: I have got the migrant ID card. I did not have the health insurance card. What is it? I have never heard about it. I need to pay the full cost.

P12: I pay the full cost. I did not know about this card [Health insurance] and I have never had any cards.

According to the need to pay full cost when accessing health care services many of these women faced financial hardships. Some women recounted their

⁵ At the time of data collection in January – March 2008, the exchange rate was 70 Baht = 1 Pound. At the time of submission the exchange rate had dropped to 55 Baht = 1 Pound.

experience with financial difficulties and debt, necessitating borrowing from various sources. Moreover, facing these difficulties made them think ahead to the additional cost for them of giving birth in hospital.

P11: I have to pay the full cost every time. My husband's income is just 170 baht [£3] per day and he does not want to ask for the advance payment so, we need to borrow from our relatives to pay for the cost. But they also work and have a limited budget, the same as us. I did not know how much I need to pay for giving birth.

It was not only facing financial problems and being a debtor that caused problems. The woman also experienced problems in trying to arrange for postponement in payments. Furthermore, there was further worry with the treatment cost for their family.

P23: I paid different amount every time. Sometime, I paid 900 Baht [£15] and sometime, I paid 500Baht [£8]. I would like to get card [health insurance card] but could not. If I was admitted in hospital and did not have golden [health insurance] card I could have a financial problem. For my child, the treatment cost was also expensive. I had asked to postpone the payment. I did not want to make the doctors [Health care workers] angry. I wanted them to understand but they did not allow it. I need to go back home and borrow the money from my friends and my sibling.

The above statements highlight the direct cost the women were required to pay when entering antenatal care. The following section presents the problems related with indirect costs facing these women.

Cost of transportation to the hospital and the time it takes to travel to the clinic was a major concern due to the assignment of hospitals to the women. They had no voice in this process and the hospital they were assigned to could be very far away from their place of residence. The most common way to travel to the hospital was by public transport in the form of jitney or passenger car run by people in the villages or by motorcycle where nobody owned a car.

The following quotes show that selecting a hospital to attend did not depend on their own will as they needed to follow their employer's guidance and the policy of the health insurance provider. They also lacked knowledge about their right in choosing a hospital.

P4: My employer took me here. He lives in this area so I was registered to this hospital. I feared that if I went to other hospitals I could lose my rights. I live in the City centre and I have to ride a motorcycle to this hospital. I would like to go to the nearest hospital to my accommodation.

P27: I had problems with transportation sometimes. My house is far from this hospital. I do not know how far it is but it takes me one hour to come here. I need to come to this hospital.

As previously mentioned, absence from work or reduction in their productivity are defined as indirect cost when obtaining health care. Consequently, another indirect cost of clinic attendance for these women was loss of working time and therefore income for themselves and their husbands. This was a significant concern to some of the women.

P5: I did not come alone because I did not speak Thai well. My husband usually comes with me and he needs absence from his work and loses the income.

In order to deal with their inability to communicate effectively in Thai, many of the women were accompanied by their husband, friends or relatives. This therefore resulted in a loss of more than one person's income for the visit.

P12: I always came with friend or husband because I could not read Thai. We could not sell our goods or earn money on those days which I came here.

For women who had health care insurance it could be assumed that having insurance cover could help them avoid financial difficulties. However, they reported inconvenience when using this health care insurance. All migrants in Thailand need to carry their ID card and show it when being asked by authorised government officers. For that reason, some experienced extended administrative processes for each visit that involved them needing to wait and to show their

migrant card and insurance card every time. This involved visiting another office, separate from the antenatal care clinic and sometimes in another part of the building causing further time delays and inconvenience as well as some degree of anxiety.

P33: After I finished each visit I needed to go to another room to prove my migrant status and my right to pay 30 baht. Then I could make a payment and received the drug. After that they would return my pink booklet [ANC booklet] back to me.

P40: When I came to hospital I had to take my migrant ID card with me every time. If I forgot the card I needed to go back home to get it.

The theme, 'implications of migrant status' was generated from the data. It presents the intricacy of circumstances experienced by the Burmese migrant pregnant women. Finding, obtaining, and paying for access to antenatal care of the migrant pregnant women appeared to cause difficulties, limitations and complications. Seeking and applying for health care insurance were also limited and having it was complicated for these women. For those migrants without health care insurance, financial hardship would occur in different situations since they needed to pay the full cost for health care.

5.1.3 Barriers to gaining information

When discussing the experiences related with getting antenatal care, attending counselling or health education session the migrant pregnant women in the study settings demonstrated a lack of understanding of the information provided by health care providers as well as some degree of fear to ask the questions.

There were internal and external factors that prevented the women obtaining more information and gaining more knowledge. The internal factors included their own concerns about their ability to speak and their fear of the reaction of health care workers. The majority of them reported that they did not perceive language as the main barrier as they could understand when the health care personnel talked to them although they could not always understand the full meaning of

terms. This is not always born out in the data for example in the earlier quote where the woman claimed to have understood that a blood test could prevent disease. It may be that women believe they understand the words but do not have the language skills to understand the fine nuances of language. However, the participants reported that they did not feel comfortable to ask for more details or information regarding HIV testing or health information as they felt that they do not have a good Thai accent and this might make the health care personnel get frustrated with their questions.

Therefore, although their own understanding did not appear to them to be a problem they worried that they could not communicate clearly to the health care workers. Avoiding bothering the professionals or being misunderstood and feeling shame were revealed by these women as barriers to gaining more information from the health care workers.

P1: Some don't want to bother. Some are shy to ask and fear they [health care workers] do not understand the questions we ask or our speaking.

P2: I do not speak clearly and they cannot understand. I was not brave enough to ask. I feared that they would be annoyed when I spoke wrong.

P5: I never asked them [health care workers] because I speak unclearly. I would like to ask but I could not ask them because I could not speak as I thought.

The external factors included time limitations and lack of opportunity to ask questions. These were elements that they felt they could not control and they also felt discomfort about their own perceived limitations in making themselves understood in an environment with little or no privacy.

Time limitation was an issue for these migrant women due to many of them or their husbands needing to go back to work as soon as possible. The journey to hospital usually took a long time and some of them had to take time off work. The faster they went back to work the less earnings they lost from their wage. Many

women were willing to ask for more information but they revealed that they did not take the opportunity to ask because they needed to return to their work.

P3: I wanted more information but I did not have time for asking. I needed to go back as soon as possible for my work.

On the other hand, when they had a time to question or ask for more information the health care personnel appeared to be busy and did not have time to respond to them. Moreover, they reported feeling uncomfortable and this was a reason for not asking, most likely because of their fear of the health care workers' reaction to their questions.

Some of them did not want to ask or did not have an opportunity for asking and getting information due to non-motivational factors (external control factor).

Perhaps this was due to feeling that control did not belong to them.

P11: I did not want to know... more than they told me. The doctor did not have time. I assumed from the number of patients. I asked when I attended the group education.

The above statements raise concerns about the migrant women's ability to communicate effectively which decreased the participants' confidence to communicate with health care workers. In addition, these findings demonstrated that the women were concerned about the reactions of the health care workers when they were willing to ask. This could be because of the perceived power imbalance between these migrant women and health care workers. It can be concluded that interaction between health care workers and these migrant women conforms with the activity-passivity form of interaction [of professional relationship] (Falvo, 1985) with the women being the passive recipient.

Therefore, enabling them to be comfortable enough to communicate and ask their questions is about gaining their trust, helping them understand and increasing the quality of care.

5.1.4 Social comparison

Some of the migrant women had experience with other hospitals or clinics both in Burma and Thailand and compared the services they experienced as well as their life with both Thais and Burmese. They also compared the standard of health care service for Thais and Burmese. When participants came to the antenatal clinics they would meet other Thai and Burmese pregnant women and they could observe the health care provided by health care workers to both of them. They felt they had many opportunities for comparison.

The following participant agreed that the minority Burmese and majority Thai pregnant women were treated equally in the provision of health care, but she also expected a better service because she knew that it was better elsewhere.

P14: Both Burmese and Thai received the same service. But I want to have the doctor and nurse who can speak Burmese same as Mae Tao [Burmese Clinic]. The doctor there can speak English and Karen.

The Mae Tao Clinic she referred to is a Burmese private clinic which is run by a Burmese Doctor and supported by various charitable funds and donations. It is located near the Thai-Burma border and also near the hospital in the city centre (one of research settings). Most of the health care workers there are Burmese so they can communicate with each other efficiently. Most migrant pregnant women in one of research settings were referred to this Clinic.

Some women also compared their life and the quality of health care in Thailand with that which they had known or heard about in Burma. Their judgements of the better lives in Thailand were based on their past experiences and, in some cases, on second-hand information.

P22: It [health care in Thailand] is good. It is better than the stories told by my parents in Burma. I never expected better care like this. My mother gave birth at home.

P23: When I was pregnant in Burma, I did not have any drugs and it was difficult. After I moved to Thailand, I could go to

hospital when I got sick. When I was pregnant, I could have the drugs and the doctors [health care workers] treated us very well.

Having experienced life in both countries enabled these migrant women to make valid social comparisons. The statements above show the upward social comparisons made by these Burmese women, as Thais were believed to be better off than they were.

5.1.5 Self efficacy

Participants had been in Thailand for 3 to 20 years. Half of them had lived in Thailand more than 10 years. Therefore many women had adapted themselves to living in Thailand to improve their quality of life. They had learnt to care for not only themselves but also for their family. They had developed their behaviour and abilities in order to improve their lives or cope with the changes in their lives.

19: I cannot read and write Tai Yai. I can read Thai but my writing is not good. I did extracurricular study..... I have developed more. My neighbour was pregnant and I followed the things that she did.

P22: I had learnt about the Thai hospital when I already lived in Thailand. Then, I learnt more and about better things such as vaccines for my child. But when we lived there [Burma] we had never been given vaccines. I did not know them. I can read Thai a little bit.

Moreover, they had found ways to get information about health care and living in the new society by learning Thai, asking friends and accessing media. As previously mentioned, most of these women had not been educated in a formal school or not beyond primary school level. Therefore, most of them were illiterate in both Thai and their own language.

Some women perceived that illiteracy in the host country language affected their lives and sought to remedy this. Therefore, there were some women who had studied or learned the Thai language in private sector or at home.

P17: I can speak, read and write Thai. I studied at home and paid monthly.

P1: I can read and write Thai a little bit. I am learning Thai from my employer.

Although, some women faced difficulties about getting information from health care workers as they lacked ability and confidence to talk, other women could ask and seek ways of getting health information through other channels. Many women revealed that they got the information about health care from listening to the radio.

The following migrant participant demonstrated how she had adapted herself when communicating with health care workers by asking more questions when she became more familiar with them.

P1: After I was familiar with the health care workers I usually asked when I had a question.

Although there were few Burmese media in Thailand these women could seek and get knowledge from the radio provided in their own language.

P1: I usually listen to Tai Yai radio. There is Tai Yai radio here.

P6: I got information about health and how to self care by listening to Tai Yai radio.

P10: I can only listen so I listen to the radio and know about the diseases from radio. I also listen to the Tai Yai radio.

Although these women usually presented more passive characteristics some of them demonstrated some considerable self-efficacy. They had learned how to survive in a new and different world. They could immerse themselves into a new and different society by using a range of strategies that linked their old world to the new one.

5.2 Vignette section: The story of HIV-positive Burmese migrant women

Vignette has been used when discuss sensitive issue and researcher can select the representatives to show their participants 'story. Therefore, the stories of two participants who had gone through the HIV testing process and learned about their HIV-positive diagnosis are presented as below.

Case 1

Pornpen, a Bamar-Burmese woman, was 25 years old and 20 weeks pregnant at the time of the study. She told that she came to Thailand with her parent when she was five years old and could not remember the reason for migrating. She was illiterate in both Thai and her language, Burmese. She had married twice with Thai men and given birth one time previously with the first husband [6 years previously]. Her first husband had died without obvious reasons [She did not know the cause of his death] and left behind one son. She had brought up her son alone and then met her second husband in the last year. He had left her after he was told that she was pregnant and had never come back. She was now living alone with her son and running the small laundry in her first husband's house near the hospital.

Pornpen was diagnosed HIV-positive but did not know the HIV status of her husband and she could not tell which husband she had been infected from. She disclosed that her second husband had never stayed with her for long and she supposed that he had had sexual affairs with other women when he went away. Therefore, she decided to take a blood test because she wanted to know her HIV status and she knew that she had some risk from previous marriages and husbands. She exposed that she was very scared of AIDS.

“I would like to know whether I have got AIDS or not. My husband never stayed with me for long and I did not know whether he slept with someone else. He left me when he knew that I was pregnant. My previous husband died a few years ago and I did not know why he died.”

She evaluated her deciding to take an HIV test as the right decision. She revealed that she was very fearful and concerned about her baby's health when she first knew about her HIV-positive result. She had been counselled by nurse in the ANC clinic and she reported that she was informed about safe sex and AZT drug. When she needed to consider the treatment with AZT she accepted it immediately because she was worried about her baby's future. She feared that her baby will live alone if she died and concerned that there would be nobody to look after her baby. It was her neediness.

“After I knew that I got AIDS I decided to receive the drug because I feared that there will be no one to look after my children. I need to take the treatment.”

Thereafter, the doctor in HIV/AIDS clinic advised her about how to take AZT and when to take it. She knew that this AZT could prevent mother-to-child transmission of HIV and she always asked for advice from nurses and doctors when she encountered any problems. She also reported that she had learnt about the side effects of this AZT and she had never had any drug allergy. She intended to give her baby the formula milk as advised by the health care workers.

She told that the health care insurance was very useful and valuable for her because she did not have enough money to buy the drugs by herself. She usually paid only 30 Bahts [£0.50] per each hospital visit.

Pornpen disclosed she felt displeasure or resentment sometimes particularly she was alone. She told that her parent did not know her HIV status and she thought that it was good that they now were living in Burma.

But she had a little hope about her baby because she was told by a nurse that her baby would not be infected. She told that there was the same standard of services for her and Thai HIV-positive women.

Case 2

Nongnang, 28 years old Burmese-Tai Yai women, was diagnosed HIV-positive while her current husband received a HIV-negative result. She was told when she was 29 weeks gestational age.

She revealed that she had migrated to Thailand with her parents when she was very young and could not remember which area of Burma she came from. She did not have health insurance because her husband's employer told them that they did not have the right to apply so she had never thought to apply for it. She hoped to apply for it next year. Her husband was employed as a part-time labourer [house painter] in a small building work site while she was a housewife and sometimes worked as a part-time housekeeper. Her husband could earn 170 Baht [£3] per day. At the time of the study, she needed to pay the full cost for health care which was around 100 Bahts [£1.65] and pay for transportation 40 Bahts [£0.70]. She always expressed concern for the coming payments when she would give birth. She reported that she faced financial problems and sometimes had to borrow money from other people. She was illiterate in both Thai and her language; TaiYai but her husband could read Thai for her. He had learnt to write and read Thai while he was a monk.

She had agreed to take a blood test because she thought that it was one of the processes involved in attending ANC clinic [It was routine]. She mentioned that she knew all pregnant women had been offered it. Moreover, she wanted to know her HIV status. But when she knew her HIV-positive result and was informed about the treatment to prevent MTCT of HIV, she decided to participate

in this prevention programme because of concern for her baby's health and safety. And her husband encouraged her to receive the AZT drug because the treatment was free of charge.

In the post-counselling section, she was asked whether she could accept or not the coming result and then she said that she could accept it.

She disclosed that she was called to the private room and then she was asked by nurse that "will you be shocked or suicidal if I tell something to you?" and then she answered that "why I need to do something like that" and confirmed that she would not do it because she thought that we have got just only one life.

She said she felt scared when talking about what happened when she first learned her HIV-positive result. She disclosed that at the early stage she could not control her mind and had been stunned with fear. [She was crying when she reviewed her first emotion to the HIV-positive result.] She told the health care worker that she would like to tell the result to her husband by herself but she did not tell him until he came to take the blood test.

When she knew that her husband was not HIV-positive like her, she was very sorry and surprised. After knowing the different results, her husband had never asked who she had been infected from. She assumed that it might be because he knew that she had never worked as a prostitute. She told how he took care of her as usual and he always reassured and supported her. He usually reminded her the times to take the drug.

After she knew her HIV-positive result and was informed about the treatment to prevent MTCT of HIV, she decided to participate in this prevention programme because of concern for her baby's health and safety. And her husband encouraged her to receive the AZT drug because the treatment was free of charge. Moreover, she did it due to the hope of living longer.

