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Investigating the role of stigma on fertility desire among HIV-positive women in Bangkok, Thailand: a qualitative study

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Abstract

Objectives: The Thai Ministry of Public Health is committed to reaching the United Nations' goal of zero new HIV infections, zero AIDS-related deaths, and zero discrimination towards people living with HIV by 2030. While significant progress has been made towards the first two targets, stigma against women living with HIV (WLHIV), particularly in the context of their desire to have and raise children, remains an issue.

Methods: We conducted interviews with WLHIV (n=10) who expressed a desire to have a child or delivered an infant within 2 years of the study date, and key informants (KI) involved in their medical care and social support. We asked women about their HIV diagnosis, thoughts about pregnancy, desires to have children, and perceived stigma. KIs were asked about their perceptions of stigma towards WLHIV and policies or recommended actions to reduce discrimination towards this population.

Results: While the WLHIV reported that their healthcare providers had generally been supportive of them having children, internalised stigma and the perceived risk of or actual discrimination by community members negatively impacted fertility desire and peripartum experiences among the study participants. KIs confirmed similar sources of discrimination, emphasising more internalised and community-based stigma rather than from healthcare providers. Both groups highlighted the importance of increasing community education and awareness about HIV to reduce stigma.

Conclusions: Complex issues around stigma and discrimination specific to women with HIV should be addressed at the community level in order to reach the goal of zero discrimination against all people living with HIV in Thailand.

Keywords: HIV, women, fertility desire, stigma, Thailand

Introduction

There are 36.7 million people living with HIV worldwide [1]. Globally, HIV is the leading cause of death for women of reproductive age [2]. In 2015, this population made up half of all persons living with HIV (PLHIV) [3,4]. More than 2 million pregnancies occur among women with HIV every year [5]. However, access to treatment can be compromised for women who want to become pregnant or are in the process of having children due to stigma and discrimination from their healthcare providers and communities [6,7]. Thailand reported the fastest initial spread of HIV in the Asia-Pacific region starting in 1990 and makes up 9% of PLHIV in Asia [8,9]. The prevalence of HIV among adults in Thailand is 1.1%, and about 440,000 Thai people are currently living with HIV [10]. In Thailand, HIV/AIDS is the eighth leading national cause of death, and the country has committed to ending the AIDS epidemic by 2030 [1,11].

As noted by PLHIV at a meeting held by the Foundation for AIDS Rights in 2010, HIV-positive women in Thailand have previously reported being persuaded by their providers not to have children or to have abortions if they were pregnant [7]. According to the WHO 2015 World AIDS Day Report, four out of five health workers in Thailand had at least one negative attitude towards PLHIV [12]. In addition, the Ministry of Public Health in Thailand adapted global tools to monitor stigma and discrimination towards women in the healthcare setting, and they found that one-third of women living with HIV (WLHIV) in Thailand reported having their status disclosed without their consent [12].

In response, the Government of Thailand and other partner community organisations have been working on implementing anti-stigma programmes as part of the National Strategic Plan that seeks to change the way HIV-positive women are treated in healthcare settings [11]. As a result, certain legal barriers that prevent key populations from accessing HIV services have been removed, and tools to measure stigma and discrimination in the healthcare setting and community were created [11]. However, there has been limited progress in policy and reproductive rights advocacy among networks of WLHIV [11]. We conducted a qualitative research study among WLHIV in Bangkok, Thailand, on whether and how internal stigma and external stigma from healthcare providers and community members affect fertility desires.

Methods

Study population

The study included individual interviews with women, and the completion of a survey about demographics, previous pregnancies, feelings of discrimination from providers and community members, and self-stigma. We also interviewed key informants (KIs), including an obstetrics and gynaecology physician, a policy advocate and two community health workers, to explore how discrimination towards this population has or has not changed alongside reductions in vertical transmission of HIV, and what interventions could further reduce stigma towards WLHIV. We initially aimed to recruit participants through referrals at community-based organisations (CBO) in Bangkok. However, our CBO partners supporting WLHIV in Bangkok were unable to identify a sufficient number of eligible study participants, which they attributed to having few members who met the inclusion criteria around fertility desire and recent pregnancy. With their agreement, we consequently revised the approach to recruit participants through local HIV clinics. Fifteen women were approached to participate by four healthcare providers in three clinics (two paediatric; one adult) in Bangkok. Women were eligible for inclusion in the study if they: (1) had a confirmed HIV-positive diagnosis; (2) were living

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in Bangkok at the time of the study; (3) were fluent in Thai or English; (4) were aged 18–45 years at the time of the study; (5) were of childbearing potential (e.g. not yet experienced menopause); (6) expressed an interest in having a child if nulliparous, or delivered a child within the last 2 years of the study date; and (7) were able to independently consent for study participation. Of those initially referred to the study, five declined to participate, citing their reason as being unable to travel to meet the research team for the interview. Ten WLHIV agreed to be screened for eligibility and all 10 consented to participate in the study. Consent was verbally obtained from participants. This process was used to minimise the risk of personal information being recorded or disclosed during the recorded interview process.

