Positive versus Pregnant

HIV positive Women and Reproductive Health in Ubon Ratchathani, Thailand

Pimontipa Malahom
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Universiteit van Amsterdam
Faculty of Social & Behavioral Sciences
Amsterdam Master’s in Medical Anthropology
The Netherlands

Supervisor: Han ten Brummelhuis
Summary

The study investigates how HIV positive women in Ubon Ratchathani, Thailand experience pregnancy. Particularly, it focuses on how HIV positive women who want to bear a child are treated by the current national health care system with respect to their reproductive choices. Furthermore, it attempts to answer the following questions: do the PMTCT program health care providers recognize women’s reproductive rights and choices? How do HIV positive women who become pregnant or want to bear a child experience stigma and discrimination? What support does family, the community and the state-sponsored health care services offer to HIV positive women? In which ways do these women experience motherhood and their desire to have a child? Are they aware of their reproductive rights and do they exercise these rights?

The study employs the interpretive medical anthropology (IMA) approach, a meaning-centered approach, to shed light on the process in which HIV positive women make sense of their experiences of pregnancy within their own HIV positive context. A major theoretical concept that underpins the conceptual framework of this study is the ‘Mindful Body’ emphasizing the effects of three different but interlinked bodies, the individual, the social and the political, on HIV positive women’s experiences of pregnancy and throughout its process.

The study was carried out in Ubon Ratchathani province, Thailand. The primary group of research subjects was twelve HIV positive women who had been pregnant in the past three years and have had experience with the PMTCT program, or HIV positive women who had decided not to bear a child or to abort their baby due to their HIV status. The study relied primarily on qualitative methods including participant observation, in-depth interview and focus group discussion in order to obtain data from HIV positive women whom were selected as key informants. Supplement data were also gathered from doctors, nurses, and PLHA group peer leaders by means of formal and informal interviews.

The findings from this study elucidate that HIV positive women’s experiences of pregnancy and its processes are to a great extent conditioned by stigma and discrimination against HIV positive women who want to bear a child. Stigma and discrimination for a large part are embedded in constructive perspectives of the community and health care providers. HIV positive women’s views towards themselves also affect their decision to bear a child. Gender practices casting gender-based violence and fixed notion of motherhood also affect HIV positive women’s desire to bear a child or to stop a pregnancy.
Finally, this study suggests that HIV positive women should not be treated with cultural or medical bias, rather they should be provided with non-judgemental and confidential support, services and advice on contraceptives, conceiving, child bearing and knowledge for bringing up children in a positive family. They also should be further encouraged to make decisions regarding reproductive choices based on their own rationales with sufficient information about medical services and support that are available to them.
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Acronyms

AIDS  Acquired Immune Deficient Syndrome
ANC  Anti natal care
ARV  Antiretroviral
AZT  Azidothymidine
CD4  Cluster of differentiation 4
CPG  Clinical Practice Guideline
FGD  Focus Group Discussion
FP  Family Planning
FWCW  The Fourth World Conference on Women
HIV  Human Immunodeficiency Virus
ICPD  International Conference on Population and Development
ICW  International Community of Women Living with HIV/AIDS
IMA  Interpretive Medical Anthropology
MCH  Mother and Child Health
MOPH  Ministry of Public Health
MTCT  Mother-to-Child-Transmission
PLHA  People Living with HIV/AIDS
PMTCT  Prevention of Mother to Child Transmission
STDs  Sexual Transmitted Diseases
VCT  Voluntary Counseling Testing
STD  Sexual Transmitted Disease
UNGASS  United Nations General Assembly Special Session
UNAIDS  The Joint United Nations Programme on HIV/AIDS
UNIFEM  United Nation Development Fund for Women
UNFPA  United Nations Population Fund
WHO  World Health Organization
Chapter 1

Introduction

When I was a community nurse I had to treat a certain number of AIDS patients. At the same time, the communities and families had not yet learned to accept and live with people living with HIV/AIDS (PLHA). Many PLHA were stigmatized, discriminated and abandoned while in the hospital. Health care personal including doctors and nurses were not well prepared to handle the situation. Their attitudes towards AIDS patients were filled with bias and discrimination too. Consequently, PLHA suffered a great deal because of stigmatization. During my work I have attempted to empower PLHA by encourage them to set up self-help groups, particularly for HIV positive women of child bearing age who are confronted with reproductive pressures.

As the access to antiretroviral therapy (ART) in Thailand has improved a great deal, a greater number of HIV positive women are living longer, healthier lives, and many of them express their desire to have children. They, however, encounter an array of dilemmas and discrimination, especially with respect to pregnancy and motherhood. In my health care setting, HIV positive women are unable to make fully informed decision about their reproductive rights. There are many HIV positive women who have been persuaded by doctors or nurses to terminate their pregnancy, not to get pregnant, or to undergo sterilization upon learning about their HIV positive status. Consequently, Thai society lacks a supportive system, information as well as good health care services for HIV positive women who wish to have children. It is apparent that Thai women living with HIV are often unable to achieve ideal reproductive health and rights. Therefore, I created a clear research agenda into this problem in order to create a more coordinated approach to policies and programs that will be supportive of the pregnancy intentions of women living with HIV in Thailand. This research inquiry attempts to put HIV positive women’s reproductive rights and needs at the center of the study with the hope that the research results will bring about the society’s appropriate responses to HIV positive women’s right to bear a child.
Research Question

The study aimed to investigate how HIV positive women in Ubon Ratchathani, Thailand experience pregnancy, what services are available to them through the national health care policy (PMTCT program), who supports their decision to bear a child, and how do they experience stigma and discrimination throughout the process. From these intentions I developed the following core research question: How does HIV affect women’s lives in relation to reproductive choices? Through the core research question I constructed the following sub-research questions:

- How do they experience the current PMTCT policy?
- If and how do they experience stigma and discrimination? If so, in what way?
- What support, if any, do they receive from family, the community, and the health care system?
- How do they experience motherhood and the desire to have a child?
- Are they aware of their reproductive rights and do they utilize them?

Throughout my thesis I will elaborate on these ideas and answer the questions of how HIV positive women have experienced themselves under many barriers such as stigma, discrimination, violated rights, violence, sexuality and reproductive health and right as well as culture, norms, beliefs and social support. I will also explore the affects from families, communities and the health care system that permit positive women to face long-term conflict and mental problems. I would like to know the perspective and reflection of health care providers on positive women’s decision-making, and I also want to know how the PLHA self-help group functions or responds to these issues. I want to acknowledge the positive women who were willing to share and give useful information associated with their rights, so the political issues can be managed. Moreover, all the information gathered proves to be significant and may be used to improve or evaluate many programs associated with HIV positive women.

Background: HIV/AIDS in Thailand

The AIDS situation in Thailand

Thailand has been globally acknowledged as a success story in undertaking the HIV epidemic with a remarkable ability to reduce new HIV infection from 150,000 in the early 1990’s to only 26,000 in 2000 (Thai working group on HIV/AIDS Projection 2001). In the first decade of the epidemic, there was unbelievable success on a massive program to control HIV/AIDS (UNAIDS 2004). The program
reduced the disease among commercial sex workers by half, raised condom utilize, drastically decreased sexually transmitted diseases (STDs), and achieved substantial reduction in new infected cases (UNAIDS 2004). In the second decade of the epidemic new case infections declined from 83 percent to 50 percent between 1990 and 2000 because of the weakened prevention efforts, it led slowly to the decline of new cases. In 2010 almost 11,000 people a year are contracting HIV (Brown and Peerapatanapokin 2005).

Since the first case of AIDS in 1984 until now, Thailand is still experiencing an epidemic of HIV infection and AIDS. The epidemic has increased rapidly and affects many groups: sex workers, men who have sex with men, heterosexual men, their wives and partners, as well as babies who got HIV from their mothers (Apinudecha et al. 2007). In 2007 an estimate suggested that there were 546,578 PLHA in Thailand, a figure that may decline to 481,770 by 2011 (National AIDS Prevention and Alleviation Committee 2008). However, UNAIDS stated in 2006 that there are 220,000 Thai women living with HIV/AIDS, and 1.5 percent of pregnant women are HIV positive (UNAIDS 2006). This is in conflict with a report from 2006 saying that the HIV prevalence rate among pregnant women in Thailand was 0.8 percent and 0.7 percent in Ubon Ratchathani (Ubon Ratchathani Public Health Report 2009).

The two major contributors to increase HIV infection during the 2000’s will be husband-to-wife transmission and sex with sex workers; the promotion of condom use in these groups and STD treatment among sex workers and clients will change in this decade. Unless the previous efforts are sustained and new sources of infection are addressed, the striking accomplishments of controlling the epidemic could be put at risk. Furthermore, the factors in which are related with an increase in risky sexual behavior and STDs cases lead to concern that Thailand could face a resurgence of HIV and AIDS in the coming years.

The PMTCT program

To better understand Thailand’s policy development on HIV/AIDS, as well as, the nation’s prevention and care service situation, documentary research and key informant interviews with health care providers and positive women were conducted in this study. After the first case was reported in 1984, Thailand’s policy development was delayed through much of 1987, after announcement of the first National AIDS Policy in 1992, the first Five-Year HIV prevention and Control Plan was developed. From the first National AIDS Policy until now there have been four plans, in the second plan (1997-2001) the National AIDS Policy adopted a more holistic care agenda and the PMTCT program started.

The PMTCT program was developed to cover three main areas: counseling and testing for positive pregnant women, use of AZT for preventing mother-to-child transmission and abortion,
which needed to focus on HIV positive women making decisions by themselves. The PMTCT is an effective national public policy that was launched in Thailand in 2000 following the Bangkok Study\(^1\) (Kanshana et al 2000). In principal the program provides pregnant women with the opportunity to decide freely whether to accept antiretroviral therapy as well as to prevent new infected cases from mother to child (Kanshana and Simonds 2002). This program was expanded throughout the country in one year, and has provided all hospitals with the resources to provide PMTCT services to HIV positive pregnant women and their babies (MOPH Thailand 2009). Studies from Medley conducted in Sub-Saharan-Africa and two countries in Asia found that women in developing countries have problems accessing PMTCT programs because of their partner’s unawareness about why the PMTCT program is necessary for HIV positive pregnant women; nor are they supportive of their participation in terms of financial support, sharing and coping with the problems faced during pregnancy, nor accompanying the women when accessing services (2004).

The Thai public policy on HIV is widely cited as one of the few examples of an effective national AIDS program. The PMTCT program has been highly successful in bringing down the HIV transmission rate through pregnancy and delivery, since the coverage of the PMTCT program for HIV positive pregnant women rose from 90.1 percent in 2006 to 95.9 percent in 2008 (Division of Epidemiology MOPH Thailand 2008). Despite the ability of the program to allow HIV positive women to bear HIV negative children, these women still encounter an array of dilemmas and discrimination, especially with respect to pregnancy and motherhood. In disregard to these shortfalls, the Thai government provides follow up treatment and care for all children and mothers, and support is given to the baby’s care provider (Ministry of Public Health Thailand 2009).

In 2009 the results of the PMTCT program in Thailand showed that the HIV prevalence rate among pregnant women was 0.8 percent, and children born HIV positive was four percent (the Thai Ministry of Public Health 2009). Shaffer and colleagues demonstrated the efficacy of a short zidovudine regimen administered orally during the last month of pregnancy and labor to non-breast feeding HIV-infected women in Thailand, which can reduce MTCT by half, to absolute transmission risk of 9.4 percent (1 child in 10) (1998). In Vietnam and Indonesia the health care providers are pleased with the PMTCT programs on the local level (Hardon et al. 2009). In Vietnam, the PMTCT program is useful at the community level, but delivery services for HIV positive pregnant women are only available on the district and national levels (Hardon et al. 2009). However, in Indonesia the PMTCT program is not covered 100 percent and unavailable on the local level; despite the lack of local services, financial incentives make it possible for women to access the program (Hardon et al. 1998).

\(^1\) The ‘Bangkok Study’ successfully illustrated in 2000 the efficacy of short-course AZT prophylaxis in preventing mother to child HIV transmission and reduced the transmission rate from mother to child from 25-30 percent to 8 percent.
These shortfalls experienced in Africa and Asia seem in many respects similar to the problems faced by women in Thailand.

I ideas of marriage, child bearing and reproductive rights

A combination of social, economic and political circumstances and physical factors contribute to putting women at risk of HIV infection; other factors affecting HIV vulnerability include one's level of education, poverty, quality of life and supporting systems. Thai women in the reproductive age group are most vulnerable to HIV infection when compared to other adults and young men, especially, women's vulnerability to HIV infection is enhanced when they do not have the legal power to make choices in their lives and to refuse unwanted sex. However, with new developments in HIV/AIDS medication and access to health care services, PLHA are living longer and healthier lives leading some positive women to marry or re-marry and consider having children. In Thai society people have the right to decide to bear children or not, regardless of their HIV status. However, some families try to push women to have children as soon as possible, influencing their decision making process. Furthermore, it is not always possible or easy for positive women to access information about reproductive decision making. As women take care of their families, including husband, regular partners, children, and parents, they also think about the circumstances of looking after and preparing themselves for a new family member. In Ubon Ratchathani, some positive women are faced with many factors, especially stigma and discrimination which violate their choices to bear children.

In Thailand approximately 250,000 women are living with HIV/AIDS and are part of the reproductive age group (15-49 years) (Population Reference Bureau and UNAIDS 2009). These women account for about half of the population living with HIV/AIDS in Thailand (UNAIDS 2009). In Thai society, the power imbalance in gender relations that favors men leads to an unequal power distribution in heterosexual interactions, in which men have the power to control and dominate women when, where and how sex takes place (UNFPA 2006). Moreover, Thai men hold the leading role in many areas, especially in sexual areas; all Thai women have traditionally been expected to be virgins before marriage, while men are free to have sex with other women, on the basis that having many partners proves a man's masculinity (Asavaroengchai 1994:109). Women are forbidden to act as promiscuous as men, and they are denied the ability to negotiate their sexual rights, because condom use among women who are married is only acceptable when used for family planning (Asavaroengchai 1994:108). Because of high gender inequity and a heteronormative cultural context, women's agency and autonomy over their body and particularly over their sexual choices are denied in Thai society (Asavaroengchai 1994:110). These problems are related to a study by Ickovicks, which explains that male domination, enrooted in Thai society and culture, has limited the ability women have to cope with their daily problems, including coping with HIV infection (2007:17).
HIV positive pregnant women in Thailand, are not only faced with male dominance but they are also faced with manifestations through gossip, rumors, verbal abuse and people creating distance between each other (Liamputtong et al. 2009:4). In addition, sexual rights, or rights to engage in sexual activities, to re-marry or to have sexual partners are limited by a medical discouragement to bear children, which has also been adapted by lay persons (ICW 2008). Extensive studies on discrimination in the health care sector in six Asian countries (China, India, Vietnam, Thailand, Indonesia and the Philippines) found that discrimination was most often attributable to the individual practice of health care providers rather than legislation or public policy (UNFPA 2006). There are many HIV positive women who have been persuaded by doctors or nurses to terminate their pregnancy, not to get pregnant, or to undergo sterilization upon learning about their HIV positive status (Bedimo et al. 1998).

Hierarchy within the medical system

In the Thai health care system the doctor is the sole person who has the authority to decide to continue or change a patient’s treatment. Thus, this creates problems when doctors do not listen, or have the time to listen, to the concerns of their patients, particularly for women who are trying to make difficult reproductive decisions. This problem is further exasperated when the patient is an HIV positive woman trying to consider or decide to continue or stop taking certain drugs which affect her life and possibly the life of an unborn child. Patients often do not have a chance to negotiate their treatment or learn more about the options available to them. Even though, the government had the process to correct inequality in this system, it has not been improved because it depends on the characteristics of the health care workers. This problem is very challenging when considering its influence on the health care system and the treatment individual’s are receiving.

This is a big barrier to the health care system even though the government has created regulations to protect both sides (health care teams and patients) it has not solved the problem. Not only are ARV and PMTCT clinics faced with this problem but it is also prevalent within general health services despite the fact that an evaluation program has been developed to listen to patient opinions and evaluations of the health care services they receive. The hierarchy within the health care system violates human rights and creates obstacles to effective decision-making about health concerns.
Chapter 2

Theoretical Perspective

Before addressing the findings of this thesis, it is necessary to elaborate on theoretical concepts that were critical for the study. By collecting the narratives the women used, I tried to understand the situation and experience of HIV positive pregnant women. Therefore, the theoretical approach of this research focuses on interpretive medical anthropological (IMA), which is meaning-centered, focusing on what people mean when they communicate experiences of illness or disease, as well as explains the origins of disease within a culture.