“I did not know what it [drug] is and what it can do for me. I took it because I hoped that I could live longer to look after my child”

She noted that she usually prayed for her baby to be safe meaning HIV negative the same as her husband and said that *“I got it [HIV] and that is enough”*.

In conclusion, these two stories illustrate the different experiences of migrant women who were HIV-positive. Although both of them had been in Thailand more than 15 years there were many different points during their journey and their lives.

To understanding the experience and lives of HIV-positive pregnant women, Pornpen’s story provides a particularly clear example of an abandoned HIV-positive migrant woman who needed to live and look after herself alone. She had made any and every decision by herself. She did not have her families’ support but she had economic support from the health care insurance system and her own career.

On the other hand, the experiences of Nongnang demonstrate the spirit of her husband who was HIV-negative [while she was HIV-positive]. Although, she had an unstable financial status and faced financial problems without health insurance she had a great deal of support from her husband.

The similar experience of these women is that they decided to participate in the treatment programme because of their babies. Both of them hoped to live longer and expected that this treatment could help them and their babies.

5.3 Emerging Themes: Experiences of health care workers

This second section focuses on the findings in phase II of the study presenting the themes that emerged from the interviews with health care workers. This section begins with an overview of generated themes presented in table 5.2.

Table 5.2 Theme emergence and coding in Phase II

Theme	Category/Coding
Individual Circumstances	Beginning with worrying/ Health care workers' self confidence
	Negative Attitude
Communication difficulties	Translating consideration/problems
	Limitation for gaining more understanding
Staff unable to provide sufficient information	Time limitation
	Manpower shortage
	Lacking of trained counsellor
Facing problems in managing the health care system.	Late entering to ANC
	Assessing barrier/obstruction

With 26 individual interviews four significant themes were generated from these data namely: individual circumstances; communication difficulties; staff unable to provide sufficient information; and facing problems in managing health care system.

5.3.1 Individual circumstances

Most health care workers described feeling frightened when they first found that they needed to care for the migrant Burmese women. Most respondents had positive or good attitudes towards their responsibility to care for these women. They understood why these women needed to come to Thailand and to their clinic. They felt sorry for these women and worried about the women's understanding due to their perceptions of the limitations in communication. They

were concerned about the migrant women's difficulties and would like to help them to pay less and to understand more.

Some health care workers revealed having previously felt worried about how to communicate with these women. Although most of them had worked and been in the Thai-Burma border province areas for several years they were not familiar with ways of communicating with migrants in everyday life. The quote below indicates that some health care workers were concerned about making sure they could make themselves understood when giving information and health advice.

C4: I thought that it would be difficult to start. We could not speak their language.

N12: At first, I was very stressed because I could not communicate with them and I have adapted myself.

Health care workers also stated their concern about the women's limitations related to accessing health care services because they understood that many of the migrant women did not have health care insurance. Moreover, they also voiced concern about difficulties in follow-up care because they perceived that the women moved around a lot and there would therefore be difficulty in follow up care. The following quote encapsulates a number of common concerns among health workers.

Dr2: I was concerned about communication, their right to health care services and how to follow them up. If they were not in our health care insurance system it would be difficult to help.

The number of migrant women attending some antenatal care clinics was very high, up to 70-80 % of all attendees. Therefore, some health care workers were worried about their ability to manage their services to serve these women.

N6: I wondered about how we could deal with these women. Their amount was twice or three time more than Thais.

Many health care workers revealed their negative feelings towards caring for these women, related primarily to the communication barrier. Some health care

workers asked many angry questions such as why they had to care for these people, why they had to provide translators for them, why they did not learn to communicate in Thai and why they could not do anything to these people when they did not pay the fee.

Dr1: When we asked them, they did not understand, their relatives also did not understand. When we asked, they did not answer. I concluded that we could not communicate with them. Sometimes, I thought why did they not learn Thai or why did they not bring someone who could speak Thai for good and effective communication.

N12: At first, I was very angry about why they came to our clinic without trying to speak Thai and why we needed to learn their language.

Dr3: It was not only coming here. They came here asking for our help but we also had to provide them with a translator. We did take responsibility for the resulting costs, but they should learn some Thai language or bring their own translators.

They felt angered and exhausted, mainly due to their high workload and lack of staff. Normally, in these hospitals, caring for clients who were migrants was not regarded as part of their responsibilities. The migrants increased their work disproportionately because of the persisting communication problems, having to constantly repeat themselves and being required to check that the women had understood what had been said. The frustration was not only with the women but also with the service which hindered them from providing a high standard of care.

N6: They made us do our job to a lesser standard. We had many responsibilities.

Caring for migrant clients generated feelings of worry among the health care workers who care for them. With the numbers of migrants, difference of language and limitation with the migrant status, the health care workers expressed concern about their abilities to care for these women. Hesitations with the migrant women's passive behaviours also occurred in the health care workers' mind. They recognised that they were not providing a good service but felt powerless to improve care.

5.3.2 Communication difficulties

In health care, communication between clients and health care providers is very important. However, the health care workers most commonly quoted the language barrier as their main problem when caring for the Burmese women. This communication difficulty was especially the case during the counselling sessions.

Most health care workers needed translators to help them communicate, but they remained concerned about the quality of the translations and about maintaining confidentiality [even whether these translators were trained]. Many of them indicated problems arising from translators missing out some of the details and information during the translation process.

N7: When using a translator, half of the information was lost by the translation process.

N15: It was difficult to communicate. If we communicate via translator the information transmitted would be about 60 to 70%. The translators never translated all the same as our information.

Some health care workers stated that they were blind when their words were translated by a translator. They could detect that sometimes their translator could not understand what they wanted to communicate with women. This was another frustration because they were again in a helpless position, unable to communicate with the women directly and unable to communicate with the translator. Again the concern of the health care workers was that they were unable to provide a good standard of service due to these barriers.

C4: Having translators was not the right or suitable thing. We did not know whether they could translate in the same way as we wanted to communicate. Sometimes, they spoke longer or shorter than we spoke. I would like to speak the same language that we could know their real emotions or feelings.

N4: The problem was that the translator did not understand what we wanted to communicate with these women.

Having various speaking languages among these Burmese migrant women also created limitations in the translation process as some women spoke a different language from the translator. I found that there were 3 speaking languages [Tai Yai, Bamar and Kereni] among Burmese migrant women in my study.

N3: There were many Burmese sub-groups. Our translator was Bamar Burmese [i.e spoke Burmese but not speak TaiYai or Kereni].

In some settings, there were no translators at all present in ANC clinics. Therefore, friends, husbands or relatives of the women were asked to help by acting as translators but this made some health care workers concerned with the appropriateness and quality of the translation and communication.

N14: Using their relative as translator was not good. [Translation by relatives was not effective] They did not understand.

N4: Sometimes, there was no translator and they had no relatives or husband. We needed to ask the relatives of the other women to help with translation.

C2: We did not have a translator. They needed to bring someone who could speak Thai with them. For counselling, we needed these translators but we needed to be aware of two issues; confidentiality and their relationships with those people [translators].

In the counselling process the clients' ability to receive detailed and specific information about HIV testing and the PMTCT programme was extremely important. This information influenced the women's decision-making about accepting HIV testing and receiving care.

According to the perception of the health care staff the limitations in communication were a significant factor that reduced the quality of care provided. Although most health care workers stated that they would like to care for these women to the same standard as for Thais, but they had to exclude the Burmese women from group activities, such as group health education and parenting

school clubs, due to communication limitations. They feared that the group activities would be obstructed by the non-Thai speaking migrant women and they thought that these women could not understand enough content to take part in the group activities.

Some health care workers experienced many obstacles when talking with the migrant women. They highlighted that a lack of fluent conversation or talking during the assessing process could decrease the quality of care planning for these women. Giving suggestions about treatments to them was also limited.

Dr1: Sometimes, our treatment mainly depended on talking. If we lost this point our work could not be effective. When we asked them, they did not understand, their relatives also did not understand. When we asked, they did not answer. I concluded that we could not communicate with them.

N12: We could only talk with them about general antenatal care. If we asked for more detail or asked deeper questions we would be misunderstood. We could not interview and find out about their past history. We could interview only about common issues.

The participating counsellors felt that, because of the communication difficulties and the low level of the women's education, their efforts to increase the women's understanding about HIV/AIDS in these women were sentenced to fail. Moreover, they found it so hard to counsel them and to evaluate their understanding that they feared for the quality of the counselling process.

C1: Interviewing them was more difficult than interviewing Thais. Their ability to communicate and their knowledge base were not equal with Thais especially in the AIDS issue. Making them understand about the disease was very difficult.

C2: Our problems were about language, AIDS knowledge, and accessibility to the media. It was very difficult to communicate and we could not understand each other.

C3: "It was difficult to communicate with them. We did not know whether they understand or not and what they understood.

With language barriers in place the health care workers were not able to get the necessary information from the women and were unable to offer complete care to them.

5.3.3 Staff unable to provide sufficient information

Time limitations, staff shortage and lack of trained staff were also revealed as limitations to providing sufficient health care information, especially in relation to HIV testing and PMTCT. Providing this information even in counselling sessions or in group health education took plenty of time and needed experienced and trained professionals. The health care workers, however, did not have time to provide information due to the large number of Burmese migrants in their antenatal care clinics and lack of staff. .

N14: We have many cases with 60 to 70 cases [in each clinic/ANC clinic]. We had much to do and needed to rush, so we could not talk with them.

N3: We offered health education for them and their family in the afternoon session and we also had a translator in this session. But we needed to discontinue it because we did not have time. Nowadays, we got around 100 pregnant and women in an ANC day and 80% were Burmese but we had only 5 health care workers including 2 nurses to deal with them.

Due to considerable time limitations, significant details about HIV testing and counselling were skipped. The health workers did not have time to provide information by talking to the women and could only give leaflets to them to read.

N8: We did it [blood test] for every case. I have never asked them whether they accepted or not. We did not have time.

C1: We did not have the leaflet for them [Burmese migrant women]. We provide leaflet about HIV infection for Thais only. We did not have time.

The counsellor disclosed that they did not have time to evaluate whether they gave enough information or not.

C1: We counselled 40 cases per day. We could not expect its [counselling] quality to have been high. We had a very high workload so we did not have time to evaluate their understanding.

Staff shortages to serve the clients in their hospitals also caused them to cut the provision of individual health information and counselling.

N1: We did not have enough staff. We needed to allocate/ provide part-time or new staff, who did not know about our system as much as the old staff. We could not offer individual health education or counselling because we did not have enough staff.

As nurses play a central role in caring for the migrant women, the nursing shortage was the main cause of the strongly perceived reduction in the quantity and quality of information that should be provided.

5.3.4 Facing problems in managing the health care system

While caring for the migrant pregnant women problems they had with managing their health care became obvious. Late entry into the antenatal care programme and barriers to assessment were the main causes for these problems. Many migrant pregnant women commenced antenatal care intentionally late due to money concerns and transportation costs. This did result in complications in monitoring the pregnancy effectively and created difficulties for the health care workers looking after them.

N15: For them, it was very difficult to earn money for attending ANC. Some attended first ANC very late and some often moved their housing.

Many Burmese women attended only one ANC clinic appointment before giving birth in a Thai hospital. Being born in a Thai hospital did result in the babies getting a Thai birth certificate, which was also a significant motivation for many Burmese migrants to give birth in Thai hospitals. However, many of them came to attend ANC clinic only one time in order to register to give birth in a Thai hospital because the birth certificate in Thailand meant a lot for them.

N3: They would come for their first ANC visit when the gestation age was more than 20 weeks because they worked and did not have time. Some crossed the border for the ANC visit when they already got big tummy. Some came nearly at the time of birth because they just wanted to give a birth in a Thai hospital. They paid for everything because they wanted the birth certificate or the pink card and they wanted to get the same rights as Thais.

C2: There were more migrant women [than Thais] who came to the hospital when they were nearly ready to give birth without attending any ANC.

N5: They came to our antenatal care clinic because they want to give birth in hospital. They usually came near the time for birth time just on one occasion. They did not see/understand the benefits to attending ANC.

Furthermore, some migrant women did not attend an ANC clinic at all due to their concern about their existing HIV-positive status.

Dr1: There were some cases who already knew their positive result became pregnant and did not come to Antenatal Care clinic. They only came when they gave birth.

To determine the gestational age the date of last menstrual period (LMP) has to be known, but the nurses had great difficulties to get this information from the women. This was due to problems recalling and indicating the exact date of LMP due to the difference between the Thai and Burmese calendars. This was further compounded by the women presenting later in pregnancy.

Dr1: I was very concerned about problems in gaining their health history such as forgetting the LMP, missing the follow-up, not knowing about quickening. These problems made it more difficult for us to advise them.

N2: Asking about LMP was very difficult. They could not remember it. We needed to ask health care workers who could speak Tai Yai to ask about the Tai Yai months. Their months' names were different from ours [Thai] and different from the international calendar. They did not know about the date. They knew only the moon or lunar phases.

N10: They did not know the calendar and their months were

different from ours. When asking about LMP, we needed to refer to the important days and the moon lunar phases.

With this difficulty in obtaining information extra assessments had to be provided which caused more costs and demanded extra resources. Ultrasound assessment becomes less accurate in dating a pregnancy as the pregnancy progresses. Confirming gestation therefore cost more than it normally would and inconvenienced staff and women alike.

*N2: For some women in whom we could not be confirm their gestational age, we needed to confirm by ultrasound assessment.
N3: They usually forgot their LMP so we needed to send all of them to meet a doctor to confirm their gestation age.*

5.4 Summary

The findings outlined in this chapter demonstrate who the Burmese migrant women were and what their experiences with antenatal care and PMTCT including counselling and health education sessions were. For them being migrants meant they were faced with various difficulties including communication limitations, financial hardships and complications with their migrant status. The passive characteristics of the women were demonstrated in their unwillingness to ask questions and their acceptance of instructions from health care workers in relation to blood screening tests. The dependence of the women on guidance from their husbands, health care workers and interpreters made them very vulnerable.

While the women experienced many problems, the health care workers who were caring for them also encountered many barriers when providing health care to this vulnerable group. The health care workers revealed their negative feelings regarding caring for these women, mainly anger and exhaustion due to their overly high workload. Normally in these hospitals caring for migrant clients was not part of the staff's responsibilities, but the migrant's presence increased the staff workload considerably. Furthermore, caring for these women did at

times increase the hospital's expenses because many of them could not pay all their fees and there was no financial support from the government to care for and treat these migrant women. Moreover, entering into the antenatal care system late did not only make these women face many complications but also made it more difficult for the health care workers to care them. This in turn increased the health care workers sense of frustration at the limitations of the service to provide care for this particular group.

The next chapter will present the findings related with women's decisions to have the blood test including interpretations of this process from the perspective of the health care workers.

Chapter 6

Women's decision-making and health care workers' perspective

This chapter highlights particularly the findings related with women's decisions to have the blood test. It verifies why these women accepted HIV testing by merging the data revealed by Burmese migrant pregnant women and health care worker participants.

6.1 Emerging themes

In order to investigate their decisions regarding HIV testing and treatment, the factors that influenced why these migrant women accepted the test and the perceptions of health care workers regarding the women's acceptance needed to be interpreted. Thirty-eight Burmese migrant pregnant women and twenty-six health care workers provided their views on why women accepted HIV testing. In analysing the data from both sets of participants, similarities and differences were identified in their views and perceptions. Their understanding of the reasons for decisions, both differing and corresponding were defined into 6 main themes. The names of the themes generated and priorities evaluated from migrant pregnant women and health care workers are shown in table 6.1.

The themes were ranked according to how many times they were mentioned in interview with participants in each group. The two themes that occurred most frequently differed between the groups. However the third and fourth most frequently mentioned were nearly equivalent. The priority was set from the frequency often mentioned by the women. However, there were three themes appearing separately in each group.

Table 6.1 Themes generated from migrant pregnant women and health care workers

Themes	Priority Migrant Women	Priority Health care workers
Fearing their own status	1	N/A
Respecting the power of health care workers	2	1
Following the others	3	3
Worrying about their baby's health	4	4
Misunderstanding of the process	N/A	2
Perceiving the benefits	N/A	5

For most of the Burmese migrant women who attended the ANC clinic, it appeared that it was not difficult to decide to have a test. The reasons why they accepted blood testing were various and the details are reported below.

