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Disclosure challenges among people living with HIV in Thailand

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Abstract

One of the main challenges facing people living with HIV (PLH) in Thailand is HIV disclosure. The goal of this study was to examine HIV disclosure barriers and motivators in Northeastern Thailand. Focus groups were conducted with 40 PLH to explore the barriers and motivators. To confirm the themes identified in the focus groups, face-face interviews were conducted with 50 PLH. Focus group findings revealed barriers to HIV disclosure in three domains: *perceived stigma, shame* and *fear of rejection*. Motivators to HIV disclosure consisted of the following: *coping with illness, seeking help* and *common experiences*. Findings from the face-to-face interviews included the following barriers: *fear of privacy breach, fear of rejection* and *communication difficulties*. The motivators to HIV disclosure included *seeking supportive relationship, duty to inform* and *catharsis.* Based on these findings, we are currently developing family-focused HIV disclosure intervention in Northeastern Thailand.

Keywords

barriers and motivators; HIV disclosure; Thailand

INTRODUCTION

With the advent of antiretroviral therapy (ART) provision in Thailand, HIV infection is shifting into a chronic illness.[1–4] Given this shift, people with HIV in Thailand are living longer. In addition, given this shift of HIV as a chronic illness, the potential positive benefits of HIV disclosure for people living with HIV (PLH) in Thailand is becoming more salient. However, HIV disclosure remains a key HIV-related stressor.

For PLH, the stressor around HIV disclosure emerges as to deciding to whom, when, what and how to disclose their serostatus to others.[5–7] If the PLH decides not to disclose, they

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face multiple stressors about how to manage their illness effectively without a clear explanation of their behaviour. Seeking social support around HIV becomes more challenging when PLH choose not to disclose. In addition, adhering to ART without adequate support presents challenges of either hiding pills or lying to others. The need for secrecy creates added burden on PLH.[8–10] In addition, disclosure decisions impact HIV transmission acts.[11] When PLH do not disclose their serostatus, the odds of being depressed are threefold, similar to the rate when family members are ashamed of the HIV+ adult.[12] HIV-related stressors around disclosure extend to partners and family members once the serostatus is disclosed. HIV disclosure is an ongoing issue in self-management of HIV and is a central issue in Thailand in HIV+ support groups.[13]

Despite the importance of addressing the various factors associated with HIV disclosure, empirical investigations examining HIV disclosure in Thailand are limited. Interventions focusing on HIV disclosure are needed in Thailand. The goal of this study is to lay groundwork in identifying the unique barriers and motivators around HIV disclosure in Thailand. The findings from this study will provide important information for the next research phase of developing and implementing an intervention to address HIV disclosure among PLH in Thailand.

METHODS

Participants and procedures

Phase 1—Focus groups—All participants were recruited at a district hospital in Northeastern Thailand. As the standard of care, PLH participate in the monthly support group at the district hospital. PLH were recruited by trained project staff following the monthly support group. For PLH, eligibility criteria specified that participants be HIV-positive, at least 18 years of age, and that they have disclosed their HIV status to at least one family member. Following screening and determining eligibility, informed consent and full disclosure about all study providers were secured by the project staff. Using these recruitment strategies, a purposive sample of 40 PLH (5 focus groups; 7–9 per group) were recruited from a district hospital in Northeastern Thailand.

Phase 2—Face-to-face interviews—Following Phase 1, an additional 50 PLH were recruited at the same district hospital to participate in the one-time face-to-face interview. Prospective participants were approached at the district hospital following the monthly support group. After screening for eligibility and if the PLH is willing to participate, the informed consent was administered to PLH to participate in the one-time face-to-face interview. A total of 50 PLH were recruited of this phase.

Approval of this study was obtained from the Institutional Review Boards from the University of California, Los Angeles, and the Thai Ministry of Public Health Ethical Review Committee for Research in Human Subjects. All participants received 330 Baht (~ $10) for participating in the focus group sessions.

Data collection

Phase 1—Focus groups—In the beginning of each focus group session, participants were provided with a clear explanation of the objective of the focus group. A scripted focus group session guide was used to gather information on participants' past experience with barriers, concerns and motivators around HIV disclosure. With participants' permission, all focus group sessions were audiotaped and transcribed by trained research staff. All audiotapes were stored in a locked cabinet, in a locked office. Tapes were labelled with a

date and time stamp of the focus group session but did not contain personal identifying information.