Through the IMA framework the definitions and experiences of illness are linked to basic cultural values (Good 1994). Good has explained the interpretive perspective of illness representation as ‘culturally constituted reality’ bringing on a ‘meaning centered’ tradition (1994:52). The women in this research are the center and I have explored the experiences these women have when faced with their particular situation. Moreover, IMA focuses on the symbolic structures and processes that have been joined together with inevitable illnesses and their effects on societies (Good 1994:54). In this part of the interpretive approach I assume that the meanings and experiences of HIV positive pregnant women are culturally constructed.

I have also used the theory of the ‘Mindful Body’ which distinguishes between the individual body, social body, and political body (Scheper-Hughes and Lock 1998:347). The Mindful Body underlines my approach by providing a helpful framework in which to analyze how HIV positive pregnant women experience bearing a child and into what type of relationships they enter (Scheper-Hughes and Lock 1998). The ‘Three Bodies’ concept by Scheper-Hughes and Lock highlights that there are different bodies or levels of relations which are dynamic and suggest why and how certain kinds of bodies are socially generated (1998:348). The ‘Mindful Body’ starts by referring to the ‘individual body’; to understand the phenomenon of HIV positive women about their beliefs, their own experiences and why they desire to have a baby and how they experience maternity. The social body is not only dominated by culture and norms but also includes family, husband/partner, community as well as peer group responses to individual women’s experiences and their function within society. The last distinction, the political body, refers to the “regulation, surveillance, and control” that is related to structure, national policies, health services and health care providers; it
reacts with the individual and the collective bodies (Scheper-Hughes and Lock 1996:248). The political body links the experiences of HIV positive pregnant women through their access and relationships with the PMTCT services and other services related to them, and how these services support or deny them the experience of bearing a child. These contexts are relevant to understanding and continuing my study. HIV positive pregnant women can share experiences that they have faced from their current pregnancy through their narratives, and how their individual experiences have been influenced by social and political factors. Finally, by using these approaches, we can put HIV positive pregnant women at the center of decisions on health policy, and help provide an appropriate constellation of services.

Core concepts

Stigma and discrimination

Stigma is socially constructed and is attributed to culture, norms and beliefs in every level of Thai society. HIV infection has become one of the greatest complications of pregnancy and is still experienced as part of the epidemic in Thailand. Stigmatization occurs when women know that the results of their blood tests are HIV positive which may lead to feelings of shame and guilt. Stigma has been described as a dynamic process of depreciation that significantly disgraces an individual in the eyes of others (Goffman 1963). Although the images associated with AIDS vary, they are patterned so as to ensure that AIDS-related stigma plays into and reinforce social inequalities that include those linked to gender, race and ethnicity, and sexuality. As men and women are often not dealt with in the same way when infected or believed to be infected by HIV, women are more likely to be blamed than men even if the source of infection is from her husband, and positive women may be less likely to be accepted by their communities (Parker and Aggleton 2003:57, 13-24).

Parker and Aggleton suggested that HIV/AIDS stigmas continue to perpetuate class, race and gender inequalities (1998). Discrimination intersects with other social prejudices, including homophobia, racism and sexism (in this study, being a woman) (Parker and Aggleton 2003). Stigma is not the only problem, HIV positive pregnant women are also faced with manifestations through gossip, rumors, verbal abuse and people creating distance between each other (Liamputhong et al. 2009:4). However, as Parker and Aggleton (2003:17) caution, it is crucial to recognize that stigma takes place “within specific contexts of culture and power”. They also suggest that “discrimination is characterized by cross-cultural diversity and complexity” (Parker and Aggleton 2003:14). Therefore, socio-cultural beliefs, values and morals within the local context play a major role in constructing stigma and discrimination. In China, PLHA have experienced stigma by individuals in the context of their daily lives, furthermore, knowledge of PLHA’s perceptions about and responses to this disease are greatly influenced by their experiences of interacting with others (e.g. families, friends and health
care workers). Conflicts interact between individual, social and political levels that lead PLHA to face stigma and discrimination in daily life (Zhou 2007, referred to by Liamputhong 2009:4).

A study called “HIV and AIDS Stigma and AIDS support groups,” by Liamputtong (2009), finds that in larger cities we find more positive attitudes from local communities. She claims that some HIV positive women deal with stigma and discrimination by joining and participating in HIV and AIDS support groups by means of self-help organizations. In addition women who are HIV positive are not passive victims, but they act on their own to counteract any negative perspectives. Therefore, community and group support can empower HIV positive women giving them confidence to continue with their desired life style. A support system incorporated into the PMTCT program may help reduce the stigma and discrimination felt by HIV positive women.

Violence

Marital violence is “a major risk factor for serious injury and even death and women in violent marriages are at much greater risk of being seriously injured or killed” (National Advisory Council on Violence against Women 2000). In a situation of violence, women lack empowerment in many respects: politically, economically, socially, physically and personally, which could be a direct cause of HIV infection. Acts of gender-based violence are likely to result in physical, sexual or psychological harm or suffering to women including such acts as psychological violence in the family, battering, sexual abuse of female children and other practices harmful to women. Gender-based violence not only violates human rights, but also hampers productivity, reduces human capital and undermines economic growth (UNIFEM). As Riches argues, “violence always encompasses both an instrumental and an expressive function” (1986:25). Many manifestations of violence and its roots are regularly examined by means of an ecological model, we will then approach violence as the result of a complex interaction of risk factors at individual, relationship, community and social levels (Krug 2002:12-15).

The evolving HIV/AIDS pandemic has shown a compatible pattern through which stigmatization, discrimination, marginalization and a lack of respect for human rights and the dignity of individuals, force women to be exposed to HIV (Richters 2004:159). Violence is not only undergone by the body but it is also still in the memory (Zur 1998).

Reproductive health and rights

The major policies and programs in Thailand that are related to the reproductive health of HIV positive women consist of a policy of HIV counseling and testing (VCT) by anonymous clinics, the PMTCT program for counseling and testing of pregnant women, AZT for positive women, provisions of abortion and prevention, treatment and care programs. It includes also a holistic care program of home and community-based care through a cooperation of PLHA and health care providers.
The International Conference on Population and Development (ICPD), which took place in Cairo in September 1994, stated that reproductive rights and reproductive health include complete physical, mental and social well-being and not merely the absence of disease or infirmity. All of these issues are related to the reproductive system, and to its functions and processes (UNFPA 2004:45). Men and women have rights to have access to appropriate health care services that will enable women to go safely through pregnancy and child birth as well as provide couples with the best chance of having a healthy infant. Reproductive health and rights are a major issue at stake when discussing HIV among pregnant women. Reproductive health has many elements which consist of, but are not limited to, family planning, maternal and childhood health, safe abortion, rights to have a good quality pregnancy and access to STD and HIV services (Yuddumnern 2004). Beck and Harvey (2005) argue that the current reproductive technologies for women who will make use of these services need to be provided with enough information for them to make a knowledgeable decision. Reproductive decision-making is a highly complicated and sensitive issue; there are many factors that influence women when faced with a need to make a reproductive choice including their own culture, norms, socio-economic, and psychosocial situation. In addition, the influences of partners, spouses, family and friends as well as the attitudes and practices of the medical providers influence the choices that women make (Bedimo et al. 1998). Furthermore, HIV and childbearing are not just an issue of health: they touch upon almost every aspect of a person’s life, from sexuality to economics to motherhood to mortality, the disease influences every spectrum of the society in which we operate (Bedimo et al. 1998).

Moreover, reproductive rights include the right to decide when and if to get pregnant, number and spacing of children, the rights to voluntarily marry and establish a family among others (UNFPA 2006). Fiore found that when many HIV infected individuals become healthier they have a desire and need to have children (2008). Due to this factor it is important for information and services to prevent vertical transmission to be available to HIV positive women of child bearing age (Fiore et al. 2008). To come up to my research, we will notice that there are many factors in the social and political structures which obstruct women from improving the quality of their lives in terms of reproductive health and reproductive rights.

**Gender and power relations**

In Thai society there exists a negative attitude towards sexuality which allows men to have power. In gender relations it is accepted that men have the high authority in families which dominate the sexuality and reproductive rights of their partners such as, having the power to neglect condom use with their wives or regular partners and disregard to respond or participate in cases of unwanted pregnancy (UNFPA 2006). In addition, HIV positive women lack the freedom to have safe sex with their husbands or partners, and the inability to require safe sex from their husbands or partners places
them in a vulnerable position for re-infection of HIV and contracting STDs, particularly since societal norms permit the husband or partner to have multiple sexual partners at the same time (Asvaroengchai 1998).

Farmer argues that gender inequality has weakened women’s ability to negotiate safe sexual encounters, and this sapping of the agency is clearly amplified by poverty, because women use their bodies as an agent (2007). Women should be empowered to exercise their rights to decide whether or not they want to have children, eliminating outside domination. The impact of gender on HIV/AIDS is an important dimension in understanding the evolution of the epidemic. In addition, gender-based discrimination affects access to quality of care and treatment that women receive from health care providers, families and communities in many ways (ICW 2008). An anthropological study showed that broader community-based initiatives that deal with underlying gender norms and social attitudes about HIV/AIDS and violence against women, must accompany individual focus on initiatives in order to create a safer and more comfortable surrounding for women to share their HIV results and experiences with pregnancy (Medley et al. 2004).

Motherhood and HIV

The importance of motherhood in Thai society is a much studied phenomenon. The mother in Thailand is often portrayed as the linchpin who keeps families together, the moral basis for all kinship and the economic as well as practical source of household survival (Tremaye 2001:3). Some women believe that motherhood means self-sacrifice and endless concern. Mothers will practice many socially as well as culturally acceptable tasks to ensure the health and well-being of their infants, so that others refer to them as a ‘good mother’ who is responsible and whose behavior is focused on her children (Liamputtong 2007). Fiore and colleagues suggest that motherhood is a situation where woman who want children need to have a long-standing relationship, be it marriage or cohabitation, a situation that is no different for HIV positive women or non-HIV positive women (2008). In Vietnam, motherhood can be interpreted in two ways; it makes women vulnerable to contracting HIV in their roles as wives and mother but motherhood also enables women infected with HIV to organize themselves successfully and get access to socio-economic support and services of the PMTCT program (Oosterhoff 2008).

In most societies childbearing plays a central role in the social identity of both men and women, and couples are expected to have children because it leads to the pleasure and happiness of being a parent, which notions are also present in Thai society (Liamputtong 2004). Some women believe that motherhood means self-offering and unlimited concern for others; motherhood brings
delight and pleasure to their lives, a perception that is linked to the Thai cultural concept of *bun khun* \(^2\) (gratitude) (Liamputtong 2004).

After reviewing a great deal of research, there appears not to exist any documentation about a Thai woman's personal choice to bear a child in terms of her basic reproductive rights. Every individual, irrespective of HIV status, must be able to act in accordance with this right, which is affected by the structure of the Thai socio-economic and political systems that depend on the National AIDS policy to control the HIV prevalence rate among pregnant women (National AIDS Indicator 2010). This research will describe the specific context of HIV-positive women who had undergone decision-making about child bearing and reproductive health and have experienced the services provided by the health care system in Ubon Ratchathani.

\(^2\) *Bun khun* (gratitude) is a notion of Thai culture which implies that any good thing, help or favor done by someone, will entail gratitude and obligation on the part of the beneficiary (Podhisita, 1998).
Chapter 3
Methodology

This research has relied on ethnographic methods and used a qualitative approach. The study dealt with the micro level, and took into account personal experiences of HIV positive women that are related with social and political factors of individual life. It can be considered a small-scale exploratory study of a short duration which intended to investigate how HIV positive women in Thailand experience pregnancy by taking into account the emic3 outlook of the participants. The study was conducted over six weeks in Ubon Ratchathani province, Thailand. It was performed in one regional hospital (more than 1000 beds), one general hospital (200 beds) and five community hospitals. I used a car to get in touch with the persons from whom I needed information for my data, altogether more than 30 people (doctors, nurses, PLHA, and PLHA group peer leaders). Five women allowed me to visit them at their homes.

The criteria for selection of the research subjects were HIV positive women between the age of 20 and 40 from Ubon Ratchathani province. I interviewed twelve HIV positive women who were pregnant, who had been pregnant in the past three years and have had experience with the PMTCT program or who had decided not to become pregnant. I divided them into three groups. Initially the key informants were found through the use of gatekeepers, who worked as HIV/AIDS support group leaders. At the beginning I sought for typical cases and when more participants were needed, snowball sampling was utilized. Using snowball sampling, it was crucial that I found new informants through more than one key informant; therefore I used more than one person from the HIV social network to avoid sampling bias.

Tools

I had been in contact with ten gatekeepers, five worked at the antenatal care clinic (ANC) in the hospital where I chose to carry out my research, while the others were leaders of HIV peer groups;

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3 An ‘emic outlook’ seeks to understand how cultures look from the inside, from the point of view of the participants (Nanda and Warms 2007).
these women helped to choose and select key informants who were willing to share their experiences. I explained the aims of my study to the gatekeepers and tried to develop a relationship of support. I collected the data by a combination of techniques: participatory observation, formal and informal conversation, in-depth interviews, FGDs and a review of documents. Throughout the first two weeks of the research I experienced obstacles from the political crisis in Thailand and my province, and I had therefore to adapt my agenda from day to day, which finally allowed me to finish my fieldwork on time.

*Participant observation*

Throughout the research, I continually observed the way of life of HIV positive women, their families, and health care providers. When I visited the hospitals I wanted to know the response to positive women and especially how the health care team provided its services and how the women responded to these services. At the hospital I presented myself as a patient or family member who accompanied a pregnant woman to the ANC clinic.

In the community, people openly shared their experiences. I had three positive pregnant women who I accompanied to their home. During our travel I could observe their personality. I noticed that they became relaxed and told useful information which they did not mention at the health care system. Why did they behave differently? I assume that in the hospital, where we had a small room and the interview took place after work time, they still had their concern about confidentiality. When I asked their opinion about the health care services in the hospital, I noticed that they answered carefully and that their voice became soft.

*Informal conversations*

During the time I spent in Ubon Ratchathani, I engaged in several informal conversations with health care providers who had the same professional background as me. I had a good opportunity to talk with two doctors and several nurses who worked in the PMTCT program. I tried to listen openly to all, even though some ideas were negative and put me under pressure.

*In-depth interviews*

Twelve in-depth interviews were conducted with positive women from Ubon Ratchathani. I divided them into three groups of four persons: HIV positive pregnant women who chose to continue their pregnancy and enter the PMTCT program, HIV positive women who had the experience of bearing a child in the last three years and HIV positive women who did not want to have children. Almost all
were willing to participate in my study through an interview session of one hour that took place at a convenient location or in their home. As mentioned before, nine positive women agreed to be interviewed at the hospital and three allowed me to visit their home.

I interviewed one or two women per day and used the next day to transcribe the interviews because I wanted to know what points I had lost, giving me the chance follow them up with any questions I had when I visited the women again. I had to talk to each woman two or three times before I had finished the whole interview. At the last visit I informed them of the information I had collected and asked them whether they agreed. There were no problems. In the hospital the positive women preferred to be interviewed in a private quiet room keep where nobody could observe them or listen to our conversation. In the community, some positive women wanted their husband to attend the interviewing. I explained to them that I would allow their husbands to attend part of the interview, but not the sensitive issues we talked about which they would like to keep confidential. They agreed with this compromise. There were three interviews where the women did not allow me to record it on tape, so I had to take notes and spend more than one hour. In the second visit one of the three women allowed me to record the interview on tape (see appendix 3 for more information about these women).

Focus Group Discussion

The final stage of my study consisted of the organization of one focus group discussion (FGD) to collect some additional information. I arranged the FGD in a district where the PLHA peer leader could select the participants for this session. As expected, the FGD did not reveal information about sensitive topics but I had the advantage that it brought up a new topic. The positive women focused on their families and especially their children. They were worried about the future, how should their children deal with stigma and discrimination in the community and how could they protect themselves. The most important lesson I got from the FGD was that the positive women not only are in the same situation but also support each other and share ideas about how to cope with their problems. The FGD consisted of eight positive women, the women were between 30 and 38 years old, the average age being 34 (see appendix 4 for information about the participants).

Review of documents

Throughout my research I reviewed documents related to the research topic, among them the national AIDS policies of the ministry and PMTCT protocols for health care workers dealing with HIV pregnant women, personal documents and guidelines for treatment. These documents gave important information about the socio-economic and political context of the epidemic as well as about influential cultural norms and beliefs.
Data analysis

"The aims of most qualitative analysis are to both reflect the complexity of the phenomena studied, and to present the underlying structures that ‘make sense’ of that complexity" (Green et al. 2004:175). In order to “make sense” of the collection data I had to be careful and to follow my objective and themes. I used a coding system that helped me to organize the empirical data with certain codes by grouping together themes with the same meaning. In further analysis I was able to bring order into to the data I had collected and to assure the meaning of my interpretations (Gerrits 2009).