6.1.1 Fearing their own status

In discussing their decision regarding taking the HIV blood test, most women reported that the predominant reason to accept screening was that they were worried or afraid about their own health. They disclosed their feelings of fear about HIV and AIDS. The possibility of being infected with HIV was the main concern that led to the decision to take the blood test.

Some women displayed uncertainty about their husbands. They mentioned the concern about their husband's life style or behaviour as a reason why they decided to take a blood test. Some already suspected that their husband had slept with other women when they were working away from home.

P10: I was uncertain whether my husband had AIDS or not because we did not stay together all the time. I fear I have got AIDS.

P19: I fear getting AIDS. I did not know whether my husband had AIDS or not.

Some women expressed fear or were worried because they had previous partners or husbands and they were unsure about their HIV status. They were concerned because the previous relationships had not been good and they suspected the previous partner had been unfaithful.

P2: I fear having AIDS. My current husband has just only me and I am his first wife. I fear having been infected from my previous husband.

P4: I fear AIDS. I could be infected but I did not know. I had another husband before having the current husband. I was uncertain with him so I would like to take the test.

Some respondents believed that they were at high risk of contracting HIV and there was the possibility to be infected from their current husband.

P28: I took the blood test because I thought that I already had been infected. I had the risk. My husband already has AIDS and I fear I have got AIDS.

P16: I was at risk because my husband went to work very far from me. He could have slept with other women and he could transmit it [HIV] to me.

Some women revealed their ignorance of HIV and its transmission but yet were still fearful of the disease. They had fear of the disease called AIDS which they believed was a severe disease even when they did not know very much about it. Despite expressing such fear and concern they had not previously sought screening.

P9: I would like to know whether I had AIDS or not. I really fear it.

P11: I fear having the severe disease because I have never been tested for it.

P36: I took the blood test because I would like to know whether I was healthy or not. I was scared and I feared AIDS.

Although the women feared AIDS they seemed to have some perception of their risk related to current or past relationships. The health care workers did not make any statement directly related with this fear. It could perhaps be concluded that health care workers did not engage with the women's feelings when they informed or counselled the women about HIV testing. Fear is an individual feeling and it seems that the health care workers were unable to evaluate their clients' emotion. This may be due to the language barrier or to limitations in time.

There are three themes generated from both women and health care worker participants. The descriptions of these themes are presented as below.

6.1.2 Respecting the power of health care workers

Significantly, the health care worker was represented as an influencing factor in women's acceptance to take HIV testing. Respect of the health care workers' power constructed these acceptances. Many of these women admitted that their decision was influenced by the way the test was offered by the health care worker. There appeared to be no hesitation in accepting the screening test.

P33: I did everything that doctors and nurses ordered me to do. I did not know what would happen if I did not do it.

The women agreed to take the HIV test because they were told by health care workers to do it as a routine test and that it was necessary. It appeared that women did not see it as a choice because it was presented as a routine part of care.

P20: They told me that all pregnant women in this clinic must take the blood test.

P27: Doctor told me that it was necessary to take the blood test. If we knew the result the doctor could treat us.

Most of women who stated they had been pressured by the health care worker into taking the test recalled that they were never asked whether they wanted to

be screened or not. They feared that their antenatal care might be discontinued if they did not take the blood test.

P18: He [health care worker] told me that if I would like to have antenatal care I must take the blood test.

P3: The doctor [Nurse] told me to take a blood test. She told me that she needed to send my blood to Maharaja hospital. She told me to do and I did it.

In addition, many health care workers recognised that they did influence the decision of the Burmese migrant women. They stated that the Burmese women usually followed their instructions and it was easy to motivate them for blood testing. The women feared the health care workers' reaction and did not want to anger them, but some of the nurses appeared to accept this reaction of the women as one of trust in the health care workers' status.

Volunteer1: They feared the health care workers.

Counsellor3: They feared that if they did not take a blood test we would blame them.

Volunteer 2: They [migrant women] told me that they accepted a blood test because they did not want to make argument with health care workers. Some revealed that they were forced by health care workers.

Nurse 5: We told them so they must accept it. They honoured us so they believed everything that we told them.

They stated that the migrant women usually followed their instructions. Importantly, some health care workers perceived and stated the evidence of how their power could motivate the Burmese women to take blood testing. They accepted that they had power and did not appear to question whether this was appropriate to the client health worker relationship.

C1: They have thought that we [the health care workers] have more authority/power than them. We [the health care workers] could overmaster them easily. They took a blood test because our staff told them to take it.

N12: They came to our service therefore we could do everything with them. I thought that they accepted our care by themselves so they needed to follow our advice. When we told them to take a blood test, they would do it.

These findings showed that the power imbalance between health care workers and their pregnant clients facilitated the high uptake of HIV screening in the Burmese migrant women. If accepting HIV screening was required by the health care worker, it was hard for the women to justify refusal. Both the women and the health care workers accepted this power imbalance without question. The women did not want to risk upsetting the health care professional in case antenatal care was withdrawn. The health care workers viewed the women as passive and saw it as their right to give instructions to the women. The health care workers did not perceive that women would be entitled to make choices.

6.1.3 Following the others

As previously mentioned in Chapter 5, these women had passive characteristics and were not confident to do many things on their own because they had little confidence in themselves. The women appeared to rely on others to tell them what they needed to do firstly in deciding to have the screening test and then later in deciding to accept treatment. The term decision making is used very loosely because it seems that the women did not realise the right to make a choice so were led willingly by others' recommendations. Their spouses, health care workers or the other pregnant women were the people who led these women to accept HIV testing.

The husband was identified as the most influential person, outside the health care system, for the women in making the decision to take a blood test. They could not make the decision by themselves as they needed to ask their husbands and they accepted to take a test due to the encouragement of their husband, or they accepted it because their husband told them to do it.

P1: I discussed with my husband and he said "no problem". He's my first husband, so I decided to take a test.

P5: I did not know about AIDS. I asked my husband and he told me to take it.

Some women needed to ask the other pregnant women and learned from them. They followed the example of their peers who told them that they had accepted screening.

P11: I had asked many pregnant women and all of them took the blood test. Then I took it. So, I could know whether I have AIDS or not.

The women still did not see themselves as having a choice when it came to the screening test.

P22: Everybody must take the test, mustn't they?

To verify these women's passive characteristics, the findings from interviewing health care workers also showed their experiences and perception of these passive behaviours of the Burmese pregnant clients.

N9: Most of them believed that it depended on our words [health care workers' suggestion].

Although they were asked to sign a consent form neither the women nor the health care workers really expected that refusal was an option.

N12: When we told them to do it they immediately did it. When we told them to sign consent form they did it without asking what it for. It was "I came to your antenatal care so you [HCW] could do everything with me".

Health care workers regarded the women as passive and lacking in self care skills. They did not view the women as individuals with the capacity to make valid decisions about their health or their lives. Whilst the women may have lacked confidence the health

N6: The nature of the patients here was that they did not care about themselves. Everything depended on the doctor [health care worker]. They never made any decisions and told us that "it depend on you [health care worker]".

It is reasonable to assume that there was evidence of the women's lack of confidence to decide about HIV testing on their own. Deliberation and discussion with the health care worker rarely happened.

6.1.4 Worrying about baby's health

Concern for the health of their baby was expressed by most of the migrant women and for many this was the primary reason for accepting HIV testing. Some of them demonstrated their understanding about what the outcome to their baby would be if they were found to be HIV positive.

P3: About blood testing, I must do it. It could be transmitted to the baby. I was afraid it could be transmitted to my baby.

P22: I feel fear. I feared that if I was infected with it [HIV] I feared that my baby could not survive and we could die. I hoped that the doctor could help my baby if I had been infected but it could not be 100%.

Some women considered that they and their baby would get benefits from this testing. However they were unclear on what the benefit might be. .

P24: I thought that it was useful for my baby.

P34: I decided to take a blood test because of my baby. I feared that my baby could be unhealthy. It [testing] was good for me and my baby.

From the above statements, it appeared that these women understood something about mother-to-child transmission of HIV and knew treatment possibility.

Health care workers also recognised that worry about the baby was a reason and motivation for these women to accept HIV testing.

C3: The important reason for accepting was for their babies.

C4: The first reason to accept blood testing was their concern about their babies

N7: They were concerned and cared about their babies.

N10: They wanted their babies to be safe.

The behaviours of the women and their husbands were observed by the health care workers when they attended antenatal care clinic. It appeared that the health care workers recognised the women as well cared for by their husbands. These women wanted to have a baby and they accepted HIV testing because they wanted to protect their baby.

*N16: They took blood test because they loved their babies.
We could assume from the number of them who came to ANC.*

Worrying about the health of the baby was therefore identified as one of the reasons to accept HIV testing by both women and health care workers participant groups.

6.1.5 Misunderstanding of the process

HIV testing was offered to all pregnant women when attending antenatal care clinic. Therefore, the migrant women may have thought that it was one of the antenatal care processes that they needed to follow. They did not know about 'voluntary' testing. Some health care workers supposed that it might be the misunderstanding of these women that made them take the blood test.

C1: May be they think that taking the blood test is one of our services or processes. They thought that it was our process. We wanted them to understand its benefits more than to think that it was a process.

N2: When they come to ANC clinic, they thought that they must take a blood test and they must do it to follow the process.

Remarkably, fearing discontinuation of their right to access the service was identified as a reason for their acceptance of HIV screening. This might be because these women did not know about their right to access health care and did not know that health care workers did not have authorisation to discontinue the care services for them.

N3: They thought that if they did not do it they would be discontinued from antenatal care clinic.

C1: They might be thinking that if they refuse it they cannot continue their ANC attendance.

Perception of HIV testing as a routine service and as a required process could lead the women to ignore the information regarding benefits of HIV testing for the unborn baby and the women. Moreover, the knowledge about mother-to-child transmission of HIV and prevention of it would be neglected.

6.1.6 Perceiving the benefits

Previous themes revealed women had insufficient understanding of the benefits of HIV testing. However, there were several health care workers who stated that these women accepted HIV testing in full knowledge of its benefits. Significantly, all counsellors were confident that the migrant women who had attended pre-counselling accepted testing due to their understanding about blood testing.

C4: Another reason was that they knew why they should take a test.

C2: They knew the benefits of taking a blood test. There was no other reason.

Their confidence of the women's understanding of HIV testing was because they believed that they ensured quality counselling to these women. Generally, the HIV pre-test counselling consists of discussion of the benefits of testing and of knowing HIV status. Consequently, these counsellors believed that the migrant women were fully aware of the reasons for agreeing to take HIV testing.

Not only the counsellor participants but also the other professionals in this participant group mentioned perceiving the purposes and benefits of HIV screening.

N1: They might know the importance of blood testing. If not, why do they accept it?

N7: They knew the benefits of taking a blood test.

Although, perceiving the benefits appeared to be a reason for accepting HIV testing there are fewer quotes from either the health care participants or the women saying that women knew the benefits of the test.

6.2 Reason for refusing the blood test and treatment

I had planned to explore the reasons why some Burmese migrant women refused to take the test for HIV. I had met some of them but unfortunately, all of them were staying at a refugee camp and their guardians did not give permission for me to interview them. The potential theories about their refusal were revealed by health care workers who cared for them or were dealing with them at clinic. The details are reported below.

One of the perceived reasons stated by a health care worker as the barrier to accepting the blood test was financial. It is possible that the cost of the blood test was more expensive for them to afford as most of them had low incomes. Almost all the women had unstable jobs. Therefore, they refused it to avoid financial problems.

N: I think that the reason for them to refuse is the money matter because they need to pay 600 BTH [£12] for themselves and 580 BTH [£11] for their husband”

C1: If they would refuse it might be because of the money especially for migrants who had not the health care insurance.

To gain health care insurance in the Thai health care system, the migrant women were required to undergo a physical examination including blood test. Therefore the women might believe that they have already undergone HIV screening when they applied for health care insurance. This is the perception of the health workers and no women reported this as a reason to refuse the test.

Dr2: They misunderstood that they already took an HIV test when they registered for their migrant status.

I spoke to a nurse who dealt with women who came from the refugee camps and she revealed their perception of their refusal to consent to testing for HIV.

*N13: It was about the budget of the camp [refugee camp].
Their institute needed to pay for them. Our project [PMTCT] provided free drug for all infected women including migrants but they did not take blood test.*

In exploring the women's reasons for accepting HIV testing and receiving the treatment it is important to investigate their decision-making.

In conclusion, the reasons why women accepted and refused to participate in HIV programme and treatment are identified and concluded in developed conceptual frameworks as below.

Diagram 6.1 Developed conceptual frameworks of facilitate factors influencing women's decision

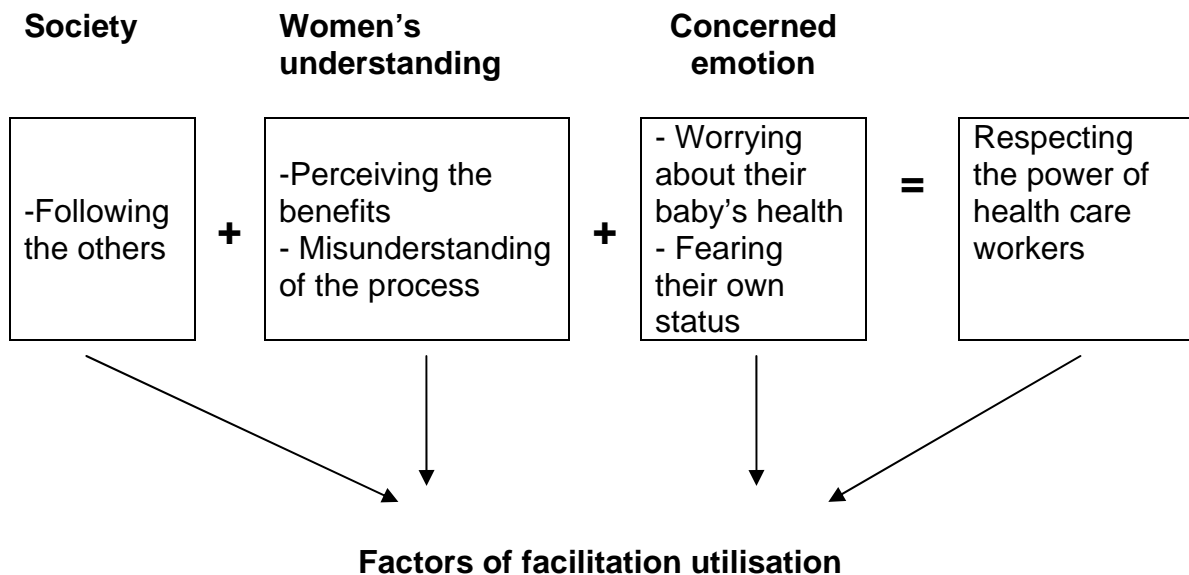
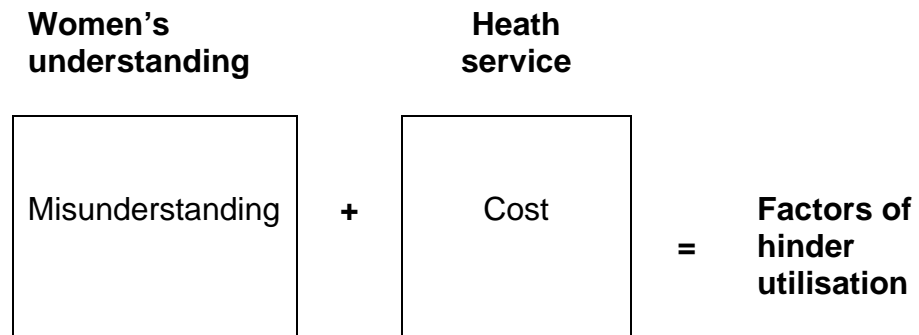


Diagram 6.2 Developed conceptual frameworks of hinder factors influencing women's decision



6.3 Summary

These data demonstrate that the migrant women tended to accept HIV testing without sufficient understanding. Often it appeared that they made a decision to be tested with wrong information or inappropriate reasons for their decision – making. The fact that they made the decision that was expected by the health care system was seen by the health workers as advantageous to the system and the antenatal care programme. Moreover, the health care workers who cared for these women had perceived these erroneous reasons and did not show much concern.

The next chapter will present the findings associated with designing an appropriate intervention programme for screening and counselling migrant pregnant women to participate in the PMTCT programme.