Table 1. Summary of key results from interviews with women living with HIV

Disclosure	Most did not disclose their HIV status outside immediate relationships
	Hesitant to disclose due to fear of reactions
	Many eventually received support from family or partner
Sources of stigma and experiences with discrimination	Evidence of internal stigma based on self-perceptions and thoughts about having children
	Identified community and family sources of stigma as influential on fertility desire
	Felt that discrimination within the healthcare setting was minimal and providers were supportive
Fertility desire and childbearing	Having children can benefit physical/mental health and give women a sense of purpose
	Combination of fear of stigma from community and concerns about PMTCT and child health affect fertility desire
	Women with HIV would benefit from society being more knowledgeable about HIV and PMTCT
Breastfeeding	Women were upset that they could not breastfeed
	They made excuses to family or friends as to why they could not breastfeed
	Need for more resources for women living with HIV about having children – from pregnancy to delivery and infant testing

Study design and procedures

Two separate semi-structured interview guides were used to interview the WLHIV and KIs to explore the following topics:

- WLHIV: diagnosis, thoughts around children, pregnancy, choosing whether to have children and stigma
- KIs: stigma, fertility desire, current actions and policies, and areas for improvement and future interventions

The interview guides contained questions and probes that were selectively emphasised or asked based on the participant's responses to the initial set of questions. The order of the questions was determined to encourage a logical progression of narrative and ease into more sensitive questions. Some of the questions were adapted from other studies assessing fertility desire or stigma [13–15]. Each interview lasted approximately 20–30 minutes. The survey included the following information: demographic information (age, gender identity, biological sex); relationship status; feelings of discrimination after disclosure of status; personal beliefs about people with HIV; desired, current or previous pregnancies; children; and perceived healthcare provider discrimination. The survey took an additional 5 minutes to complete.

Data management and analysis

The interviews were digitally recorded by a member of the study team. The audio recordings were transcribed and then translated, if necessary, into English for analysis. We used a phenomenological approach to understand the lived experiences of our participants [16]. We then employed framework analysis – a process of creating shared definitions for codes, coding transcripts, and organising them to determine relevant themes across participants – to analyse the interviews and identify themes from the data [17]. The study team used Atlas.ti version 1.0.49 and Microsoft Excel to complete the framework analysis. The results yielded common themes among the WLHIV and KI interviews, which were then summarised.

Results

All of the WLHIV participants were female and none identified with a specified key population (i.e. injection drug user, sex worker, transgender person). The median age was 33 (mean 31.4, standard deviation [SD] 7.8) years. The median duration since diagnosis was 5.5 (mean 6.9, SD 7.1) years. At the time of the study, one participant was pregnant, one was trying to become pregnant, and eight were neither pregnant nor trying to become pregnant. Eight participants had children, and the median number of children per each participant was 1 (mean=1.67 children). We did not collect information on the ages of the participants' children.

WLHIV interviews

We identified four key themes that appeared to influence the decisions of WLHIV to have children: (1) disclosure of HIV status, (2) experiences with stigma and experiences, (3) fertility desire and concerns of HIV transmission, and (4) breastfeeding concerns. These themes are summarised in Table 1.

Disclosure of HIV status

Nine of the 10 participants indicated on the survey that they had not disclosed their status to any friends or neighbours, other mothers in the community, or other PLHIV. However, all of the women reported during the interview that they had disclosed to a family member or partner. There were several reasons given why the women hesitated to tell others about their HIV-positive status. Their explanations primarily reflected an uncertainty or fear of others' reactions to learning about their infection.

> 'It depends on [the] person. I don't think that way, but people have different ideas, some people might be afraid of me, some are not. There are many kinds of ideas. So, I don't want anyone to know.' Participant 04

However, the majority of participants were eventually able to gain support from their family members and partners. Family and partner reactions to the diagnosis could also affect the way the women processed and accepted their HIV-positive status. Each woman had a different approach for dealing with their diagnosis, including forming relationships with other WLHIV, if they were willing to disclose their status, or taking ART to maintain their health and well-being. Oftentimes, pregnancy served as an opportunity for a woman to disclose her status to her partner or family.