Ethical considerations

HIV/AIDS is a very important and sensitive issue and the informants must know the extent of the research, for what it will be used and who will have access to the information after publication. It is essential to have respect for each individual when conducting research regarding HIV positive women on sensitive topics such as stigma, discrimination, gender inequality, motherhood, sexuality and reproductive health and rights. Confidentiality of the informants was therefore guaranteed. The names of all informants used in this thesis are pseudonyms. All participants were asked for informed consent before the interviews and they also gave permission to audio-record the in-depth interviews and the focus group discussion. Moreover, the women were not obliged to answer my questions and had all opportunity to stop or refuse questions.

Difficulties and limitations

There are many limitations to this study including the time frame of only six weeks; however, I have tried to concern myself with the biases from sampling and data collection, and have been reflexive of the influences from my background and my own experiences in the field.

Access

At the beginning I was very worried about collecting data in my own province because I had worked here on this topic for more than fifteen years but in the function of a policy maker. I realized, however, that in this study my situation was that of an outsider, that there was no bias caused by everything I had learned and that I was able to listen to the truth from the point of view of the participants. The most difficult thing in my fieldwork was not the political crisis in my country and my province but rather the fact that I needed to collect data from different life spheres of positive
women; about their experience to have children, the kind of support that they got from their family, community and health care services and whether it was of the same standard as in other groups. Furthermore, I also wanted to visit positive women, who had faced domestic violence, learn more about how they managed to be patient in their situation and find out how the government could deal with their issue.

Language Barriers

I used the local Isan language to collect my data, which was most convenient for the participants since most positive women used this local language to communicate, also with the health care team. It made the conversation easy and many local words could explain the insights of positive women or how they felt at that time. The translation of these insights into English appeared, however, sometimes quite difficult.

Sampling

I planned to find my informants mainly through convenience sampling. The positive women who participated in the in-depth interviews and focus group discussion were happy to share their personal experiences under the conditions I had explained to them. The multi qualitative techniques that I used to conduct the interviews were comfortable for participants. I allowed them to stop and terminate their participation if they felt insecure. I discussed with my gatekeepers how we could allow the participants in the in-depth interview to express their feelings and not to feel dominated by the gatekeepers. Therefore, I selected different kinds of gatekeepers such as PLHA peer leaders and health care providers, who have different perspectives on this topic.
Chapter 4
Local Notions and Traditional Medicine

In order to deepen the discussion of my field work findings, in this chapter I focus on mapping out the Thai notions of culture, norms, beliefs and traditional treatment in discourses surrounding HIV positive women. I will connect local notions of family and gender norms to point to women's vulnerability and present misconceptions surrounding HIV which place individuals at a higher risk of contracting the virus. The use of traditional medicine will also be elaborated on in the last section.

Social positions and vulnerability

Rural Thailand is characterized by a social system in which the father has the power in the family; that power is passed to the husband with marriage giving him authority over women and children. After their marriage most of the women hold the position of housewife or work in the fields. Agriculture depends on the rainy season, however, and after the harvest season they move together to work in a big city such as Bangkok, Pathumthani, or Chonburi. In the cities many women work in factories which do not require skilled workers or higher education such as weaving or fish canning factories, while other women work as maids in guest houses or hotels.

Women who have migrated belong to a risk group. To consider the interaction between human agency, and the powerful forces that restrain it, we will focus especially on reproductive decision-making. In the community of Ubon Ratchathani, the most powerful constraints come not only from family members or the community but from social judgment. Gender inequality, deepening poverty and political disruption leads to the rapid spread of HIV. For instance, several women told stories of discovering their positive blood result and deciphering how they came to get HIV. An in-depth interview with Tar illustrates:

In my first marriage my economic status was good; my husband gave me allowance of 10,000 baht (200 euro) for me and his son every month. My position was just of housewife and mother to take care of my son. I had no power to make decision because my husband was older than me by more than ten years, or negotiate condom use to protect myself. At the same time my husband had high risk behavior from drinking and having sex with sex workers without condom use. During my first pregnancy my blood test was negative, but in the second
marriage when I got pregnant the blood result became positive. I thought I got HIV from my ex-husband who passed on.

Tar’s lack of power and room to negotiate put her in a vulnerable position to contract HIV from her husband who was spending his evenings drinking and having unprotected sex with sex workers. Tar’s position within her family and society placed her in a situation where she was susceptible to contracting HIV.

A focus on local culture

In pre-modern times, the Thai family was comprised of members who were related directly through blood. In addition, the marriage system continues to help Thai people to establish fictive kinships and to form the kindred group. Marriage as a social institution has served as a means for Thai people to form their alliances and to extend their social networks to ensure that they access resources such as land or social rank. In the past the majority of families were rice farmers and owned small or large plots of lands. Tradition required the youngest son-in-law to move to his wife’s parental family to provide labor for growing rice; however recently the Thai family has tended to change towards a nuclear family in which only parents and children live together (Chandhamrong 1987:17-28).

This development is very important because the traditional pattern after a wedding was to strengthen the position of the woman’s family because they needed to increase members in their family to support their household. The functionalist viewpoint works well in traditional society and it is still common on the local level; however, some communities have received the impact of the reduction of employment opportunities in agriculture and of the socio-economic crisis which pushes family members to move from the village to work in big cities. With the spread of the HIV epidemic this phenomenon of moving to the cities has led to people getting infected with HIV and returning to their hometowns. Many women describe such experiences:

My family was poorer than every other household in the village. After I graduated grade 6, I decided to go to Samutprakan Province. Lack of knowledge limited me ability to find a good job. Once all my sisters were married, I decided to marry a guy who worked in the same factory. He was a gallant male and took risks by drinking and having unsafe sex with many women. While I stayed with him, he abused me many times when he had drunk too much. I divorced him; we had no children and returned to stay with my father in Ubon Ratchathani. A month afterwards I got sick, had a high fever, severe cough, and skin allergy. My sister took me to Sappasittipasong hospital and I knew I had HIV. (Niyom)

Because of poverty and the need to up-scale one’s social status, village women are encouraged to migrate to urban areas. Low education levels, lack of knowledge of disease and unawareness to
protect themselves, induces women to risk infection and be confronted with violent males as Niyom illustrates. On the other hand, it appeared from my interviews that several positive women after a second wedding when they moved to live with their husband’s family or in another city were able to adapt themselves and become happy in their new situation. Aeoung, Art, and Nong are examples of women who have created a satisfying life situation. Positive women described how to create a satisfying life situation; they could work in the fields or take care of nephews or nieces in husband’s family as normally people. Moreover, my key informants were not happy to only take the role of housewife but they also preferred to help their husband’s parents as much as they were able to do, even though they were sick and often pregnant.

After my ex-husband died, I married a new man who is the youngest in his family and he stayed with his family so when I married him I moved to stay with him and just took care of my daughter and cleaned his house. Sometimes I helped my mother and father-in-law when they needed and they loved me like their own daughter. (Art)

Misconceptions

As HIV spread in Thailand so have misconceptions spread, which have led to the formation of stigma, discrimination and right violations, which I will discuss in Chapter 6. Misconceptions are not only caused by a lack of knowledge of HIV/AIDS but they are also related to cultural norms and beliefs that make women vulnerable to HIV infection. Male and female risks have to be distinguished since new HIV infections can be affected by reproductive decision-making. Many positive women who held misconceptions needed time and the opportunities to understand the correct information; it is the same for family and community members as well as health care providers. Some common misconceptions are illustrated in the narratives below:

In my first marriage, I believed that my husband was a good person, kind when I had sex with him, I trusted him because he was my husband and I never asked him about his history. Since I got pregnant I knew the result of my blood test, I don’t know how I got the infection because I only had sex with my husband. (Bin)

Bin believed that she could not get HIV because she was only having sexual relations with one man, her husband. Her second husband held a different misconception of how HIV is transmitted:

My new husband told me about his history before he got HIV, he was proud of himself when he became a singer while he was a conscript. At that time he had sexual relations with many women mostly without using a condom. He never thought that he would get HIV because he was very healthy, until he married and his wife got HIV and died. He had unsafe sex because he believed that withdrawal could protect against HIV and unwanted pregnancy. He told me
this idea was very popular while he was conscript and he thought it was the truth because no women blamed him for getting them pregnant. Now he has changed his idea.

When positive women and couples are on ARV and become healthier, adequate information has to be provided to them to correct misconceptions about HIV that are related to treatment, as Bin formulates:

I was confused about the negative virus load of my husband, what did it mean. I understood he did not have HIV in his blood because the care providers told him that they could not found the virus in his blood. I believed it because he looked normal and healthy. After he had practice many methods such as a meditation, ARV, use of herbs and the consumption of plants we grew, sometimes we did not use a condom because he thought he did not have the virus in his body.

Bin and her husband’s lack of understanding the reduction of his viral load placed the couple at risk of re-infection, a dangerous situation that could have been prevented by further HIV counseling and better explanation from the health care providers.

Traditional medicine

As HIV attacks the immune system PLHA have to deal with many health problems. Common illnesses and symptoms associated with HIV/AIDS infection include loss of appetite, change of the taste of foods, diarrhea, digestive problems, vomiting, mouth sores, skin problems, depression, and fever. In addition, PLHA become more susceptible to major diseases such as tuberculosis. To counter these symptoms and opportunistic diseases traditional medicine is used by the majority of the population in developing countries, more than 80 percent depend on traditional medicines (Holley and Cherla 1998). Traditional medicine is particularly relevant for the poor who may have difficulty accessing ARV programs. Furthermore, individuals who do not have a low enough CD4 count to enroll in an ARV program, as per the protocol of the WHO clinical guidelines, they may utilize traditional treatment. I found several cases among my key informants that illustrates they could not wait to access an ARV program and decided to use traditional medicine in the meantime.

Traditional medicine is broadly available and affordable in remote areas and people of every socio-economic level can use it. The drugs are not only very cheap and easy to access but have also been reported to be helpful in the part of mental support. Furthermore, the majorities of PLHA in Thailand spend their last stage at home, where they use good and safe traditional medicine to treat themselves. Some PLAH choose to use a combination of ARVs or AZT with traditional medicines and consult their health care provider for instruction, while others follow their own beliefs and use traditional treatments without the consultation of a doctor.
Many positive women from the fieldwork shared their experiences with using herbs as treatment. One woman used some kind of herb to clean her body and eliminate pimples. To increase CD4 count there are many kinds of herbs one can drink or eat, as num ya-nang (a drink made from the Tiliacora triandra plant), the fresh leafs of phlukhao (a kind of betel pepper) and mara khinok (bitter melon or Momordica charantia), which seeds are used to prepare a filtrate for a daily anal edema.
Chapter 5

Stigma and Discrimination

In this chapter I will explore people living with HIV/AIDS concerning the phenomenon of stigma and discrimination, with a particular focus on individual positive women and the social environment in terms of context and impact. Most of my informants had experienced stigma, discrimination and rights violation. Although there is a law through which the Thai government protects women's rights, women still have to deal with these problems in their daily life. I found that many HIV positive women who have sexual desires or enter a sexual relationship are condemned by their families, communities and the health care system. It is especially necessary that the health care teams do not disclose the blood test results of positive women, because it is extremely painful for them when their status is disclosed to the public. They need time to adapt, strengthen and trust themselves as well as to manage their way of life under new circumstances.

The chapter focuses on setting a framework for understanding stigma and discrimination that is associated with HIV/AIDS through many factors including misunderstanding of illness among family members and in the community, misconceptions about how HIV is transmitted, lack of ways to access treatment, and irresponsible coverage by the mass media since the period the Thai government attempted to stop AIDS. Stigma can lead to discrimination and other violations of human rights which affect the well-being of PLHA. HIV is not only related with stigma and discrimination but also linked to the impact placed on women that reinforce pre-existing socio-economic, educational, cultural and social disadvantage and unequal access to information and services (Aggleton and Warwick 1999). This part provides an overview of the key insights from the fieldwork that will show how stigma and discrimination affect HIV positive women in terms of decision-making about reproductive health, which is influenced by individuals and the community as well as it is connected to right violations and the health care system controlling new HIV cases by following the national AIDS policy. A WHO study in India, Indonesia, the Philippines and Thailand found that 34 percent of respondents reported that health care providers cannot keep confidentiality (WHO 2008), a huge violation of individual rights, which influences how PLHA view the health care system. In this chapter, I argue that HIV positive women will be confronted with stigma and discrimination as well as right violations, as long
as societies have a poor understanding of HIV/AIDS, pain and suffering caused by negative perspectives and bad practices.

I will further argue that HIV positive women are confronted with further difficulties due to misunderstandings of how to cope with stigma, discrimination and right violations, which leads to minimal support, causing some women and families to move to new villages. Not only are these women faced with poverty, gender-bias, lack of ways to access knowledge, but they also must attempt to find space to share and release their tension. It is very hard for them to deal with these problems by themselves even though they have the support of a PLHA self-help group.

This chapter concerns not only HIV positive women themselves, but also the health care system and the perspective of its health care providers as well as the notions of the communities. All these groups are, in some way, involved in the experiences of HIV positive women who either want to give birth to a child or who do not want to have a child. However, this should not only be explained from the experiences of the HIV-positive women themselves but the explanation should also include the health care team and the socio-cultural community to which the affected HIV positive women belong. Their voices and choices have to be kept silent but they could reveal in what measure the women were disrespected by communities, the health care system and health care providers and how the health care system persuades women to use the services at the ANC or ARV clinic irregularly or to change hospitals.

**Keeping the secret**

The first thing most patients I interviewed did when they learned the result of their blood test was to keep it secret and to blame themselves, out of shame and fear to tell anybody, including their own family. Nevertheless, I found that the rights of three of the twelve women I interviewed were violated by the fact that the health care providers told the result of the blood test to their parents. Aeo is one of them:

My younger sister said that she did not want me to return home and stay in our village if the people in the community knew that she had a sister who got HIV, they would denounce and discriminate our family. I should stay with the doctor here... I cried and suffered, and was upset about what my sister said. I was very tired and only 27 years old. I didn’t want to die.

The aversive attitude of her family and community forced Aeo to consider suicide, but she changed her mind when she realized that she had already faced many bad conditions in her life, for example, the risk of being arrested and put in jail in Malaysia and Indonesia. She didn’t have money and had to have sexual relations with clients to earn money to buy a ticket to return to Thailand, as she did not have anything and fought with the broker many times. Her infection challenged Aeo to cope with her
suffering and to become a member of the PLHA staff of the Sadaowan group which supports PLHA and people affected by HIV/AIDS within the community.\textsuperscript{4} She worked in the area of reproductive health and women’s human rights.

The story of Aeo is also interesting because it tells us how she became HIV infected before she started to work as a member of the staff of the Sadaowan PLHA peer group:

I left from my home town when I was 16 years old, no ID card, with a man who promised to let us work elsewhere, traveling by van with many girls that did not know the future plan. Before I worked in Malaysia, some friends and I learn how to do oral sex by using a banana; I had no idea why we would need to know this I crossed the border to Malaysia at Suhaikolok international check point, and stayed in a small house in the city. My work was having sexual relations with clients, about 30 per night. I worked for contact person who had picked me up from Ubon Ratchathani and paid money for me to work in Malaysia. During my work I did not know how to use condoms. My job finished in one month and I went back to Had Yai. Later I returned to work there again and again until I was 30. I had one guy offered to take care of me and I had three persons who I loved and with whom I stayed much longer than in the case of all the others that came into my life.

The widespread fear of being disgusted (kan rang kiat or kan titan) after a positive blood test leads HIV positive women to keep silence, become depressed and finally to consider suicide. Five of the twelve women I interviewed had attempted suicide and there are many others who had to deal with it in some way. Aeo expressed this in the following way:

I had two children but I did not look after them, and I had two times an illegal abortion. I knew from a blood test that I took at an anonymous clinic while I was pregnant from my second husband that I had HIV. He was a rich man and gave me a house, a car and a regular allowance. I was suffering and decided to kill myself by jumping from the seventh floor of the mansion we lived in. It was very hard for me to deal with the blood test. I spent time the whole day from the morning until the evening on the seventh floor. At that time I asked myself, ‘why should I have HIV?’ I did not want to die because I was young [she cried again and again]. I needed support from my friends, when I tried to contact them, they’d disappeared and turn off their phones, as well as they said everything that I borrowed from them to keep and not to contact them again.