Chapter 7

How to design an intervention programme

This chapter describes findings from the interviews with the health care workers and women participations which relate to ways in which they think the service could be improved. Of particular importance within the data are findings related to improving communication and women’s understanding of information. .

7.1 Themes emerging

In discussing developing screening and counselling in prevention of mother-to-child transmission of HIV programme, health care workers revealed potential solutions particularly to facilitate migrant women. Findings from their perceptions of how care should be developed emerged into five themes. The names of the themes generated are shown in table 7.1.

Table 7.1 Themes for improving screening and counselling process

Theme	Category/Coding
Gaining precise and accurate understanding	Repeating the information
	Improving and providing instruction media
	Rechecking their understanding
Generating familiarity	Generating familiarity
Promoting ‘networking’	Internal Collaboration Working:
	External Collaboration
Developing ‘people’	Training translator
	Increasing manpower
Making policy changes	Changing health care insurance process
	Improving Rules and Laws of migration

7.1.1 Gaining precise and accurate understanding

The health care worker participants believed that the women’s understanding of information given by them was essential to improve the effectiveness of

screening and counselling in the prevention of mother-to-child transmission of HIV programme. They suggest suitable techniques to inform the Burmese migrant women about AIDS, HIV, counselling, HIV testing, mother-to-child transmission of HIV and the prevention programme.

Repeating the information was the main issue cited by many health care workers. They perceived that most of the women could not remember and retain the information given. Consequently, health care workers confirmed that repetition of the information could help these women to remember or to remind them of information previously given.

N6: We need to counsel them several times.

N4: When we rechecked /recalled them, they could not remember. The frequent repetition could help. We need to tell them to repeat and copy our words.

Time limitation was also previously mentioned and perceived [by these health care workers] as a significant barrier when caring for and counselling the Burmese migrant women. Therefore, they recommended providing extended time when providing care for migrant women especially in the health education or counselling section.

V2: I had observed that health care workers spend not enough time with these women. There were a lot of pregnant women here.

C4: We must spend more time with them than usual.

Fear to ask or speak with health care workers was the common characteristic of the migrant women and was recognised by health care workers. Giving them plenty of information in a form they can understand was suggested as a way to increase knowledge related with HIV testing and mother-to-child transmission. Speaking with them more clearly and offering them the opportunity and time to ask questions were stated as possible solutions to help these women gain more knowledge or understanding.

C4: We must explain more details for helping them to understand.

N5: We must try to communicate more clearly and ask them to ask. We should give them an understanding.

Techniques to educate the women about HIV testing and counselling needed to be adapted as written language was not helpful when talking with the migrant women. A Counsellor suggested using images to counsel migrant women who could read neither Thai nor Burmese languages but did not indicate where they would obtain the images and how they could be used effectively. Images might be helpful in addition to language but not as a substitute. In addition, using body language and demonstration were applied when health care workers needed to communicate or counsel these women to increase their understanding. However there was no way of checking the women's understanding when using this means of communicating. In reality, these recommendations already demonstrated that had thought about ways that they could help to increase these women's understanding.

The data suggest that the counsellors had more creative solutions to the problems than the nurses. This may be because they receive more training and education in communication.

C1: Using the picture increased their understanding in pre test counselling.

C3: We used pictures when we counselled them. We demonstrate condom use for them. They could understand.

N1: I used the pictures in Thai ANC booklet to teach them for health education.

Preparing a proper Burmese leaflet was suggested to the health workers by women themselves as some migrant clients could read and required their own language leaflet [TaiYai language]. With this leaflet, the women could read it repeatedly to ensure understanding. Moreover, for the women who were illiterate, they can ask their husbands or friends to read for them.

V1: They asked for Tai Yai leaflet so they could read in again and again. Their husbands could read for them as well.

Because of time restrictions, health care workers stated that they did not have enough time to check the women's understanding. Asking the women to summarise information following counselling or education was seen as good

practice to evaluate women's understanding and help health care workers determine level of their understanding. One nurse suggested that a checklist could be developed to help staff evaluate how much women had understood of the information given.

C1: I asked them to conclude what I said to check their understanding.

N2: We should have check list to evaluate their understanding.

The health care workers tried to provide advice to meet women's needs ensure that they had precise understanding about HIV testing and prevention programme. They stated that increasing their understanding should be done by repeating information, using instruction media, extending time allocated to appointments and rechecking understanding. Health care workers also perceived that the migrant women had passive response when talking with them. Therefore, some tried to ask the women to make questions or summarise the information given.

7.1.2 Generating familiarity

Trust in health care workers could create more effective HIV counselling and education in health care provided to the migrant women. Acceptance of HIV screening is related with trust in health care workers' protection of client's confidentiality. Additionally, these migrant women were uncomfortable with talking to and asking questions of health care workers. Therefore, many of the health care workers emphasised generating familiarity as a significant way to improve care and increase HIV screening proper acceptance.

N13: The familiarity influenced their trust in us.

Dr1: We need to generate the familiarity between us and them.

C1: We needed to create or generate the familiarity between our health care workers and them.

These findings highlight the importance of generating familiarity between health care workers and clients especially migrant clients. The differences of culture and language made these women unfamiliar with health care workers.

Moreover, the findings described in chapter 6 demonstrated that there was a clear power imbalance between the migrant women and health care workers. As a result, generating familiarity should be promoted to improve relationships and health care.

7.1.3 Promoting 'networking'

Health care workers stated that in providing care to Burmese migrant women they needed the health care services to engage in collaboration with migrant communities. Health professionals who provided antenatal care, HIV screening and counselling, and PMTCT programme to Burmese migrant women included nurses, doctors, counsellors, migrant health volunteers. Therefore, as a starting point the need for internal collaboration among these professionals was recognised.

N9: We did only post-test counselling to HIV negative women. We did not know what they already knew from counsellor when they attended individual pre-test counselling.

Dr3: We need to act as team work because we did not have time with them. We need to plan who will and when we should inform them.

N6: We need clearly job descriptions to staff. We do not need to do everything.

Some health care workers perceived that providing care to these migrant women only in hospitals was not enough to achieve the aim of improving their knowledge about HIV. External collaboration with community workers or health care services in the community was suggested to improve the migrant women's knowledge about AIDS/HIV or mother-to-child transmission of HIV before they attend antenatal care clinic:

Dr: We should work or cooperate with PCU [Primary care Unit].

N14: We should emphasise public relations especially at the Village level or in community meetings. Word of mouth is the best method of public relations for these people.

There was evidence that the migrant women could access their own language public media. In one hospital, health care workers already provided health education via radio which was run by Burmese people in the Burmese language. They suggested adding more information related with HIV infection and mother-to-child transmission.

N15: We should provide more health education in their community and more MTCT information on the radio. There is the radio in TaiYAi language in evening time here. This is provided by the Health Promotion department of our hospital.

These health care workers perceived that working as a team was important as they did not have sufficient time to provide information to these women. Therefore, they suggested using their internal staff networks to improve care given to the women to ensure everyone knew everyone else's role. This would ensure that women were given the right information at the right time by the right person. The external networks such as public health networks and community links to reach the women before they even attended antenatal clinic.

7.1.4 Developing 'people'

As previously reported, some hospitals did not provide translators to facilitate communication between Burmese migrant women and health care workers. Moreover, in some settings, the HIV counselling was not complete and was not provided by trained counsellors. Although health care workers had stated previously their concerns about translators some of them considered that having translators was still useful to connect them with Burmese women. However, they also stressed that training for these translators was essential.

N3: Increasing the staff could help because nowadays, we work non stop until 4 pm. We should have a translator to help us for explaining and repeating.

N6: We want translators and they must come to learn with us, with our system. They need to understand our jobs. We need quality staff.

All health care settings reported shortages of health care staff particularly nurses. Nurses were recognised as the key professional to care for the migrant women. However, nurses were required to work within a wide role

which included counselling, educating, and administrator to deal with appointments and registering the migrant women's details. Therefore, there were health care workers' shortages in some setting.

N6: The number of our staff had never changed for ten years [while number of Burmese migrant pregnant women had increased]. We need more staff and want to divide our care for Burmese women separately.

Dr2: Nurses spend time with these women more than us. Increasing the number of nurses to serve them will help but it is difficult.

Dr1: Nurses were the main /key persons who care, advise and encourage these women about health care and taking drugs.

Caring for these migrant women required a great deal of time and increased the health care staff's work load significantly. Trained translators can assist and reduce the workload of the main health care workers. Moreover, increasing the number of nurses was identified to decrease workload and increase quality of care, education, and counselling provision to the migrant women.

7.1.5 Making policy changes

Some health care workers believed that these women were being difficult experiences with Thailand's migration policy. They were also difficult to apply health care insurance to reduce the payment for health care. There was concern among the health care workers about illegal migrants being unable to access health care. They suggested the removal of the need for advance payment of health insurance for migrant women. The need to produce a work permit to get health insurance made it difficult for illegal migrant to access health care without paying the full cost.

N1: We should provide them with the golden card [the programme of 30 Baht fee for curing every disease scheme] so they will feel that they pay less.

Dr1: We need to increase their chances to access health care insurance. Then we could do more prevention. If not it [HIV] would be transmitted to our Thais.

It is interesting to note that the migrant women were regarded as a source of risk to the health of the local Thai population so the concern about improving access to health care was to prevent spread of disease rather than to protect the migrants. They regarded it as important that women were able to receive health care and stated that the migrant status should not influence the right of access. Furthermore, the health workers were concerned that illegal women might refuse HIV screening because they feared being deported. Being a legal migrant could enhance their confidence to accept HIV testing and treatment.

Dr1: We should change the illegal migrants to be legal migrants promptly. We need to increase their chances to access health care insurance. Then we could do more prevention. If not it [HIV] would be transmitted to our Thais.

From these findings, health care workers believed that with health care insurance these women will come to health care services and accept HIV testing as the women do not need to pay full cost for health care or testing laboratory fees.

7.2 Summary

Repeating information, rechecking the understanding and providing early health education or information were all suggested by health care workers. Their suggestion also included promoting networking among hospital colleagues and between hospitals and communities. Moreover, developing people by training staff in health care services was considered important. Finally, changing policy about migrant registration including health care insurance was also regarded as important in terms of public health and disease prevention.

It can be concluded that suggestions from health care workers were derived from their experiences with these Burmese migrant women when they cared for them. These findings showed that some health care workers already attempted to facilitate these women when accessed to their services. These suggestions were also drawn from their expectations as they assumed that

the migrant women will gain more understanding and accept HIV screening or treatment properly if these suggestions were applied to usual care.

Part 4: Discussion, Recommendations, Limitations and Conclusion

Chapter 8

Discussion Chapter

Introduction

This chapter elaborates upon the data and interprets them within the existing theoretical frameworks and findings from other research. It critically discusses the findings and links them with literature reviewed previously and since data collection has taken place. It also links between existing theories and the theory which I was generating from my own analysis of data.

8.1 Accessing Antenatal care

The experiences when they accessed the antenatal care clinic showed that the Burmese migrant women both legal and illegal were not limited in terms of physical access to a health facility in Thailand. Being pregnant was the main reason for these women to access antenatal care. However, there were related factors that motivated them to seek health care.

In term of health care utilisation, I would like to discuss my study based on the initial behaviour model designed by Andersen in the 1968 (in Andersen, 1995). He stated that predisposing characteristics, enabling resources and need for care are associated with individual's seeking and using health care services (Andersen, 1995).

Predisposing factor

Being women is a significant predictor of greater health care utilisation (Fasoli et al, 2010). Moreover, Chakraborty et al (2003) found that mother's education influences the use of maternal health service among women in Bangladesh. They found that the women who have better education have more health and risk perception, know more about the health care services' availability, and can use health information more effectively. However, this predisposing factor could not be applied to my participants as most of them had low educational

attainment and this factor may not be enough for these women to seek health care. My qualitative study did not allow for the prediction of predisposing characteristics with health utilisation such as gender and age (Leclere et al, 1994; Andersen, 1995) and health belief (Andersen, 1995) and need quantitative analysis. Hence, I will emphasise how the other factors, enabling resources and need for care, affect these Burmese women's seeking and using health care in my study.

Enabling resources

Enabling resources consist of cognitive resource; knowledge of the health care system and financial resources; the possession of health care insurance and income (Leclere et al, 1994).

For Burmese migrant women however, as Thai is not their first language and health care information is mainly available in Thai, it is doubly hard for them to gain knowledge of the health care system and insurance schemes. It is significant to explore how they learn about the health care system and access health care with these significant limitations. Information obtained from their husband, friends and in some case from their employers was revealed as useful resources to enable them to seek health care.

Need for care

For illegal migrants, it is obvious that they accessed health care due to need of care. They accessed the Thai health service even when they were at risk of being deported and they needed to pay full cost for health care. It might not be applicable in western society but I have found that need of care is a very strong theme to be addressed and therefore I have decided to include this element. However, need of care was being used among these women because it is most appropriate in the context of Burmese migrants.

The need of health care is possibly the most important factor in that women realise the need to access health care when pregnant. Women recognise the need to nurture and protect their unborn child. Expectation for benefits of care is categorised as need of care (Anderson and Newman, 1973). Some visiting

migrant women access Thai health care services as they expected a Thai birth certificate for their baby and better services. The recognition of better service provision in Thailand encouraged the women to cross the border to seek the best available care for their pregnancy.

Moreover, Andersen and Newman (1973) added environmental variable as another factor to influence health care utilisation and it can refer to health services system.

Environmental variable factor

Environmental variables related with healthcare system include the policies, resources, organisation, and financial arrangements which influence the accessibility, availability, and acceptability of care services (Philips et al, 1998). Many of these women came to the current services due to their right related with their health insurance.

A great many of the migrant women had health care insurance which made it easier to access antenatal care. A study involving Latinos in Southern California found that the access to health care was dependent on whether they possessed health care insurance (Hubbell et al, 1991). However the United States does not have a state funded health care service in the same way as Thailand. In United States, there are not only migrants but also Americans that confront the high cost when accessing health care services and applying for health insurance (Ku, 2006).

Moreover, some of these women were illegal but they could access health care services and antenatal care. This is due to the fact that the Thai government provides migrants an opportunity to apply to be legal migrant workers and includes migrants into the health care insurance system. Accessibility of services can increase utilisation of health care (Chakraborty, 2003; Fosoli et al, 2010) especially in a developing country (Timyan et al, 1993). Nowadays, many countries support health care to migrants openly and

many studies found that there was no difference in access to health care between legal and illegal migrants (Tores-Catero et al., 2007).

Some women in my study stated their husband as the encourager who suggested them to come to the health services. The five studies in one project in Borgou, Benin also showed that the husband or father was the key person to decide about seeking health care (Ngom et al, 2000).

Phillips et al (1998) states that health care provider characteristics may influence clients' health care utilisation. In my study, ability to communicate in Burmese language and positive attitudes of health care workers were revealed from some participants as the reasons for choosing health care services. They preferred to attend antenatal care services which had health care workers who could speak their own language. This could increase the health care utilisation and confidence to communicate of migrant women.

Utilisation of antenatal care or health care was unproblematic for women who had health care insurance. However, difficulties related to financial and administrative issues in applying and accessing care under the health insurance scheme were reported by my participants. These women need to pay costs in advance and have a health check performed in order to apply for health care insurance. Moreover, there was an additional process when they attended antenatal care or other health care in hospital as they had to bring their identity card and health insurance card and need to have these checked by an administrator every time they attended a clinic appointment. This extra layer of administration makes direct access to the health professionals slightly less straightforward and can be off putting for some women.

The health care workers should understand factors that influence health care utilisation of the Burmese women and encourage an appropriate utilisation to these women.

8.2 HIV and mother-to-child transmission knowledge

These pregnant women lack concern for prenatal transmission. This study showed that most Burmese migrant pregnant women have learned about HIV testing and their HIV status 'incidentally' when being given HIV counselling or told about HIV testing when they became pregnant. Their knowledge about HIV and its testing was poor. Only few of them had knowledge about HIV testing and mother-to-child transmission before attending antenatal clinic. These findings are comparable with previous studies which aimed to investigate knowledge, beliefs and attitudes towards HIV/AIDS among 'pregnant women' (Ho and Loke 2003; Adeneye et al 2006; Roger et al 2006; Abiodun et al 2007 and Kominami et al 2007). These findings showed that the majority of pregnant women had little knowledge about HIV in pregnancy and mother-to-child transmission of HIV, while they had a good general knowledge of HIV/AIDS and its transmission. My findings are countering these studies as my participants had a low knowledge of HIV/AIDS and its transmission, even despite the fact that some of them had undergone previous pregnancies.

