

Chapter 22

AIDS Support Groups and Women Living with HIV/AIDS in Central Thailand

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1 Introduction

Currently, Thailand is still experiencing an epidemic of HIV infection and AIDS. Ever since the diagnosis of the first case of AIDS in 1984, the epidemic has risen rapidly, and now it has affected people ranging from injecting drug users, sex workers, heterosexual men, their wives and sexual partners, to the infants of infected mothers (Singhanetra-Renard et al. 2001; Maneesriwongul et al. 2004; Aheto and Gbesemete 2005; Sringernyuang et al. 2005; Apinundecha et al. 2007). In late 2005, the estimated number of people living with HIV/AIDS (PLWHA) was 560,000 (Kartikeyan et al. 2007). Currently, however, about one million Thai people are still living with HIV/AIDS (UNAIDS/World Health Organization (WHO) 2008).

Although Thailand has successfully reduced the spread of HIV among female and male sex workers and their clients (Ungphakorn and Sittitrai 1994; Mason et al. 1995; Mastro and Limpakarnjanarat 1995; Visrutaratna et al. 1995; Nelson et al. 1996; Sanondhavat et al. 1997; Lyttleton 2000; McCamish et al. 2000; Ainsworth et al. 2003; Apinundecha et al. 2007), the number of HIV seroprevalence among women has steadily increased (Brown et al. 1994; Ruxrungtham and Phanuphak 2001; National AIDS Prevention and Alleviation Committee 2008; Rasamimari et al. 2008). According to Thai Ministry of Public Health (1999), HIV

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seroprevalence among childbearing women was 1.6 % nationwide and 4–5 % in the northern region. There were approximately 23,000 HIV-positive women who gave birth in Thailand (Siriwasin et al. 1998), and around 26 % of HIV-infected women in Bangkok had HIV-negative partners. Many of these women have contracted HIV from their husbands who had sexual contacts with sex workers (World Bank 2000). HIV prevalence among women continued to rise and by 2000, about half of new cases occurred among women infected by their husbands or partners (Ainsworth et al. 2003). The recent report by the National AIDS Prevention and Alleviation Committee (2008: 10) suggested that “the increasing trend of HIV prevalence in ANC women at 2nd and 3rd pregnancies indicates that the infection is spreading more deeply into families in general, and probably will remain at relatively high levels going forward.” It is likely that the HIV/AIDS epidemic among Thai women is still an urgent public health issue (see also Chaps. 21 and 23 in this volume).

Culturally, HIV is still perceived as a “death sentence.” It is also stigmatized due to its association with physical decay (Ungphakorn and Sittitrai 1994; Lyttleton 1996, 2000; see also Goldin 1994; Bennetts et al. 1999; Parker and Aggleton 2003). AIDS in Thailand, as elsewhere, is seen as self-inflicted and associated with deviant behaviors relating particularly with sex. It is also seen as only those who indulge themselves in sexual endeavors that the infection will occur. As such, sex workers are inevitably seen as the transmitters of the infection (Jackson et al. 1992; Lyttleton 2000; McCamish et al. 2000; Kerrigan et al. 2001). It is not too surprising then that people living with HIV/AIDS experience the stigma attached to HIV/AIDS and most are discriminated against in their everyday life (Songwathana and Manderson 2001; Boer and Emons 2004; Sringernyuang et al. 2005; Apinundecha et al. 2007).

Despite decades of the epidemic within the country and the extensive media campaigns throughout the 1990s, the Thai people do not have sufficient knowledge and understanding of HIV/AIDS, its transmission, and prevention (Ungphakorn and Sittitrai 1994; Apinundecha et al. 2007). Many misconceptions about modes of transmission still abound (Singhanetra-Renard et al. 2001; Boer and Emons 2004). As physical and moral appearances are important in Thai society, shame is therefore experienced by Thai people infected with HIV/AIDS (Bennetts et al. 1999). The continuing high rates of HIV/AIDS and shame and stigmatization attached to the epidemic contribute to inappropriate knowledge and understanding of the infection and its transmission among the Thai people. Hence, HIV/AIDS remains a public health problem in Thai society (Lyttleton 2000; Singhanetra-Renard et al. 2001; Boer and Emons 2004).

During the first decade of the HIV/AIDS epidemic in Thailand, most PLWHA dealt with stigma by keeping their HIV status secret (Apinundecha et al. 2007; see also Ukosakit 1990; Hongvivatana et al. 1993; Pradubmook 1994; Knodel et al. 2001; Songwathana and Manderson 2001; Dane 2002). People living with HIV/AIDS had to deal with stigma arising not only from their communities but also within their families. Reactions such as separation of clothing and eating utensils and being excluded from community activities were very common. Although recently, we have seen many communities who became more sympathetic and started to accept PLWHA, many are still concerned about risk of HIV infection

from contact with PLWHA. A study in Khon Kaen province in northeast Thailand (Manijsin et al. 2003) still revealed that more than a quarter of young adults were unnecessarily anxious about contracting HIV through their proximity with PLWHA (such as living or working nearby), sharing meals or utensils (such as plates and glasses) with PLWHA, and eating food prepared by PLWHA.

However, recent studies have started to point to more positive attitudes toward people living with HIV/AIDS in Thailand (VanLandingham et al. 2005; Apinundecha et al. 2007).