\textsuperscript{4} Klum Sadaowan is established by PLHA and located close to Warinchumrab hospital. It has more than 400 members from Warinchumrab district and some districts in the neighborhood. Its objective is focused on home visits, services to PLHA, holistic care and similar activities.
That the long-term relationships with her friends were suddenly stopped when they learned the result of Aeo’s blood test, led Aeo to deeply understand the meaning of stigma and discrimination, loss of confidence and severe suffering. Later the relationship between Aeo and her husband started to conflict over the blood test, because her husband hide his blood test but Aoe knew, which made her feel angry and guilty, even though he said at this time they will support each other. Everyone in her family knew about the big problem, all friends who had always worked and supported her cut their ties after they heard of her infection. Since her husband had many partners and risky contacts he became sick from HIV and was enrolled in an ARV program. Aeo still took care of him, preparing food and drugs, and sometimes to attending the PLHA group meeting at the hospital. During the two years he was on ARVs he did not change his behavior and continued to drink and smoke until he got tuberculosis and died. His legal wife took everything that he had and did not allow Aeo to be the owner of anything. Aeo decided to go home and called her sister to bring her back. While traveling, Aeo got a severe fever and heavy cough, causing her to faint at the station. Her sister brought Aeo to Had Yai hospital, and at this place she learned of Aeo’s illness because the doctor explained the program of her treatment, they planned to refer Aeo to continue curative treatment at Suratthani hospital because she got the new disease. Aeo disagreed with this commitment and really wanted to go home but her sister did not want her to return home because she worried about the aversion and discrimination from the villagers. Aoe begged her sister to call her father (at that time a monk in the village of her sister) and he ordered to pick her up and bring her home.

Even though Aeo was a second wife and became HIV infected, she never abandoned her husband during his crisis and stayed with him until he died. She did not leave him because of the support and allowance he gave her and she transferred money to support his family. The most important thing, he never abused or hurt her and he also accepted her society. She was aware of his bun khun, and therefore stigma and discrimination did not hinder her to take care of him. His illness was not a big problem for her although she was not accepted by his family.

**Discrimination within the family**

The family represents an important center of love, warmth, and safety for HIV positive women. Many HIV positive women need the help and support from their family to continue their life. I argue that family and kinship in Thai society are very strong and, generally, will provide help and support to those members who face bad situations; however, severe conditions can hinder a family from supporting it’s members. Especially one’s mother is a very important person who generally provides assistance and brings solutions when her daughter has problems. However, when a woman’s mother

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5 *Bun khun* is the traditional Thai cultural idea of reciprocal obligation, especially to those who brought one up or who have offered one assistance such as, allowance, house, car or respect.
fears her, due to her infection, feelings of despair and loneliness arise, as shown through the story of Tar.

Even though the mother of Tar knew that HIV/AIDS could not be transferred in the way she acted, she could not change her perspective, which seemed to become a point of disagreement between Tar and her mother. Tar was unable to explain this issue to her mother, although her sister, who worked in a medical clinic in Lopburi province, helped her by confirming how a HIV infection occurs and calming down her mother. Finally, Tar’s mother treated her like a daughter who never was infected. Tar, who got infected by her husband in 2008, illustrates that HIV/AIDS is not only connected to stigma outside the family but that it happens also within the family and threatens the acceptance of the community. As Tar explains:

My mother wore long rubber gloves when she cleaned the toilet or when she washed and dried my body twice a day after cesarean section. I think that my mother was frightened but she did not say anything because she loved me and was afraid that I would suffer and become upset. I felt irritated and sad, but I think that I could understand how she behaved.

From the focus group discussion I learned that stigma and discrimination by the community still happens in daily life as can be seen in the case of HIV positive women who want to re-marry or become pregnant. If they become pregnant and deliver their baby in the normal way or by cesarean section, they will be faced with people in the community making suggestive remarks like in the case of Kason:

When I was pregnant and after the delivery, I could not breast feed my children, I had to give them powdered milk until they were one year old. People in my village gossiped about me, saying maybe I got HIV. Yes, I knew myself that I got it, but I did not want to make it public at that time.

Local societies with culture systems that place greater emphasis on individuals, especially in local belief and explanations of disease and causes of illness, may also contribute to HIV being associated with stigma and discrimination. As Phisal illustrates, HIV positive women have difficulty adapting after their husbands die because of blame from the community, which causes women to hide themselves:

I got the infection from my husband. After our marriage, my husband returned to work in Bangkok. After he had passed away I became worried that the people in my community could not accept me and that their behavior toward me and my daughter would show this. Many cases who suspected that I got HIV had died and I went to attend their funerals.
Women who get HIV tend not only to hide themselves from the community during pregnancy, out of fear of violation of confidentiality by health care providers, but they also attempt to conceal various signs and symptoms from their family members, as Samay explains:

When I became pregnant I stayed in my room because my body lost weight rapidly, and I got red, brown and black blotches that are related to AIDS symptoms. I thought my husband’s parents would gossip and say, ‘didn’t we tell you?’ (somnamna lae nthitha). I rarely listened to them but from the way they behaved. I could guess it from how they moved. I felt lonely but my husband still consoled me, he was a person that I could always trust.

**Stigma from the community**

From the research I realized that a positive blood test influences the decision-making process of HIV positive women and changes their perspective on motherhood and reproductive health and rights, which may lead them to stop the idea of having children. Aeoung, a HIV-positive woman, who had to face stigma and discrimination within her family and community, was also forced to remain silent about her illness because it would harm her image as a good woman. Almost all the information I collected in my fieldwork illustrates that HIV positive women are faced with more than their own problems, their situation also directly affects any children they may bear. The community strongly believes that when HIV positive women become pregnant, HIV is transmitted to the child, even though they had access to the PMTCT program.

Aeo attempted to use the result of her blood test in a positive way when she disclosed herself to the community and showed that HIV could not be transmitted by touching each other, sharing a meal, or staying in the same house. In addition to the family support she received from her father, it was necessary for Aeo to continue her life by completely changing to be a good model as a PLHA volunteer.

An interesting question, however, is why pho pu\(^6\) (Aeo’s father) accepted Aeo. As a monk he represented religion, he is a Buddhist monk who enjoys the highest status in the social hierarchy; however, through his example he tried to integrate the disease into society, showing that they would live together and support each other. Furthermore, he was a father and he wasted a lot of time taking care of Aeo after her mother died. She was very young when she left her home town to work far away and always supported her family until she got sick. As Aeo said the response from family is more important than the support from people in the community.

These words are truth because kinship in Thai society is very strong providing support and care for family members. HIV positive women are not the only ones faced with stigma and

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\(^6\) Pho pu is the most important older person in a community or village who people highly respect; in this study pho pu is an aging monk.
discrimination but their families and the groups that help and support them are also affected by the fact that these women are HIV positive. As Aeo expressed, she suffered from anger towards her family and community, especially because of the refusal of her sister to let her stay in the house that she had helped to pay for with her own money. Even though Aeo transferred money to support her family until her sister had a new house, when Aeo got infected they did not allow her to live with them. Her family built a small hut (kratom) for her far from the big house and without electricity, and they refused to share food with Aeo. During crisis periods Aeo received food from her father, who was a monk (pho pu). He shared his food with her two times every day around 7 a.m. and 11 a.m. Phupo was the best mental support for her. Aeo got tuberculosis from her ex-husband and had to take medication. One day she wanted to eat vegetable that hang on her neighbor’s fence. The neighbor did not allow Aeo to walk close to her house because he feared to get tuberculosis from Aeo. This factor made Aeo suffer. Aeo not only faced stigma and discrimination from her neighbor but she was also confronted with violence from her brother-in-law who tried to rape her while he was drunk. Luckily Aeo was able to flight him off and he was not successful in his endeavor. At that time nobody could help her because they went to work in the city. Aeo decided to leave from her home town again by taking back money and a necklace from her sister and went back to Had Yai and stayed with her friend who had worked at many places such as Singapore, Indonesia, and Taiwan. Aeo underwent horrible experiences until she joined Khum Sadaowan and became a staff member. Now she uses her experiences about reproductive health and rights to help her friends.

The various forms of contempt and disdain that HIV positive women undergo in their communities affect, without doubt, their confidence and ability to protect themselves. Several people expressed similar experiences to that of Aeo.

Within a community the level of stigma and discrimination one experiences is based on the perspective community members have of HIV/AIDS. Community reactions to PLHA may have a huge effect on an individual’s life. In some communities the reaction is unfriendly and against positive women, leading to community sanctions. Moreover, community stigma can force positive women and their family members to leave their homes, and change all daily life activities. Stigma also exacerbates problems faced by children and orphans of AIDS that may cause these children to be viewed negatively in the community and school. Fear, shame, and violence towards HIV positive women are also portrayed against children of HIV positive women who are pestered by other children at school. As Samay said:

My son went to school and had a problem with his classmates because his friends pester him about me: ‘Your mother has AIDS.’ It made my son angry when he returned home. I went to the house of the chief of the village and told him to inform community members not to do like
this again. Even though I got HIV I did not beg for money from community members to treat me; I used only my money to take care of myself. If the situation happens again I will sue.

HIV positive women do not only experience stigma and discrimination for being HIV positive, but also for desiring to carry on with their lives by getting married and having children. They have the right to marry and become pregnant, particularly because they receive good support from the PMTCT program which prevents transmission of HIV from mother to child. For example, both Baunsaun and Chom are healthy and their CD4 is still high, in addition, their families wish them to have children; however, they have been faced with disdain from community members:

People in my village asked me whether I knew that I got HIV and why I became pregnant again. They said I should know that it will cause several problems for my child. ‘Why didn’t I have an abortion? Do you worry about your child or not?’ they asked. (Bauwsan)

I think people who live in my community do not respect my rights. I have the right to become pregnant and the government has a good program (PMTCT) to prevent HIV from being transferred from the mother to the baby during pregnancy and delivery; and after that it supports powder milk for children. Why are people so worried about me and other HIV positive women who become pregnant? (Chom)

Many women mentioned that the contempt of some communities toward somebody can have a huge effect on a person’s life since it blames those who got HIV because such a person behaved in a risky manner. This both hurts and devalues a woman, as Son and Chom formulated in the same discussion:

Some community members look at me and other HIV positive women with AIDS as bad women who had sexual relation with many clients and caused infection (mae ying khiaw man chuang tid et). When I married for the second time the first thing that I considered was to tell my husband I got infection and keep isolation by only looking after my children and working in the field. Because of social support from the local administration (o bo to) to ask for the so-called AIDS fund, my status was disclosed. On a certain day the village head (phu yai ban) announced through the community radio, ‘Mrs X (her name) who is HIV-infected please come and receive the money from the AIDS fund.’ It made me very angry and a shame. I had still kept my secret with me and within my family. Could the phu yai ban not respect my right to privacy? I went to his house and asked why he said that. My children were still young. I did my best from the beginning to keep my secret but he did not respect it. He said that he could not correct it but next time he would change his words so that it seems like a normal disease.

HIV-infected people often fear that the community will reject and abandon them even though they try to conceal their status. Some people only allow their own parents to know the result of the blood test
and they do not want their husband’s parents to know it, as Son said: “I tell the result of the blood test only to my parents but I will not tell it to the parents of my husband. I’m not sure whether they will accept me and my children.”

**Right violations by the health care system**

In Ubon Ratchathani province the national health care insurance system provides, through the PMTCT program, help and support to HIV positive women who are healthy and wish to have a child. This program was launched more than ten years ago and is monitored and evaluated every three years. My field work included a visit to the regional hospital (Sapphasitthipasong hospital) and the community hospitals. While I was there waiting for interviewees, I could observe the services of the PMTCT program and found that in the regional hospital the health care providers at the ANC clinic follow precisely their job description, a process that is quite smoothly conducted according to the Clinical Practice Guideline (CPG), however, it depends on the personalities of health care providers.

In regional hospitals and community hospitals that follow the CPG, all pregnant women will have access to the same standard of care and treatment, voluntary counseling and testing (VCT) and for all the women this testing is done by highly confidential personnel. In the community hospital, on the other hand, the PMTCT process is quite different from the regional hospital, even though they both follow the same guidelines. In the community hospital health care providers work together with PLHA peer leaders and PLHA volunteers, they support each other in some sensitive points, allowing PLHA to talk freely with the PLHA peer group. The self help group provides space to share their own experiences about HIV problems. The community hospital has this group work closely with positive women in the community. It is not only a good network to share and support each other but it is also the best alliance to support health care providers.

Unfortunately, stigma and discrimination make it difficult for HIV positive women to access good health care services, especially for HIV positive women who are confronted with rumor, gossip and contempt from family members, community members and health care providers. The Thai government has many programs to support these HIV positive women, while health care teams also attempt to improve their services through capacity building. However, lack of knowledge or limited access to knowledge as well as the difficulty to understand technical medical terms, make women reluctant to participate with the health care team, and create a negative influence on care and treatment. Even if HIV positive women become part of the PMTCT program they still are faced with stigma, discrimination and right violations. Look for example at the experience of Niyom with the health service of the regional hospital:

When I met a new boyfriend in the PLHA monthly meeting, we talked to each other and exchanged ideas about our lives. I did not tell him that I cannot have children because after
my first delivery the doctor decided to sterilize me. But the doctor and nurse never asked my permission. If I marry again and cannot give a child to my husband, he will leave me for another woman. I find it painful and I am upset that the regional hospital treated me like this. (Niyom)

A similar incident happened to Chom:

After the first attempt of the health team to convince me to be sterilized because I was HIV infected and they thought that it was not proper to have children again, I kept quiet. In my mind, however, I said no, because I was unsure whether this marriage would hold on since we had different results of the blood test. When two years later my menstruation was delayed by more than two months, I suspected that I had become pregnant and went to the same community hospital and the same ANC clinic that I had visited before. They tried to convince me to undergo an abortion at the hospital and suggested that the child could get HIV from me during my pregnancy. I thought I should stop the pregnancy but I did not want to do something that is sinful (tham bap). I continued my pregnancy until delivery and refused again to be sterilized.

The focus group discussion suggested that stigma and discrimination from the community still happens in daily life such as observed by HIV positive women who marry and become pregnant again. They can become pregnant and deliver by normal delivery or cesarean section, give their children powder milk, not disclose their blood test and do everything like ordinary people. Even then some women were asked many questions by people in the community, as Kason demonstrates:

I got infected from my first marriage. When my husband passed away his family told me he died from liver cancer, and I married again. Throughout my pregnancy until delivery I never talked with anybody in my family and community about the result of the blood test. After delivery, I gave powdered milk to my child with the reason that my breast feeding had stopped early because of my admission to the hospital. So I hid it until the blood result of my child appeared negative. To disclose my status after more than one year will not be easy to do, but I will do it because I would like to protect my daughter from community stigma, as I faced before.

The reflection of stigma, discrimination and rights violations may differ depending on class. I could not find HIV positive women who are from the upper class and were willing to share their experiences by volunteering in this study. Having a high education or being a member of a higher class causes them to feel ashamed or to hide themselves from this group. They also have an opportunity to access
different health care services because of their status, which helps them to avoid stigma, discrimination, and rights violations.

I argue that the negative effects HIV positive women are faced with in the community are not limited to individuals with a conflict in their families. Stigma forms also a significant barrier to accessing the health care system in local areas. In the area of my study social stigma and discrimination were caused by socio-economic and cultural norms and beliefs of the people in the community. They think that AIDS is a severe disease which can destroy relationships and spread very quickly, especially in the form of rumors and gossip that force HIV positive women to hide themselves. It may be that stigma and discrimination have no immediate effect on HIV positive women, their parents and their children, but it will in many cases influence the decisions of these women, whether or not to have a child after marrying again. It is difficult to deny the influence of fear, shame and the perspective of the community, as Aeoung illustrates:

I talked with my second husband after I knew the blood result and he had the opposite result, therefore I completely stop the idea of having a child because I did not want my husband to get infection from me [Her voice became soft; she no longer had a smile on her face]. My husband agreed with this idea. My husband had many children from his brothers and sisters and my mother-in-law and I take care of them. I think men run much more risk because they do not excrete their blood every month. If my husband would become infected, he would have a greater chance to die than a woman because he does not change his blood as often as a woman. If he passed away who would take care of me?

