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Regional variations in HIV disclosure in Thailand: implications for future interventions

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Summary: People living with HIV (PLH) in Thailand face tremendous challenges, including HIV disclosure. With the advent of antiretroviral (ARV) therapy in Thailand, the positive benefits of HIV disclosure are becoming more salient. However, there are regional variations in the levels of HIV disclosure in Thailand. We examined and compared the levels of HIV disclosure in Northern and Northeastern Thailand. PLH ($N = 410$) were recruited from four district hospitals in the North and the Northeast. More PLH in the North reported disclosing HIV status to at least one family member in the household. PLH in the Northeast reported significantly lower levels of HIV disclosure within family and outside of family. HIV disclosure remains a significant challenge in Thailand, especially in the Northeast. We propose future interventions focusing on HIV disclosure to address the specific concerns and barriers to HIV disclosure, taking into account the regional differences in HIV disclosure.

Keywords: HIV disclosure, regional variations, Thailand

INTRODUCTION

HIV disclosure is a key stressor among HIV-affected families in Thailand. People living with HIV (PLH) face tremendous physical, psychological and social stressors.^{1–3} Coping with these HIV-related stressors may be influenced, in part, by PLH's decisions made around the process of disclosing their diagnosis (e.g. whether to disclose or not, their reasons behind the decisions, who to disclose to and how).^{4–6} For example, perceived social support is positively associated with HIV disclosure,^{7,8} whereas potential negative emotional reactions (e.g. depression), as well as negative consequences of HIV disclosure (e.g. rejection and isolation by loved ones), are inversely associated with HIV disclosure.^{9–11}

With the advent of antiretroviral (ARV) therapy provision in Thailand, HIV is becoming a chronic illness, where PLH can manage their illness and live for a long time. Given this shift of HIV to a chronic illness, the positive benefits of HIV disclosure in Thailand are becoming more salient. While HIV disclosure may lead to positive outcomes (e.g. more support from family members, sense of relief, linkage to care), there are potential negative consequences to disclosure (e.g. stigma and discrimination). Therefore, HIV disclosure does not automatically lead to better outcomes for PLH and their families. What does lead to better outcomes is when disclosure pathways are thoughtfully chosen and carefully planned.^{12,13}

When addressing HIV disclosure dynamics in Thailand, there is evidence to suggest regional variations between the North and the Northeast. One plausible explanation for the regional differences in the disclosure trajectories is the variation in the epidemiology of HIV epidemic in Thailand. In particular, the age of the HIV epidemic in the North is much more mature compared with the epidemic in the Northeast. The HIV epidemic in the North started in the late 1980s through injection drug users (IDUs) and commercial sex workers (CSWs).¹⁴ Since the epidemic began, the Thai government mounted major public HIV prevention programmes.¹⁵ Initiatives included the 100% condom programme among CSW, broad social marketing campaigns, broad access to HIV testing, high-level government endorsement, aggressive prevention programmes among military conscripts and programmes for IDU.¹⁶ In addition to the national campaigns, more grass root-initiated activities were launched in the North to address the HIV epidemic, particularly focusing on stigma reduction.¹⁷ With well over 20 years of HIV-related initiatives in the region, HIV may be perceived as a relatively normalized disease in the North.

In the Northeast, however, the epidemic began much later (mid-1990s), mainly through heterosexual transmission. Husbands working in urban construction sites during non-rice harvesting season would contract HIV through CSWs and bring it back to their wives in the Northeast. Given that the epidemic started much later, the potential problem of stigma and discrimination may still act as major barriers to HIV disclosure in the Northeast.

Regional variations in HIV disclosure have significant implications in designing and implementing future interventions focusing on HIV disclosure in Thailand. The specific barriers

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and concerns around HIV disclosure among families in the Northeast may be very different from families living with HIV in the North. Despite the importance and influence of regional differences in HIV disclosure, empirical investigations of these differences in Thailand are limited. The goal of this paper was to examine and compare the levels of HIV disclosure within and outside of family in Northern and Northeastern Thailand. Empirical evidence on the regional variations in HIV disclosure in Thailand will provide a better understanding of the ways to further address potential challenges, concerns and barriers facing PLH around HIV disclosure.

