

ORIGINAL ARTICLE

Experiences of Living with HIV: Social Stigma and Discrimination among HIV-Positive Mothers in Southern Thailand

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ABSTRACT

Introduction: This paper discusses the lived experience of mothers living with HIV/AIDS in the southern region of Thailand. **Methods:** We employed semi-structured interviewing and drawing method with 30 HIV-positive mothers. Thematic analysis method was used to analyse the data. **Results:** Most mothers living with HIV found their HIV status through a blood test service at the Antenatal Care Clinic of local hospitals while some visited the doctors because their partner showed severe symptoms of illness. When they learnt about the infection, they experienced a great shock and feared that illness would be disclosed to others in the community. The women were concerned about keeping HIV secret because they would be blamed by people in locality, labeled as “disgusting” people, and excluded from social networks. Nevertheless, we found that social support played a crucial role in assisting these mothers to cope with their HIV status. Religious beliefs and living positively also helped them to deal with their health conditions. **Conclusion:** Health care providers should design sensitive programs to promote self-confidence for HIV-positive mothers as this could increase their quality of life. The findings revealed that tangible and emotional support from family members and religious sources, as well as positive thinking, played a significant role in supporting these women to deal with their health and well-being, and negative effect associated with their HIV condition. These can be incorporated into the provision of health care, which would enhance their well-being and reduce the feeling of isolation and discrimination among these vulnerable women.

Keywords: HIV-positive mothers, Social stigma and discrimination, Lived experience, Social support, Rural community Thailand

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INTRODUCTION

Evidence suggests that a discriminatory attitude towards HIV-positive individuals has declined slowly but this has not been consistent across countries or between genders (1). Reports surveying stigma towards people infected by HIV found that they were still denied public services and facilities to meet their needs (2). Social stigma and discrimination can create a marked impact on life of people with HIV/AIDS (3, 4). Thornicroft & colleagues (5) contend that “a marks or signs of disgrace usually eliciting negative attitudes to its bearer” are common (p. 192). Not only do individuals with HIV/AIDS face physical hardships, they also encounter psychological and social burdens resulting from social stigma and discrimination (6).

Stigma can occur when society labels a person as deviant and hence undesirable. Stigma, as theorised by Goffman (7), results in the “spoiled identity” of the individual

and it can lead to feelings of loss and uncertainty. This situation increases the stress associated with illness which leads to psychological and social morbidity. Social stigma may threaten individuals’ social life and economic opportunities, and can affect the lives of stigmatised people (3, 4, 8). The literature suggests that HIV-positive individuals have to cope with many challenges resulting from various emotional burdens, including: loss, anxiety, fear, despair, and social stigmatisation (4, 8).

It has been theorised that social support can be a buffer against adversity in people’s lives (1, 9). According to Bloom et al. (10), social support comprises two aspects: structural support and functional support. Structural support refers to the network of relationships which is in place between individuals and others including relatives, friends, and neighbours. Functional support comprises tangible assistance, emotional support and the availability of information (10). Tangible support refers to the specific assistance that other people provide to the individuals: financial assistance, household chores, childcare, or the provision of transport to places. Emotional support includes messages that signify the care, love, and value of individuals (11, 12). Informational

support means the knowledge provided is appropriate with the situation the individual is encountering (10).

Cohen and associates (13) stated that each type of social support plays different roles in meeting the needs of individuals. It can be obtained from varied sources and may become essentially important at the different stages of the person's illness. Landmark and colleagues (14) point out that typical sources of social support a person may have included family members, close friends, peers and health care professionals.

There have been a number of studies conducted on stigma and discrimination among HIV-positive individuals in different countries (1, 3, 4, 6). However, only a few researchers have focused on examining the lived experience of stigma and discrimination with Thai women in Thailand (15-17). Thus far, there has been no current research that reports on the lived experience of HIV-positive mothers in rural communities, southern Thailand (18). In this paper, we will demonstrate the lived experiences and social support that play a crucial role in helping HIV-positive mothers to cope with the stigma and discrimination they experienced in their community contexts.