Nevertheless, when comparing with the studies among migrant women (Bandyopadhyay and Thomas, 2002; Fitzgerald et al, 2003; and Mullany et al, 2003), my study found parallel results in that knowledge regarding HIV/AIDS and its route of transmission was inadequate amongst 'migrant women'.

My study did not evaluate the factors impacting on knowledge of these women. However, a study in Shanshai, China found that the migrant women who had high level of education, resident husband and high income were shown to have better knowledge (Zhao et al, 2009).

For migrants, there are many HIV/AIDS prevention projects run by Thai government services and NGO institutes. The biggest project is Prevention of HIV/AIDS among Migrant Workers in Thailand (PHAMIT project). It was run by Rak Thai foundation and aimed to reduce new HIV infection among migrant workers (Chamrathirong and Boonchalaksi, 2009). The Ministry of

Public Health of Thailand had supported and promoted it for 5 years since 2003. Nearly 45,000 migrant workers had been reached within this project (Pinyosinwat, 2009). However, this amount is less than 10 % of the existing migrants as there are around 2.2 million migrants living in Thailand (UNDP, 2004). Moreover, education and HIV/AIDS information is mainly available in the Thai Language. Therefore if little thought has been given to the effective communication of information, it is no doubt that these women had inadequate knowledge of HIV/AIDS.

However, my study found that the only women who could explain about mother-to-child transmission and the prevention programme were those who were infected and attended the National Access to Antiretroviral Program for People Living with HIV/AIDS programme.

The contrast between those who were HIV positive and those who were HIV negative is informative. It could be postulated that the women who already knew their HIV result was negative did not feel the need to retain the information. It would seem unlikely that those who were HIV positive had better communication skills or better prior education. They retained the information because it was directly relevant to them and it was important to their own well being. Moreover, to protect of their child, they needed to make sure that they understood everything they needed to know. Those who were HIV negative saw no need to retain information about mother to child transmission or HIV transmission routes because as far as they were concerned they were safe and so were their babies.

8.3 HIV counselling

This study provides evidence that health care workers in the northern part of Thailand who deal with Burmese pregnant women were willing but were not able to provide proper counselling and information. They failed to give good quality HIV counselling due to high workloads, lack of human resources and lack of guidelines. In Thailand, the health care workers did not have pre-booked allocated time for pregnant women while United of Kingdom provide

pre-booked time for interview, health history and discussion about blood tests (NICE,2008). This pre-booked time can guarantee that all pregnant women will have sufficient time and adequate information. The UK experience however seems to suggest that even this is not adequate. However, Thailand does not have adequate health care workers to provide the pre-booked time for all pregnant women as nowadays, the nurse to population ratio in Thailand is 1.5: 1,000 (Pagaiya and Noree, 2009). Moreover, the number of migrants is not included in this ratio. As a result, with this time limitation, the findings highlighted that these women did not receive clear or understandable explanations about HIV testing, counselling and PMTCT programme. The time health care workers spent with the women and the amount of information given were not enough to gain these migrant women's understanding.

In addition, in terms of ethical considerations when providing HIV counselling or information, health care workers should supply sufficient information before asking for consent for blood tests (UNAIDS, 2007; UNAIDS, 2008). Moreover, as advocates, health care workers need to include advocating for clients' rights. However, the findings demonstrate that these women did not know about their rights when accessing health care or when deciding to accept HIV testing. They did not receive adequate counselling on PMTCT options. As advocates for women the health care workers should be raising their concerns with managers and with professional bodies to try to improve provision for this group.

The best predictor about HIV testing acceptance of women is the time spent for counselling (Sorin et al, 1996). But in this study, time limitation was one of the barrier factors to gaining more understanding about HIV testing and prevention mother-to-child transmission from Burmese migrant pregnant women during counselling or health education session. There is evidence that a counsellor or nurse as counsellor spent insufficient time and gave inadequate information when counselling the pregnant women especially for migrant women who stated the need of plenty of time for counselling. Moreover, the findings reported that most of these women decided to take

HIV testing within a few minutes and all of them accepted testing in the first meeting.

Peltzer (2005) also found that pregnant women in the Eastern Cape, South Africa required extended time with a counsellor. Moreover, the findings from western Canada indicated that HIV testing was offered with inadequate information and there were pregnant women who often make this decision with little information (Katz, 2001).

However, for these Burmese women time is not the only important factor for acceptance rate; clear and understandable information is also needed to enable them to make fully informed and considered decisions. Although many of the participants got complete HIV counselling before making their decision for these migrant women it cannot guarantee that they could understand and made the decision properly. The information about prenatal HIV testing should be given in a different way depending on individual clients. Katz (2001; page 190) also suggests that for HIV screening, health professionals should provide pregnant women with information 'in a format that best suits their need'. Improvements to the ways of giving information to these women are required.

Moreover, the importance of emotional support needs to be recognised in facilitating the health education and counselling process (Falvo, 2010). Nonetheless health care workers in my study could not consider emotional support when they provided care, health education or counselling due to communication limitations and barriers.

8.4 Decision making regarding HIV testing

Hawley (2007) states that culture; parental teaching, school learning and norms of society contribute to values and beliefs which influence individuals' decisions. The traditional decision-making model is a simple case of 'if....then' (Knoebel and Lovelace, 1998). What is likely to happen and the value of outcome is considered when people need to make decisions. Decisions

regarding HIV testing and treatment of these migrant women are revealed in different perspectives.

The main reason to take the HIV test among these women is fear about their own status as they are concerned about the possibility of being infected with HIV. This supports the finding from the study by Ransom et al (2005) which collected data from non-pregnant women in Midwest, USA that the possibility of being infected with HIV was the reason for deciding to seek a test for HIV. However, the women from my study did not mention about seeking an HIV test before being pregnant or attending antenatal care. In the Eastern Cape, South Africa, pregnant women highlighted that they would take the HIV test if they would be pregnant due to their fear (Peltzer, 2005). Some women in my study stated fear and possibility to be infected with HIV as reasons to accept HIV testing and so it can be deduced that they use risk assessment in their decision-making process (Fan et al, 2007). Nevertheless, perception of the risk is related with knowledge and how to increase this knowledge need to be considered. Their perception of risk only came into play when they were already pregnant.

The Burmese migrant women stated fear of AIDS as the reason to accept HIV testing. This fear can be identified as individually driven in the decision-making process (Knobel and Lovelace, 1998). The past or previous experience influences decision making (Garing, et al, in Ranyard, et al, 2001) as some women had learned that their husband had been infected with HIV and knew the benefits of HIV testing. Moreover, they wanted to know their own status and this can be categorised as preference in their decision-making process (Verplanken and Svenson, 2001).

Concern about health care workers was a significant reason to accept HIV testing for some women in my study. In this theme, power and health care worker-client relationship (Murtagh, 2009) is a factor. From these results, we can learn how power in health care worker-client relationship affects the women's decision-making. There are partnership models related with patient's decision making; paternalistic, informed, and shared decision-making models

(Rothert and O'Connor, 2001). When patients need to accept or agree with authorised health care workers due to the power imbalance, it is categorised within the paternalistic model (Rothert and O'Connor, 2001; Edwards and Elwyn, 2009) and this model appeared in my study as many women accepted HIV testing due to fear of health care workers' reaction and their authority. The second model is an informed model which occurs when the patient makes decisions with all relevant information provided by the health care worker. Shared decision-making model is identified when both health care worker and patient disclose their own preferences (Edwards and Elwyn, 2009). Its process needs more interaction in order to make decisions together. Therefore, offering shared decision-making can help to improve the communication between health professional and client. However, the achievement of shared decision-making needs 'mature agreement and active participation' (Suurmond and Seeleman, 2006: page 254). It is good to offer shared decision-making but difficult to practically apply in some health care settings because of time limitation and work load of health care workers as well as the incapacity of the women in some cases, to make shared decisions (Crozier et al, 2007).

Remarkably, the decision to take the HIV test in some women occurred with indefinite relation to HIV due to the fact that they did not know what diseases they took the blood test for. Knowledge is considered as effective factor for decision (Lipicnik, 2002). Without perception or knowledge, it is concern that what these women's decision process is based on. After evaluating their reasons to accept HIV testing, I found that decision-making among these women is related with people staying around them. Women in my study decided to take the HIV test following their husband's suggestion, the example of other pregnant women's decisions and the health care workers' instructions. The influence of the partner in the women's decision making regarding HIV testing has been revealed in several studies (De Paoli et al, 2004; Semrau et al, 2005; Kakimoto et al, 2007; Kebaabetswe, 2007; Dahl et al, 2008). Following the health care worker's instruction to take the test is related with fear of their reaction or trust in health care worker. The finding of

HIV testing acceptance relating with trust in health care worker supports the results of Mawn's study (1998).

In Katz 's study (2001) most women accepted the HIV test because of their desire to have a healthy baby or because of their baby. This is similar to my results as some participants decided to have a HIV test because of their baby but her participants accepted with understanding as they could identify specific benefits to their baby. Most of her participants had 'a very basic knowledge of HIV and routes of HIV transmission' and some knew about mother-to-child transmission of HIV. The study from Southern India also stated the benefit to the child as a reason for acceptance of HIV testing among pregnant women (Solomon et al., 2000). Moreover, decision making with anticipation of the future (Ranyard, et al, 2001) was demonstrated in this theme by two HIV positive women in Chapter 5. They thought about the future of their lives as well as their baby's future when they decided to take the HIV test. They perceived that HIV testing and treatment could help them to stay longer to look after their babies. They feared that their baby would be neglected if they died. In addition, Field and Lohr (1992) stated that cost is an influencing factor in decision-making in health care. In my study, there were women who accepted HIV testing due to the fact that it was free of charge with their health insurance.

There are differences in personal decision making and risk management. These women used a different perspective to make their decision regarding HIV testing. Their decision-making process was unspecified. To understand these migrant women's decision-making, categorising these decisions should illuminate how these decisions were taken.

Processes of decision-making are related with three important factors; people, network, and information (Hubert et al, 1998: O'Connor, 1999). For these migrant women, the people factor can be implied to their partners and health care workers who played a vital role in the decision making process as these women followed their direction or encouragement. Depending on the spouse is common to these migrant women as their social life, economy and

health care depend on their spouse's support and this could impact on decision-making. Network factors which influence these women's decisions can be their migrant women friends as they received information about their friends' decision and followed their direction. In this study, information factors for these women to make decision refers to the information received from the counsellor or health education provider and it can influence their judgement to accept or refuse HIV testing. Fan et al (2007) indicate knowledge or information collected as the basic first step of decision-making which has an effect on people's attitude when making the decision. The doubt in my study is that in only a short time spent providing information about HIV counselling or health education and with communication barriers, if these women could have a good attitude for deciding to accept HIV testing. With limited information and counselling due to time constraints and language barriers it is unlikely that they received adequate information on which to base an informed decision.

According to Rosenstock et al (1994), taking the health action depends on health perceptions including perception of susceptibility, severity, benefits and barriers. There are some women in my study who decided to accept HIV testing and treatment due to concern about their risk to be infected with HIV and knowing about what benefits they would get from taking HIV testing and treatment. These decisions appear to be related to perceived susceptibility [defined as perception of the risk] and perceived benefits.

Significantly, it is importance that shared decision-making should be applied when caring for or counselling pregnant women. Shared decision-making is identified if there is involvement and participation of at least one health care worker and one patient, and they share information regarding decision-making and agree to the decision (Charles et al., 1997; Edwards and Elwyn, 2009). From the findings, women-centred care and shared decision-making have never clearly occurred in these settings.

These migrant pregnant women displayed passive characteristics which is influential to their decision-making not only in HIV testing but also in health care generally. Therefore patient-centredness (Edwards and Elwyn, 2009)

should be applied as well as empowerment promotion when caring for these migrant pregnant women. Involvement of women in health care particularly in HIV/AIDS issue is sensitive (Dhai and Noble, 2005).

Physical or mental health is usually considered as a decision-making limitation (Devettere, 2009). However, communication barriers or passive characteristics have never been clearly indicated as limitations affecting the patient's ability to make health care decisions. The health care workers should learn the specifics of the Burmese women pattern in making the decision about HIV testing or other health services.

8.5 Self efficacy

Self-efficacy has been described as a persons' belief in their capability to perform a task to achieve their lives' goals (Bandura, 1997a). It can be a 'predictor of health behaviour change and maintenance' (Strecher et al, 1986). The lack of self-efficacy can affect a person's life especially in a changing society (Bandura, 1997b). It can motivate migrant women to change or adapt their behaviour.

Although these women had passive responses and characteristics regarding their health decision-making or communication with health care workers, some of these women actively took actions to secure their lives both in health care by seeking to access health care and health insurance and social lives by trying to marry Thai men, applying for legal status and having a baby to secure their marriage. Mweru (2008) also found that for securing a job, the migrant women workers in Kenya slept with their supervisors. Whilst none of the women in my study declared that they had done such a thing their other behaviours also open them to risk. While the migration of these women and changing partners seems likely to increase their quality of life, it will also increase their risk to HIV infection.

Self-efficacy is an important 'pursuit' for individual achievement and quality of life and it influences 'how people think, feel, motivate themselves and act' (Bandura, 1997b; page 2). To survive in a different culture and society, these migrant women demonstrated their self-efficacy by seeking out access to health care, applying for health insurance, and adapting their health behaviour. In adopting good health behaviour while being pregnant, some women followed the 'competent people' who can influence self-efficacy belief. Although self-efficacy plays an important role as a predictor of adopting health behaviours it was found to be insignificant with condom use related with HIV prevention (Schwarzer and Fuchs, 2002).

Furthermore, Self-efficacy is necessary and related with women's decision-making. If they have self efficacy and perceive it, they would have confidence and belief in themselves when making decisions.

8.6 Buddhism precepts and life security

Most Thai and Burmese are Buddhist and would normally expect to adhere to the five precepts of Buddhism. These precepts include do not kill, do not steal, do not lie, do not misuse sex, and do not use alcohol or other drugs (Sayadaw and Pandita, 2004). However, there was evidence that these women had broken two of these Buddhism precepts; they did lie and misuse sex.

Living in the foreign country without their own families' support made these Burmese women try to do things they felt necessary to secure their lives. They had lied to their current husband in Thailand about another husband in Burma and had been dishonest in their sexual behaviour. Moreover, for HIV positive women, disclosure of HIV status to other people especially to their husband is a major problem. They needed to secure their marriages as well as their individual life in their Thai family and in Thailand. Therefore, they tried to hide their HIV positive status as long as they could. Moreover, the health care workers helped them by suggesting to them how to keep it secret. Although this is a poor clinical decision the health care workers wanted to help

women in short term. For example, they suggested to the women to tell others that they did not have enough breast milk for their baby if they were asked why they did not breastfeed their baby. This activity as a professional liar (Ryan, 2004) seemed to be an attempt to try to help their client. However, while protecting the women health care workers are potentially colluding in putting others at risk. Perhaps health care workers could be helped to consider other ways of enabling women to address the HIV status.

8.7 Social comparison

People are part of a social network and they interact with other people. Therefore these women usually compared their experiences with the people who were living in their past or current society. Moreover, they also compare the experience of Burmese and Thai people.

These women had been in Thailand for 3 -20 years but the ways that they adapt themselves to survival in changing societies were different. For the women who lived near the borders and had people communicating with them in their own language [MaeSot, MaeSai, MaeHongSOn], they have opportunities to maintain some of their culture including language or health behaviour. This can be classified as integration strategies (Lazarus, 1999) by maintaining their own culture language and tradition. They were resisting attempts at integration.

On the other hand, the women from settings located in big cities had adapted themselves by involving themselves in Thais' activities with marginalisation strategies (Lazarus, 1999). Therefore, with the opportunities to share their lives' activities and the need of survival in a different society, these women applied a social comparison concept when taking action or making decision. They learned from people in their community and perceived the others' rights and benefits both in health care and everyday life. With these perceptions, these women compared themselves to Thais or other women to make sure that they would have the same health care service and quality of life.

Therefore, the health care services need to ensure equality, affordability, and availability for migrant women

It is important that health care workers realise that Burmese migrant women expect to receive the same standard of care. There was evidence that some health care workers had tried to improve health care specifically to these women by providing a translator and leaflets and adapting teaching or counselling methods. However, with communication barriers and time limitations as well as financial hardship, it is difficult to guarantee the equality of information giving and ensuring that women are getting the full benefits of the health care system.