METHODS

Participants and setting

This study uses the baseline data from a randomized controlled family intervention trial in the Northern and Northeastern regions of Thailand.¹⁸ These data were collected at baseline before randomization and prior to the delivery intervention activities among the participants. PLH were recruited at four district hospitals in the two regions (two district hospitals per region) using the existing cases of PLH in the district hospitals. Initial screenings of PLH were performed by health-care workers and research staff specifically hired for the study. The eligibility criteria for enrolment were as follows: PLH having disclosed their serostatus to at least one family member in their household and PLH having at least one child in their household aged six to 17. Once the PLH had been screened and had agreed to participate in the study, written informed consent was obtained.

Following informed consent, a trained interviewer, a member of the assessment team hired by the project staff, administered a baseline assessment to the PLH using Computer-Assisted Personal Interview on laptop computers ($N = 410$). During the baseline assessment, PLH were asked about their demographics, including age, gender, annual income and educational status. In addition, PLH were asked detailed questions about their perceived stigma, social support and depression. PLH received US\$10 (320 Baht) for participating in the baseline interview. The participation rate of the baseline interview was 95%. The study was approved by the Institutional Review Boards of the University of California at Los Angeles and the Thailand Ministry of Public Health Ethical Review Committee for Research in Human Subjects.

Measures

Disclosure within family was determined by dividing the number of people in the household who are aware of PLH's HIV status by the total size of the family (0–100%). *Disclosure outside family* was calculated as a composite variable (range = 0–5), based on the count of HIV disclosure among members outside of the family (co-workers, outside family members, village leaders, village health workers, people in the community).

Emotional social support was constructed as a composite variable based on the two subscales (emotional/informational support and affectionate support) in the Medical Outcomes Study Social Support Scale.¹⁹ The social support scale included both emotional/informational support, measured by eight items, and affectionate support including three items. Responses to individual items ranged from 1 (none of the

time) to 5 (all of the time). We combined the two subscales because they were highly corrected to yield a composite scale with a satisfactory internal consistency ($\alpha = 0.86$). This summative composite score ranged from 11 to 55.

We also included PLH's demographic information, including gender, age in years, education, annual income, marital status, family size and family composition.

Data analysis

All analyses were performed using SAS statistical software version 9.1 (SAS Institute Inc., Cary, NC, USA). First, descriptive statistics were used to describe PLH's demographics, family composition, social support and HIV disclosure within and outside of the family. Second, Pearson correlation coefficients were calculated to examine the relationship between region, demographics, emotional social support and HIV disclosure. Third, a series of multiple regression analyses were conducted to examine associations between PLH's disclosure, region and emotional social support, controlling for the simultaneous effects of participants' age, gender, income and education. Disclosures within family and outside of the family were treated as two distinct outcomes. Regression coefficients estimation and their significant levels were also reported.

RESULTS

Table 1 outlines the descriptive characteristics of PLH in the study, stratified by the region (North and Northeast). The mean age (range = 23–64) of the participants was 37.7 years (standard deviation [SD] = 6.6). A majority of PLH in the study was female subjects (73%). Almost all subjects (81.4%) received less than high school education. The mean of individual annual income was 27,194 Baht per year (US\$850/year). About half reported being married or living with a partner. The PLH in the study described living with the following family members: one child (70%), parent (41%), grandparent (3%), sibling (23%) and other family member (26%). The mean score of *emotional social support* (range = 11–55) was 39.3 (SD = 8.3). Comparisons by region revealed that PLH in the Northeast had higher income, larger family size, more children, less disclosure within family and less disclosure outside of family.

The correlation coefficients among demographic characteristics, emotional social support and HIV disclosure are presented in Table 2. Significant regional differences were observed on income ($r = 0.26$, $P < 0.001$), average family size ($r = 0.176$, $P = 0.0004$), disclosure within family ($r = -0.195$, $P < 0.0001$) and disclosure outside of family ($r = -0.375$, $P < 0.0001$). Gender (female) was negatively correlated with age ($r = -0.162$, $P = 0.001$), education ($r = -0.161$, $P = 0.001$) and income ($r = -0.140$, $P = 0.005$). Age was negatively correlated with family size ($r = -0.168$, $P = 0.0007$) and positively correlated with disclosure within family ($r = 0.160$, $P = 0.001$). Education was positively correlated with income ($r = 0.205$, $P < 0.0001$) and emotional social support ($r = 0.097$, $P = 0.05$). Income was positively correlated with emotional social support ($r = 0.102$, $P = 0.04$) and negatively correlated with disclosure outside of family ($r = -0.140$, $P = 0.005$). Disclosure within family and outside of family were positively correlated ($r = 0.264$, $P < 0.0001$).