Experiences with stigma and discrimination

Sources of stigma could be loosely organised into three categories: internalised; community-based; and within the healthcare setting.

Internalised stigma was characterised by attitudes and perceptions the women had about themselves related to their HIV status and fertility desire. Community-based and healthcare-related discrimination were categorised by feelings, actions and reactions from other people within those two settings. While participants expressed internalised stigma and continued to feel stigmatised by community members, none of the participants indicated that they felt discrimination from their healthcare providers. The women indicated an internalised form of stigma through personal reflections on their diagnosis and thoughts about having children. Three out of the 10 participants living with HIV said that PLHIV were right to be ashamed of their status.

> ‘I felt scared. It was like the world was shut down. I did not know how to handle it and importantly, I am certainly sure that the society will hate me.’ Participant 06

Additionally, internalised stigma played a role in their decisions and thoughts about having children.

> ‘I thought I would have kids someday when I’m ready. However, when I found out that I’m infected, I stopped thinking about kids. It was like my defect. When a woman gets married, she wants to have kids. But I definitely couldn’t have one, so I stopped thinking.’ Participant 03

The community’s behaviours towards and interactions with HIV-positive people appeared to be based in misconceptions about the virus, transmission, and how the disease affected WLHIV. KIs mentioned that women who disclosed their status may be asked to leave their jobs by their employers or their homes by their families, but indicated that these severe forms of discrimination were currently less common. They noted that they were more likely to face judgement from other women and mothers in the community for their decision to have children.

In contrast to the adverse feelings of stigma from community members and internalised sources, reactions to interactions within the healthcare system were more nuanced. All of the participants in this study showed satisfaction with their own healthcare providers and denied feeling discriminated against because of their HIV status. However, a few participants mentioned that this may not have been the case within other healthcare settings in Bangkok. Several of the participants chose their providers because they were more confident that the physicians and nurses in these particular clinics would not discriminate against them based on their status. It appeared that discrimination from healthcare providers was less of a concern than internalised and community-based stigma for the women interviewed in the study. All eight of the participants who had delivered were asked to consider sterilisation surgery after delivery. While this may be a topic discussed with postpartum women without HIV, the survey reported that half of them believed the recommendation from the provider was due to their HIV status.

Fertility desire and concerns of HIV transmission

Although many of the pregnancies among the participants were unplanned, most participants expressed having had a desire to have a child at some time in their life. They described various benefits of having children, including improving mental and physical health and giving women a sense of normalcy and purpose by having an experience with motherhood similar to HIV-negative women.

> ‘I feel I became stronger [compared to] before I got pregnant…[The] feeling of motherhood forces me to eat good food and to rest sufficiently. So, I feel stronger and encouraged. That’s delightful…Yes, I would like to have one more kid.’ Participant 03

The participants cited several factors that affected their fertility desires, including stigma and initially hesitating to have children due to a fear of transmitting the virus or premature death from HIV. However, learning how to prevent vertical transmission of HIV led to reduced concern during subsequent pregnancies. Ultimately, a combination of worries about the child being infected and uncertainty about the mother’s health influenced fertility intentions and desires among the women.

Breastfeeding concerns

Breastfeeding emerged as a major concern for the HIV-positive women who were pregnant or had recently delivered children. Although the standard of care in Thailand is for HIV-positive mothers to bottle feed instead of breastfeed, only six of the eight women who had children noted that their providers explained alternatives for breastfeeding after delivery such as formula feeding. The eight participants who had delivered a child were upset that they could not breastfeed their babies, which commonly arose from feelings of inadequacy as a mother or concerns about their infants missing out on the immunological benefits of breastmilk.

> ‘The only thing I feel is pity. I pity [that] I can’t breastfeed. As a mother, I’ve failed myself for that. Nothing more.’ Participant 10

Women were also asked by family and members of the community about why they were not breastfeeding their children. Many participants gave alternative explanations, including that they could not produce milk or they had a condition (other than HIV) that prevented them from breastfeeding. The participants voiced a need for more education and options around breastfeeding for HIV-positive mothers. In general, the women noted that additional resources for WLHIV about planning to conceive, pregnancy, delivery, and breastfeeding could make the process of having children easier and less worrisome.

KI interviews

The four KIs were an obstetrics and gynaecology physician, a policy advocate, and two community health workers. The KIs agreed that WLHIV still faced stigma within the healthcare setting and community. Each of the KIs provided a unique perspective on the challenges this population faces in combating stigma in the context of having children. One KI noted that discrimination has evolved to be less of a concern than in previous years.