In their recent study, VanLandingham and colleagues (2005) claim that there are different reactions to PLWHA and their families in community. Overall, these reactions are more positive than what has been widely assumed. These studies did not focus on women, and so knowledge about how women living with HIV/AIDS are treated in Thailand is largely absent. Since Thai women are now experiencing high prevalence of HIV/AIDS, there is an urgent need for healthcare providers to understand their experiences so that more sensitive healthcare can be achieved.

In this chapter, we examine community attitudes toward women living with HIV/AIDS in Thailand at the present time. We also look at strategies employed by women in order to deal with any stigma and discrimination that they may feel or experience in their communities. We argue that women are not passive victims, but rather, they act in their own agencies in order to counteract any negativity they might encounter. The chapter is based on our larger study of the experiences of women living with HIV/AIDS and their participation in clinical trials in Thailand.

2 HIV and AIDS: Stigma and Identity

In this chapter, we attempt to link Goffman's original insight (1963) concerning the impact of stigma in the construction of a spoiled identity (see also Chaps. 1 and 2 in this volume) with a more contemporary thinking about identity. Hall (1990) has pointed to the socially construction of identity and suggests that identity is constantly changing. Parker and Aggleton (2003: 19) suggest that this theory alerts us to "theorize changing constructions of identity" not only in relation to the experience of stigma but more importantly "resistance to it" (Castells 1997: 8). According to Castells (1997), there are three identities. First, legitimizing identities are "introduced by the dominant institution vis a vis social actor." Second, resistance identities are "generated by those actors that are in position/conditions devalued and/or stigmatized by the logic of domination." And last, project identities are formed "when social actors, on the basis to whatever cultural materials are available to them, build a new identity that redefines their position in society and, by so doing, seek the transformation of overall social structure" (Parker and Aggleton 2003: 19). Indeed, it is within the last two identities that we focus on in this chapter. In our study, we will show that the women attempt to deal with stigma and discrimination by going public as a collective identity, that is, to join PLWHA support groups.

3 Methodology

This chapter is based on our larger project on the experiences of women living with HIV/AIDS who have participated or are participating in drug trials in Thailand. A qualitative approach is adopted in this study. The qualitative approach is appropriate because qualitative researchers accept that, in order to understand people's behavior, we must attempt to understand the meanings and interpretations that people give to their behavior (Barbour 2007; Liamputtong 2013). Using a qualitative method enables the researcher to examine the interpretations and meanings of HIV clinical trials within the women's perspectives. The strength of using qualitative methodology is that it has a holistic focus, allows for flexibility, and also allows the participants to raise issues and topics which may not have been included by the researcher, hence, adding to the quality of the data collected. This methodology is particularly appropriate when the researcher has little knowledge of the researched participants and their world views (Liamputtong 2007, 2013).

In this study, in-depth interviews (Serry and Liamputtong 2010) and some participant observations (Liamputtong 2013) were conducted with 30 Thai women. The number of participants was determined by theoretical sampling technique, which is to stop recruiting when little new data emerges (Liamputtong 2013). Previous experiences indicate that saturation tends to occur around the 25th interview. In this study, we continued to recruit HIV-positive women until we had 26 participants and saturation occurred.

Purposive sampling technique (Liamputtong 2013) was adopted, that is, only Thai women who had experienced HIV/AIDS and who were participating, or had participated, in HIV/AIDS clinical trials and female drug users who have been participating in vaccine trials were approached to participate in the study. The participants were recruited through advertising on bulletin boards at hospitals and personal contacts made by the Thai coresearchers, who have carried out a number of HIV/AIDS research projects with Thai women. In conducting research related to HIV/AIDS and with drug users, the recruitment process needs to be highly sensitive to the needs of the participants (Renzetti and Lee 1993; Singhanetra-Renard et al. 2001; Spirig 2002; Smith 2003; Liamputtong 2007). The sensitivity of this research guided our discussion of how we would approach the women and invite them to take part in this research. We only directly contact potential participants ourselves after being introduced by our network or gatekeepers. Due to the sensitive nature of this study, we also relied on snowball sampling techniques, that is, our previous participants suggested others who were interested in participating (Liamputtong 2013). We also enlisted the assistance of leaders of two HIV/AIDS support groups to access the women in this study. We also took part in the activities of the groups as part of the methodology of this study.

Interviews were conducted in the Thai language to maintain as much as possible the subtlety and any hidden meaning of the participant's statements (Liamputtong and Naksook 2003a, b; Liamputtong 2010). Prior to the commencement of the study, ethical approval was obtained from the Faculty of Health Sciences Human

Ethics Committee, La Trobe University, Australia, and Ethics Committee at Chulalongkorn University, Thailand. Before making an appointment for interviews, the participant's consent to participate in the study was sought. After a full explanation of the study, the length of interviewing time and the scope of questions had been explained, the participants were asked to sign a consent form. Each interview took between 1 and 2 h. Each participant was paid 200 Thai baht as a compensation for their time in taking part in this study. This incentive is necessary for a sensitive research like this, as it is a way to show that research participants are respected for their time and knowledge (Renzetti and Lee 1993; Liamputtong 2007, 2013).

With permission from the participants, interviews were tape-recorded. The tapes were then transcribed in Thai for data analysis. The in-depth data was analyzed using a thematic analysis (Braun and Clarke 2006; Liamputtong 2013). All transcripts were coded and subsequently emerging themes were derived. The emerging themes are presented in the results section.