In conclusion, this study considers the phenomena of stigma, discrimination and the violation of rights as the most important effect on the life and well-being of PLHA and their family members, particularly influencing how HIV positive women decide to or not to have a child. Both women who have had the experience of bearing children and women who do not want to have a child are concerned and worried about the reactions from family, the community and the health care system. Much of the information about HIV/AIDS and PMTCT is ambiguous to the perspective of family members and people in the community, causing them to misunderstand the viewpoint of HIV positive women and their needs to lead a fulfilling life. Community relations play an important role in the lives of women living with HIV; the support the community either provides or denies HIV positive women greatly affects how women cope with their disease and how they continue with their lives.

7In Thai traditional beliefs women have menstruation period three to five days every month that helps women have a new blood flow in their bodies. If they have HIV, the disease will also be excreted every month. Since men do not have menstruation it causes HIV positive men to die earlier than women.
The causes of stigma, discrimination and violation of rights still remain active and heavily influence how HIV positive women deal with their situation and continue their lives. The government has organized many campaigns to reduce these problems and people in communities can now more often live together without experiencing the disgrace and isolation that used to be so prevalent. PLHA receive good support from PLHA self-help groups which emphasize mutual cooperation and provide more information about HIV/AIDS.
Chapter 6

Violence Against HIV Positive Women

In this chapter I examine HIV positive women who have experienced the delivery of a child and are faced with violence. Nine in twelve of the women I interviewed intensively and two of the FGD participants were willing to share their experiences with their partner or spouse who had used violence against them. I will focus on the personal experiences of HIV positive women from Ubon Ratchathani who had to undergo life-threatening incidents in the presence or in the past. In addition, I will give attention to the ways they cope with violence, demonstrating how women deal with violence and seek a solution. In my study I had more than five participants who have experienced violence within their family but for some people the issue is too sensitive to share in public or to talk openly in their family.

The cases from my field work that I will present are victims of both violence and silence. Most of the women come from rural areas, live in a situation of poverty, have only finished primary school, and earn a low income. They are not in a condition that enables them to take initiatives to improve their knowledge, avoid domestic violence, or improve the health and happiness of their family. In terms of violence, HIV positive women face many different kinds of violence, particularly during sexual encounters with their husband or regular partner, for instance when they negotiate whether or not to use a condom during sexual intercourse. But the problems are not limited to sexual relations, they also occur in everyday life. Sometimes they are caused by socio-economic and political circumstances, such as the national AIDS policy to decrease new HIV positive cases by post delivery sterilization or by convincing women to terminate their pregnancies through abortion. It is true that women often face violence due to a lack of adequate services, for instance when they want to end an unwanted pregnancy by abortion, or try to find support to deal with an abusive situation at home. I argue that positive women suffer from abuse and violence on the part of their partners as well as psychological violence from partners, family, and health care providers. Thus, it is effective to approach the situation from a gender perspective and combine the efforts of education, empowerment and women’s rights to reduce domestic violence.

Domestic violence

“Violence is the eyes of the beholder. It must be understood as a continuum” (Schepet-Hughes and Bourgois 2004). Violence had many types that have direct effects on the public, physical, and mental
health of positive women in daily life. Domestic violence has not only an immediate effect on HIV positive women, their children, and family members but its influences also raise awareness. It will influence their reproductive health decisions or the wish to have a child to continue their lineage (sueb sakul), the kind of care they choose when they become sick or old, keeping a pregnancy or choosing the most appropriate method of family planning (condom use, contraceptives or sterilization). It makes a great difference whether these decisions are made with or without force from family members or health care providers.

When I met this group and listened to their experiences, I had to conclude that many sensitive issues are related to violence within the family. Nong, one of the HIV-positive women I interviewed, who is also a daughter-in-law, a spouse and the mother of a child, tried to hide the result of her blood test from her family members and the community. This led to a severe conflict with her mother-in-law, which compelled her several times to attempt suicide by hanging herself or jumping in the water. However, violence is not only physical harm but also includes emotional trauma that again and again hinders a person’s insight, as Nong told to the psychologist and me:

I had one daughter [now twelve years old] from my first marriage and I decided to divorce him because he was irresponsible to me and my daughter, and my mother adopted her to be but buntham. Two years later I married again with a local officer, a policeman who assured my family that he could take care of me and help me to lead a secure life. Violence started from here, even though he always said that he loved me, he abused and threatened me many times. He had a jealous personality, liked to use rough and insulting language, as well as looked down (dathuk) on people. When he was drunk, he threatened me by putting his gun on my head and sometimes shot into the sky. When he became moody, he liked to say, ‘I am a government official, you belong only to the common people.’ I felt very unsafe with him and feared that one day he would kill me. I told my mother that I had wanted, and attempted to divorce many times by directly contacting his boss and finally I got my freedom again. I decided to go to Bangkok to find work there.

Nong protected her life from domestic violence through family support and avoided facing the problem again, but the impact from her second marriage still affected her mind and she needed time to heal. Domestic violence and the failure of her marriage made Nong vulnerable so that she was forced to look for work in Bangkok and there she got HIV. She experienced several forms of violence. In her first marriage it was caused by the socio-economic problems that forced her to abandon her daughter and put her under the care of her mother. After that, her marriage with a local officer made her the object of extreme harm from her husband. Unfortunately she was confronted with violence again; in
the new situation Nong was not only faced with violence but also had to deal with a severe crisis as a consequence from the result of her blood test which completely changed her life yet again.

I married my present husband, who was younger than me six or seven years and got pregnant from him. I decided to return home. My husband and I learned from the result of the blood test that we were HIV positive. Because of the stigma and discrimination in my home town, my husband and I had the intention to move away from my home town in Ubon (Khammarat district, close to the Lao PDR). I felt happy because we went far from the rumors and gossip that had already caused the first sign of psychiatric problems. Domestic violence started however here. My husband had a violent temperament and could not control himself. After the delivery of my first child, I had many problems with my husband and his mother, because he had an ex-wife and a son with her. His mother came to stay with him here again, but he told his mother that he could not come back to continue with his ex-wife because he was married with me and we had children also. His family did not like me and my children, even though they were his children. During my first pregnancy he abused me many times. I had not only physical injuries but he let me suffer so much that it led to mental problems. I decided to go home and stayed with my mother and my daughter. At that time, I thought I could no longer deal with all the problems. Therefore, I decided to finish my life by jumping in the water during a walk along the bank of the Mekhong River with my first daughter. She started to cry and her voice awoke me and brought back my consciousness. From then on I never considered the idea of suicide again. I discussed my problem with my mother and she said that she would like me to divorce my husband and return home to stay with her and my daughter. She could take care of me and my children. But I was not able to do this because my children needed to have a father.

Despite deciding to attempt suicide she was not successful because she worried too much about her children. Many people regain their consciousness in time and stop the idea. Self-directed violence is a very important element of suicidal behavior and self-abuse. It is also necessary for health care providers to be informed about this when they have to follow-up cases, so that they will be concerned and become aware about the issue. Nong had some additional and complicated problems. Not only socio-economic problems cause stress and tension, but often HIV positive women also attempt to solve these problems by themselves, which sometimes may bring women to attempt suicide. Due to the best support from her mother and daughter, Nong was able to carry on with her life and cross the obstacles from her second marriage. On the other hand, many positive women are faced with a negative attitude from their mother-in-law, which provokes another kind of conflict, as the mother-in-law of Nong did not want her to have children again because of economic problems, but Nong had
more than that problem. When she was young she did not know who was her father, thus when she
had children she attempted to continue her marriage though confronted with violence in daily life, not
only from her husband but also from his mother. She was extremely patient because she wanted her
children to have a father.

From my in-depth interviews I found that five of the twelve women had to deal with violence
in their daily life, and three of the five had attempted suicide. In studies in Kenya and Cambodia 49
percent of the Kenyan women reported the experience of violence and 16 percent of Cambodian
women are physically abused by their spouse (Nelson and Zimmerman 1996). The report indicated
that in a range of nations, among them Thailand, South Africa, and New Zealand, between 20 and 40
percent of the men admitted that they were violent toward their wives or intimate partners (ICRW
2002).

Positive women who mentioned being abused also mentioned multiple ways to cope with the
violence they experience. Tar explains:

When my husband showed signs of violence such as making noise, and starting to threaten
me, I grasped my son and moved as fast as I could out of my house. He did not follow me
outside and I did not want him to beat me again and again. When my mother stayed with me
he could not abuse me because my mother told him to move away from my house.

Art further illustrates: She hurt because her mother-in-law announced in the village that she was
dishonest with her son while he stayed in the hospital, while in reality she looked after him and stayed
with him until he was discharged and returned home. Meanwhile, the best way for her to cope with
this problem was to be patient and keep quiet as long as possible, allowing Art to keep the conflict
insight.

**Divorce and violence**

Almost all the participants were divorced and had remarried, including positive women whose
husbands had died during their first marriage. In the focus group discussion there was only one
woman whose husband had passed away; she decided to stay alone with her daughter and not to
remarry. Four of my twelve key informants decided to divorce when they could not continue because
of the irresponsible and domestic violence in their marriage. Furthermore, eight of the twelve married
again after the death of their first husband from HIV. To decide to divorce in Thai society, especially
within communities, is a very sensitive issue and brings shame to a woman. They tend to hide
themselves from society because they are not only faced with stigma and discrimination, but it also
affects their way of life. When women make a decision to marry this implies that they will keep their
marriage as long as they can. Positive women who decided to divorce do so frequently because of domestic violence and the support of this decision by their families. HIV positive women’s desires to divorce are reinforced by a need to protect their lives and keep their freedom, as Phon describes:

Even though I had children, I decided to divorce because I could not accept that my husband had more than one woman. I had my honor and my family supported me to carry on. I divorced two times, which made me lose my confidence about how to establish a warm family. When I married and became pregnant again, I had all kinds of ideas to get an illegal abortion but then I realized that I wanted to continue and that there was the PMTCT program to support me and my baby. So I no longer worried about it and I could choose the method to give birth safely. My new husband and I both had experienced divorce in the past, and we needed to support each other.

The most important themes the positive women shared with me during the interviews were: marriage, divorce and being a widow. The main point that pushed them to a marriage was the need to create and look after a family. When considering a marriage it is important to be concerned about the partner’s history and his risk behavior, as in the case of Sommay, she decided to divorce to save her own life, but she also needed a new life and married again.

I got sick and the blood test was positive after divorce, the important point that forced me to divorce was his use of violence. I decided to marry because my mother told me that she could not take care of me all her life, I must look for a good guy to take care of me. I got HIV how could I search for a good guy to take care of me? I decided to search within the PLHA group because I had disclosed the result of my blood test in the community even though I look healthy. Who wants to marry with a HIV positive women? My husband did not care about my background because he had divorce three times before marrying me. I met him while I attended a monthly meeting at the hospital. I told my family that I would marry, create a new family and move to another province.

Community violence

Violence consists not only of stigma and discrimination, but social sanctions in different ways can produce violence against HIV positive women. Although social sanctions are invisible, they can encourage the threat of physical force and also of continuous psychological harassment. They can form a main obstacle in the development of a person and disturb his or her life. An example is the attitude of health care providers who try to enforce their notions on the decisions of HIV positive women who want to marry and raise a family. Lack of negotiating skills, economic dependency and certain cultural convictions all contribute to the fact that positive women cannot eliminate violence
from their lives. Many forms of violence manifest themselves as psychological and emotional violence induced from stress and the pressure to follow social norms. Confidentiality of blood test is very significant for positive women at the beginning and they often attempt to hide it from family members and the community because stigma and discrimination strongly affected positive women in daily life and emotionally, the issue has caused many positive women to move from their parents' home, as Nong illustrates:

When I went to buy something in the supermarket in my hometown I was suspicious that people would know that I had tested positive. Sometimes I was very anxious when somebody looked at me. But the people did not know my frightened feelings caused by severe pressure and suffering. I was lucky that I had decided to transfer my treatment from Khamarat hospital to Sapphasittipasong hospital. In this place I could meet and talk to somebody whom I could trust to keep my secret. Instead of stigma I experienced good care. It raised my spirit (kamlang-chai) and led me to think that my life is valuable (mi khunkha).

Everybody in the community knows that sexual contact is a major route of HIV transmission. It is therefore important that a partner in a sexual relation is persuaded to use a condom and the positive woman is not confronted with violence, as Nong illustrates:

Even though the community in my home town knew my status, I got pregnant again after I had delivered my first child with my second husband. I could not negotiate with him about using a condom that led me to get pregnant again and I could not tell him about my pregnancy because emotionally he was an unstable person and could change his mood very fast if he felt upset; he could then abuse me. In the big city people did not snoop or observe my daily life, even if my husband abused me many times, and he was never worried whether I got pregnant or not. During the first pregnancy he abused me when he became angry. Sometimes my mouth was bleeding. Some parts of my body showed many abrasions.

It is obvious that a woman who is in fright during pregnancy and is HIV infected at the same time, is not able to speak freely because she is objectified and cannot share her problems with anyone else, unless she is sure that her secret will be kept confidential. Gender-based violence can lead to physical, sexual or psychological suffering and undermine the confidence of the women to confront violations from their family, community or health care providers in public and private life. The lack of support services or a referral system for HIV positive women who live in a violent relationship makes it very difficult for health care providers to deal with these issues like in the case of Nong:
When I learned the result of the blood test from the community hospital in my home town, everyone in the community looked at me as if they knew the result, my mother cried when I told her about it. At that time I knew that I could not stay in the community. I wanted to confirm my blood test again at the regional hospital, where I was sure the health care team would keep the result confidential.

Nobody can help HIV positive women, pregnant or not, who are faced with domestic violence such as in the cases of Art, Nong and Sommay, even though they visited health care providers regularly. The voice of these women is silenced by the norms and values of society. According to local belief, as soon as a woman is married she becomes the property of her new family. Her life changes from freedom to being controlled by her husband’s family. A good woman will accept the authority of her husband and listen to him. She will be patient and keep silence when problems in the family arise because she has to maintain her marriage status as long as possible, as Art describes:

When I was married with my former husband, from whom I got HIV, I could not talk to anybody when I had a problem with his mother. My husband got sick from HIV and tuberculosis and was admitted to the hospital. My mother-in-law distrusted me in everything I did for her son, and therefore, she used this reason to keep my son with her. She said that I was very young and could marry and have new children later.

The attempt to avoid violence may limit a woman’s ability to negotiate safe sexual behavior and to exercise her reproductive rights. Nevertheless, the efforts made to decrease or eliminate violence that is related to reproductive health and rights appear also to be unsuccessful. No one appears concerned about the spread of domestic violence in this sleepy rural area, where most people make a living as agricultural farmers and housewives. The norm highlights a husband beginning an evening by going to get drunk and then heading home to physically and verbally abuse his wife, as Sommay recalls:

My ex-husband was ten years older than me. He looked good and I decided to marry him after he told me that his wife had died. He could be extremely emotional and when he had drunk too much he beat me, sometimes I fell from the stool. If he needed money to drink and I did not have it he beat me again and again. He did not care when I was pregnant, he forced me to work hard until I had a miscarriage.

I assume that HIV positive women who are confronted with violence have no space to share their histories and seek mutual support from their family or community, as Nong explains:

My husband is emotionally unreliable. Several times he clashed with somebody without a reason. When I was seven or eight months pregnant he beat me every day. When I thought it would be finished I faced violence again after my second marriage [cries]. I did not think it
would happen again. I told his mother about his habits but she said that it is a family affair, not her business.

I am convinced that if these women would have room or space and time together, they could break down the barriers and discuss areas that are concealed or forbidden for them. It could help to prevent women from becoming victims of domestic violence. My interviews shows that several HIV-positive women are confronted with new forms of violence which directly affect their children, reduces their power to negotiate, causes them to lose their jobs or lose the financial support from their husbands, like Tar explains:

I attended the human rights for HIV/AIDS workshop at the Warinchanrab hospital that was organized by Klum Sadaowan. The program was two days, and I decided to attend all the courses. The first day no problems occurred in my family, but the second day my husband left my son soak in his poop and pee (non chae chi chae yiao). My son cried until he fell asleep in this bad situation. I suffered very much but I could not complain to my husband because if he became angry, he would abuse me. He had lost his job but he did not try to find a new one. My brother gave me 100 baht [2.50 euro] for two or three days, but if my husband needed a coke or needed to smoke he ordered me to buy it for him.

The “culture of violence theory” argues that both in the past and the present, but less so today, the unequal distribution of power between the sexes has resulted in societies that are dominated by men and that most women occupy subordinate positions of power, which increases their vulnerability to violence, especially within the family (Martin 1976; Dobash and Dobash 1979). In Thai society domestic violence still happens and overshadows women in every level leading woman to be unsecure in their lives despite the attempts of the Thai government to stop domestic violence through new laws.