MATERIALS AND METHODS

Study design

This study employed a qualitative approach to understand the lived experience of HIV-positive mothers (19). We combined two methods in this investigation, thus expecting to gain insight into the lived experience of HIV-positive mothers in rural communities, southern Thailand: semi-structured in-depth conversation and drawing method (20). We conducted a semi-structured in-depth conversation with each participant at times and places that best suited them. Each interview was carried out between one and two hours. They were asked several open-ended questions created through the review of the literature and our research objectives, including: 1) How do you see HIV/AIDS? 2) How does it affect your life? and 3) How do you manage with difficulties resulting from living with HIV? The conversations were communicated in the southern Thai dialect to enable the women to express their views and meaning with ease (20). The researchers are southern Thai who can converse with the participants in a local dialect. All interviews were recorded digitally for data analysis. The study was conducted in 2017.

Participants

We purposively invited 30 women who could provide rich data relevant to the study purposes (21). The participant criteria were: 1) mothers who were HIV-positive and living in southern Thailand; 2) HIV-positive mothers who has a child aged under five years; and 3) they were willing to share their lived experiences of living with HIV. The participant exclusion criteria

were: 1) HIV- positive mothers with comorbidity, and 2) those who moved to other communities during the data collection phase. 30 mothers living with HIV and aged between 19 and 46 years participated in this study. Nearly half had been living with HIV/AIDS between 6 and 14 years. 26 out of 30 were married whereas three were widowed and one a divorce mother. Amongst them, most had remarried because their husband passed away from AIDS. However, we found no HIV infection among these husbands because they learned how to prevent HIV transmission by using condom. Also it was because these mothers undertook HIV prevention and treatments which could reduce the chance of transmission to their husbands. Their educational profiled varied from primary to secondary levels. The monthly income ranged from 900-12,000 Thai baht. The number of children they had was between one and four with the youngest being one month and the oldest 18 years old.

Data collection method

This study was approved by the Thaksin University Ethic Committees, Thailand, prior to data collection (E 006/2558). Before the interviews, the participants were offered a full explanation of the study background, the length of interviewing time and the scope of questions we asked. They were then asked to sign a formal consent form. We introduced the drawing method after the interview had finished to assist the participants to visually express their feelings and meanings of their lived experiences. This visual imagery method has become known widely with vulnerable people and about sensitive issues (19, 22). Individual participants were provided with 48 coloured pens and drawing papers for this session. They were asked to draw and describe images about meaning of HIV/AIDS, how it affected their lives and how they managed the difficulties they encountered. Their narratives relating to the drawings were recorded digitally.

Data analysis

We used the thematic analysis method to analyse the data (19). First, we analysed the data through the process of coding, which involved reading carefully, line by line, to identify the underlying meanings that we could construct in each participant's transcript. Once the initial codes were identified, axial coding was undertaken to identify several main themes. Later, we integrated the main themes to form the concepts that could answer our research aims. The themes were revised a number of times to represent the experiences of the study participants. To present the findings, we use a fictitious name when referring to the individual participants to ensure their anonymity.

RESULTS

Several themes were constructed from the data analysis and they are illustrated in the following sections.

Being labeled with HIV

Most participants learnt about their HIV status during their period of pregnancy. All the pregnant women were required to attend antenatal care at health care centers and were tested by health care professionals as part of the antenatal care service. Some decided to visit the hospital to seek a blood test when they noticed that their husband became chronically ill without obvious causes, or a sudden death of the husband occurred.

All participants stated that they could not accept being labeled as a HIV infected woman. They described their overwhelming anxiety and uncertainty about their future lives. HIV was perceived to be a life threatening and a frightening disease that involved a high level of stress. HIV was seen as an alien and a killer. Lahn described her perception of HIV as alien through a drawing as shown in Figure 1.