Phase 2—Face-to-face interviews—Face-to-face interviews were conducted by trained interviewers using a laptop to examine concerns, barriers and motivators around HIV disclosure. All the interviews were conducted in a private space at the district hospital. The measures used in the interview included Reasons For and Against HIV Disclosure, which examined PLH's reasons for disclosing and not disclosing to someone about the serostatus. The instrument consisted of 46 items with 11 subscales associated with reasons for self-disclosure and reasons for nondisclosure.[14] In addition, distress disclosure index (DDI), a 12-item assessment about one's willingness to disclose information in times of distress, was administered.[15]

Data analysis

The focus groups were digitally recorded and transcribed verbatim, and translated into English. Transcripts were checked against the original audio recording for accuracy by trained research staff and then imported into ATLAS.ti (version 5.0; ATLAS.ti Scientific Software Development GMbH, Berlin, Germany)[16] to maintain and organize the focus group transcripts.

A modified grounded theory was employed to identify themes[17,18] that might explain the predicted barriers, concerns and motivators around HIV disclosure. Data analysis began with the development of extensive list codes generated from the focus group sessions. Additional codes and potential themes were identified through multiple readings for the transcripts. The initial codes were pre-tested by having the coding team, which consisted of the first author and a co-investigator review and discuss the codes and identify exemplar quotes associated with each code. Codes were then sorted into general categories and collated along with data excerpts. Data excerpts were then reviewed by the coding team to identify emergent themes and to identify recurring patterns of responses to assess prevalence of themes and for refinement of themes. The results presented in this study represent the findings captured and organized by the final themes around barriers and motivators around HIV disclosure identified in the analysis. The final themes were organized by barriers and motivators. The final analysis consisted of three themes under barriers and three themes under motivators. Face-to-face interviews were analyzed using SAS 9.2 software (SAS Institute, Inc., Cary, NC, USA). Frequency and mean values for reasons for and against disclosure are reported.

RESULTS

Focus group findings

Barriers to HIV disclosure—Table 1 summarizes the focus group findings on the barriers to HIV disclosure with sample quotes from the participants. PLH identified three distinct barriers to HIV disclosure, consisting of the following domains: (i) perceived stigma; (ii) shame; and (iii) fear of rejection and disapproval.

Perceived stigma: Stigma influences choices about disclosing.[19–21] HIV-related stigma is associated with making HIV disclosure decisions.[14] If perceived stigma risks are high, it is likely that PLH will opt for concealing their status; therefore, instead of taking the chance of opening their privacy boundary and gambling on further humiliation and hurt, PLH are more liable to use protection rules and not disclose.[22]

Shame: Thailand is a family-oriented society. PLH may exhibit a deep sense of shame from their family, friends, intimate partners, workplace and their community. This feeling of shame may influence their decisions not to disclose their status to others.[23]

Fear of rejection and disapproval: Cultural norms around HIV in Thailand may provoke a sense of disapproval toward PLH. For example, others may disapprove of the PLH because they assume that he or she has violated some moral code or group standard.[24] Such perception of disapproval may influence their decision not to disclose their serostatus to others.

Motivators to HIV disclosure—Table 2 summarizes the focus group findings on the motivators to HIV disclosure with sample quotes from the participants. Some people have a high need to tell others because it helps them cope with their illness. Thus, when PLH want to disclose, they regulate their boundaries more loosely, allowing some or a great deal of access to their private information. Participants reported several motivators to HIV disclosure, consisting of the following domains: (i) coping with illness; (ii) seeking help; and (iii) common experiences.

Coping with illness: PLH may use HIV disclosure as a coping mechanism to help them cope with their illness. Instead of keeping it a secret, PLH may feel a sense of relief once they disclose their status to others. Thus, when PLH want to disclose, they regulate their boundaries more loosely, allowing some or a great deal of access to their private information. Keeping secrets is often more draining than telling.[25] PLH with secrets have to remain alert about who knows and who does not know, whom they have told and whom they wish to keep in the dark. Disclosing one's status is a way to let go of their secrets.

Seeking help: PLH may also disclose to seek help to deal with their personal difficulties. To achieve this goal, PLH may disclose their serostatus.[6] PLH may disclose their status as a way to accelerate relationship development and to foster intimacy. PLH may disclose so that they can protect themselves by depending on people they trust and feel close as friends and family members.

Common experiences: PLH may disclose to others who have shared a common background or who have similar health problem.[26] PLH rely on the comfort of knowing that the confidant has some knowledge about the disease that came from a similar experience. Because they have common experiences, they are anticipated to react better.