Art had lost the opportunity to take care of her son and did not have the money to support her family because her husband had passed away and her mother-in-law wanted the son to stay with her forever. She decided to return home and to stay with her mother until she got married and had children again. Even though this seemed a satisfying solution, the situation had a lot of influence on Art:

My mother-in-law said that she had only one nephew who descended from her son who had passed away. She used his surname therefore and he would stay with her since she could better take care of him than when he lived with me. When my son needed anything he got it because my mother-in-law loved him and spoiled him very much. Nevertheless, I could visit him twice a month. I had a short time to touch him, he just said hello to me and played with the many toys that his grandmother (ya) had bought him. I suffered very much, but realized that my mother-in-law would take care of him and create good chances for him.
Structural relations and social norms of the community limit the power of HIV positive women to negotiate with their family about stopping the violence they experience. Several women I interviewed showed that sometimes their families avoid supporting women who are confronted with domestic violence because it is a family matter and should be solved by insiders, even though women experience physical traumas and mental problem, as Sommay illustrates:

Many times my husband’s harm it did not only hurt my body, but it led repeatedly to psychic traumas. One day I decided to flee from my house and to live with my mother. I told my mother about the violence from my husband and I showed her the evidence on my body. My mother said I should be patient and try to continue my marriage. It was like a fight between the tongue and the teeth (*lin kap fan*) which could happen in any family. My mother did not know what happened to me when he begged me for money to drink alcohol and started to abuse me again if I did not give him money. I decided to escape from him and stay with my mother; I urged my mother to help me separate from my husband because he had tortured me many times and I wanted to end my marriage before he kills me one day. I showed her the scares and abrasions that were caused by his violence. My mother and father gave me permission to divorce him and one year later I decided to marry with a person who was HIV infected and whom I met at the monthly PLHA peer group meeting. I got a new life and I never again became the victim of my ex-husband.

Because of the dominant form of masculinity in Thailand, the male dominates the relationship and may inflict violence toward his intimate partner, causing the power of HIV positive women to control their husband or male partner in using a condom during sexual relations to be seriously limited. This causes not only a risk of re-infection but also the risk that women are forced to become pregnant as well as to give birth to a child, as Chom formulates:

After I knew the blood result, that I got HIV from the first husband, I became very careful while having sex relations with my husband because he had a different blood result. I told him to check the blood test and he said that this was no problem. I was worried that I got HIV; I did not want him to get HIV from me. We continued as a warm family. I warned him each time when we had sexual relations. I wanted him to protect himself by the use of a condom and I did not want to become pregnant again. However, he still refused to use condoms and wanted to make me pregnant although he knew that I did not desire a child. My husband refused to respect my rights and caused me to have a second child. Even though I did not want to have a child, my motherhood sense pressed me to access the PMTCT program again. The result of the blood test of my child was normal.
This is a form of violence which is related to cultural norms as well as to power relations between genders, which leads men to take power and to use force to control and dominate their families. It is the cause of blame and discrimination against women living with HIV/AIDS within society as well as in the setting of the health care service. The impact of this problem is that women still continue to feel ashamed, are silent and anxious, and finally end up with psychiatric problems. My interviews showed that there are many HIV positive women who are still confronted with this problem. How can local communities, health care providers and the health care system create the space for these groups to solve and share their own experiences? More specially, how can this group be empowered to realize the equality that can help them to stop or cope with violence in a safe manner? Violence is not only forcing women to risk an infection with HIV through physical trauma but it also limits women’s ability to negotiate safe sexual behavior. Avoiding violence may limit a woman’s ability to negotiate safe sexual behavior and to exercise her reproductive rights, but the avenues taken to decrease or eliminate the violence that dominates reproductive rights have proved unsuccessful.

During my field work I listened not only to the voice of HIV positive women but I also visited the leaders of PLHA peer groups who informed me about the many obstacles in the health care system that obstruct decision-making regarding reproductive health and rights of these women, as Rattana, the peer leader of the Trakansotsai PLHA group notices:

HIV positive women do not have a space to share their histories and seek mutual support. We also feel that HIV positive women do not have a safe area or the time together that could break down the barriers to an open discussion of all secrets and taboos about which they cannot talk with their families in a comfortable way. I developed an idea with a monthly PLHA peer group meeting and decided to share it with the health care providers who cooperate with this group. We were not successful because the health care providers responded that they did not have time to listen to all the problems of PLAH. They should be sent to the leader of the PLHA group who represent them within the health care team. They never had a private room to talk with them confidentially.

Newly married young women face a high risk of HIV infection and have a greater probability of becoming a victim of violence since they have less access to information concerning HIV than women longer married and have great difficulty in negotiating condom use within their marital relationship. Furthermore, their husbands tend to be older than them and the women do not know the history of their husbands before marriage, which may have exposed them to HIV.

The marriage of Bin is one more example of the many forms of gender-based violence that are the result of cultural practices and supported by the imbalance of power between men and women, as Bin demonstrates:
My ex-husband, from whom I got HIV, was more than ten years older than me and had a better socio-economic position than my family. For financial support I depended therefore on my husband's family. My mother said that I was married to a person to whom I was repaying my kindness (tobthaen bunkhun) and who would protect and support our family. 'You are the only person in our family who can do this.' At that time I was 17 years old and I had never heard about HIV/AIDS. When after my marriage I got pregnant and learned the result of the blood test, I was very distressed and my life was a mess at that time. I asked myself what I did wrong to become infected with HIV and how could I survive and continue my pregnancy.

When Bin learned the result of her blood test, she told her husband that the result was positive. Her husband said that his blood test was normal and perhaps she had got it in another way. His family believed him, because he was the only man in his family, but people in the community told Bin that he went many times to work abroad and that his blood was never tested. In the same way as sexual violence mirrors gender inequality it reflects other forms of social inequality.

Evidence from cross-cultural anthropological studies suggests that "male sexual aggression and violence is not biologically inevitable, but that it rather occurs because masculinity is associated with aggression and sexual conquest, domineering sexual behavior and violence, which become not only a means of structuring power relations between men and women but also a way of establishing power relations among men" (Hesise 1995:130). In the case of HIV positive women it is no different, they are also addressed with sexual violence that may lead to direct physical harm, emotional trauma, stigma and social ostracism. It also carries the additional risk of unwanted pregnancies, STDs and increasingly new cases of HIV infection or new cases of drug-resistance (WHO 2004). In Ubon Ratchathani the health care system was not monitoring the impact of violence against HIV positive women, neither was there a program to refer cases to a safe area to protect them against domestic violence.

Women often face violence and a lack of supportive services places HIV positive women in a vulnerable position. Several persons who I interviewed reported that when they got pregnant, health care providers in several ways violated their reproductive rights. Violence is not only stigma and discrimination, but social and community sanctions also produce violence against HIV positive women, such as in the case of health care providers who try to influence the decisions of HIV positive women who desire to marry and raise a family. Furthermore, all these problems are not only characteristic of HIV positive women or HIV positive pregnant women but also for families and communities in general.
Chapter 7
Reproductive Health and Rights

After the International Conference on Population and Development (ICPD) held in Cairo in 1994, it was generally acknowledged in Thailand that reproductive health and reproductive rights also include the complete physical, mental and social well-being of individuals and not merely the absence of disease or infirmity all related to the reproductive system and its functioning and process (UNFPA 2004:45). The Fourth World Conference on Women (FWCW), held a year later in Beijing, stimulated the Thai government further to develop work on these issues (Warakamin 1998). The activities of the Thai program on reproductive health and rights were focused on ten key areas, but the program that could help positive women to get access to good services consisted only of five components, family planning (FP), mother and child health (MCH), fertility, HIV/AIDS and Sexual Transmitted Diseases (STDs), and abortion and its consequences. Nevertheless, all programs managed to make the impression that it worked well on a range of new components such as quality of reproductive rights and health care and equal opportunities among women in making reproductive decisions. In this chapter I will show that the program that promotes reproductive health and rights and has been followed for a long time in Thailand, and that it has been successful in two areas: family planning (FP) and mother and child health (MCH), which induced the mother-to-child-transmission (MTCT) program to support HIV positive women who desire to have children.

Moreover, I will look at the factors that influence the decision-making of HIV positive women who have had the experience of pregnancy and want to have children as well as of positive women who do not want to have children. These factors include the right to have sex; the right to have a child; sexuality in relation to reproductive health and rights in the community; motherhood, HIV and the way to arrange delivery; the manner to balance fear, security and desire; the way to let PMTCT support reproductive health and rights and, finally, the manner in which these factors cause a violation of reproductive health and rights by the health care system.

In Ubon Rachathani, the health care system provides services related to reproductive health and rights that are accessible for general groups who can access the services which consist of an ANC clinic, a family planning clinic, a STD clinic, an anonymous clinic for risk groups, and a health check program through which health care providers reach the community. In the case of HIV positive persons the health care providers follow a different approach toward family and community. Thus
some programs seem only to support the general population, but for specific groups like HIV positive women, who need to keep confidentiality, it is often difficult to access these services.

From my in-depth interviews I learned that many women who have HIV/AIDS lack the power and the commitment to protect themselves against unwanted pregnancy even though they know about the importance of using condoms and how to them. My interviews and discussions with HIV positive pregnant women on reproductive health and rights made clear that there are many elements involved: like family planning, health of mother and child, safety of abortions, the right to enter pregnancy care of a good quality and access to HIV services.

The right to have sex and children

It is necessary to provide HIV positive people with knowledge about reproductive health and rights so that they know how to access the services and eliminate the barriers in this process, since many HIV positive women complain that several elements related to reproductive health and rights seem only to support persons of the higher class. The lives of many women change significantly as soon as they learn about their HIV diagnosis. How they, for example, felt about sexual relationships is affected and they ask themselves whether or not to continue to have sex. Many women got pregnant again with the same partner; some entered a program to delay sex or planned to be careful and not have a child.

For HIV positive women who know the result of their blood test, sexual relationships can still be a necessary and healing part of their lives, as Aeoung explains:

I agreed with my husband to have sexual relations about three to five times per month. I would take control to make sure that the condom was working because the result of his blood test was negative. I did not want him to get infected like me. He accepted this agreement and when I was not in the mood to have sex with him I allowed him to have sex outside because I could not respond to his needs. He told me that he could not do it because he loved me and did not care about the positive blood test, sex was not necessary in our lives, supporting each other was more important.

An important issue is the perspective of health care providers about the right to have sex and children. I got some information about this topic when I waited for a woman to be interviewed and in that time had a discussion with Tik, a health care provider at the community hospital:

After their husband or partner dies, many women become a member of the PLHA group here and meet there a new friend with whom they share their suffering. Their close contact sometimes leads to a sexual relationship and later even to marriage. Many women visit our clinic before they decide to have children to ask information about how to prevent the child from getting HIV. I tell them, if you are healthy, any time when you have sex you can become
pregnant. But I warned them to be concerned about their CD4 count because if the woman has a low CD4 count it is a bad moment to become pregnant.

Many women decided to marry again and they said that sexual pleasure was not only the best way to release pressure and tension and cope with stigma and discrimination from the community, but it also helped them to be motivated to continue. Even the perspective of the community, which looks down on positive women with a new partner, cannot influence their illness, as Son describes:

Sexuality is essential in our relationship, because it removes my feelings of loneliness. It seems that AIDS could not stop me from having sex because I know how to prevent an unwanted pregnancy and re-infection. Although I have sex more than four or five times per week, we never forget to use a condom because we decided that we would not cause a new case of HIV.

**Deciding to have a child and motherhood**

HIV positive women are confronted with a range of dilemmas and discrimination, especially in relationship to pregnancy and motherhood. It is very difficult for HIV positive women to fulfil their reproductive needs as there is a different ideal about positive women having children; who should have and who should not have children, and who makes this decision, individuals or families? As I found from the fieldwork, there are many factors that affect positive women who choose to have children, especially those who receive good support from their families, having access to advanced treatment enables them to lead a longer life and greatly increase the likelihood that they can bear a HIV negative child. Reproductive health and rights involve, however, complete physical, mental and social well-being. It therefore implies that people are able to have satisfying and safe sex, which right is not limited to the general population but includes HIV positive women who have the capability to reproduce and the freedom to decide to do so. People have the right to access appropriate health care services that will bring about a safe pregnancy and delivery as well as provide the couple with the best chance of having a healthy infant.

Most positive women with whom I held in-depth interviews and all the participants in the focus group discussion gave the same information: after the first partner passed away or after they divorced, positive women decided to marry again, not only for sexual pleasure or to have children but they needed each other for care and support. Many women had undergone some form of pressure, sexual domination or violence to push the decision to desire children, as Bin demonstrates:

After my ex-husband died, I married again my husband had blood test positive also, I myself did not want to have a child that is infected. My husband really wanted to have children because his family had only him. Due to his family’s need to have children, I changed my
mind and decided to have children again. We discussed with the health care providers and entered the PMTCT program that supported me until I gave birth to my twin sons. Luckily, their blood tests were normal. Now I have been sterilized after a caesarean section.

Decisions around motherhood throw into shape unequal power dynamic in personal relationships and cultural expectation about marriage as Sommay describe about her new marriage:

My mother said she could not take me and protect me, because she was very old and she suggested me to marry and find a good male to support me. I found a new husband who was a PLHA in the same group. We decided to have a child because I want my children to look after me when I am elderly. I hoped that the PMTCT could help make him safe from HIV, like a normal child.

Even though, Bin made the decision to have a child by learning about the reproductive system and how to prevent a new life from being infection from the PMTCT program, she gave definition to becoming a mother again not only to have a new member but also because of love and the desire to be protected and cared for later in life. Bin explains more about motherhood:

Though I got HIV that could not stop my feelings of love and concern for my children and I hoped to see them grow up. My twin children had a brother from my ex-husband who died more than ten years ago to support them. My new husband did not tell the result of the blood test to his family. I decided with my husband to build a small hut in the field. We were very happy that my husband followed the way King Bhumibol has suggested to his people. He advised to be self-reliant in agriculture and to grow organic plants because our children should eat fresh and safe food and vegetables. I loved my children and prayed every night for them as well as I would like that my husband had a long life to stay with them as long as possible. I think that I accepted the result of the blood test that I got from my ex-husband because of karma (kam). However, before I got pregnancy, I was a vegetarian; I did not eat meat until I got pregnant. I decided to stop eating only vegetables and start to eat meat for the health of my unborn babies. It was not easy to adapt but I tried because I wanted my baby to be healthy and safe from infection.

Some positive women believed that they got HIV because of karma, because of things they did in the past affected them in the present. By following this belief some women are able to accept their positive blood result and learn to cope with the situation with the help of local cultural norms and the

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8 Karma (kam) refers to the group of causes in the chain of cause and effect and is directly linked to the motives behind an action. This motivation usually makes the difference between a "good" and a "bad" action, which is built up from the past and effects the present and the future.
belief in Isan (a local belief in the northeast of Thailand). It leads them to contribute to accept karma and their fate. Even though women cannot correct the past, they illustrate that they can do the best thing for their life and follow the teaching from Buddha, prayer, and forgiveness; they can change their bad situation to good karma. Although people believe that some get HIV due to bad karma, this is not always the case.

**The right to choose the delivery method**

Several women lack good knowledge of their right to choose a safe method of delivery to prevent their child from infection. From the twelve in-depth interviews, only two women had experienced a delivery through caesarean section because this method can prevent the children against HIV contamination, as Tar experienced:

> I know the ANC and attend a group every month. It is the best way to protect my baby against HIV and I have to choose delivery by caesarean section. I requested the health care team to help me to protect my baby and they were willing to do so.

In Niyom’s case, because she belonged to a high risk group during pregnancy and got infected at the same time her reproductive rights were violated by the health care team through forced sterilization during her caesarean section, as described in Chapter 5. Undergoing sterilization unknowingly during a caesarean section operation violates an individual’s human rights and can cause severe suffering, but through good counseling during family planning and giving the information to positive women to make the decision to choose between further pregnancies or sterilization, women can take the initiative themselves.

There was only one participant from the focus group discussion who planned to undergo a caesarean section by paying money for the service:

> I decided to earn money because at that time I did not know I could choose the delivery method. I got the information from my friends that explained that caesarean section could prevent my child from getting HIV, but the health care provider did not suggest that I choose this method. When I learned from the result of the blood test that I got HIV, I loved my daughter who got HIV more than the young one because her blood result was normal. She could not be breast fed from me; she was milk fed from the bottle. She differed from her elder sister who breast fed and got a hug from me each time I fed her. During the delivery my baby did not engage the birth cavity, so the doctor decided to do a caesarean section because of the normal labour obstruction, not only from the medical point of view. (Rak)
Three positive pregnant women wanted to choose caesarean section to prevent their children for HIV infection and they had a lot of interesting information to share with each other, as Bauwsan describes:

I forgot what it was like to give birth [she laughed and smiled] and I feared to see blood, but if caesarean section was the best way to save my children from infection, I would choose this way. The health care provider's team was very friendly with me and suggested that this is the best method to help me to get a healthy baby. I will love her like I love my other two children.