Figure 1: HIV as alien

Most often, the emotional reaction to their HIV status was expressed as a moment of shock and it was very difficult for them to accept. They believed that they would encounter many losses and difficulties for the rest of their life, especially with the long-term treatment and its negative side-effects. This included the social consequences of being HIV positive. Somsri elaborated:

"...[I] was shocked ... feeling stuck, confused and overwhelmed ... [I] don't have anything left in my life ... I have no hope, ... to be alone. I hate this word... whenever I heard [it], I felt like a knife was stabbing into my heart".

The participants indicated that HIV ruined their entire lives because such a disease was not only incurable, but it also stigmatised. People in the community would not accept or even talk to a person who was living with HIV. HIV-positive individuals had to face physical, mental, and social suffering. All participants thought about death after being diagnosed with HIV/AIDS. One participant, Malai, shared her story after being diagnosed with HIV:

"[I] thought of walking to the street to be killed ...but [I'm] afraid [to do so]. I walked along the street and cried

... [I] cannot change anything ... [I] don't know what to do next ... [I] want to commit suicide ... HIV is a death disease and no cure. It is something like a thunderbolt ... [I] never thought ... still questioning if this is true ... is it real ... am I really infected? It remains in my deep heart all the times".

Songkean expressed a similar idea about HIV through her drawing (Figure 2).



Figure 2: HIV as a killer

Effect on our life: Disclosure, stigma and discrimination

All participants were cautious about disclosing their HIV infection to anyone. They would make known to their health care providers and physicians treating them. For one third of the women, only their husbands knew about their HIV status. A few disclosed it to the one family member they trusted, which was usually their mother. They were fearful that if their HIV status was disclosed to a broader community, they would be labeled and blamed as poo ying mai dee or poo ying sam-son (a shameless woman). A bad woman in Thai society would be seen as a woman who has many partners and a night woman who works in clubs and bars. Often this would result in discrimination.

"[I] was so worried... [I'm] afraid if friends will know... it is shaming. When I applied for a job, I was asked for a medical certificate ... I then did not go for it. I feared that others would know my HIV status. No one should know about it. I separated myself from others ...".

HIV not only caused stigma, bringing painful consequences for a mother living with HIV, it also had impacts on their family members. All HIV-positive mothers were anxious regarding the impact of their HIV condition on their child. They feared that if their health status was known to the public, their own family members and children would face discrimination. Many tried to separate themselves from community and social networks, expecting to conceal the HIV status. Pang told us her negative experience of being a HIV-positive

mother:

“At the beginning, [I] could not tumjai (accept) when my neighbor treated us badly. My kids went to their home, but they did not allow my kid to go in their house. They said to my kid that “you go back to your house ... don’t come to my house again. You will bring bad disease here ... go ...”.

Sopee experienced discrimination from her neighbor because they suspected that she was a HIV-positive mother. She illustrated such negative experience by saying she was seen as a kind of alien or a bad germ. No one would stay close to her (Figure 3).



Figure 3: HIV as bad germ and isolation

There were some physical signs of HIV whereby most people would recognise signs of being an HIV infected person. A person with HIV would show symptoms such as body rashes and bumps, rapid weight loss, darker skin, and being pale. This was illustrated in Flow’s drawing (Figure 4).

These symptoms created shameful feelings on the part of the infected person:

“This disease causes skin rashes [on] the body. Other people will know if I am an HIV-infected person. It is a noticeable symptom and it makes me very shameful...”.

Many participants who had not yet experienced bodily changes showed their worry and fear that resulted from these symptoms. They imagined that they might soon develop the symptoms of HIV: rash, frailty, mouth ulcers, and lesions. Many participants did not want their children to see the changes and their body markings. Often, they isolated themselves from their children.

“I don’t want my children to see me like this... dark skin, frail, skin rashes and very thin...I feel very sad for her. I cannot accept it. I just stay in my room”.

For many participants, their bodies had changed due to the side effects of antiretroviral drugs (ARV). These women thought that they did not look like a woman, but



Figure 4: Noticeable signs of HIV

more like an alien. They could not dress up like other women. Most experienced decreased self-confidence and could not lead a normal life. Physical changes resulted in stigma and discrimination towards many women in our study.