4 Being Infected with HIV: The Discourse of *Rang Kiat*

We asked the women about how people in the community see them as a woman and also being a mother who is infected with HIV. Most women would keep the illness secret by not telling people outside their immediate families. HIV/AIDS still carries a stigma among Thai people, despite the recent media campaign and health education to promote better understanding about HIV/AIDS (Lyttleton 2000, 2004; Apinundecha et al. 2007; see Chaps. 21 and 23 in this volume). Within a social climate where PLWHA are stigmatized, Mak and colleagues (2007: 1550) suggest not too many people would be willing to disclose their HIV status (see also Lau and Wong 2001; Lau et al. 2003; Zhou 2007; Chap. 6 in this volume).

The Thai discourse of *rang kiat* was expressed by most of the women to mean being discriminated against in their narratives (cf. Chap. 21 about the feeling of disgust toward PLWHA). The words have the same connotation as in other stigmatized illness or living conditions such as leprosy, tuberculosis, living in poverty, and being a sex worker. Pailin said that she kept her HIV status secret because of the fears that people would discriminate against her:

I am afraid that people will *rang kiat* me. Everyone is the same, and they think the same about the illness. It does not matter how many thousand people have HIV/AIDS within the populations of more than 60 millions, I would say that only zero percent will accept people living with HIV/AIDS.

Women tend to be more vulnerable to stigma and discrimination (de Bruyn 1993; Green 1995; Nyblade et al. 2003; Lekas et al. 2006). Lyttleton (2000: 198) says this clearly in his work in northeastern Thailand that during his fieldwork, he found many villagers referred to women as the agents of the emergence of AIDS in phrases like "AIDS comes from bad girls" and "women selling themselves outside of home and being a prostitute." The women in our study too suggested that women in

particular would be more stigmatized than men. Women who contract HIV/AIDS would be perceived as *pu ying mai dee*, that is, being “bad” women who liked to have sex with many men. Women contracted HIV from *rok mua* (promiscuous disease – contracting from having sex indiscriminately).

As Lyttleton (2000: 198) has found in northeast Thailand, the women in our study also expressed that nowadays most Thai people still see women living with HIV/AIDS as in the past, and they associated these women as *pu ying sum son* (promiscuity; sexually indulged women) who like *pai tiaw* (going to clubs and bars and drinking alcohol and having sex with men indiscriminately). In a way, this bad image of women living with HIV/AIDS is similar to that portrayed in the early mass media campaign in Thailand (Lyttleton 2000, 2004). As Arunee suggested, people do not see or believe that they are infected by their husbands or partners. Hence, women are blamed for having the disease, and this is the reason for them keeping the illness secret. Sinjai elaborated on this that:

People in community tend to see this disease as *rok mua*. As women, we can have only one partner or one husband. But, for those who have HIV/AIDS, people tend to see them as having too many partners and this is not good. They are seen as *pu ying mai dee*. And they will be *rang kiat* more than men who have HIV/AIDS. Men who live with this disease are not seen as bad as the women are. If you are women and have HIV/AIDS, it is worse for you.

To the women in our study, people in Thailand still have insufficient knowledge about HIV/AIDS. Yenta suggested that she kept her HIV-positive status secret from neighbors due to societal discrimination against people living with HIV/AIDS. People still believe that those who had HIV would die quickly and they would be put in a special place. This means that HIV/AIDS is still seen as a contagious disease that people should avoid. She said that this is mainly due to how the media portrayed HIV/AIDS in its early days. The negative images continue to live in Thai people’s minds. Hence, discrimination continues to live in Thai society (Lyttleton 2000; Songwathana and Manderson 2001; Sringernyuang et al. 2005). Most people still believe that once a person has HIV, he or she would die quickly and would pass it on to others (Lyttleton 2000; Kubotani and Engstrom 2005). Sinjai gave us an example from her own father who shunned people living with HIV/AIDS:

Once there were people standing outside our house trying to raise funds for people living with AIDS, but my father chased them away. He told them not to step into the house as people in his family would get AIDS too. He walked in and said this to me “if I knew anyone in this house has AIDS, I would leave that person at Wat Phra Baht Nam Phu [a temple where many terminally ill AIDS patients stay and die]”. I looked up onto his face and thought that I would get this reaction from him if I told him that I have also got it.

Sinjai also told us about her sister who believed that HIV/AIDS could be passed on from breathing in the disease from an infected person despite that fact that her sister had obtained a bachelor’s degree from a university:

My sister saw me taking a lot of medications and she started to tell me a story of her colleague who has got AIDS and she said she had to breathe the air from the same room as the AIDS person and therefore she would have contracted AIDS from the that person.

Pensri said that she would not tell anyone outside her own family. She did not mix much with her neighbors but only worked on her own farm. Hence, no one would question her about her illness. She said that she could not anticipate how local people would treat her if she disclosed her HIV status to them. It would be best for her that she kept it secret. Arunee, too, told us that:

I don't tell anyone that I have HIV. I keep it as my secret. I also think that people will not be able to accept the disease. This disease, everyone *rang kiat* it. I know that people *rang kiat* this disease, so I will not tell anyone that I have got it.