Phon was very anxious and wanted to choose caesarean section as well, but she did not have the power to negotiate with the doctor or the health care team and she asked me to help her to speak to the doctor about what she wanted:

I very much would like to give birth by caesarean section, I need a healthy girl. I know her gender from the ultrasound. I do not want a positive infant baby although I take my medicines on time. I want a child that is negative; I will save money if I have to in order to pay for a caesarean section [her voice changes, as if she cries] and I want sterilization after that.

Many HIV positive women who desire a child have the same goal. They want a healthy child and not a positive baby, even though they have to face many questions from family members and the community about the reason why they feed their child by powdered milk. In terms of reproductive rights, most positive women were not in a good situation as several women demonstrate a lack of knowledge and information, which should be seen as a necessary reason for a reinforcement health care system.

**Why positive women undergo abortion**

HIV positive women need to feel strong in order to speak openly with health care providers about their sexual concerns because it could help them to make decisions about reproductive health concerns. Many positive women have numerous reasons to undergo an abortion. It is not only against the social sanctions of the community and family but also forms of violence are involved that I mentioned in Chapter 6. Five women I interviewed have been affected by domestic violence, and one woman, Nong, had an unwanted pregnancy due to sexual violence and her husband's refusal to use condoms. It had been only two months since her last pregnancy and she became pregnant again against her wishes, leading her to desire an abortion. She drank yadonglao (an alcoholic drink with herbs) that induced uterus contraction and should have led to the abortion, but this was not successful and she had therefore to continue her pregnancy until now. Nong not only wanted to terminate an unwanted pregnancy, she showed also a lack of access to appropriate contraceptives and had no power to negotiate decisions regarding family planning and childbearing. Other HIV positive women refused to access safe abortion care because they were misinformed about the possible impact on their
health, such as an incomplete abortion, postpartum haemorrhage, septicaemia, abortion failure and abnormality of the child.

The problems of HIV positive women become more complicated when they have children under the pressure to hide the result of the blood test and to avoid again and again stigma and discrimination from family, community and health care providers. Therefore they may decide to have an unsafe abortion. It is the best solution for them because the costs are very low and secrecy is guaranteed. Four of the twelve women from the in-depth interviews illustrate the various reasons and the methods used to perform abortions.

Art was two months pregnant when she decided to buy illegal abortion drugs to initiate an abortion. It led to a lot of blood loss from bleeding from her vagina. Due to the complications she was forced to go to the health care centre to be treated by an injection and oral tablets to increase her hematocrit.

Aeo has experienced abortions twice, the first time it was done in an illegal clinic by the curettage method (khud mod luk). It led to abortion and also to bleeding from her vagina. After the abortion, she took two paracetamol tablets to stop the pain from uterine contractions. The second time, she got the idea from a PLHA peer educator during a monthly meeting, a mixture of lao khao and ya thamchai (white alcohol) caused the termination of the pregnancy.

Two months after Nong’s delivery she learned that she was pregnant again; she kept it secret and attempted to terminate because she already had two children from her former three marriages and had lost her job. She believed that ya khab luead, a medicine that directs the blood used to induce menstruation, could cause an abortion but was not successful.

When Sommay was five months pregnant, she planned to visit the ante-neonatal care (ANC) unit at the health care centre, but since she worked very hard in the field at that time, a complete abortion was caused by her hard work and lack of rest. After the abortion she was pale and weak and at that moment she still did not know the result of the blood test because she miscarried before going to the ANC. The feelings after abortion were strong; she felt suffering and missed her baby because she had carried the baby for more than five months.

How the PMTCT program supports women who want to bear a child

In Thailand the PMTCT program was launched more than ten years ago and has supported HIV positive women when they have expressed the need to become a mother, the wish to have a complete family, and the desire to have children take care of them when they become older. The PMTCT program may provide an essential entry point for positive women to prevent transmission of HIV from mother to child, but the relationship with family planning is only limited to sterilisation even though fertility is aimed at during ante-natal and post delivery care. This program misses many opportunities to give more information about family planning to positive women to help them to plan
their life after childbirth. Despite the fact that most PMTCT programs are offered within the existing mother and infant health facilities, there is little room for family planning counselling. It seems that the family planning part of the ANC is not related to the PMTCT services. It leads to many positive women who become pregnant and decide to have an unsafe abortion, as Art relates:

When I first married, I was 16 years. We had one son and then my first husband died two years ago. I married again and became pregnant once more. The result of my blood test was positive and I assumed that I got it from my ex-husband. My husband and I decided to hide the result of my blood test for my family, while health care providers advised about the PMTCT program. I decided to enter the program. I think the program is good for positive women and can give a normal infant, as they did with mine who was HIV negative.

My research on reproductive health and rights shows that the knowledge of these issues is difficult to acquire. But in reality the rights of HIV positive women have still been violated by the health care system when they were convinced to terminate their pregnancies and prevent future pregnancies. Moreover, reproductive rights include, among others, the right to decide if and when to become pregnant, how many children one will have and how long the space between them will be and the right to marry voluntarily and establish a family (UNFPA 2006). Fiore found that when HIV infected individuals are healthier they tend to have a greater desire to have children (2008):

I had two children and got pregnant again after I had my child 14 years. I got infection from my husband 6 years ago due to his risky behaviour. Because I forgot to take an oral contraceptive pill to protect myself against an unwanted pregnancy, I became pregnant. At the beginning when I found out I was pregnant, I was afraid that my baby would get HIV from me. I consulted the doctor and the health care team, they advised me to enter the PMTCT program however that because of my age, 37 years, there was a high risk and the doctor allowed me to choose for myself the method of delivery. I wanted to delivery by natural birth but health provider suggested that labour by caesarean section could protect my child from contamination and they allowed me to make the decision. I changed my mind. I love my baby as the first one that I had and I would like to protected her as much as possible, even though I almost forgot how to care for her [smile and touched her pre pregnancy. (Bauwsan)

Bauwsan was lucky to receive the advice and support from the PMTCT program, however, not all woman have this opportunity. Lack of appropiable knowledge to apply to the PMTCT program also has an effect on the prevention of the transfer of HIV from mother to child. Many positive women needed more opportunity and time to study the information because the guidelines or brochures gave explanations that used medical terms, as Sommay explains:
My present husband and I are both infected with HIV. I married him after the divorce from my ex-husband. When I got pregnant I was very worried because I had once experienced a full abortion while I stayed with my ex-husband. At that time I had never heard of the PMTCT program and I worried that my baby could become infected through me. The health care providers suggested entering the PMTCT program. But I did not understand much because all handbooks and brochures were written in a kind of medical language. I want health care providers to give more information and take time with me. Further, I would like to know what is forbidden when I am in the program.

The nurse who is responsible for antenatal care and whose work I could observe during my visit, wanted to share her own experience in an informal conversation I had with her:

I think HIV positive women have rights to marry and become pregnant on their own and plan their lives themselves. In this hospital we have a PLHA peer group which cooperates with the health care team and functions as a support group at the same time. So some PLHA look healthy and better than normal people. But for some HIV positive women who have a high education and high status it is very difficult to disclose themselves and share their experiences within the self-help group. I try to advise them to attend or observe a monthly group meeting, but they feel ashamed to disclose themselves before everyone and they do not want the society to gossip about their family. (Tik, ANC clinic)

That the health care providers support the idea that HIV positive women have the right to have sex and children, does not mean that they agree with the PMTCT program. Su, who has worked in this field more than ten years, explains:

I work at the ANC clinic for more than ten years. After we had the PMTCT program to look after positive women who desired children, I followed the national policy and PMTCT program that we work with and used the Clinical Practice Guideline (CPG), which follows the Department of Health of the Thai Ministry of Public Health. It is useful for infected women who are healthy and desire a child. In the regional hospital, community hospitals and health care centers in our province they follow the CPG and use the same standard. Some positive women when they become pregnant are uncomfortable to access the community hospital in their home town and would like to change place for treatment, they have the right to do so. But the community hospital is in a small area and confidentiality cannot be kept there because of rumors and gossip. I had many cases move from their home town to attend at PMTCT clinic here.
Cooperation among reproductive health services

The health care system is concerned about sexuality, reproductive health and rights of positive women and has incorporated all forms and implementation into the policy on both the regional and local levels. They have set up a comfortable program to support child bearing women including a STD clinic and gynecological clinic that include pap smear and breast exam. Prevention of breast cancer is important for women living with HIV/AIDS as well as for HIV negative people, but it is often neglected. In the focus group only two of the eight participants were able to access the reproductive health services at the health care center, as Kason describes:

I just got this information when I went to the health care center and the health care providers told me that the government had a program for women who are 35 years and older to check cervical cancer (by pap smear). Then I took the test for cervical cancer and they taught me how to perform a breast cancer exam. In my village almost all the older women would go to do a check up pap smear and a breast examination. But I had no idea about the exact meaning of sit anamai chareunphan (reproductive health and right). I never heard these words before.

Daenduang further illustrates:

One day I went to visit the health care center and the health care providers taught me how to check for breast cancer. After that we practiced it together [loud laughter from the focus group, they seemed to enjoy this]. I also did not understand the meaning of anamai chareunphan (reproductive health and right), but health care providers just say you would be concerned and check by yourself. So I just know only breast exam, if I know more I can tell you [laughing again].

These issues are very important for positive women. They must know their rights and the way to access reproductive health services.

Reproductive decision-making is a highly complicated and sensitive issue; there are many factors that influence women when they have to make decisions regarding reproduction, factors that are related to their own culture and norms, socio-economic circumstances, and their psychosocial situation. The PLHA peer leader of the Jitarree group that takes care of the PLHA in Kheaongnai district gave the following information:

I think sometimes that we (positive women) are not sufficiently recognized by health care providers and are treated with double standards so that we do not have the force to defend our rights, as my friends in our group have discussed. They know that reproductive health and rights services are too complicated to understand them as a part of the routine services, because the health care providers do not have enough attention to listen to the voices of HIV
positive women who need support and protection of their rights. The rights of many of these women are violated by a lack of power and knowledge to make decisions regarding reproductive health. I think that the health care providers and the PLHA peer group should work together in a holistic care center. HIV positive men and women who understand these issues should be part of them.

Reproductive health violation by the health care system

Most positive women in Ubon Ratchathani who have married again and became pregnant entered the PMTCT program. The health care providers attempted to force them to be sterilized by persuading them or their family members not to have a child and by emphasizing the risk of a long-term infection and the risk of giving birth to a positive infant now or in the future. Even though, positive women know about the process and impact of the methods to prevent future pregnancies, they are still vulnerable to manipulation to make decision on reproductive. Beck and Harvey (2005) argue that current reproductive technologies have to be provided with enough information for the women who use these services in order to enable them to make a knowledgeable decision. Lack of information to clarify reproductive rights and health lead many positive women to face complicated problems after giving birth. Health care providers have an obligation to pay attention to the rights of people, not only positive women, but people in general.

I did not decide to finish the possibility to become pregnant ever again. I still have the wish to marry again and to have a child although I am older. I feel sad and disappointed to know that I never can become pregnant again. I do not know why the doctor did not ask whether I really want to stop the possibility to become pregnant. (Niyom)

For the health care provider who likes to protect the reproductive rights and health of positive women, it is sometimes very difficult to find the balance between violation and concern with the patient. Pued describes this:

I was worried about positive women in age-group (35 years and older) who have been infected more than five years and have decided to bear children again, that is very risky and many complications during their pregnancy such as pre-eclampsia, low birth weight and risk of post partum haemorrhage can arise. Some women have many partners and never used a condom during sex, so they become pregnant. They not only have problems such as drug addiction or loss of contacts, but often the illness has progressed because of a high viral load and low CD4 count. I think that it is very difficult to save children, and the health care team
would like to save the mother more than her child, because it affects the indicator of mortality rate. They would, in such cases, advice sterilisation.

The most important barriers that affect HIV positive women are not only the force and pressure health care providers exert on them but they also lack a proper understanding of reproductive rights and health and the knowledge of how to access these services. Even though the PLHA peer group was motivated to cooperate with health care providers, this was not sufficient, as I found from the focus group discussion about reproductive rights and health. Most women did not understand the meaning of these services and how to access them. This information forms a challenge to finding out how these obstacles can be eliminated. Art demonstrates:

After my delivery I stayed three days in the hospital and I could not breast feed my baby. During that time many health care providers tried to convince me to undergo sterilization. They said to me, ‘do not have more children’ (*tham man cha*). ‘Think of your children’ (*songsan luk*). ‘That you got HIV, is that not enough for you?’ Some health care providers said, ‘think of your child when it goes to school and is pestered by friends because the father and mother got HIV.’

There are many social factors which hinder women to improve the quality of their life in terms of reproductive health and reproductive rights. Culture, norms, beliefs, and lack of knowledge, also contribute to women’s fertility problems. Women need to have access to the best reproductive health services and have the opportunity to pick out the method that is most comfortable for their lives. However, in terms of reproductive health and rights; culture, norms and beliefs are necessary to support positive women to make decisions.

Many obstacles to good care of HIV positive women were identified throughout my fieldwork in the areas of sexuality, reproductive rights and health services. I found also poor knowledge, lack of room to discuss sensitive issue and problems and the absence of time and attention among the health care providers to listen to the voices of the women before they make a decision regarding reproductive health and rights. A culture shift in care and treatment together with one in education is necessary to protect HIV positive women against violations of their rights by the health care system. Thus positive women attempt to reinforce themselves by family and community support as well as PLHA peer groups to learn and share about decision-making on reproductive right. It is vital to ensure that HIV positive women are provided with non-judgemental confidential support, services and advice on contraceptives, conceiving, child bearing and bringing up children, and those positive women are empowered to make decisions regarding reproduction without negative outside influences.
Chapter 8

Conclusion and Recommendations

This study has focused on how HIV positive women experience their decision-making on childbearing as well as on their experiences and concerns regarding reproductive health services. Through the analysis of the findings it is apparent that there are wide ranging and varying experiences and concerns depending on the perspectives of the individual, family members, community members and the health care team. Women's experiences are greatly affected by stigma, discrimination, and violence as well as influences on reproductive health and rights. These factors include culture, norms and beliefs in Thai local society, lack of knowledge, gender inequality and power, sexuality, male dominance and socioeconomic problems.

Cultural and social norms

The power imbalance in gender relations in Thai society placed women in a risky position for HIV infection. The inequality of power leads men to control and dominate women over when safe sex takes place. Many men become sexually active before and even outside marriage, placing women at risk of infection when they are not able to negotiate condom use. The risk of infection for women is not only caused by poverty and the socio-economic crisis in their families but includes also obstacles such as gender bias, lack of knowledge, misunderstandings about HIV/AIDS, lack of information and limited access to reproductive health and rights services.

Dialogue from positive women presented in this study deal to a large extent with the barriers that have obstructed and often changed their whole life. It is not only an individual affair but it also affects their family, especially children who have positive and non-positive blood test results. Some sensitive topics for positive women are taboo; they cannot talk openly or in public about things like sexual pleasure, domestic violence or the result of the blood test at the moment they meet their partner for the first time. Rather, positive women tend to challenge and consider themselves as ashamed in the first stage of infection. As discussed in this study, some positive women in Ubon Ratchathani believe that they got HIV because of their karma (kam) and not because of lack of knowledge, power to negotiate condom use or the dominant position of men. In everyday reality many positive women look
healthy, believe that they can give birth to a HIV negative child using their right to make reproductive decisions themselves.

Nevertheless, local norms and beliefs directly influence positive women and my study shows the confrontation of their individual body with the illness they have to experience which causes difficulties in making the decision to have children even though they look healthy and have good facilities to continue their pregnancies with minimal risk of passing HIV onto their unborn child.

Experiences of stigma, discrimination and right violations

As my finding show HIV positive women have experienced stigma, discrimination and right violations that have not impacted solely on the individual body but also affected the social body on many levels, particularly when concerning family and community members. The perspective of health care providers greatly influences the support provided to HIV positive women and signs of stigma and disapproval are still present as many positive women have complained about forced sterilization and abortion. The most important thing, the notions and knowledge of positive women within their illness, have been misunderstood and ignored.