“I cannot go out at all... [I] stay home only. I was too thin...I have a thin cheek and leg...no buttock. I have lesion and scar on my body. My top part of body is bigger than lower part, fat moved to other parts. People will stare at me...”.

Social support: Dealing with social stigma and discrimination

Despite living with a stigmatising illness, the participants attempted to deal with their situation as best as possible. One important factor that encouraged these women to stay strong was the support they received from their children and husbands. Their children and husbands provided support during diagnosis and throughout the stages of treatment. They shared responsibilities and provided good care when they encountered emotional and physical problems. This helped to raise their hopes and allowed them to cope with the disease better. Songkean described the support she received from her child:

“I was very happy that my kids were concerned about my illness. The older one always prepares medicine for me. He knows how many tablets I have to take. For the younger one, just a kindergarten kid, when he saw me taking tablets, he then remembers how many tablets I

have to take and prepares medicine for me too”.

Religious support was also crucial for the participants to deal with HIV and its burdens. Buddhist beliefs played a crucial part in reducing emotional sufferings among these mothers. Many mothers made more merits while some opted to go for meditation practices. Meditation practice was a common practice to relieve the feeling of loss, grief, and despair. They would do this in their daily lives as these practices are perceived to be factors that help them to be strong and to have a peaceful life.

We found that many participants tried to change their thinking about their HIV status and lives. Positive thinking about the disease helped to relieve the burdens they were encountering. From their experiences, a HIV-positive person could live longer than many chronically ill people because of advanced medical intervention. Many paid attention to self-care and adhered to medical advice, thus hoping to lead a healthy life. Common practices that most HIV-positive mothers in this study followed included eating healthy food, doing exercise, and adhering to medication regimes.

They also believed that stigma and discrimination currently less. The women pointed out that some HIV-positive people received more work opportunities and contributed to society. They stated that health policy continually promoted positive information about people with HIV all over the country, and access to health information was also easier. This allowed them to have a better understanding about the disease and how it was transmitted. Jai remarked:

“It is not that scary like before because [they] have better medicines. People do not die soon like in the past. They have better drugs...in the past, an HIV person looked horrible and disgusting. Nowadays, it is not like that anymore...”.

Nevertheless, it was interesting to see that the participants still would not want anyone to know that they were HIV-positive. Disclosure was still a major concern among the mothers with HIV participating in this study.

DISCUSSION

Our study revealed that all women took part in this study felt shock and fear when they knew they had become HIV positive. This condition destroyed their hopes and futures because HIV infection is considered as life-threatening disease, and it brings stigma upon individuals and their families. In the study conducted by Sanders (23) in the United States, the women in her study had different reactions on hearing they were diagnosed with HIV. All recalled their feelings of psychological distress and that it could have a long-term emotional effect. For some women, this diagnosis was unexpected because they had not undertaken risky behavior. All participants

who took part in the study stated that being diagnosed with HIV was a life-altering experience. Being diagnosed with HIV certainly led them to feel stigmatised. Research conducted with Thai women from central Thailand (15) indicated that after their HIV-positive results were confirmed, they feared that they would die even sooner than later.

Apart from this, being stigmatised and despised by others was unpleasant to experience. Mosack et al. (24) pointed out that HIV is a life-threatening illness which brings about the physical and emotional disruption of individuals. The emotional burdens were not only experienced by the individuals who were HIV-positive, but also by their family members and social networks. The study by Paudel & Baral (1) showed that being diagnosed with HIV was received with fear. People anticipated the burden of disclosure and perceived that these psychological consequences would shorten their lives.