It has been suggested that rural people tend to accept PLWHA more than urban people (VanLandingham et al. 2005; Lyttleton et al. 2007). In certain areas in the north of Thailand, almost all families would have someone living with HIV/AIDS, and most people provide certain support, physically, emotionally, and financially. This has not really happened in urban areas like Bangkok. Ajchara lived in an affluent area in Bangkok. She suggested that these people tend to discriminate against people who were seen as socially abnormal and this includes people living with HIV/AIDS. She was afraid that they would *rang kiat* her:

I am afraid that people in my area would see me as a bad woman and that they would *rang kiat* me. People in my area are very different from others. Once they know that someone has got some bad diseases, they would *rang kiat* those people. They are all very rich. So, I am afraid that they might know about me having HIV. Even nowadays, they always ask me what I have done that I am so thin like this. Whenever I go out, they will ask me where I go, and I have to tell them that I go to see a doctor because I have diabetes. I have to lie. For people who have HIV, who dares to tell them the truth! So, I tell people that I have diabetes, but they keep making comments that I am very thin.

Often, women used other less stigmatized illnesses as an explanation of their ill health, as illustrated in Ajchara's narrative. This is a rather common strategy in locations where HIV/AIDS is highly stigmatized. Zhou (2007), for example, shows that PLWHA in China strategically claimed that they had diseases like hepatitis B, tuberculosis, and cancer as a way to cover their HIV/AIDS as the symptoms of these diseases are similar to those of AIDS (see also Chap. 7). Arunee too said that her neighbors kept asking her why she was so thin. She had to say that she was not feeling too well. As she was not a person who likes going out and having fun, rather she tends to stay home and work, people did not continue to question her. Arunee told them that she had problems with her lung and liver.

However, we also found that some women indicated that their local community knew about their HIV status, and they were not discriminated against. They contended that it was dependent on where people live. If it was a small community and people know each other, discrimination might not occur, as people would help each other. But, they also suggested that this might not happen with all smaller communities. Sukhwan's husband was from the north of Thailand. When his conditions became worse, he wished to return to his hometown to die. Sukhwan said most households in his village would have at least one member who had got HIV/AIDS. Hence, people tended to know who had it, and there was no discrimination against them in this village (see Lyttleton 2000; Boer and Emons 2005; VanLandingham et al. 2005).

According to the women in our study, stigma against people living with HIV/AIDS in Thailand has decreased to some extent, and this was due mainly to the media. In recent years, contrary to the campaigns in the last decade or so, the mass media in Thailand have started to present issues relating to HIV/AIDS in a more positive light, as they started to understand the lives of those living with the illness. Daranee, for example, suggested that as many people in Thailand will be likely to have their family members infected with the HIV/AIDS, they are more likely to acquire knowledge about the disease and have a better understanding of the issues.

5 Being Discriminated Against

The physical appearance of many women in our study changed after they were infected with HIV. These changes had a great impact on their lives. Several researchers have pointed to the social meanings located within the bodies of PLWHA (see Sontag 1990; Murphy 1995; Varas-Diaz et al. 2005). The beginning of a bodily change related to the HIV conditions, which often reveals a more deterioration of the illness, as Varas-Diaz and colleagues (2005: 182) have found in their study, brings forth more stigmatization because “people associated these changes with prolonged illnesses and imminent death.” And all too often, job loss is a consequence. Pacharee, for example, had to leave her job due to the changes in her body:

At the beginning of my illness, my face turned black. I did not know about this illness and my husband had already died. I had to work to bring up my two children. But, later on I could not do so because my face was black and I was very thin. I was much thinner than I am now. I was asked to leave my job. When I went to apply for any other job, no one took me in and this had an impact on my children.

Lau and Wong (2001) have shown in Hong Kong that if a person was HIV positive, he or she would be dismissed from work, and coworkers had ungrounded fears and misunderstandings about PLWHA. Similarly, Simbayi and colleagues (2007) have shown that in South Africa, more than 40 % of their respondents experienced discrimination and one in five persons with HIV/AIDS had lost a job because of their HIV status. One woman in our study, Isara, was working in a jewelry shop, and after her employer learned that she had HIV, she was told to leave her job. They were afraid that she would pass on the disease to her customers. Pacharee too was ordered to leave her job as a hairdresser in a town outside Bangkok. She was informed that if the customers knew about her HIV status, her employers might lose their customers. When she applied for a job at other shops in that town, she was told that they did not need any new workers. Eventually, Pacharee had to move to Bangkok where people would not know about her illness:

I was crying because I could not find any job for my survival. So, I made up my mind to move into Bangkok. When I applied for a job at [X], no one wanted to take me in because my physical appearance had changed. They all told me that they did not need any one at the moment. No barbers or hair studios gave me a job. I was living in that town for a long time, they all knew me and so they knew that I had AIDS.