8.8 Application of Maslow's Hierarchy of needs

According to Maslow's theory, individuals are motivated to behave for survival by the needs (Maslow, 1987). Maslow had developed conceptualisations of his theory. The first four levels in his initial conceptualisation include physiological, safety, love, and self-esteem needs (Huitt, 2007).

The details of needs in Maslow's theory (Maslow (1954) in Huitt, 2007; Maslow, 1987) are as below.

- Physiological needs refer to the basic needs which are required for life to survive such as oxygen, food, water and sleep.
- Safety needs refer to needs for 'a sense of security' including physiological and psychological safety. Safe shelter, security of family, health, morality, secured employment, clothing are defined as safety needs.
- Love or belonging needs are needs to be affiliated with and accepted by the other people.
- Self-esteem needs refer to needs of respect of and respect by others. Needs to be achieved and confident are also included.

The Burmese women's life journey demonstrated fulfilment of some of these needs since they migrated to Thailand. According to Maslow's initial

conceptualisation, all women in my study achieved their physiological needs as they were the basic needs to be alive. Safety needs were appeared among these women. They migrated to Thailand due to expectation of better quality of life and better income. They also needed the safe shelter in Thailand as some of them were forced to migrate from their own country's military. Expectation of security for themselves occurred when these women married Thai man and intended to having baby to secure their position in Thailand and in society. Moreover, to secure their expecting babies' healthy, these women accesses antenatal care services. Furthermore, the visiting migrant women came across the border and paid full cost to attend Thai hospitals.

According to needs of love and belonging, the Burmese migrant women needed to secure their relationship with their husband, family and friends. According to the interviews of health care workers, some HIV positive Burmese migrant women did not disclose the HIV positive result to the others including their husband. This was because they needed to protect their relationships with the other people especially with their husband. Moreover, for women who had a husband in Burma before their migration to Thailand, there was evidence that some of them did not reveal their previous marriage life to their current husband.

Living in the neighbouring country as a migrant can decrease these women's confidence. They faced communication, financial hardship and sociological barriers. However, many women had achieved the needs of self-esteem. They had their own jobs and some had their own business. Moreover, more than half had health care insurance which needed advanced payment and more processes to get it.

Maslow's initial conceptualisation also consists of one growth need calling self-actualisation.

- Self-actualisation is defined as "the full use and exploitation of talents, capacities, potentialities, etc." (Maslow, 1987 page 150). Its needs can be reached with high capabilities and they include acceptance of the fact, creativity, and problem solving.

Many women showed their ability to solve their problems and were learning to adapt themselves in the new society and system. This can indicate that they had self-efficacy to reach self-actualisation needs. Moreover, they applied and learned from their social comparison by noticing the differences between their lives and those of Thai women and making conscious effort to close that gap to improve their lives.

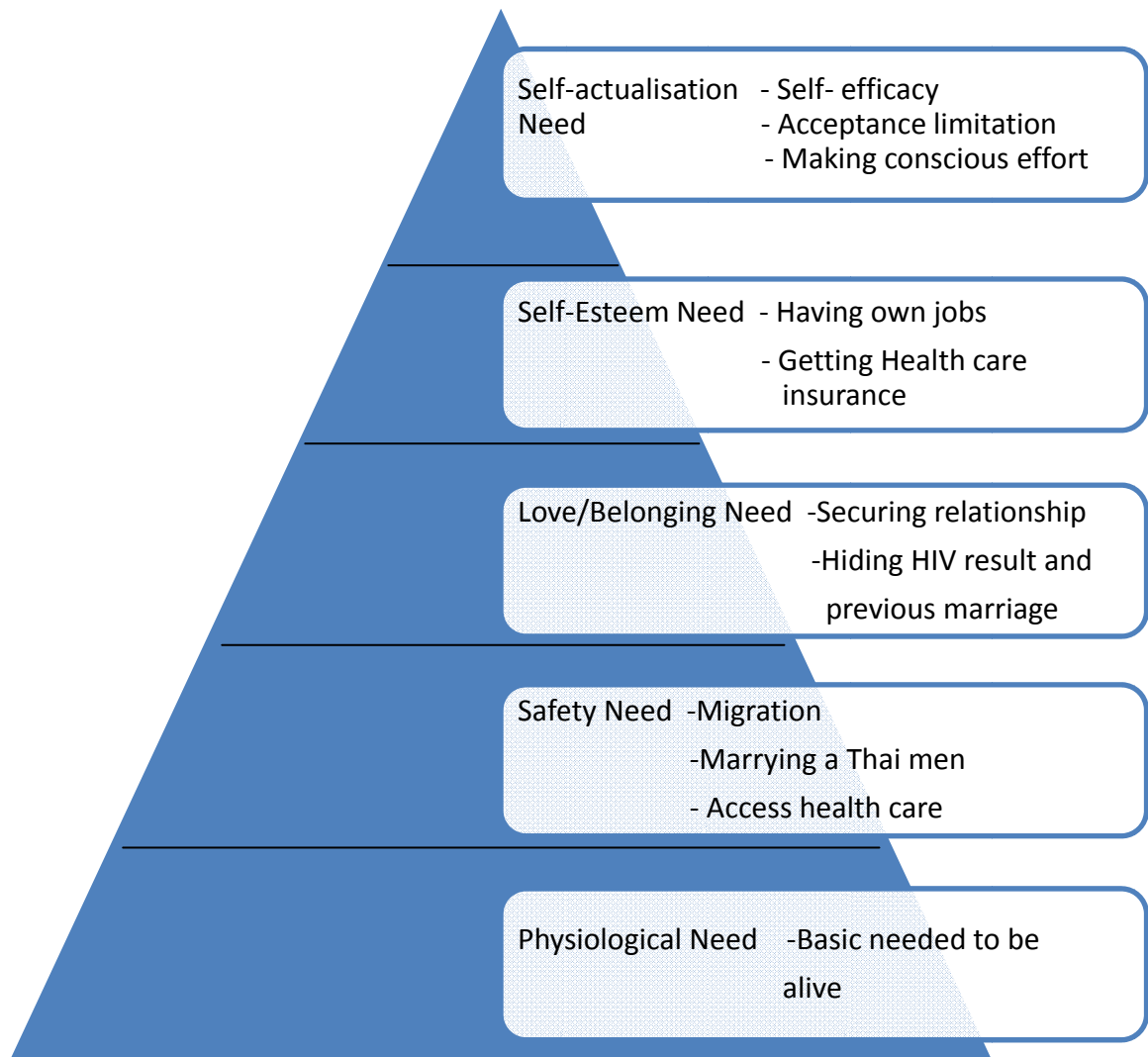
However, Maslow pinpoints that his proposed hierarchy cannot be followed by all personalities (Huitt, 2007). If the lower needs are not achieved, the upper level of needs cannot be reached. Therefore, while some of these women achieved their highest level of needs, many Burmese migrant women could not achieve the higher level needs. They had not develop enough confidence and self-esteem and therefore were not yet ready to meet their need for self-actualisation.

Many women had passive characteristics such as concern about Health Care Worker reactions and following the others when they made the decisions about health care. Moreover, the women were less responsive when they communicated with health care workers as they feared to communicate with and ask for more information from health care workers. Their passive characteristics influence their decision-making and obstructed their opportunity to gain full understanding. These passive characteristics influenced the achievement to reach their needs both in health care and everyday life.

However, the experiences revealed by these women showed that most women were constantly acting to fulfil their needs on multiple levels of the Maslow's hierarchy of needs. Understanding the clients' needs both in physical and health and in general and the limitation are essential for health care worker as they can be applied for holistic care to migrant women.

The below figure [Figure 8.1] shows the characteristics that women used to achieve each of the needs as previous described.

Figure 8.1 Applying Maslow's Hierarchy of Need



8.9 Summary

The experiences of the Burmese migrant women in my study when accessing antenatal care and PMTCT programme reveal how and why they access health care by using health utilisation model in order to fulfil a range of needs related to health and everyday life. Their decision-making was critiqued using several decision-making models and to seek understanding and explanation of how and why they make their decisions regarding HIV testing and treatment. This has enabled exploration of influencing factors to their

decision-making. Moreover, existing self-efficacy of these women is also described as well as the religious precepts which underpin their lives. Finally, the experiences of these women since they migrated to Thailand are linked with and illustrated by Maslow's Hierarchy of needs.

The next chapter will be the recommendations to improve health care, enhance Burmese migrant women's capacities for decision-making and increase their self-efficacy. It also includes the limitations and conclusion of the study.

Chapter 9

Recommendations, Limitations and Conclusion

This chapter presents the recommendations drawn from research findings. The recommendations are linked clearly to the data and analyses and are aimed at national regional and local level for improving health care and increasing health knowledge to migrant pregnant women. Moreover, recommendations about education and research are also included. The limitations of the study are acknowledged before concluding.

Recommendations for health care

From the findings, I have been able to identify that Burmese migrant women experience limitations with communication, financial hardships and complications with their migrant status while attending health care services. The effective provision of health education, HIV counselling and general care, were hindered by communication barriers, time limitations and health care workers' workload.

These findings suggest that the pregnant Burmese migrant women need to be motivated to participate in health care including the Prevention of Mother-to-child transmission of HIV programmes. However they also need to be facilitated to access health care and accept HIV testing or participate in the prevention programme with full and proper understanding. It is clear that motivating factors and influences should be started before they access health care and should be included at all levels from national policy to local practice level and individual level.

9.1 National Level

9.1.1 Integrating migrant pregnant women as the target in the national projects

Since the beginning of 1990s, the Thai government has recognised the increasing number of migrants year by year and generated many long or short policies to control registration of migrants and prevent illegal migration (Kanchai and Kaung, 2002; Chantavanich, 2007; Mon, 2010). Improving the health of existing migrants is an important concern in government policy. The Thai Ministry of Public Health (MoPH) with collaboration from the International Organisation for Migration (IOM) began the IOM-MoPH Migrant Health Program (MHP) to provide migrant-friendly health services at the end of 2003 (IOM, 2006; IOM, 2009). These services were provided in 10 selected provinces to support migrants by providing Migrant Health Assistant (MHA) to help as communicators or translators (Pinyosinwat, 2009). Moreover, many hospitals in this programme provide signs in migrants' languages to guide for direction as well as to show migrants are welcomed and respected.

Increasing collaboration with neighbouring countries and improving or implementing HIV prevention programmes are the goals of the current policy on HIV prevention and border area issues in Thailand (IOM, 2008). The current National Plan for Strategic and Integrated HIV and AIDS Prevention and Alleviation 2007-2011 (BATS, 2007) aims to improve accessibility to information and treatment. However, the indicators for success of the plan are the number of refugee camps and provinces that provide comprehensive and continuous health services. It would be important to include Migrants and refugees' participation and understanding about HIV/AIDS, HIV testing and prevention among the key indicators for success. The findings from my study indicate that understanding is low and therefore if awareness of this was raised within government policy and targets were set for increasing awareness and understanding of prevention and testing then improvements could be expected.

A three year HIV prevention plan was implemented in 2004 from the Bureau of AIDS, Tuberculosis and STI (BATS) aimed at preventing HIV Infection among migrants. The MoPH intended to improve border area health but the project was discontinued after two years due to budget constraints (IOM, 2008). Improving health in border areas must remain an important policy area. This is a gateway to Thailand and if health in these areas deteriorates then this can impact on the wider Thai Population. My study findings help to highlight the very real need for improvements in border areas to enable women in particular to access the right health services at the right time.

Nowadays, the main project to prevent HIV infection for migrants is the Prevention of HIV/AIDS Among Migrant Workers in Thailand (PHAMIT) project organised mainly by Non Government Organisations with collaboration to develop health services to migrants from Thai's Department of Health Service Support (DHSS) (Pinyosinwat, 2009). Nevertheless, there is less than 10% of Burmese migrants who has been given the information about HIV infection and prevention as previous discussed (in Chapter 8). Remarkably, the policy does not place an emphasis on the needs of migrant pregnant women. My data could be used to provide evidence of the need for a focus on women in particular. It is important that women have raised awareness before as well as during pregnancy.

The HIV prevention project for pregnant women in Thailand is the Prevention of Mother-To-Child Transmission of HIV (PMTCT) programme run by MoPH. It includes offering voluntary counselling and HIV testing to all pregnant women and treatment to prevent mother-to-child transmission of HIV before, during and after the birth of their baby. It is regarded as a successfully implemented HIV prevention programme for pregnant women (Kanshana and Simonds, 2002). However, there is no precise objective within the programme for migrant women as its information and counselling are mainly provided in Thai. The data from my study have shown language barriers prevent these women from gaining full understanding and making proper fully informed decisions regarding HIV testing.

The lack of knowledge and misunderstanding about mother to child transmission of HIV and its prevention may increase the risk to migrant pregnant women and their babies. Therefore, the Thai government under the Minister of Public Health as well as the various NGO projects should integrate migrant pregnant women as an important target for the respective programmes. Moreover, proper understanding for participation in the programmes and projects should be a key indicator for success. Importantly, promoting and providing a chance to access HIV/AIDS information and knowledge about mother-to-child transmission (MTCT) of HIV before being pregnant will increase understanding of MTCT and accurate perception of benefits of HIV testing and Prevention mother-to-child transmission (PMTCT) programme.

9.1.2 Increasing and improving the health workforce

Nurses often provide and include patient education in most of their care activities. In the findings of this study, nurses were identified as the key professional to provide information about HIV testing, mother to child transmission and prevention. Health care workers need not only to educate women but also to act as their advocates. However, the data showed that effective care, health education, and counselling, are affected by time limitations as there is a shortage of health workers in the Thai health service. Therefore, health human resource should be increased and developed. Moreover, health care services in border areas should employ health care workers who can speak Burmese or migrants' language in border areas. Translators should be trained and given information about health, HIV/AIDS, HIV testing and counselling before working. Creative thinking could be used to increase the workforce by providing specialist counsellors and support workers who can take on the role of education and counselling leaving the nurses to provide care. This measure could increase the number of workers available without the need to spend 4 years training nurses. In addition, the Thai health care services should consider increasing and registering migrant health assistants or migrant volunteers in various projects for migrants.

9.1.3 Increasing Health Utilisation

Individual's income, education, and poverty levels influence their ability to access health care and health insurance (Flores et al, 2002). From my study, the women had little or no education and had financial hardship. Moreover, there are barriers to accessing health care as the migrant women lacked knowledge about the Thai health care system. These migrants are poor and have no or low education. Therefore, the government should consider how to increase migrants' health utilisation. Promoting and providing supportive or appropriate policy to increase access to health care and health insurance should be considered. Migrants' awareness on basic health rights should be raised. Moreover, migrants' capacity for health access should be increased.

As previously discussed, there are many projects for migrants and it is necessary to promote them appropriately to encourage and increase health utilisation among migrants.

9.2 Practice level

9.2.1 Proactive strategy to prepare migrant women's knowledge

There have been many supportive projects for migrants in Thailand. They have been run mainly by non-government organisations and also by government. However, not all migrants are aware of the projects therefore some thought needs to be given to improving access to the projects.

Migrants move frequently between provinces and cities within them often living in temporary accommodation. Therefore, we need to act pro-actively to give them knowledge and information.

The work place should be one of the first important settings to provide information and knowledge to migrants and their spouses as most migrants need to secure their lives in Thailand by working. Migrants usually work in factories; therefore, health care workers need to work together with the factory

employers to gain access. Information about health care and HIV testing could be provided in written leaflets using their Burmese language for them to take home. Multimedia materials for listening or watching at lunch time could be provided in the work place with the co-operation of employers. If health care workers could access the workplaces then interactive activities could also be provided. Persuading employers that allowing health sector workers access to their employees is potentially good for business because it can ultimately improve the health of the workforce which leads to greater productivity.

Many migrants living in Thai communities had previously lived in refugee camps. Therefore, preparing them at the refugee camp should be recommended. However, the various refugee camps in Thailand are organised by many authorities and organisations such as Thai authorities, Refugee committees, NGO organisations and UN agencies (TBBT, 2007). Therefore, collaboration between staff from the Thai government and other staff in the refugee camps should be strengthened to develop understanding of each other's responsibilities and expectations.

Furthermore, these women still maintain their culture and attend their home-country spiritual activities in their community such as the Tai Yai temple in Thailand. Therefore, providing health education and information at these places could be possibly effective. Having health care volunteers who can provide activities and information at the temple will be an ideal way to target women before they become pregnant in order to make them aware of ways to maintain and improve health.