Social stigma is described as an undesirable attribute reducing the status of an individual in the view of society (3, 7, 25). Our study confirms that being diagnosed with HIV creates both stigma and discrimination for individuals as well as their families (1, 6). This effect still remains a public health issue in the south of Thailand. As a result, most HIV-positive women have attempted to conceal their status because of the fear of being rejected and discriminated against (8). Non-disclosure is a major concern among all the women in this study due to their fear of stigmatisation and discrimination (1, 4). Their lives were affected by the ways they attempted to hide their HIV status. They tried their best to keep their HIV status secret in order to avoid negative reactions from community members. This finding is congruent with those studies in various contexts where stigma is very high when the status of individuals with HIV/AIDS is disclosed to public (1, 4, 6, 15).

Stigmatisation brings negative effects to the lives of individuals in many ways (3, 26). It could, for instance, destroy personal relationships, exclude or separate individuals from their social networks, lead to rejection by family members, bring on financial hardships, lead to discrimination at work, and undermine the role and potential of individuals (3, 4, 27-29). The women in our study experienced these negative effects. Some were forced to leave their home town and were excluded from community membership. They also isolated themselves from others to avoid stigma, and this reduced their social connections within the community. Asby et al. (26) confirmed that the fear of stigma resulting from the disclosure of their HIV status was a dreaded feeling among African-American mothers living with HIV.

Although the participants in our study had to manage with emotional challenges and difficulties, there were some coping means that assisted them to improve their quality of life. Social support provided by their family

members, children and husbands, played an important part in helping the women to cope with the disease and its associated stigma. Mason et al. (30) found this in their study. Social support strengthened the bonds between individuals and this could help people coping with HIV to live a better life. The study conducted by Dyer et al. (9) in the Los Angeles Region confirmed that social support can lessen depression among mothers living with HIV. This supportive factor allowed them to fulfill their roles as mothers. Paudel & Baral (1) suggested that social support should be made available to vulnerable people with HIV/AIDS as it plays a critical role in reducing difficulties and the sufferings that individuals are facing to better further their well-being.

Religious and emotional support acted as a support for the participants in our study to deal with their HIV status. In response to their fear and anxiety, all tried to accept the diagnosis and to deal with the reality of their condition. Thus, they used their religious beliefs and practices as coping strategies. Such practice could help reduce the isolation and lack of psychosocial and emotional support experienced by these vulnerable mothers. The authors (15), demonstrated this in their study of HIV mothers in central Thailand. These women followed Buddha's religious practices by performing good deeds and making merit to reduce their suffering and achieve a better life. Buddhism professes the belief that if one keeps on doing good deeds in the present world, the individual can gain merit to enable her to be better off both in this life and the next. This is in line with the study among African-American mothers living with HIV/AIDS (26). It found that religion was a key factor that helped to enhance an individuals' ability to cope in order to endure the stress associating with HIV status. Religion is recognised as an emotional resource that buffers negative effects resulting from depressed feelings and helps them fulfill their responsibilities and roles.

The participants attempted to maintain their wellbeing and lead normal lives. They adopted common strategies as a way to cope with the negative impact of HIV on their lives. These included taking care of their health and thinking positively about their lives. Such practices are situated within the discourse of 'living positively' which encourages the individual to combat HIV infection and boost self-fulfillment (15, 31). According to Levy & Storeng (29 p. 56), living positively creates "a sense of optimism about combating the HIV epidemic" among people who are HIV positive. Living positively can assist the mothers in our study to deal better with hardship and their threatening health status.

Thus, HIV/AIDS is a feared disease. It creates stigma and discrimination for those who are infected. Whilst such stigma and discrimination are decreasing, all mothers living with HIV in our study did not want to take the risk of being identified. They attempted to keep their HIV status a secret because of their fear of being discovered

and identified as a person who is HIV positive.

CONCLUSION

HIV-positive women experience varied life threatening situations; these include physical, psychological and social burdens. They thus need intensive support and good understanding about their circumstances and contexts on the part of community members and health care providers. Our study revealed that social support from family members and religious sources, as well as positive thinking, played a salient role in supporting these women to deal with their health and well-being, and negative effect associated with their HIV condition. Health care programs that incorporated these types of social support need to be implemented as it would help to enhance self-confidence and hope among these HIV-positive women.

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