Although nowadays healthcare providers tend to have better attitudes toward PLWHA, some women in our study expressed their views that they were treated negatively by healthcare providers (see Chap. 3 in this volume). As Varas-Diaz et al. (2005) and Lekas et al. (2006) have suggested in their studies, the women maintained that there was still discrimination within the healthcare system. The case of Sinjai presents an interesting aspect about discrimination from healthcare providers in the Thai society. It was from a nurse who worked in a counseling office of the hospital where she learned about her HIV status. She went to have a blood test when she was 7 months pregnant:

After the doctor told me, a nurse called me to go to the counseling office. She said she would give me some advice. But, she spoke negatively about me. She asked me if my husband knew about the illness, and I told her that he did not know as I had just been told about it too, and I was about to go to tell him. I asked if she wanted my husband in the room but she wanted to talk to me first. She asked me what type of person my husband was and I said he is *khon jai ron* [a hot-hearted person who has a tendency to become angry easily]. She said if my husband knew that I was the one who brought the disease into the family, how he would react to this. She implied that it was me who contracted the disease first and passed it on to my husband. She said that if he knew about it, wouldn't he shoot me to dead because I was the one who made him sick. She said I looked so sick and so it must be me who passed on the disease. She said I would be dead three months after giving birth. I would not live that long because I was so sick and I probably passed the disease onto my baby too.

In Sinjai's case, the nurse's attitude was a reflection about how society perceives women living with HIV/AIDS. They still see women as the carriers of HIV infection.

6 Fears of HIV/AIDS in Community

Our data suggest that Thai people still have great fears about HIV/AIDS. Earlier educational programs and advertising campaigns through the media played a major role in creating fears (Lyttleton 2000, 2004; Maneesriwongul et al. 2004). Ironically, this is opposite to the recent information, communication, and education (IEC) programs which have the intention of creating more positive attitudes toward people living with HIV/AIDS in Thailand. The IEC policy aims to promote an environment which is "conducive for the prevention and alleviation of HIV/AIDS" (Aheto and Gbesemete 2005: 36). This policy is aimed to succeed by several means including the media campaigns. As found in the study of Maneesriwongul and colleagues (2004: 31), most caregivers believed that the widespread fear of AIDS in the community was the direct result of the sensationalism of the media. As a result, many Thai people still had great fears about AIDS. Despite the fact that the media has recently started to publish more positive messages, fear of HIV/AIDS contagion continues to be prevalent in local communities. Sinjai, for example, suggested that her parents still have fears about HIV/AIDS although they lived with a person inflicted by HIV:

My parents are still very afraid of AIDS, particularly when they see advertising about AIDS or movies or TV programs or news on AIDS. Whenever they see these, they would take their children and grandchildren to have a blood test... Most people still have negative attitudes toward AIDS.

Deng and others (2007: 1566) showed in their study with the Dai in China that even within the family, the use of separate kitchen utensils was common. The parents did not reject their HIV-infected children, but they still treated them differently, and it was due to the distrust and dislike of the disease (see also Varas-Diaz et al. 2005; Lekas et al. 2006). The women in our study also suggested that in the early part of their illnesses, parents would separate everything from them. Sinjai said that at the beginning of her illness, her mother would keep things separated. Her mother would not share even glasses or plates and often would eat separately from her. Puangthip, too, elaborated on this that:

As most people would not know how we actually get HIV/AIDS, they *rang kiat* women like us. You don't need to look that far. It is my own sister who has already accepted that I have got HIV. She says she does not *rang kiat* me, but she will be very careful about everything as she still thinks she might get it from me, like, when she sleeps, she will get another piece of bed cloth to cover where she sleeps. She is very careful. Even water, she will buy her own... What I mean that even if an educated person like my sister is still like this, what about other people? When they know about my HIV status, they will *rang kiat* me for sure.

7 *Chom Rom* AIDS: PLWHA Support Groups

The rapid spread of HIV and AIDS in Thailand has placed a great burden on the public healthcare system as well as the PLWHA and their families. Governmental, nongovernmental officials, local communities, and the PLWHA themselves have responded to this crisis by establishing PLWHA support groups as an alternative healthcare approach for PLWHA (Del Casino 2001; Lyttleton et al. 2007).

Presently, there is a large number of AIDS support groups existing throughout Thailand. These support groups have been formed particularly to help people living with HIV/AIDS. The main functions of PLWHA support groups include the provision of counseling and educational campaigns and making home visits to PLWHA. The establishment of PLWHA support groups in the community has been increasingly accepted by people in the community (Im-em and Suwannarat 2002). However, Lyttleton (2004) suggests that HIV/AIDS support groups are formed as an attempt by PLWHA to defend their HIV/AIDS status. The formation of these support groups, Lyttleton and others (2007: S46) contend, accommodates "social normalization of HIV infection by creating the social platform and moral support for public disclosure of HIV status." PLWHA support groups are the most salient exemplar of a collective identity emanating from the epidemic of HIV and AIDS in Thailand (Lyttleton 2004).

The first AIDS support group, known as the "Wednesday Friends Club" (WFC), was set up in Bangkok at the Thai Red Cross Anonymous Clinic in 1990. By early

2002, more than 400 support groups for PLWHA in Thailand have emerged (Lyttleton 2004). Most are community based. In 2003, the Family Health International (Kubotani and Engstrom 2005) indicated that there were 465 support groups in Thailand. And by early 2006, there were 920 groups (Lyttleton et al. 2007). Most of these support groups operate in northern Thailand, the region which is hit heavily by the AIDS epidemic. According to Lyttleton and colleagues (2007), in central Thailand and mostly in Bangkok, there were 89 groups in 2005. Many groups meet at local hospitals, while others at NGO offices, and some assemble in rented houses or the homes of members. The Thai government, as well as foreign donors, encourages and supports regular meetings. They tend to be organized by local health authorities and/or NGOs, who provide administration and some medical assistance (Smitaketarin and Paowanaporn 2000). Some groups meet weekly, but most groups meet monthly. The activities and atmosphere in the group meetings may range from informal group functions to formal training and educational sessions (Lyttleton 2004).