> ‘Clearly, among the community I have seen especially among women, a sense of hope and encouragement…[compared to] when I started working on HIV ten years ago’ KI 02

The KIs who were interviewed agreed that most Thai providers were well equipped to counsel pregnant WLHIV. However, education about the transmission of HIV, particularly around vertical transmission, was limited for people in the community. A KI working closely with WLHIV in a clinical setting cited a need for greater education among WLHIV and to the larger society of HIV-negative people to raise awareness around WLHIV having children.

> ‘We need to change society by giving them information…We should teach [young] students what HIV is…I think we have

> to give the information when they are still students…when they grow up to be adults in society, this will be better and better and better.' KI 01

In addition to education about vertical HIV transmission, KIs expressed a desire to have more information about their various fertility options to share with the WLHIV they worked with, particularly for health workers interacting with this population in a community setting. This included facilitating additional counselling from healthcare providers, training WLHIV support groups to encourage open and advance discussion about fertility plans, and educational materials to support both interventions.

> 'I wish to have hotline or organisation where these groups can seek for consultancy. This organisation should provide sufficient information on living with HIV while having their own children.' KI 03

Discussion

We found that the effects of stigma on fertility desire may have impacted our participants at different levels, ranging from the internal/individual level and expanding to interactions with healthcare providers and their larger community. From our interviews with the HIV-positive women and supplemental interviews with the KIs, we found that although discrimination from healthcare providers impacted fertility desire earlier in the Thai HIV epidemic, it was less of a current concern among the participants. However, several participants chose their providers based on prior knowledge of their likelihood to respect their HIV status, and they rarely disclosed their status to others in their community. This suggests that women are still concerned enough about the risk of stigma to be cautious who they trust with their medical care.

These findings parallel the recent accomplishment in Thailand of eliminating vertical transmission of HIV, according to WHO criteria [18]. Key to Thailand's success was the increased testing and counselling of mothers with HIV that led to referrals for antiretroviral use for prevention. Furthermore, nationwide monitoring of the incidence of HIV and early testing of newborns allowed for close evaluation of national progress over time [19]. Physicians and other healthcare providers played a key role in this success, and received additional training on caring for pregnant WLHIV. In the community setting, however, fear of stigma continues to prevent women from disclosing their fertility intentions to others. We also discovered that WLHIV were reluctant to discuss their fertility desires with their peers in the community, and still preferred to keep their status a secret. The KIs noted that while stigma from society has decreased in the last few years, women still face difficulties with the process of having children due to their status, both on the personal family level as well as with the healthcare system.

Both sets of interviews highlighted the need for additional supportive services and education for HIV-positive women and community members around the process of deciding and preparing to have a child. Importantly, our study indicated that advocacy for WLHIV by other HIV-positive women around fertility desire could serve as a powerful medium to change feelings of internal and community-based stigma. Since many of the women had not disclosed their status outside their immediate families, they did not have access to other HIV-positive women to talk with in a support system.

Study limitations

A key concern about the study's implementation was that the sampling strategy was altered *post facto*. This could have introduced bias by selecting WLHIV who were more likely to be satisfied with their healthcare providers. However, the potential study participants were consecutively identified based on clinic appointment dates and primarily through paediatric providers for their children. Although study participation was anonymous, our recruitment strategy may have biased us against finding stigma and discrimination in the healthcare setting. In addition, this is a population of women retained in healthcare. While their viewpoints are reflective of those with health-seeking behaviours, this may indicate more frequent contacts with the healthcare system, particularly with care received post-delivery, on which they could base their comments.

Conclusions

We found that while discrimination experienced with WLHIV within the reproductive healthcare setting in Bangkok is less of an issue now than in previous years, internal stigma and fear of discrimination from the community remained relevant concerns for this population. In addition to describing how these sources of stigma contributed differently to fertility desire among Thai HIV-positive women, our study highlighted areas for future interventions. As the national programme moves towards zero discrimination against all PLHIV, addressing the effects of community-based and internalised stigma on fertility desire among HIV-positive women is one avenue to reach this goal.

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Ethics approval and consent to participate

Ethics approval was provided by the University of California, San Francisco, Institutional Review Board, which reviewed and approved all documents prior to study initiation (16-18559). All women were offered 700 Thai Baht (~US$20) for their participation and travel costs. In order to protect the participants' privacy, the interviews were held in a location of the participant's choosing and all personal identifying information was subsequently redacted from the transcripts prior to analysis. All surveys were manually destroyed after the information was entered into an encrypted database.

Declaration of interests

The authors declare that they have no competing interests.

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