INFLUENCE OF PERCEIVED SECONDARY STIGMA AND FAMILY ON THE RESPONSE TO HIV INFECTION AMONG INJECTION DRUG USERS IN VIETNAM

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Abstract

The full impact of secondary stigma (stigma directed at family) on an HIV-positive individual is unknown. This qualitative research explores perceptions of secondary stigma in the Vietnamese context and its influence on the ways in which an injection drug user (IDU) copes with HIV infection. Data on experiences learning one’s HIV status, disclosure decisions, family reactions, and stigma from family and community were collected through in-depth interviews with 25 HIV-positive IDUs recruited through a health center in Thai Nguyen, Vietnam. Participants felt despair
when learning they were HIV-positive and expressed concerns focused on the emotional burden and the consequences of HIV stigma that extended to family. Many participants engaged in self-isolating behaviors to prevent transmission and minimize secondary stigma. Data illustrated the strong value given to family in Vietnam and underscored the importance of secondary stigma in the coping process including gaining social support and engaging in risk reduction.

In Vietnam approximately 65% (UNAIDS, 2004) of all HIV cases occur among injection drug users (IDUs). The overall national prevalence of HIV/AIDS among this group is estimated at 33%, ranging from 3% to 58% by province (Hammett et al., 2006; Ministry of Health VietNam, 2006; Quan et al., 2004). IDUs are a marginalized and highly stigmatized group. An association between injection drug use and criminal behaviors, such as stealing; behaviors that damage the family financially, materially, and spiritually; and behaviors that deviate from moral values, such as drug use and prostitution, contribute to IDU-related stigma in Vietnam (Hong, Ahn, & Ogden, 2004). With the advent of the HIV/AIDS epidemic and the epidemiologic associations among HIV, injection drug use, and commercial sex work, Vietnamese government programs to prevent “social evils” (defined as behaviors that deviate from moral values and threaten traditional norms (Luong, 2006)) were closely tied to programs to control HIV/AIDS (Hien, Giang, Binh, & Wolfers, 2000). As a consequence of years of fear-based control and policy, HIV/AIDS stigma now exacerbates the preexisting stigmas attached to these “social evils” (Hong et al., 2004; Maher, Coupland, & Musson, 2007; Tran et al., 2006).

Fear of additional stigma related to HIV/AIDS infection poses a major challenge in limiting the spread of HIV among already stigmatized groups (Maher et al., 2007); research has shown that HIV-related stigma undermines efforts to curb the epidemic (Malcolm et al., 1998; UNAIDS, 2006) by negatively affecting HIV-test-seeking behavior (Chesney & Smith, 1999; Fortenberry et al., 2002), willingness to disclose HIV status (Clark, Lindner, Armistead, & Austin, 2003; van der Straten, Vernon, Knight, Gomez, & Padian, 1998), health-seeking behavior (Chesney & Smith, 1999), quality of health care received (Khoat, Hong, An, Ngu, & Reidpath, 2005; UNAIDS, 2000), adherence to treatment regimens (Chesney & Smith, 1999; Vanable, Carey, Blair, & Littlewood, 2006), and social support solicited and received (King, 1989; Malcolm, 1998; Sowell, Lowenstein, Moneyham, Demi, Mizuno, & Seals, 1997).

Although additional stigma may be directed at persons living with HIV (PLWH), it may also be directed at those closely related to the stigmatized person, a form of stigma known as secondary stigma (Hong et al., 2004); Thus perceptions of secondary stigma directed at one’s family, friends, or caretakers may influence health-seeking and risk behaviors. A few HIV stigma studies have investigated secondary stigma experiences, but little research has focused on anticipated reactions to secondary stigma from the point of view of PLWH and subsequent behavior (Cao, Sullivan, Xu, & Wu, 2006). Feeling responsible for secondary stigma may influence an HIV-infected person’s decisions to disclose HIV status, risk behaviors such as condom use, or seeking medical treatment for HIV or other infections.