Table 3 outlines the multiple linear regression models examining the correlates of HIV disclosure within family and outside

Table 1 Demographics, family composition, social support and HIV disclosure among parents living with HIV in Thailand (N = 410)

Characteristics	North (n = 230) Frequency (%) or mean (SD)	Northeast (n = 180) Frequency (%) or mean (SD)	Total (n = 410) Frequency (%) or mean (SD)
Female subjects	165 (72%)	132 (73%)	297 (73%)
Age (years)	37.6 (6.4)	37.8 (6.9)	37.7 (6.6)
Education			
Less than high school	192 (84%)	140 (78%)	332 (81%)
Some high school or more	36 (16%)	40 (22%)	76 (19%)
Individual annual income in Baht*	18,747	37,987	27,194
Married or living with a partner	124 (54%)	83 (46%)	207 (50%)
Average family size*	3.0 (1.3)	3.5 (1.8)	3.2 (1.6)
Family composition			
Children*			
One child	178 (77%)	110 (61%)	288 (70%)
More than one child	52 (23%)	70 (39%)	122 (30%)
Parent	95 (41%)	73 (41%)	168 (41%)
Grandparent	8 (3%)	3 (2%)	11 (3%)
Sibling	50 (22%)	44 (24%)	94 (23%)
Other family member	46 (20%)	61 (34%)	107 (26%)
Emotional social support	39.1 (8.3)	39.6 (8.2)	39.3 (8.3)
Disclosure within family*	77.4 (27.3)	65.9 (29.9)	72.5 (29.2)
Disclosure outside of family*	3.1 (1.8)	1.7 (1.6)	2.5 (1.8)

SD = standard deviation

*P < 0.05

of family. Adjusting for demographics, family size and emotional social support, PLH in the Northeast report significantly lower levels of HIV disclosure within family compared with PLH in the North (standardized beta [β] = -0.205, $P < 0.0001$). Women ($\beta = 0.116$, $P = 0.02$) and older PLH ($\beta = 0.196$, $P < 0.0001$) reported higher levels of HIV disclosure within family. Similarly, for disclosure outside of family, PLH in the Northeast reported significantly lower levels of disclosure outside of family, compared with PLH in the North ($\beta = -0.363$, $P < 0.0001$). Emotional social support, controlling for all selected independent variables, was positively associated with disclosure outside of family ($\beta = 0.113$, $P = 0.016$).

DISCUSSION

With the advent of ARV therapy provision in Thailand, HIV infection has shifted into a chronic illness.²⁰⁻²² However, HIV disclosure remains a key stressor, especially in Northeastern Thailand. In the Northeast, the HIV epidemic began much later (mid-1990s) than in the central or northern regions, mainly through heterosexual transmission. Married men working in urban construction sites during the off season for rice harvesting would contract HIV through CSWs and bring it back to their wives in the Northeast. Given that the epidemic

started much later than in the central or northern regions, the problem of stigma and discrimination are still major barriers to HIV disclosure in Northeastern Thailand.

Our findings revealed that HIV disclosure with family was significantly lower among PLH in the Northeast compared with the North. Our examination of the regional variations in HIV disclosure in Thailand provided evidence that HIV disclosure is an ongoing stressor in Thailand, especially among PLH in Northeastern Thailand. Non-disclosure within the family was high (35%). Similarly, HIV disclosure to members outside of family was significantly lower among PLH in the Northeast compared with PLH in the North. HIV disclosure to members outside of family was significantly associated with higher perception of emotional social support. This finding is consistent with the existing literature.^{7,8} Furthermore, the challenges around HIV disclosure may be even greater than what we found in our study sample. One of the entry criteria of the study was 'HIV disclosure to at least one family member.' Given this criterion, HIV disclosure challenge is under-represented in our study sample. Patient registry data from the study sites suggest that HIV disclosure is a major problem, especially in the Northeast. For example, in one of the study sites in the Northeast, over 30% of the PLH registered at the hospital had not disclosed their HIV status to anyone in the family; therefore, these PLH were not included in our study.