Migrants are required to attend for work permits and health insurance annually. Therefore, health education including HIV testing and MTCT can be provided at the hospitals where they attend for the registration process. Improving information during these annual health checks can help to prevent HIV by educating everyone about its routes of transmission and risks associated with HIV in pregnancy.

9.2.2 Empowering and increasing self-efficacy

The data from my study suggests that some migrant women cannot reach their potential in terms of Maslow's Hierarchy of needs as they have passive characteristics. Consequently, their self-efficacy should be increased by improving their capacity to make decisions about caring for themselves. Therefore, we need to increase their self-efficacy and empower them.

Empowerment is defined as the process that "encompasses people's rights, strengths and abilities, implying competence or the development of potential" (Jones and Meleis, 1993: page 7). It is also defined as a process to recognise, promote and enhance individual's ability (Anderson, 1996).

Education is often considered to be an important factor to increase empowerment (Jayaweera, 1997; Solidar and European women's Lobby, 2005). However, educational provision for migrants in Thailand is directed only towards children of school age (Fu Yang, 2009; IRIN Asia, 2009; CPPCR, 2009). For migrant women, there are many Non-government organisations running projects to increase women's knowledge. The adult education for migrants and refugees has been provided mainly by World Education Thailand under the SHIELD project in which the Thai government has collaborated. Moreover, Women's Organisation (KWO) have educated and trained Karen women in Karen refugee camps along Thailand-Burma border since 2001 (KWO, 2006). This programme provides educating adult's literacy skills to enable women to help their family and themselves to read necessary documents. Furthermore, Shan Women's Action Network (SWAN) have conducted a women's empowerment program for Shan women along the border and in Shan state (Feraya, 2008). Nevertheless, these education and training programmes have been run in their minority Burmese languages or in English not in Thai. Therefore consideration should be given to providing education in literacy and numeracy and life skills which would equip the migrants to live and work productively in Thailand. However, it is worth remembering that the main objective of these projects is to prepare migrants for returning to country of origin or moving to a third country (Sawade, 2008).

Remarkably, there are no or few projects to support migrants who already are living in the Thai community as opposed to those living in refugee camps. Hence, migrants who are living in Thai communities should be empowered and educated in Thai and learn to communicate in Thai to increase their abilities to survive in their community. Moreover, this can enhance their self-care and health care utilisation and thus enable their development according to Maslow's hierarchy (See figure 8.1 on page 142). The empowerment programmes should be integrated within existing health or AIDS prevention programmes to prevent extra burden on the workforce.

However, support from others is not enough to achieve empowerment. Kar et al (1999) pinpoint that individual efforts influence the outcome of empowerment. Recommendations can be made to educate and empower women in Thai communities.

9.2.3 Providing effective and appropriate information and counselling

With language barriers and time limitations, health care workers need to give health education or information effectively. The information about prenatal HIV testing and counselling should be given in different ways depending on individual clients. Katz (2001 page 190) suggests that for HIV screening, health professionals should provide pregnant women with information 'in a format that best suits their need'. The findings suggest that health care workers should apply appropriate techniques when giving information or counselling. Information sheets in their own language should be prepared for take home information.

These women hold a strong belief in the truth of what they are told by their husband, Burmese friends and employers. They also followed the people who were the same nationality or ethnic group. Burmese women who can speak Thai fluently and have experiences with HIV testing or PMTCT programme should be trained and employed as mentors to increase these women's trust

and understanding. Peer support from women who have a sound knowledge of the health system and the health insurance schemes will enable information to be passed to women by someone they can trust.

However, health care workers are the key persons at whom the recommendations are directed. It is therefore important to ensure that the results of this study increases their understanding OF THE EXPERIENCES AND NEEDS of these women. Therefore, my research and recommendations will be presented in Thai journals and reported to the local hospitals. Moreover, they will also be presented directly to health care workers who care for migrant women. To do this I can organise a study session for the health care workers via the education service in the hospital in partnership with my nursing college.

Recommendations for Education

In Thailand, there is integration of midwifery courses into the nursing curriculum. However, there is no subject for caring specifically for migrants or migrant women. There is no specialist nursing curriculum about caring for migrant women and vulnerable pregnant women.

However, the curricula have integrated concepts of holistic care with the policy 'Health for All' from the Ministry of Public health (PBRI, 2009). Therefore, the nursing or health lecturers should integrate caring for migrant pregnant women as vulnerable people into the maternal and child nursing subjects especially in the universities or colleges in the border areas. Selecting migrant clients to be case studies during students' placement will increase understanding and insight of migrants' characteristics and barriers. Integrating holistic care in the nursing curriculum will encourage students to learn to care by considering not only the physical condition but also emotional, social, economic, and spiritual conditions. These contents should be integrated in general subjects and students will apply these perspectives to specific care. Importantly, in educating nursing and health students, lecturers

should aim to help them determine their roles to facilitate and care for migrants.

Short courses to train support workers such as counsellors and translators for migrants should be provided by nursing or health educators to ensure quality.. The training courses should contain learning to counsel and translate effectively. Preparing material for facilitating counselling or translation should be taught and considered. Nevertheless, speaking or written language used in these assistant materials should be selected carefully as there are various ethnic migrants from Burma and they do not share a common language. Importantly, knowledge of HIV/AIDS, HIV testing and counselling, and prevention programme should be given to these support workers to gain understanding of contents and ensure the accuracy of translation.

Recommendations for research

There is little or no research focusing on migrant women's understanding of mother-to-child transmission of HIV and its prevention. Moreover, evaluating migrants' understanding before deciding to accept HIV testing or HIV prevention programmes were also limited. Quality of HIV programmes including HIV testing and counselling should be studied.

As previously suggested in recommendations for health care section, empowerment is needed for migrant women. Therefore, the researchers should apply research as a tool to empower these women. In addition, suggested implementation such as peer support groups for migrant women should be assessed by research.

Kanchai and Kaung (2002) advise that if the research has not been commissioned by government it is difficult to make a link between researchers and policy makers. Therefore, passing our research findings to policy makers and implementing them to improve care is a necessity. Effective

dissemination of research findings will increase the chance for real implementation to migrants. Moreover, how to decrease barriers such as communication limitations or time limitations should be considered. Collaboration among researchers, health care workers, NGO organizations involved in projects for migrants and policy makers will increase effectiveness of the research.

Key recommendations

Based on the findings of this study, it is recommended that policy makers and health professionals should

- Consider and target migrant pregnant women within their in HIV prevention projects
- Increase the awareness and understanding of HIV prevention and mother-to-child transmission of HIV among migrant women
- Provide easy access to health care services, health care insurance and HIV prevention projects for all migrant women
- Improve the quantity and quality of health care workers who deal with migrant women, including counselling and translation services
- Provide appropriate approaches to counselling and mechanisms for the provision of relevant health information
- Integrate caring for migrant women into the teaching for health professionals [including nursing students]
- Consider providing access to education for migrant women and improve training for support health staff
- Provide a research focus on the migrants' understanding of mother-to-child transmission of HIV and prevention programmes
- Empower migrant women by improving their access to education and doing research

Limitations of the study

My study was undertaken on a high priority topic area which is important for clients and nursing. It had the potential to produce interesting and important questions as well as data and implementable recommendations (Gerrish and Lacey, 2006). However, aims of study are not achieved all of general purposes of research. Producing knowledge, increasing understanding and predicting are the general purposes of research (Richey and Nelson, 1996). My study expands knowledge about migrant women accessing health care including HIV counselling and increases understanding about these women's decisions regarding HIV testing and treatments though it does not allow for prediction.

The reasons for refusal of HIV testing among Burmese pregnant women could not be explored fully. I had planned to explore the reasons why some Burmese migrant women refused to take the test for HIV. I had met some of them but unfortunately, all of them were staying at a refugee camps and their guardians did not give the permission to interview them.

Most of these migrant women's decision making depended on other outside factors. The reasons that they accepted involvement in my study might be because of the health care workers 'direction, their husbands' agreement or following the lead of the other participants. Because of the passive nature of these women their ability to volunteer could be called into question. However, through the course of the interviews they willingly disclosed details of their lives and experiences. So, although it is unclear why they chose to participate in the study. It is clear from their interviews that they were voluntarily given information.

Although all participants could communicate in Thai there were practical problems during accessing and interviewing the migrant pregnant women. There was evidence drawn from my study that communication limitations are the the main difficulty when doing research with migrant women as it could

occur often during giving research information, asking consent, and interviewing. It could happen due to their inability in communicating as well as the varieties of languages used. With this limitation, conducting a pilot study should be considered before doing fieldwork.

Health care workers' focus groups did not include all professionals for all focus group due to the demands of their workload it was impossible to schedule a time which was convenient for all. With time limitation, I could not wait for all of them to organising the completed focus groups. However, this allowed the researcher to learn about the different dynamics of groups including different professionals or a single professional group. I would like to do member check by translation all interviews and give them to women participants to check. Unfortunately, most of these women were illiterate in Thai as well as in Burmese.

Conclusion

This qualitative study examined the experience of Burmese migrant women in the northern part of Thailand. It aimed to explore the health care experiences of Burmese migrant women whilst pregnant in relation to HIV testing, to investigate why they accepted or refused to participate in these programmes and to design an intervention programme for screening and counselling for migrant pregnant women to participate in PMTCT programmes. The study was conducted among Burmese migrant women and health care workers in the Thailand-Burma border provinces in the northern part of Thailand.

This study used a qualitative grounded theory approach to collect data by interview and focus group in 2008 – 2009. The findings demonstrate various difficulties when Burmese migrant women accessed antenatal care services including communication limitations, financial hardships, and complication with migrant status. The health care workers who were caring for them also faced many barriers when providing health care, health education or HIV counselling to this vulnerable group.

The findings of the study reflected that Burmese migrant women demonstrated their acceptance of HIV testing in pregnancy without sufficient understanding. Moreover, the health care workers who cared for these women had perceived these erroneous reasons and did not show much concern. However, there were attempts to facilitate and increase these women's understanding. Unfortunately, time limitations and work load prevented the success of these facilities.

The experience of these women allows insight into their decision-making and knowledge about HIV testing and treatment in pregnancy. This should influence the way in which health care workers individualise care to meet the needs of this vulnerable group. Recommendations for policy change to facilitate better access to health care and health insurance are made based on the findings. Changes to local practice that could provide a means of education to empower the women are also suggested. Further research is needed to identify the most effective way in which care and information can be provided to this vulnerable group to improve the health of mothers and babies.

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Appendices

Appendix A: Participant Information Sheet for Burmese migrant women

Appendix B: Participant Information Sheet for health care workers

Appendix C: Consent form for Burmese Migrant Women

Appendix D: Consent form for Health Care Workers

Appendix E: Burmese migrant women interviews: Issues to consider

Appendix F: Health care worker Interviews: Issues to consider

Appendix G: Interviews of Burmese migrant women who did not participate in the PMTCT programme: Issues to consider

Appendix H: Research ethical approval letters

Appendix I: Ethical approval and permission letter from hospital

Appendix A

Participant Information Sheet for Burmese migrant women

Pregnant Burmese migrant women and the PMTCT programme in northern Thailand. A qualitative exploration.

My name is Pleumjit Chotiga; I am a doctoral student at the School of Nursing and Midwifery of the University of East Anglia in England.

I would like to invite you to take part in a research study. Before you decide you need to understand why and how I want to talk to you. Please take time to listen to *[or read]* the following information carefully. I *[this leaflet]* will tell you what this study is about and what will happen to you if you take part.

Talk to others about this study if you wish. You can also ask me if you have any questions or if you would like more information. Take time to decide whether or not you wish to take part.

This research wants to find out about your experience with the Prevention Mother-to-Child Transmission of AIDS programme and to learn about your decisions about testing and treatment.

I would like to talk to you because of your experiences with the PMTCT programme. However, it is up to you to decide whether you wish to take part. This leaflet will explain the study to you. You can take it home with you. You do not have to decide now, I will be happy to see you again in three days time and answer any questions you might have. I will then ask you to decide whether you want to take part and, if you are happy to talk to me, to sign (or make your thumbprint on) the consent form. Taking part in this study is entirely voluntary. You can stop at any time, without giving a reason. This will not affect the care you receive or will receive. If you choose not to take part, you will not be identified in any way.

I cannot promise the study may help you but the information I get from you will help improve the PMTCT programme for Burmese migrant women.

If you agree to talk to me you will be interviewed for about 60 minutes in an interviewing room near this clinic or at your accommodation if you prefer. What you say will be recorded by tape-recorder, transcribed and translated into English.

All information about you will be handled in confidence; I will not allow anyone else to read what you have said. I will be the only person to know your name. For everybody else a false name will be used in the report of the findings so that you cannot be recognised.

If you join the study, some parts of your Antenatal records and the data for the study will be looked at by me.

I will keep what you tell me secure for five years. Then I will destroy the recordings.

This study has been funded by The Royal Thai Government and approved by Faculty of Health Research Ethics Committee, University of East Anglia. Its overall results will be used to improve the health care service and PMTCT programme. I will also write a University thesis and articles for international journals.

This is my contact detail:
Mrs Pleumjit Chotiga
Chiangmai Nursing College
A. Mae Rim, Chiangmai
Tel No. 0 5312 1121 or 08 6913 6226

If you are worried about any aspect of this research you can also contact Head of obstetric department.

Appendix B

Participant Information Sheet for health care workers

Pregnant Burmese migrant women and the PMTCT programme in northern Thailand. A qualitative exploration.

I would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about this study if you wish.

Part 1 tells you the purpose of this study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study.

Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Part 1

This study aims to explore the experience of Burmese migrant women with Prevention Mother-to-Child Transmission of HIV (PMTCT) programmes and to learn about their decisions about HIV testing and treatment. It is the purpose of this project to improve the design of the intervention programme.

You have been chosen for this study because you are the health care worker who deals with/care these Burmese migrant women in PMTCT programmes. However, it is up to you to decide whether you wish to take part. I will describe the study and go through this information sheet, which I will then give you. You do not have to decide immediately whether you wish to take part, I will be happy to see you again in three days time and answer any questions you might have. I will then ask you to sign a consent form to show you have agreed to take part. Participation in this study is entirely voluntary. You are free to withdraw at anytime, without giving a reason. If you choose not to participate, you will not be identified in any way.

You have been invited to participate in this study as someone with experiences I am interested in. The total time expected for participation in the study for each participant is about 60 minutes. You will be interviewed in an interviewing room near this clinic or your workplace if you prefer. All information about you will be handled in confidence; I will be the only person to know your name, for everybody else a pseudonym will be used instead of your name.

I hope that not less than 12 health care workers will participate in the study. I cannot promise the study will help you but the information I get from you will help improve the PMTCT programmes for Burmese migrant women.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Part 2

I want to interview you to learn about your experiences with the PMTCT programme when caring/dealing with Burmese migrant women. The interview will be recorded by tape-recorder, transcribed and translated into English. All information gathered during participation in the research will be treated confidentially. If the information obtained from your participation in the study is disseminated or published, this will be done in a way that does not identify you as its source. Pseudonyms will be used in the report of the findings so that you cannot be recognised.

All data will be kept in secure storage when not in use, during the lifetime of the study. After analysis, report and acceptance of the thesis by the University, all tapes and transcripts will be destroyed.

I have a duty of confidentiality to you as a research participant and I will do my best to meet this duty.

The results of this study will be reported to the authorised persons for improving the health care service and PMTCT programmes and published in University thesis and international journal.

This study has been funded by The Royal Thai Government. I will carry out this research; I am a PhD student at the School of Nursing and Midwifery of the University of East Anglia in England. This study has been approved by Faculty of Health Research Ethics Committee, University of East Anglia and the provincial health offices, of the Thai Ministry of Public Health.

The contact detail of researcher:

Mrs Pleumjit Chotiga
Chiangmai Nursing College
A. Mae Rim, Chiangmai
E-Mail address: P.Chotiga@uea.ac.uk
Tel No. 053 121121 or 086 913 6226

If you are worried about any aspect of this research you can also contact Head of Tak provincial health office, of the Thai Ministry of Public Health.