Investigating perceptions of the potential psychological, social, and economic effects of one’s HIV status on one’s family is particularly important in Vietnam where the family is central to the self. Viewing family as an extension of self stems from Confucian traditions, which form the social and moral structures of Vietnamese society. Confucian teachings describe the position of the individual within society by emphasizing obligations based on relationships (Marr, 1981). To provide strength, stability, and continuity to the family group, Confucian doctrine stresses that family is more important than the individual and should be honored. Hence, the center of society is the family, and one of the most important
responsibilities of an individual is to protect his or her family (Hong et al., 2004; Ogden & Nyblade, 2005).

Given the central role of family in Vietnamese society and the limited research on secondary stigma particularly in Vietnam, we explored the role of family in IDUs response to their HIV status. Specifically, we used qualitative research methods to interview IDUs about their thoughts and experiences after learning of their HIV seropositivity. Qualitative methods emphasize depth and insight rather than breadth and generalizability to yield rich data from a purposefully selected, relatively small sample of participants with personal knowledge of the research topic (Ulin, 2005). Understanding the influence of family in relation to HIV status and stigma may help contribute to more comprehensive HIV prevention and stigma reduction programs in Vietnam. Moreover, for HIV intervention programs to be successful, we must understand the social and cultural factors that affect IDUs living with HIV/AIDS and the behaviors used to cope with HIV diagnosis and stigma. For this article, we seek to understand the role of family and perceptions of secondary stigma in the ways an IDU copes with an HIV diagnosis, including self-stigmatization; behaviors such as self-isolation or unwillingness to disclose HIV status, driven by concern about family members; and suicidal ideation. We also include a description of the role of family support in coping with HIV.

METHODS

This research was conducted as part of the formative phase of a randomized behavioral intervention trial to assess intervention effectiveness on reducing HIV transmission risk behaviors and increasing support for HIV-positive IDUs in Thai Nguyen Province—an economic and academic center located 80 kilometers from Hanoi in northeast Vietnam. This region has a tradition of opium cultivation and use, making opium and heroin relatively easily accessible. The population includes approximately 1 million residents and an estimated 43,000 migrant workers drawn by employment in gold and tin mines (Van, Singhasivanon, Kaewkungwal, Suriyawongpaisal, & Khai, 2006). In 2004, an estimated 6,450 IDUs resided in Thai Nguyen. Based on our previous study of 1,432 IDUs living there, approximately 97% of IDUs were male, 5% had been previously tested for HIV, and of those tested, 35% were HIV-positive (unpublished data).

To understand stigma and disclosure experiences of HIV-positive IDUs, we conducted in-depth interviews with 12 men who had disclosed and 13 men who had not disclosed their HIV status to their primary sexual partner. Topics covered during the in-depth interviews included general perceptions of the community, experiences with drug use, experiences related to testing for HIV and to learning one’s HIV status, disclosure decisions, family reactions, and stigma within the family and within the community.

Participants were selected using purposeful sampling to maximize data relevant to research aims. To be eligible for an in-depth interview, men had to be aged 18–49, provide informed consent, be a resident of Thai Nguyen Province, have undergone voluntary counseling and testing (VCT) within the last 2 years, have been diagnosed with HIV, and report injecting drugs in the last 12 months. All participants had learned of their HIV status through VCT procedures following the LifeGAP protocol.

Participants who had disclosed their HIV status were recruited for interview from 499 participants who were screened in a previous research project but who were ineligible due to being HIV-positive. Among those who had indicated interest in participating in future research, 23 were screened and 12 participated in the current project. The other 11 did not participate because they had not disclosed to their wives/partners or did not meet eligibility criteria. Participants who had not disclosed their HIV status were recruited through
counselors at a VCT center in Thai Nguyen Province, Vietnam. All 13 nondisclosers who were screened participated.