Similarly, in the northern region of Thailand, Chiang Mai province, PLWHA, NGOs, and government health agencies have established PLWHA support groups. These have created new social support structures for PLWHA. The groups meet often to discuss health-related issues. They meet in a number of locations, including government healthcare settings such as hospitals and health stations and local community sites (e.g., temples or the homes of PLWHA or community activists) (Del Casino 2001).

Although there have been some obstacles for PLWHA to participate in community groups, most PLWHA continue to meet and support each other. They share their lived experiences as PLWHA. According to Smitaketarin and Paowanaporn (2000), lack of adequate funding and deteriorating health prevent members from participating. Location and distance of groups and too few government and NGO supporting organizations also deter many PLWHA participating in support group activities.

Smitaketarin and Paowanaporn (2000) point out that PLWHA support groups initiated by government health facilities tend to be located in local hospitals and this accounts for half of all PLWHA groups in Thailand. Lyttleton and colleagues have also recently revealed this (2007). Our study indicated that many hospitals in Bangkok and surrounding provinces organized HIV/AIDS support groups where PLWHA were able to join. The women in our study referred to these groups as *chom rom* AIDS (AIDS clubs). Most groups would meet monthly, and the hospital staff would organize some activities on the day, which tended to run for the whole day. In the PLWHA support group that we participated in Bangkok, each one who joined the activities of the day received a government compensation of about 100 Thai baht. However, this did not apply to all groups, as some groups do not receive any compensation but may be given compensation for transportation costs. Activities of PLWHA groups that Lyttleton (2004) has observed covered immediate personal assistance, collective treatment strategies, and activities with support community functions (including health promotion initiative and public parades on World AIDS Day). The support groups in which we

have taken part during the fieldwork of this study included similar activities to that Lyttleton witnessed and included relaxation activities (yoga and meditation), games, information relating to HIV/AIDS and treatments, and the provision of haircuts to members (and these included healthcare providers who participated on the days and us as researchers). One group that we took part in also provided free lunch prepared by a family of one HIV-positive woman. Some groups also included information about drug trials and new drugs and also some government initiatives.

Lyttleton (2004: 3) points out that, in reality, anyone living with HIV should be able to join PLWHA groups in Thailand. But in practise, not everyone does so. There are many reasons for this including personal disinclination, practical constraints, lack of family support, and the financial assistance. This is also true with the women in our study. Some did not join in support groups because they did not have enough time to do so, as they had to work. Others were not interested in doing so. And there were those who could not leave the children with anyone else. But, most women would join in. There were many reasons for this as we set out below.

7.1 *Gaining Knowledge and Assistance*

Commonly, when the women were asked what benefit they received from joining the group, most would refer to knowledge they gained from joining. Niramol, for example, said that:

Before I join this *chom rom*, I did not understand much about HIV/AIDS. I only knew that we can get HIV/AIDS from having sexual intercourse and so each time we have sex, we must use condoms. If a mother has HIV/AIDS, she cannot breastfeed her baby... But, after I had my baby and have joined this *chom rom*, I have gained a lot of knowledge about HIV/AIDS. Now, I know a lot about this disease.

It is typical for most *chom roms* to have their names reflect their life and what they hope to have. For example, a woman living with HIV/AIDS set up her own support group, and she named it as the “Life With Hope Group.” The name “Life With Hope” was used to pronounce that people living with HIV/AIDS have the same hopes and dreams as others who are not HIV positive (Chomsookprakit 2008). Pensri joined in a club called *Chom Rom Arom Dee* (the Good Mood Club). She often received some dried food when going to the club. The club also organized several activities such as fund raising, information about illnesses and illness management, health-care card (30 Baht HealthCare program), and/or even some social and political activities around Bangkok. In a way, the club acts as a social network for the women (and anyone living with HIV/AIDS) (Lyttleton 2004; Kubotani and Engstrom 2005; Chomsookprakit 2008).

7.2 Puag Diew Kan: *Sense of Belonging*

Lyttleton (2004: 3) suggests that joining a support group is the means that PLWHA obtain knowledge and use it to deal with their “personal and social disadvantage.” Becoming a member of PLWHA support groups is a form of belonging, and it is a strategy that the women use as a means to deal with their HIV status. The main argument of Lyttleton (2004: 7) is that belonging to an HIV/AIDS support group “takes specifically mandated forms to reverse the shame and stigma associated with HIV infection.” Joining HIV/AIDS support groups may, on the one hand, pose the danger of making oneself known to others in a wider community, which in turn, may make oneself vulnerable to stigma and discrimination. On the other hand, a group member “functions as an active rebuttal of the stigma widely directed at those with HIV” (Lyttleton 2004: 3). Collectively, a support group is a means that the women employed to fight against stigma and discrimination that they may feel or experience in the society.

Most women also suggested that there was an opportunity to meet other people who were in the same situation as them (Davison et al. 2000). For Kanokwan, joining an HIV/AIDS group allowed her to be able to talk to people who have similar experiences whom she referred to as “our group of people” (*puag diew kan*) (cf. Lyttleton 2004 for Thai women who suggest belonging to the same bloodline (*sai luat deaw gan*) for those who join PLWHA support groups). Belonging to the same group of people, she felt that she could make jokes and tease others in the group without fear of offending them. It also made her feel *sabai jai* (feeling relief) about living with HIV/AIDS.