The contact detail of Head of Tak provincial health office:

Director of Tak provincial health office
Tak provincial health office
167 Moo 7 T. Maingam A. Meung, Tak 63000
Tel No. 0 5554 1515 – 19

Appendix C

CONSENT FORM for Burmese Migrant Women

Antenatal Care Unit
Mae Sot Hospital
A. Mae Sot, Tak Province

Title of Project: **Pregnant Burmese migrant women and the PMTCT programme in northern Thailand. A qualitative exploration**

Aim of Project: **To inform the development of the programme.**

Name of Researcher: **Mrs Pleumjit Chotiga**

Date:

Please initial box

1. I confirm that I have received the information from Mrs Pleumjit Chotiga (researcher) for the purpose and method of the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I volunteer to participate in this study and I am aware that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected

3. I understand that relevant sections of my medical notes and data collected during the study may be looked at by Mrs Pleumjit Chotiga. I give permission for this person to have access to my records.

4. I agree to take part in this study

.

.

Name of Participant

Date

Signature [or thumbprint]

Name of Person
taking consent

Date

Signature

Appendix D

CONSENT FORM for Health Care Worker

Antenatal Care Unit
Mae Sot Hospital
A. Mae Sot, Tak Province

Title of Project: **Pregnant Burmese migrant women and the PMTCT programme in northern Thailand. A qualitative exploration**

Aim of Project: **To inform the development of the programme.**

Name of Researcher: **Mrs Pleumjit Chotiga**

Date:

Please initial box

1. I confirm that I have received the information from Mrs Pleumjit Chotiga (researcher) for the purpose and method of the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I volunteer to participate in this study and I am aware that I am free to withdraw at any time without giving any reason.

3. I agree to take part in this study

.

Name of Participant

Date

Signature

Name of Person
taking consent

Date

Signature

Appendix E

Burmese migrant women interviews

Issues to consider

The Burmese migrant women's experience of accessing the Antenatal Care Clinic (ANC) and of their pregnancy.

- How they found out about the ANC.
- What their experiences of the ANC are.
- Whether they believe that ANC is beneficial for them.
- Any difficulties they might have had to access / when accessing the ANC clinic.
- Their recall of how they were asked to participate in Prevention mother-to-child transmission (PMTCT) Programme.

Issues relating to the PMTCT Programme.

- How they came to know about the PMTCT programme.
- Their understanding of the programme.
- Their first encounter with the health care worker of this programme
- How it felt to talk with health care workers about this programme
- Did they have questions or concerns about the programme.
- Did they [How did they] ask for more information.
- Their recollection of the decision process whether to participate in the programme.
- Their reasons for accepting to participate.
- What information did they have that made they decide to participate with this programme.
- Who and / or what influenced their decision.
- Their experiences in the PMTCT programme.
- Did they make the right decision? [Their perception then and now].

Participant validation of the main issues in the interviews.

Appendix F

Health care worker Interviews

Issues to consider

The Health care worker's experience of working with Burmese migrant women in an Antenatal Care Clinic.

- How long they have worked in a ANC clinic.
- Their experience with migrant women attending the ANC clinic.
- Any difficulties they experienced when caring for these women in the ANC clinic.
- Any experiences of dealing with Burmese migrant women in the Prevention mother-to-child transmission (PMTCT) Programme

Information relating to the PMTCT Programme.

- How long they have worked with it.
- Their opinion of it.
- Whether the programme is beneficial to all women.
- Description of a typical consultation with a Burmese woman about PMTCT programme.
- How it feels to talk with these women about the programme.
- Their experience and estimation of difficulties when inviting these women into the PMTCT programme.
- Their experiences of migrant women who refused the programme.
- Their experiences of migrant women who decided to participate in the programme.
- Their perceptions of reasons behind the acceptance or refusal
- Their perception of co-operation by migrant women who accept the invitation to participate in PMTCT programme [i.e. attendance and taking the drug].
- What they did when women refused to participate in the programme.
- Their opinion of the women who refuse to participate in PMTCT programme.
- How participation levels could be improved.

Participant validation of the main issues in the interviews.

Appendix G

Interviews of Burmese migrant women who did not participate in the PMTCT programme

Issues to consider

The Burmese migrant women's experience of accessing the Antenatal Care Clinic (ANC) and of their pregnancy.

- How they found out about the ANC.
- What their experiences of the ANC are.
- Whether they believe that ANC is beneficial for them.
- Any difficulties they might have had to access / when accessing the ANC clinic.
- Their recall of how they were asked to participate in Prevention mother-to-child transmission (PMTCT) Programme.

Issues relating to the PMTCT Programme.

- How they came to know about the PMTCT programme.
- Their understanding of the programme.
- Their first encounter with the health care worker of this programme.
- How it felt to talk with health care workers about this programme.
- Did they have questions or concerns about the programme?
- Did they [How did they] ask for more information?
- Their recollection of the decision process whether to participate in the programme.
- Their reasons for refusing to participate.
- What the information made them refuse to participate with this programme?
- Who and / or what influenced their decision.
- Their experiences in the PMTCT programme.
- Did they make the right decision? [Their perception then and now].
- What they think now about the decision that they made.

Participant validation of the main issues in the interviews.



University of East Anglia
Norwich NR4 7TJ England

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01603 593028

Research Telephone
01603 591720

Fax
01603 591132

Pleumjit Chotiga
15 Village Close
Wilberforce Road
Norwich
NR5 8NA

1 August 2007

Dear Pleumjit

Pregnant Burmese migrant women and the Prevention Mother-to-Child transmission of HIV (PMTCT) programme in northern Thailand. A qualitative exploration

Your research proposal was discussed at the Ethics Committee meeting held on 25 July.

The Committee had some concerns they would like you to consider and amend appropriately:

1. The Committee request that you convey the purpose of the project which is to improve design of the intervention programme throughout information sheets and consent.
2. Page 3 - The Committee have asked that you confirm that 20 is the age of consent in Thailand.
3. Page 3 - The final paragraph should read have duty to 'care for' rather than 'work for'.
4. Page 5 - Second point – Please could you confirm whose consent will be sought to interview the participants.
5. Please could you confirm that acutely ill women are to be excluded.
6. The Committee are concerned that there are issues of consent for people who cannot confirm in writing, they suggest using an illustrated consent and information sheet for those who cannot read. Participant can then have something to take away with them
7. All participants should have an option of consent in writing if it can be given.
8. The Committee recommend that you simplify the language on all documentation to help with translation.

9. The use of the word "informant" could be loaded. It may be better to use "someone with experiences we are interested in".
10. The Committee recommend that you need Burmese and Thai translations of the document and independent back translations in English.
11. Appendix A page 1 – The penultimate paragraph should read "may help" rather than 'will help'.
12. Page 2 - Research findings will be 'disseminated' rather than 'reported'.
13. The Committee have asked that you clarify why you need to go to medical notes of participants.
14. The Committee were concerned as to how you will find the non-participating groups?
15. Please could you confirm the protocol for approaching case workers? How will you get in touch and how they will respond/agree?
16. Appendix B. "I will have a duty. . ." the Committee have asked that you rephrase this in lay language eg will not allow anyone else access.
17. Appendix D. The Committee feel that the questions asked during the interview should be more open if you are using grounded theory.
18. Please could you include an interview schedule for those women who have not participated in the scheme.

Please resubmit your application when you have resolved/clarified the above issues. I require documentation confirming that you have complied with the Committee's suggestions. I have emailed you a copy of the letter and the committee have requested that you detail the changes below the relevant point on the text. The deadline for the next meeting is Wednesday 12 September 2007.

As your project does not have ethics approval until the above issues have been resolved, I want to remind you that you should not be undertaking your research project until you have ethical approval by the FoH Ethics Committee. Planning on the project or literature based elements can still take place but not the research involving the above ethical issues. This is to ensure that you and your research are insured by the University and that your research is undertaken within the University's 'Guidelines on Good Practice in Research' approved by the Senate in July 2004.

Yours sincerely



pp Debbie Graver
Notetaker
Faculty of Health Ethics Committee
Tel: 01603 591023
Email: Deborah.Graver@uea.ac.uk

Institute of Health
Finance and Research Offices



Pleumjit Chotiga
School of Nursing and Midwifery
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University of East Anglia
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Finance Telephone
01603 593028

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01603 591720

Fax
01603 591132

31 October 2007

Dear Pleumjit

Pregnant Burmese migrant women and the Prevention Mother-to-Child transmission of HIV (PMTCT) programme in Northern Thailand – A qualitative exploration - 200727

The resubmission of your research proposal was passed to the Chair for action.

The proposal was approved and the committee wish you luck with your research.

Please send the Committee a report at the end of your project.

Yours sincerely

A handwritten signature in blue ink, appearing to read 'D Graver', with a horizontal line extending to the right.

Debbie Graver
Notetaker
Faculty of Health Ethics Committee
Tel: 01603 591023
Email: Deborah.Graver@uea.ac.uk

Dr Suzanne Collins
Faculty of Health Ethics Committee
Yorkon Building
UEA

26 August 2007

Dear Dr Collins

Thank you very much for your helpful comments. I have complied with the committee's suggestions. The details are as follow:

Title: Pregnant Burmese migrant women and the Prevention Mother-to-Child transmission of HIV (PMTCT) programme in northern Thailand. A qualitative exploration.

1. The Committee request that you convey the purpose of the project which is to improve design of the intervention programme throughout information sheets and consent.
I have included relevant sentences into these forms. Please see appendices A to C.
2. Page 3 - The Committee have asked that you confirm that 20 is the age of consent in Thailand.
In Thai law 20 years is indeed the legal age of consent. For any younger participant the legal guardian would have to sign the consent form. This would not be appropriate for this study.
3. Page 3 - The final paragraph should read have duty to 'care for' rather than 'work for'.
I changed this as requested in the proposal.
4. Page 5 - Second point – Please could you confirm whose consent will be sought to interview the participants.
I will ask the head of each department for permission to approach their patients [p4, proposal] and I will seek the participants' consent [p5, proposal].
5. Please could you confirm that acutely ill women are to be excluded.
I will indeed exclude acutely ill women; this is an exclusion criterion [p3, proposal].
6. The Committee are concerned that there are issues of consent for people who cannot confirm in writing, they suggest using an illustrated consent and information sheet for those who cannot read. Participant can then have something to take away with them.
I will supply these women with the Burmese language information leaflet. After returning home they can then ask a literate friend or family member to read it to them.
7. All participants should have an option of consent in writing if it can be given.
I have made this more clear. Please see Appendix C and p4 of the proposal.
8. The Committee recommend that you simplify the language on all documentation to help with translation.
I have revised the information leaflet for the Burmese women and have tried simplifying it as far as possible [Appendix G]. However, the leaflet for the healthcare workers has not been changed. I am a health professional myself and cannot see any problems with translating this form into Thai. The quality of the translation will be ensured by a Thai Professor in English Language Studies.

hope that the committee can understand and accept my reasoning about this issue.

9. The use of the word "informant" could be loaded. It may be better to use "someone with experiences we are interested in".
I have done this as suggested by the committee. See Appendices A and B.
10. The Committee recommend that you need Burmese and Thai translations of the document and independent back translations in English.
The information leaflet and consent form will be translated into both Burmese and Thai. I will use a university lecturer, who is a native Burmese speaker, to translate the materials into Burmese for me [see proposal p4].
11. Appendix A page 1 – The penultimate paragraph should read "may help" rather than 'will help'.
12. Page 2 - Research findings will be 'disseminated' rather than 'reported'.
I have changed both of these
13. The Committee have asked that you clarify why you need to go to medical notes of participants.
*The medical notes will be required to confirm the participants' eligibility for the study [i.e. the participants have either accepted or refused the HIV screening test within the last year].
The notes will also provide me any existing appointments, this will enable me to meet the participants, consent and interview them on the days of any existing appointments.*
14. The Committee were concerned as to how you will find the non-participating groups?
These women are 'non-participants' only in terms of the HIV testing, they still receive general medical and nursing/midwifery care.
15. Please could you confirm the protocol for approaching case workers? How will you get in touch and how they will respond/agree?
Having secured permission from the heads of the relevant departments I will provide the information leaflets to all members of the relevant professional groups and invite them to volunteer. Only one member of each professional group in each department will be required for the study.
16. Appendix B. "I will have a duty. . ." the Committee have asked that you rephrase this in lay language eg will not allow anyone else access.
Appendix B is the information leaflet for the health workers. However, I have used your advice for Appendix A, the leaflet for the Burmese women.
17. Appendix D. The Committee feel that the questions asked during the interview should be more open if you are using grounded theory.
I have adapted the interview schedule to ensure that it is used only as an aide memoir, ensuing that all important issues are considered during the interview. I will use these points only if the interviewee has not brought up these issues herself.
18. Please could you include an interview schedule for those women who have not participated in the scheme.
Yes, please see Appendix F.

Please let me know if there is anything else I can do.

Yours sincerely



Pleumjit Chotiga

3 October 2007

Pleumjit Chotiga
School of Nursing and Midwifery
Edith Cavell Building
UEA

Dear Pleumjit

Pregnant Burmese migrant women and the Prevention Mother-to-Child transmission of HIV (PMTCT) programme in Northern Thailand – A qualitative exploration

The submission of your research proposal was discussed at the Ethics Committee meeting on 26 September 2007.

The committee have approved your application in principle. However, they have some concerns they would like you to consider and amend accordingly.

- Appendix A, Part 1 – The committee recommend that you amend this to 'inform' development of the intervention programme and not use 'improve' as there is no guarantee that the programme can be improved.
2. Appendix C – The title of this document should be the same as used in Appendix A.
3. The committee note your response to point 6 which was raised in the previous letter but recommend that you consider carefully who the women will ask to read the leaflet to them. There is a danger that an unacceptable level of disclosure may be incurred by them having to explain to a close relative the reasons for them having the leaflet. You do not need to respond to this point.

Please write to me once you have resolved/clarified the above issues. I require documentation confirming that you have complied with the committee's suggestions. The revisions to your application can be considered by chair's action rather than go to a committee meeting, which means that the above documentation can be resubmitted at any time. Please you could send you revisions to me as an attachment in an email as this will speed up the decision making process.

As your project does not have ethics approval until the above issues have been resolved, I want to remind you that you should not be undertaking your research project until you have ethical approval by the FoH Ethics Committee. Planning on the project or literature based elements can still take place but not the research involving the above ethical issues. This is to ensure that you and your research are insured by the University and that your research is undertaken within the University's 'Guidelines on Good Practice in Research' approved by the Senate in July 2004.

Yours sincerely



Debbie Graver
Notetaker
Faculty of Health Ethics Committee
Tel: 01603 591023
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Pleumjit Chotiga
School of Nursing and Midwifery
Edith Cavell Building
UEA

Dr Suzanne Collins
Faculty of Health Ethics Committee
Yorkon Building
UEA

12 October 2007

Dear Dr Collins

Thank you very much for your helpful comments. I have complied with the committee's suggestions. The details are as follow:

Title: Pregnant Burmese migrant women and the Prevention Mother-to-Child transmission of HIV (PMTCT) programme in northern Thailand. A qualitative exploration.

1. Appendix A, Part 1 – The committee recommend that you amend this to 'inform' development of the intervention programme and not use 'improve' as there is no guarantee that the programme can be improved.

I have changed this as requested in Appendix A, Part 1.

2. Appendix C – The title of this document should be the same as used in Appendix A.

I have changed this in Appendix C.

3. The committee note your response to point 6 which was raised in the previous letter but recommend that you consider carefully who the women will ask to read the leaflet to them. There is a danger that an unacceptable level of disclosure may be incurred by them having to explain to a close relative the reasons for them having the leaflet. You do not need to respond to this point.

I will consider carefully when I inform these women about this leaflet. I will suggest that they bring the leaflet to the translator in hospital or the people that they can trust.

Please let me know if there is anything else I can do.

Yours sincerely



Pleumjit Chotiga



No CR 27.102/5430

Chiang Rai Prachanukrao Hospital
1039 Satanpayaban Street, Amphur Muang
Chiang Rai, 57000

26 February 2008

To Director of Boromrajonani College of Nursing, Chiangmai

Re: Ethical Approval

Mrs Pleumjit Chotiga, RN5, Boromrajonani College of Nursing, Chiangmai, has sent her research proposal asking for Ethical approval and permission to collect data in Chiang Rai Prachanukrao Hospital. Her research title is "Pregnant Burmese migrant women and the PMTCT programme in northern Thailand: A qualitative exploration".

Her research proposal was approved by our committee. Mrs Pleumjit Chotiga has been given permission to collect data in hospital because her research is useful and not harm to research participants.

Sincerely Yours,

Signed

Sutas Srivilai

(Director of Chiang Rai Prachanukrao Hospital)