As discussed in chapter five both stigma and discrimination and also right violations lead many positive women to become anxious and feel ashamed. This causes them to hide their sero-positive status from both their families and the community, even though some positive women receive good support from others. At the same time discrimination through social sanctions takes place, not only in the form of cultural norms and beliefs but also by husbands and partners as well as peer groups who did not respond to individual women’s experiences and their functions within society. Stigma and discrimination directly limit the possibilities for women to live up to the values attached to being a daughter, a mother, and a wife, which emphasizes that women work to support their family.

We can see stigma, discrimination and right violations in terms of the political body. It links the experiences of positive women through their access to and relationship with the PMTCT program and other services. The obstacles from the health care team and the national policy for positive women, lead, finally, many of them to consider to have children, but then they have to deny this because they are informed and sometimes forced to undergo sterilization or abort pregnancies. I have, however, also argued that the manifestation of stigma, discrimination and rights violations may depend on education and class, even though the government attempts to reduce these problems.

When positive women undergo violence in the present or the past their vulnerability to violence will necessarily increase, especially within families if the cause of violence is unable to stop or be reduced then women will still be confronted with insecurity in their lives. Women are controlled and dominated by cultural norms and beliefs that lead them to be quiet about violence and in the long term this may cause mental problems.
Perspective from family, community and institutions

As I argue in chapter five the negative effects HIV positive women are associated with in the community are not limited to individual conflicts in their family but it also affects the community and creates barrier to accessing the health care system in local areas. Moreover, people think that AIDS can lead to broken relationships between family members and people in the community, spreading very fast to affect many groups.

The reflection of stigma and discrimination among family has been created do-to the perspective family members got from the mass media or government programs to stop AIDS, which illustrate AIDS as the devil. The government is trying to correct this messages but it may be too late because it has already combined with culture, norms and beliefs, which now look at HIV positive women as bad women. Furthermore, people’s attitude toward HIV/AIDS directly affects children and schools, and induces individual conflict in the community as well as cuts off relationships between women and their environment. In the community, women attempt to interpret and protect themselves from stigma and discrimination that forces them to feel shame, hide the blood result and blame themselves, as well as push them from the community. The influences of stigma and discrimination are related to violence and attempted suicide. Stigma and discrimination against HIV positive women is shaped though individual, social, and larger institutional aspects. Furthermore, the phenomenon of stigma, discrimination and right violations are the most important affect on the human well-being of PLHA and their family members.

Reproductive health decision-making and motherhood

All positive women used the individual body to decide whether to desire and continue their pregnancies or forgo having children even though they had many obstacles against them, including influences from society and the developed health care policy. I discussed the ways in which positive women deal with sexuality and reproductive health and rights. The social body is associated with the individual body when women lack power to make decisions on their own, and the affects from culture, norms and community values obstruct and restrict women, causing them difficulties when making decision to have sexual pleasure and desire children.

After divorce and remarriage, many positive women want to establish a new family, meaning they will need a new family member. Women have the right to make this decision on their own and with the help of their partner. However, the decision-making process is generally influenced by the social body and political body. When positive women decided to marry and have children, the problems are very complicated to deal with, not only from their families but also from the community and health care system. It is often very difficult for community members and health care providers to
accept positive women who have their own ideas about sexuality and reproductive health and rights because they are still influenced by their own perspectives. Throughout the government tries to reduce the conflict between positive women and health care teams, but knowledge of this topic is very difficult to obtain and this leads to many problems in the health care system.

Access to the PMTCT program

Almost all positive women who know their blood result and desire children will be suggested by the health care team to join the PMTCT program. However, this program affects positive women after delivery, allowing the community to question why children are fed with powdered milk, and why they cannot be fed through breast feeding. These observations are associated with stigma and discrimination. Even though the workings of the PMTCT program are designed to be positive and reduce the likelihood of a new HIV case, it also pushes women to be face with social sanction through stigmatization.

A factor that causes a big barrier to women is their worry about how health care providers will keep their blood test confidential. HIV status disclosure by health care providers caused women that I contacted during my fieldwork to change the place for treatment to a place away from rumors, gossip and social sanction. Moreover, women have to worry about the physical and emotional consequences that their family may face from the community.

The most significant notion in the narrative of HIV positive women who want to bear children or who do not, comes from the women themselves (individual agency), their right to decide for themselves to continue pregnancy or become pregnant by using their experience of dealing with multiple obstacles. In addition, the political body can, of course, try to bring control over the individual body; however, HIV positive women use their experiences with the PMTCT program to influence the government who designed the program. Moreover, the program is not only representation of the political body but it also challenges the individual decisions of women and tries to influence their decision-making process. Despite the fact that some health care providers still have a negative idea about positive women who decide to marry and give birth, HIV positive women still have the right and the agency to make their own decisions.

Social support

I started the research with the argument that HIV positive woman who have or want to have children should have the right to make reproductive decisions themselves. The interactions between individual desires of the women and society’s expectations are often creates pressure on their self-representation. In the part of social support there are many levels to support positive women; on the national level there is the PMTCT to support women who really desire children, which can support women both
physically and mentally at the same time, and provide information about AIDS even though there are still barriers. On the local level, there is the Tambon Administrative Organization (TAO) that created an AIDS fund for positive women who disclose themselves in public and the support of HIV/AIDS self-help groups. On a more individual level, women have the support of their family and friends as well as their own agency. Here we see the relation between the individual body, social body and political body and how they work and support each other, even though the research findings have shown that women do not always have access to all of these support levels or that they also function in a beneficial way, their presence is a step in the right direction.

**Recommendations**

The following part presents some suggestions for policies and program actions based on the findings of this study and especially on the rights of HIV positive women. Eventually, a culture shift in care and treatment together with one in education is necessary to protect HIV positive women against violations of their rights by the health care system. It should not only focus on confidentiality and privacy but also particularly on disclosure. Health care providers have to be aware of the complex psycho-social dynamics of the association of gender based violence. The greatest barriers for positive women can be eliminated by providing accurate information and teaching them how to access updated information about reproductive health and rights; for example, information about contraceptives for males and females, about how to access reproductive health services and about the consequence of unsafe sex.

Although stigma, discrimination and right violations have seemed to decrease, in reality they still occur in the daily lives of positive women. The community should be linked with the political level and they should cooperate to support PLHA self-help groups and mobilize their work in the community by listening to the voices of positive women.

As far as violence is concerned, we have to ask how the government should deal with this issue. What kind of new interventions have to be created to deal with it? Or, if the government has organizations that work on violence, how can positive women get access to these services, or how can it be announced to the public and become part of the national AIDS policy?

In addition to supporting PLHA peer groups and their activities, it is necessary to monitor and control the effectiveness of the cooperation of the programs with the positive groups. This should include a degree of participation of the positive groups and their creation of new innovations by themselves that are not part of the national policy. Even though the AIDS epidemic in Thailand had trended to decrease, it is important to initiate ideas and activities that convince men that they are responsible and have to treat women as equals, despite the fact that men are still dominant. Health care providers should develop and enforce a firm policy to assure confidentiality. Although it might
be impossible to change the perspective of some health care teams, they could certainly be convinced of the necessity to protect the rights of positive women.

Future studies on the same topic should be conducted with HIV positive men in order to understand their experiences of decision-making on reproductive health issues. Such a study needs to highlight gender differences and similarities. It should also provide significant information about HIV/AIDS service organizations and policy makers, and suggest ideas about how to extend reproductive options for men by increasing male involvement in family planning and participatory condom use. Furthermore, such research should be based on in-depth interviews with HIV positive men. It should examine how they manage to survive, and include family members such as parents, or a grandfather or grandmother who looks after the children. The results of such a study could lead to changes or improvements of some parts of the national AIDS policy.
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Appendix 1: “Three Bodies” Problem Analysis Diagram

How does HIV affect women’s lives relation to reproductive choices in Thailand?

Social Body

How does HIV affect women’s lives relation to reproductive choices in Thailand?

Individual Body

How does HIV affect women’s lives relation to reproductive choices in Thailand?

Political Body

How does HIV affect women’s lives relation to reproductive choices in Thailand?

Culture/Norms

How does HIV affect women’s lives relation to reproductive choices in Thailand?

Personal Experiences/Emotion

How does HIV affect women’s lives relation to reproductive choices in Thailand?

Personal Beliefs

How does HIV affect women’s lives relation to reproductive choices in Thailand?

Health Care Policy/Services/Health care providers

How does HIV affect women’s lives relation to reproductive choices in Thailand?

PMTCT Program

How does HIV affect women’s lives relation to reproductive choices in Thailand?

Sexuality/decision-making

How does HIV affect women’s lives relation to reproductive choices in Thailand?

PLHA Peer Groups

How does HIV affect women’s lives relation to reproductive choices in Thailand?

Power Relations/Gender Roles

How does HIV affect women’s lives relation to reproductive choices in Thailand?

Community Values

How does HIV affect women’s lives relation to reproductive choices in Thailand?

PLHA Peer Groups

How does HIV affect women’s lives relation to reproductive choices in Thailand?

Motherhood

How does HIV affect women’s lives relation to reproductive choices in Thailand?

Own Experiences, Culture, Norms, Beliefs, Gender, Stigma, Decision-making, Policy/Health Care Services

How does HIV affect women’s lives relation to reproductive choices in Thailand?
Appendix 2: Topic List for In-depth Interviews

- **Health care providers (doctor/nurses)**
  1. What do you think about HIV positive women who re-marry?
  2. How do you feel about HIV positive women becoming pregnant?
  3. How does the PMTCT program support HIV positive women’s experiences of pregnancy?
  4. Why are some HIV positive pregnant women’s access to the PMTCT program denied?
  5. How are the reproductive health and rights of HIV positive women supported by the PMTCT program?
  6. Do HIV positive pregnant women have a choice in choosing the delivery method and do they have as many options as non-HIV positive women?

- **HIV positive women/HIV positive pregnant women**
  1. How many children do you have?
  2. Have you ever undergone an abortion? Why?
  3. Why did you decide to re-marry? Do you want to have a child in this marriage? Do you feel you need to? Why?
  4. Are you concerned about this pregnancy? Why or why not?
  5. Have you experienced any problems with your last pregnancy and/or the present pregnancy?
  6. How do you cope with these problems, and who is helping you to solve the problems? Who has responsibility to solve them?
  7. What emotions do you feel about this pregnancy?

- **Health care system (for key informants)**
  1. What has been your experience with pregnancy? Was it smooth? Did you register for the PMTCT program? Why or why not?
  2. What do you think about the process to access the PMTCT program? Do you think it’s useful for you? Why or why not?
  3. Can you tell why you decided to become pregnant again and go to the ANC?
  4. How did/do you react and feel when you visit the health care provider (doctor, nurse)?
  5. How did you get the information of the PMTCT program?
  6. What are your expectations of the health care system/PMTCT program?

- **Family**
  1. How is the relationship between you and your family after you told them about your new marriage?
  2. How do they feel and react towards you?
  3. Did your family support you when you decided to bear a child?
  4. Do you have enough power in your family to choose your way of life by yourself?

- **Community**
  1. Has the attitude of your community changed after your new marriage?
  2. How did the community react to you when you became pregnant?
  3. How did you deal with the situation?
  4. Did you receive social support from the community after they learned that you re-married or became pregnant?
Appendix 3: Background for Key Informants

Aeo

Age 36, lives with her regular partner and was married three times. She worked as a sex worker in several Southeast Asian countries. She has two children, the first one lives with her first husband (she was his second wife), and the second one is adopted by her brother. She had two times an illegal abortion, got HIV from her third marriage and attempted suicide. She returned to Ubon Ratchathani after her third husband died, became a member of the Sadaowan PLHA group, and has entered the ARV program. She does not want to have more children.

Aeoung

Age 36, lives in a sub-district in Ubon Ratchathani, she is a housewife. Her former husband was an army officer and died more than seven years ago. She was infected by him. Now she lives with a HIV negative husband and is accepted by his family. In her community nobody knows that she is infected, but her sister in another community knows. She and her husband agreed not to have children anymore. She has entered the ARV program.

Art

Age 21, she is a housewife, and she lives in a sub-district in Warincharnrab district. She was married three times, got pregnant three times and once had an illegal abortion. At 16 years old she married for the first time and had one son who was adopted by his grandmother. Her former husband who was ten years older died from AIDS three years ago. Now she is married with a new husband of the same age and they have one daughter. Only her husband knows the result of her blood test. She has entered the ARV program and is a member of the Sadaowan PLHA group. She wants to have another child but at her last delivery the health care providers attempted to convince her to undergo sterilization.

Bauwsan

Age 37, she lives as a farmer in the countryside. Her marriage was arranged by her family and she has two children. She got HIV from her husband more than six years ago and became pregnant since she forgot to take the pill. Her pregnancy is in the seventh month and she has entered the PMTCT program, although at the beginning she considered abortion.

Bin

Age 36, she works as a farmer and she has married two times. She got HIV from her first husband who was ten years older. They have one son. She married again with a person with HIV from the same group (Sumrong group). Her new husband wants to have children because he is the only son in his family. They consulted the PMTCT program and recently Bin has given birth to twins. Bin and her husband are a good model in their community; they grow organic vegetables, follow the self-reliance method of agriculture, and practice meditation every day.

Chom

Age 25, she is a farmer and she has married three times. When she married at 18 years old she moved to work in Bangkok. Her first husband died from liver cancer (the village rumor said AIDS). Chom married again and had two children in that marriage. She knew that she got HIV during her first
pregnancy after a visit to the VCT clinic. She knew also that she was infected by her first husband. Both children tested negative and she divorced from the second husband who also tested negative. She married again with a person with HIV from the same group.

Niyom

Age 39, she is a housemaid and lives with her sister in an urban area. She got HIV from her first marriage and after she was divorced she returned to stay in the country side. When she got sick she knew the result of the blood test but delayed treatment from the regional hospital. Her family took Niyom back to her hometown and started a traditional form of treatment. One year later, her health got worse and the family decided to go back to the regional hospital where she entered the ARV program.

Nong

Age 31, she lives in an urban area with her third husband from whom she got HIV. She married three times. Her present husband is three to seven years older, they have one son and a second child is coming. She has many problems with her mother-in-law and attempted suicide several times but her first daughter put her off this idea forever.

Phon

Age 37, she lives in a big city 40 kilometers away from downtown and has a small shoe business. Only her husband knows the result of her blood test. She has divorced and had one child from the first marriage. After that she had a regular partner with whom she had a relationship for two years. When they had sex she never used a condom while her partner had many sexual contacts. Finally she married a guy who was ten years older and worked in the same factory.

Sommay

Age 30, she is a housewife and has married for the second time. She got HIV from her first husband, who used to be violent toward her. Sommay decided to divorce and married with a person with HIV in her group. She is now pregnant again and has entered the PMTCT program. She is still faced with stigma and discrimination from her village and she moved to live with her husband, who has accepted the result of her blood test.

Son

Age 35, she is a farmer and she has married two times. Her former husband died from HIV. They had one daughter together. After his death Son decided to return home to live with her brother who is disabled. Strong discrimination led Son to attempt suicide. She married again with a member from her PLHA group and they decided that they no longer want to have children. Both of them entered the ARV program and both use herbs.

Tar

Age 23, she is married, lives in Warincharmrab district, is a housemaid and has one son of four months old. She lives with her brother and her husband, who lost his job and is an unstable and violent person. Tar has worked in the entertainment business. She assumes that she got HIV from her husband. During her pregnancy she entered the PMTCT program and gave birth by caesarean section.
followed by sterilization. Now she participates in the ARV program and she is a member of the Sadaowan PLHA group.
Appendix 4: Background for Focus Group Discussion Participants

Champarat

Age 30, lives in an urban area, works as a farmer, married twice and has no children. With her husband she decided not to have children because they do not want to create a new infected case. Champarat got HIV from her first marriage.

Chawee

Age 32, lives in the countryside of Ubon Ratchathani province and she works as a farmer. She has married twice and has two children from her second married. She got HIV from her first husband who told Chawee after the divorce that he got HIV.

Daenduang

Age 32, lives in an urban area in Ubon Ratchthanani, she works as a farmer and has married two times. She got HIV from her first husband and after he died she married with a member of the same PLHA group.

Kason

Age 37, she lives in an urban area of Ubon Ratchathani and works as a farmer. She married once and became infected by her husband who died six years ago. She has two children who are both HIV negative.

Long

Age 38, she lives in an urban area in Ubon Ratchathani, works as a farmer and has married two times. She got HIV from her first husband and has one child.

Phisal

Age 35, she lives in an urban area of Ubon Ratchathani, works as a farmer and has married twice. She got HIV from her husband who got it while he worked in Bangkok.

Rak

Age 38, she lives in an urban area and works as a farmer. She has married twice and was infected during her first marriage.

Samay

Age 30, she lives in an urban area and works as a farmer. She has married once and her husband died from AIDS.