Most women who joined PLWHA support groups would regard others, particularly those whom they had met for a period of time, as their real friends (cf. Lyttleton 2004). They also suggested that the group helped to reduce the sense of isolation that most women living with which HIV/AIDS had to deal. Naree suggested that she was able to have time to chat with other friends by coming to the group activities. This again helped her not to feel too isolated. And for Pensri:

I feel that coming to a group allows me to meet my friends. I feel so good when I see that everyone in the group is still alive. We have fun, and we laugh and do things together. I feel good and happy when I come to the group. Coming to the group and seeing many others who have the disease like me makes me feel that I am not the only person who lives with HIV in this world.

As we have suggested earlier that not all HIV-positive women joined *chom rom*, but we also found that women would try their best to attend group activities. Naree also suggested that the group activity was a positive thing for her. Although she could not attend all group activities, she would try to attend as often as she could.

Joining the group helps me to have more knowledge about the disease and other things. If I only continue to sell things in the shop like this, I would not be able to see or know anything and hence I would not have any knowledge about it. Because I join the group, I know a lot more about new information about the illness, disease and others, as the group leader tends to find new information for us.

Kesaree too told us that she never missed any group activity. This is what she said:

The group is very important for me and I never miss one. What we don't know, we will learn in this group activity. Like, some people don't want to wash their clothes with others in the family because they are afraid that they might infect others. There was one person talked about this thing at the group, and that helps to clarify our beliefs. Sometimes we know but we do not feel confident enough, and when someone comes and tells us the correct information, it helps a lot. Whenever they have a speaker talking about HIV/AIDS issues, there will be lot of people in the group asking questions and this improves our knowledge of our health status.

7.3 Kam Lang Jai: *Emotional Support*

Due to the issue of disclosure and social acceptance, most PLWHA tend to seek emotional support from people who share similar conditions such as other PLWHA, rather than close friends and family (Mak et al. 2007: 1557; Davison et al. 2000). Belonging to a support group allows PLWHA to access more emotional support from their peers. In our study, PLWHA support groups provided emotional support to many women. As we have said above, Kanokwan felt *sabai jai* (relief) after joining an HIV/AIDS group as it allowed her to be able to talk to *puag diew kan* (people who have similar experiences) (see Davison et al. 2000). Learning more about others in the group also made women emotionally stronger about their HIV status. Wasana had this to say:

Joining the group activity is good as I can meet many of my friends there. Everyone in the group looks good [no negative physical appearances], and this makes me to have more *kam lang jai* (emotional strength) that it is not only me who has got this disease in the world.

Arunee joined a group activity in her local area outside Bangkok:

Joining the group helps me to meet other friends. If someone is not well or something happens to a person, we would all know. We talk and share information. There are many people who join the group so I can meet others. It makes me realize that I am not the only person who lives like this. X [the group leader] is also supportive and keeps telling me not to *khit mak* [worry too much] about my illness, and I should look after my mind [emotional well-being].

For Wasana, whenever she joined the group, it was difficult for her to leave as she enjoyed hearing different life stories from the members which not only helped her to understand the life of other women who are living with HIV but it was also fun, and this has helped her to deal with her emotional health better.

Puangthip was going to abort her baby when she learned that she had HIV/AIDS as she thought that she would pass HIV to her baby and she would not live long afterward. However, after joining the group, she learned that it was not necessary to be the case. This helped her to keep her baby. And again this helped her with emotional strength.

I think joining the group is very good. It helps people with emotional support (*hai kam lang jai*) and so we have more emotional strength. At first, I thought my baby would have HIV too, so I thought I would get it out [abort]. I also thought I would not live very long. But, when I join the group, outreach workers gave me a lot of emotional support and they told me that the chance of my baby getting HIV/AIDS is smaller than before. So, I decided to keep the baby.

8 Home Visit and Local Group: Still Some Stigma and Resistance

One main aim of support group functions is to provide a home visit for PLWHA (Im-em and Suwannarat 2002). But, this may not be acceptable to many women. What is interesting about the findings of our study is the fact that most women did not wish to have any home visits by outreach workers from AIDS support groups, hospitals, or other health settings. Arunee, for example, said that the group leader that she attended wanted to make a home visit, but:

I told him that it was inconvenient for him to visit me at home. If he comes to see me at home, my neighbors would start asking me about him. Who is he and why does he pay me a visit? As not too many in my local area have visitors, people might even become frightened about a stranger too. But if I go out, they might say do you have an appointment with a doctor? And I don't have to lie about it.

Additionally, we found that some women would not attend groups closer to their homes or in local areas for fear of being known that they were HIV-positive. For these women, they prepared to travel to another area to join groups. Puangchompoo, for example, would not attend local HIV/AIDS group but would go to the group in another suburb.

I would not go the group in my area, only if I really needed to go. I go to another group in Bangkok. I go every month. It is far from my home, but I can meet my friends there. It is better than staying by yourself as we can exchange information and we can obtain more knowledge and we know about the advance of HIV-related stuff.