Face-to-face interview findings

Table 3 outlines the demographic and HIV disclosure factors among PLH who participated in the face-to-face interview ($n = 50$). The majority of the participants was female (70%), with a mean age of 37.5. Most had less than high school education (78%) and over half reported married or living with a partner. Participants scored high on the reasons from non-disclosure on a 1–5 scale, score ranging from 3.41 (self-blame) to 4.11 (privacy). Similarly, participants also scored high on reasons for disclosure on a 1–5 scale, ranging from 3.51 (others' reactions) to 4.25 (supportive relationships). Participants scored a little above 3 on a 1–5 scale DDI, suggesting moderate distress.

DISCUSSION

The HIV disclosure process is multidimensional and impacts PLH's health and well-being, as well as that of the family members to whom they disclose. HIV disclosure to family members has significant impact on the disease prevention and health promotion of PLH.[27]

HIV as a chronic illness creates a tremendous strain on the family system,[27] and family members often take on the responsibility as caretakers.

However, HIV disclosure to family members has significant influence on the extent to which the family members will get involved in providing care to PLH. Disclosure decisions to these groups appear tied to relative perceptions of HIV-related stigma.[9,11,14] In addition, in some cases, nondisclosure may be the optimal solution, given potential negative consequences of HIV disclosure. This was confirmed in our study; PLH who feared perceived stigma were less likely to disclose their status to their family members. PLH may also not disclose because of their feeling of shame. They may feel that they have done something terribly wrong and may feel it is necessary to keep the information concealed from others.[28] This barrier was captured in our study; PLH who felt the sense of shame were less likely to disclose their status to others. Similarly, those who feared rejection and disapproval were less likely to disclose their status to others.[23]

Despite the barriers to HIV disclosure, our findings from focus groups and face-to-face interviews also revealed potential motivators to HIV disclosure. PLH who were motivated to seek help from friends and family were more motivated to disclose their status to others. Our study provides a closer examination of the complexities surrounding HIV disclosure among PLH in Northeastern Thailand. This is consistent with past research suggesting that PLH disclose their status to others because they long for positive relational issues, such as feelings of closeness, caring and trust.[22] PLH were also motivated to disclose to others who have shared a common background or who have similar health problems.[14] PLH may rely on the comfort of knowing that the confidant has some knowledge about the disease that came from a similar experience. Because they have common experiences, they are anticipated to react better to the news. This motivating factor was also confirmed in our study.

The findings from our focus groups and face-to-face interviews provide a crucial step in developing an intervention to address HIV disclosure. PLH's decision of HIV disclosure carries different consequences. Past studies on HIV disclosure suggest that no particular disclosure pathway automatically leads to better outcomes for PLH. What is associated with better outcomes is when disclosure pathways are thoughtfully chosen and carefully planned.[29,30] Our findings revealed that PLH in Thailand face barriers to HIV disclosure as well as potential motivators to HIV disclosure. PLH in our study identified perceived stigma, shame and fear of rejection and disapproval as distinct barriers to HIV disclosure. Future intervention programmes should address these barriers so that they have enough resources to make an informed decision on HIV disclosure.

Despite the barriers to HIV disclosure identified in our study, our findings also revealed motivators to HIV disclosure. PLH reported disclosing their status as a way to cope with their illness, as a means to seek help from friends and family, and as a way to share their common experiences with others who are dealing with the same challenges. Future intervention programmes addressing HIV disclosure should focus not only on the barriers to HIV disclosure but also on the potential motivators to HIV disclosure.

Our study findings provide important information for the next research phase of developing and implementing an intervention to address HIV disclosure among PLH in Thailand. Future programmes to help PLH around HIV disclosure should empower PLH with the concept that the knowledge, strength and decision to disclose reside within them. The programme is not to focus on the assumption that disclosure will always lead to positive outcomes but acknowledge the barriers and the motivators to HIV disclosure and provide the PLH with enough resources and tools to make informed decisions about HIV disclosure. Based on

these findings, we are currently developing a family-focused HIV disclosure intervention in Northeastern Thailand.