Table 2 Correlation coefficients and significance levels among selected variables

	1	2	3	4	5	6	7	8	9
1. Region									
2. Female subjects	0.014								
3. Age	0.018	-0.162*							
4. Education	0.086	-0.161*	-0.028						
5. Annual income	0.260*	-0.140*	-0.014	0.205*					
6. Average family size	0.177*	0.002	-0.168*	0.022	0.015				
7. Emotional social support	0.039	0.026	-0.073	0.097	0.102*	0.085			
8. Disclosure within family	-0.195*	0.087	0.160*	-0.051	-0.086	-0.029	0.005		
9. Disclosure outside of family	-0.375*	0.048	0.049	-0.073	-0.140*	-0.094	0.085	0.264*	

*P < 0.05

Table 3 Multiple linear regression examining correlates of HIV disclosure

	Disclosure within family		Disclosure outside of family	
	Std. β	P value	Std. β	P value
Region (ref. North)	-0.205	<0.0001	-0.363	<0.0001
Female subjects	0.116	0.021	0.049	0.305
Age	0.196	<0.0001	0.066	0.169
Some high school or more (ref. less than high school)	-0.010	0.844	-0.033	0.489
Individual annual income	-0.014	0.778	-0.043	0.386
Family size	0.040	0.419	-0.027	0.573
Emotional social support	0.023	0.632	0.113	0.016

Std. β = standardized beta coefficient

Our finding underscores the importance of providing PLH with adequate social support to help them make informed decisions about HIV disclosure.

Women in our study were significantly more likely to have disclosed to at least one family member compared with men. The profile of PLH in our study may provide a plausible explanation of this finding. Over 70% of PLH in our study were female subjects. This gender composition is consistent with the heterosexual HIV transmission patterns in Thailand, where most women acquire HIV from their husbands. Another plausible explanation of this finding may have to do with the transmission mode of the HIV epidemic in Thailand, especially in the Northeast. Most women in the Northeast find out about their HIV status after their husbands get diagnosed with AIDS or die of AIDS. Therefore, the gender composition of our study sample may be reflecting the large proportion of women who lost their husbands due to AIDS and subsequently find out that they themselves are HIV positive.

As with all studies, there are some limitations to this study. First, we conducted data analyses based on cross-sectional data; therefore, causal interpretations of the results cannot be established. For example, PLH who reported high emotional social support also reported higher HIV disclosure outside of family. However, due to the cross-sectional nature of the study, we cannot make inferences on whether higher social support contributed to more HIV disclosure. We can only confirm that there is an association between emotional social support and HIV disclosure outside of family. Second, we did not have detailed information of the duration of time of participants living with HIV. We found in our study that older PLH were significantly more likely to have disclosed to at least one family member. Older PLH may have lived with HIV for longer duration compared with younger PLH, thus providing them with more cumulative time to disclose their HIV status to their family members. Unfortunately, we did not have detailed information in our study on the disease stage of PLH to further investigate this hypothesis.

Despite our limitations, our findings have significant implications on the wellbeing and adjustment of PLH and HIV disclosure as they cope with living with HIV. For PLH, the stress around HIV disclosure emerges from having to decide what, when, how and to whom to disclose their HIV status to their family members and others. If the PLH decides not to disclose, they face multiple stressors about how to manage their illness effectively without being able to completely explain their daily routine and behaviour to family members. Seeking

social support from family members and those outside of family become more challenging when PLH choose not to disclose. In addition, adhering to ARV therapy without adequate support presents such challenges as having to either hide their pills or to lie to others. The need for secrecy creates added burden on PLH.²³⁻²⁵ HIV disclosure decisions also impact HIV transmission acts.²⁶ In addition, when PLH do not disclose their HIV status, the odds of being depressed are threefold, similar to the rate when family members are ashamed of the HIV-positive adult.⁹

Current research on HIV disclosure is largely based on the premise that knowledge of serostatus and awareness of risks automatically leads to serostatus disclosure and protective behaviour. This premise has never been supported by the data.²⁷ Our study provides empirical evidence on the regional variations in HIV disclosure in Thailand and underscores the importance of conducting additional research to explore the culturally unique concerns and barriers of HIV disclosure, with a specific focus on the regional variations. HIV disclosure process is an important area to address in Thailand, yet empirical investigations of HIV disclosure in Thailand are limited. In order to design an effective family-based intervention focusing on HIV disclosure in Thailand, it is essential to investigate the unique barriers and concerns around HIV disclosure in Thailand and to consider them within the framework of the cultural, social and relational contexts from which they emerge.

In designing future intervention on HIV disclosure, it is important to consider both the potential benefits and risks associated with HIV disclosure. It is also important to consider HIV disclosure as a process, not a one-time event; therefore, interventions should be designed to provide ongoing support throughout the disclosure process. Future interventions need to be culturally appropriate and gender sensitive. To address this important issue, we are currently mounting a formative study to examine the barriers and concerns around HIV disclosure among HIV-affected families in Northeastern Thailand. The findings from this study will shed light on the design of future interventions focusing on HIV disclosure.

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