As Del Casino (2001: 415) has shown in his study in Chiang Mai, PLWHA are cautious about where they will attend support groups. Attending some meeting sites may invoke discrimination. For example, walking into a health station for a PLWHA support group meeting is like announcing one's HIV-positive status to others in the local community. Sometimes, PLWHA prefer to meet in sites which are away from their residence or formal public healthcare spaces. Both Del Casino (2001) and Lyttleton (2004) suggest that more women join and participate in PLWHA groups than men. Both contend that PLWHA support groups in Thailand are gender focused. Although our study focused on women only, we also observed this. Our participation in PLWHA groups both in Bangkok and its vicinity revealed this pattern. More women living with HIV/AIDS turned up at group meetings than men. The men who actually participated came because their wives requested or asked them to come along.

9 Conclusion

Despite the fact that Thailand has a progressive national approach to deal with HIV/AIDS, the stigma of HIV/AIDS and the fear of the infection remains. We have thus far suggested that stigma and discrimination toward PLWHA in Thailand still exists, although it was not as marked as others have found earlier. Thai people, even family members of the women in our study, still have fears about HIV/AIDS. This fear, as Lyttleton (2000: 224) contends, is created by the AIDS campaigns in the nation. Although the initial mass media campaigns in Thailand acted as an “effective buffer against high rates of transmission,” the campaigns have also created fear of AIDS among Thai people. The aggressive campaigns have created a continuing sense of stigma that Thai people attach to HIV/AIDS (Busza 2001; Lyttleton 2000, 2004). Although in some parts of Thailand, such as the North and in rural areas, there is more local acceptance due to the commonplace presence of HIV and AIDS (Im-em and Suwannarat 2002; Lyttleton 2004; VanLandingham et al. 2005), PLWHA are still rejected even by their family and close kin and more so among others in community (Lyttleton 2004; see also Songwathana and Manderson 2001; Maneesriwongul et al. 2004; Sringeriyuang et al. 2005; Apinundecha et al. 2007). The advancement of HIV treatments, such as ARV, has prolonged the life of many PLWHA as well as reduced AIDS to a manageable chronic condition (Lyttleton et al. 2007). But, this has also increased the disclosure of HIV/AIDS, and many PLWHA are opened to stigma and discrimination in community (Apinundecha et al. 2007; Liamputtong et al. 2012).

As Im-em and Suwannarat (2002) have pointed out that community attitudes toward PLWHA in Thailand are mixed our data also suggest that there is a variation in how the women are perceived by the community. Some women do feel stigmatized, but not all feel that way. Some women express positive attitudes from the community. Following Goffman (1963) and Mechanic (1995), VanLandingham and colleagues (2005: 407) suggest that community reaction to PLWHA is “complex, dynamic, and dependent on both the context and the observer” (see chapters in Part I of this volume). This may account for the fact that different studies reveal different pictures in Thailand as we have indicated in our study.

Due to stigma and discrimination, PLWHA attempt to find strategies to deal with or to fight against it. In this study, we contend that joining AIDS support groups was used by the women as a strategy to counteract stigma of their conditions and lives in Thai society. As Lyttleton and colleagues (2007: S49) contend, PLWHA support groups act as “a panacea for stigma and alienation”; hence, it is not too surprising to see many women in our study join and participate in group activities regardless of their physical conditions.

Lyttleton (2004: 11–12) theorizes that PLWHA individuals join support groups for several reasons. First, support groups lend critical assistance for PLWHA including educational, material, and emotional assistance. More importantly, however, support groups “challenge social discrimination” by allowing the

members with a very specific means of “being publicly positive.” This in turn enables the PLWHA to “reposition his/her life and to refashion a subjective sense of self.” When individuals join a support group, they disclose their HIV status. But, they also enter “a forum that offers the potential to reformulate a sense of “worth” that has been categorically devalued by mainstream associations with HIV in Thailand.” Precisely, a critical function of PLWHA support groups is “their ability to convert the shame induced by social discrimination into a more positive sense of self-identity.”

Our study supports Lyttleton’s suggestion (2004). Support groups offer women more knowledge about the illness and how to deal with it better. Foucault (1980) posits that with more knowledge, individuals feel that they have more power to deal with their situations. This is echoed in our study. Support groups also provide women with a sense of belonging. Women get to know more about others who are in the same situation as themselves. By joining the group, it makes them realize that they are not alone in the lonely world of living with HIV/AIDS. With more knowledge and with the sense of belonging, support groups offer the women emotional strength to deal with stigma and conditions. We contend that joining support groups creates collective power for all women, and this collective power allows the women to defend their conditions and deal with their self in a more positive light.

As Parker and Aggleton (2003: 21) suggest, the most powerful way to fight against stigma and discrimination of HIV/AIDS occurs when the communities are able to mobilize themselves to do so. Several studies have clearly demonstrated the empowerment and social mobilization in response to HIV/AIDS in societies (see Daniel and Parker 1993; Altman 1994; Epstein 1996; Parker 1996). Parker and Aggleton (2003) advocate that it is time for us to begin thinking more seriously about using new models for advocacy and social change in our response to HIV and AIDS-related stigma and discrimination, and building community strength is one of these models. The development of PLWHA support groups that we have articulated in this chapter is a good example of community strength.

This study contributes to our understanding of the construction of HIV/AIDS stigma and discrimination as well as the means that affected individuals can employ to deal with stigma and discrimination in Thailand. We contend that such knowledge will help to develop more responsive and effective strategies in order to reduce or even eradicate stigma and discrimination at personal, community, and national levels.

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