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Table 1

Focus group findings on the barriers to HIV disclosure

Barriers	Samples quotes
Perceived stigma	'I was afraid to disclose my HIV status to my neighbors because I saw what happened with Khun GG who is HIV-positive in our village. He was stigmatized by others when they found out he was positive.' (Female PLH, 34 years old)
	'One of my neighbors got infected and passed away. There was another guy in my village, he got infected and died as well. People in my village talked about the disease and dared not to talk to them or their families. So I decided to keep it private because I was afraid that people in my village would treat me like the others with AIDS.' (Female PLH, 28 years old)
Shame	'At that time we had very little understanding about the disease and I didn't dare join the support group because I was scared and ashamed … I was a bus driver at that time and I was not sure whether passengers would be disgusted with me or dared to get into the bus.' (Male PLH, 36 years old)
	'When I was pregnant with second child, I found out that I was infected. I dared not disclose my status to my siblings because I was afraid that they might be disgusted at me. I kept it private for a long time.' (Female PLH, 32 years old)
	'I was ashamed of myself. My parents come from a good family. I didn't dare tell them that I got infected. It would be a disgrace to my parents and my family. My parents still had good jobs and I feared that they'd get fired if their company found out their daughter has AIDS. I didn't think they'd understand.' (Female PLH, 37 years old)
Fear of rejection and disapproval	'After the test, I never thought of telling anyone. I thought after I delivered my baby, I would separate from my family, either to become a nun or go somewhere away from other people. I didn't want to stay here. I was afraid that my siblings would disapprove me and reject me because of my sickness.' (Female PLH 36 years old)
	'I was afraid that others will reject me. I still worked and needed to interact with others. I needed to have friends. If they felt repulsed by my infection, I will be hurt. I couldn't face it. Even my younger brother, when he found out, he didn't allow me to carry his child. You see? Even my own brother treated me this way. Both he and his wife got bachelor's degrees. He told my mom to tell me not to hold his child any more.' (Female PLH, 29 years old)
	'I have seen how others treat someone with AIDS. I have many friends but I didn't know who to tell. Sometimes, you don't know how your friends would react to things like this. I was afraid of negative things. I couldn't face it. So I decided to not tell anyone. But I got sick. My parents found out from the doctor. Now, many of my friends also know. But I never told them directly. But they knew.' (Male PLH, 35 years old)

Table 2

Focus group findings on the motivators to HIV disclosure

Motivators	Samples quotes
Coping with illness	'For my first sister, I was frustrated whether I should tell her and how I should tell her so that she wouldn't be sad … But after I disclosed to her, I was relieved. My sister was very supportive. She and I care for each other.' (Female PLH, 37 years old)
	'After I disclosed to my parents, I felt so free and relieved. And I was able to openly go to the hospital to get medications without making up excuses. It was much easier to cope with my illness. I felt like a big rock was lifted off my chest.' (Female PLH, 33 years old)
Seeking help	'Now, I can live happily because of my siblings and my family … They have given me moral support. For example, when I got sick, my grandma told me not to work too hard. She reminded me to think about my child, and thinking about my child's future gave me strength to fight against difficulties. Nowadays, I am healthy both physically and mentally. I ask for help from my friends and family.' (Female PLH, 36 years old)
	'My friends used to talk to me that no matter what I suffered from, they will not be disgusted at me because I am their friend. I thought that my friends could accept me. I felt that I could ask for help. After I disclosed, my friends and my parents gave me moral support and helped me with my daily chores.' (Male PLH, 35 years old)
	'I told my older sister … I mean, getting infected with this is a serious matter. My health would get worse and worse and I was concerned about my child. And I knew that my sister is the one who would take care of my child. Now, I'm doing much better because I take ARV from the hospital and my sister helps me everyday to remind me about the medicine and she helps me with my child.' (Female PLH, 37 years old)
Common experiences	'After I found out about my infection, the doctor told me about the Sunshine Support Group for PLH at the hospital. At first, I dared not go because I was afraid others might find out I have AIDS. But after I told my sister, I decided to join the group. The support group is great because we all have common problems and we all struggle with same issues. So we help each other out and we meet more than once a month. I rely on them and they rely on me.' (Female PLH, 34 years old)
	'After I disclosed to Khun HH, I found out that she also has a young son, just like me. She shared her experience telling her son about her infection and what helped her through the process. Talking to her helped a great deal to come up with a plan to tell my son about my disease. I have not told my son about my infection but I feel more ready because Khun HH shared her experience about telling her son. Her son now helps her with stuff around the house.' (Female PLH, 38 years old)

Table 3

Demographic and HIV disclosure factors among people living with HIV in Thailand ($n = 50$)

Characteristics	Frequency/mean	% or S.D.
Gender (female)	35	70%
Age in years	37.5	8.5
Education		
Less than high school	39	78%
Some high school or more	11	22%
Individual annual income in Baht	70 273 Baht (~ U.S. $ 2 000)	
Married or living with a partner	29	58%
Reasons for Non-disclosure (1–5 scale)		
Privacy	4.11	0.83
Self-blame	3.41	1.17
Communication difficulties	3.81	1.11
Fear of rejection	4.03	0.93
Protecting others	3.96	0.99
Superficial relationship	3.85	1.07
Reasons for Disclosure (1–5 scale)		
Catharsis	3.70	1.03
Duty to inform	3.81	0.75
Others' reactions	3.51	1.09
Supportive relationships	4.25	0.70
Similarity	3.25	1.18
Distress disclosure index (1–5 scale)	3.05	0.54