DATA COLLECTION, MANAGEMENT, AND ANALYSIS

A team of three ethnographers conducted interviews in private rooms at a health center near the participants’ homes. Ethnographers had previous experience with qualitative interviews and were intensely trained in interview techniques during a 1-week workshop. Interviews were semi-structured and included questions asked of each informant. The research plan, interview guides, and consent forms were reviewed and approved by the institutional review boards of Johns Hopkins University Bloomberg School of Public Health and the Centre for Preventive Medicine in Thai Nguyen, Vietnam. Responses to all interview questions and topics were open ended, allowing for probing to clarify. Interviews lasted approximately 1–2 hours and were tape recorded, transcribed in Vietnamese, translated into English, and entered into Atlas TI (Muhr, Scientific Software Development, 1997). The data were reviewed for main themes, coded for analysis, and organized into matrices to facilitate comparisons.

RESULTS

All IDU participants were male with ages ranging from 27 to 47 years old (median: 34; interquartile range: 32, 37). Education ranged from secondary school to vocational training to postgraduate. Most participants were farmers, laborers, vendors, small business owners, or unemployed. Marital status included married, never married, and divorced (Table 1). Most reported multiple lifetime partners, and about half reported having visited sex workers sometime during their life. All reported having smoked opium, injecting either opium or heroin, and previously sharing needles and syringes. All but two participants believed they acquired HIV through shared injection equipment. These exceptions thought they acquired HIV from a sexual partner.

The median amount of time since learning HIV status was 18 (mean: 20) and 14 (mean: 13) months for disclosed and nondisclosed participants, respectively. Since learning of their HIV infection, the majority continued to inject drugs but reported a reduction in high-risk HIV transmission behaviors. Many reported that they no longer shared needles or syringes because these are cheap and easily purchased and because they did not want to transmit HIV. Reasons given for decreased drug use included the following: the desire to maintain health, receiving drug rehabilitation, having family support, having a family member control their money, or taking antiretroviral drugs (ARVs) or opportunistic infection (OI) prophylaxis or treatment. Six of those who had disclosed were taking either ARVs or OI prophylaxis, whereas none of the nondisclosed participants reported taking ARVs or OI treatment. Most nondisclosers suggested that they would either disclose when they needed medicine or when medicine became available. Several, however, stated they were not taking any medicine in order to hide their infection.

Many participants had reduced their sexual activity after learning of their HIV infection either as a means to prevent transmission or from a lack of desire. Most also reported using a condom when having sex with their wives or other sexual partners, whether they had disclosed their HIV infection or not. One man who had not disclosed, however, did not use a condom to avoid raising suspicion from his wife. Another man and his wife, to whom he had disclosed, chose not to use condoms so that they could conceive.

Although the intent of the interview script was to elicit information about community attitudes and stigma experiences, participants repeatedly responded to interview questions and probes in a way that demonstrated the central role and importance of family. Moreover,
the majority of fears expressed were in terms of one’s family—whether they be fear of the family’s reaction to the participant’s HIV status or fears of the effects of his HIV infection on the family. Despite these fears, the majority of those who decided to disclose to certain family members reported eventually receiving their support. In this article, we focus on the role of family in IDUs’ experiences with HIV. Specifically, we will discuss initial depression and fears when learning they were infected with HIV; self-stigmatizing behaviors to prevent transmission to family; concern for emotional burden on family members; concern for associated/secondary stigma directed at family; suicidal thoughts to prevent secondary stigma; and family response and support.

INITIAL DEPRESSION AND FEARS

When participants recounted first learning that they were HIV infected, many reported immediate shock, disbelief, and generalized fear. A few indicated that they had expected a positive result because they injected drugs. Even when they were not surprised about the result, all but one participant felt some despair. Interestingly, some participants’ first thoughts were not about themselves. A married 30 year-old who had disclosed to his wife and mother, stated: “I thought most of my wife. I felt sorry for her.” The vast majority of informants also described feeling depressed and afraid of rejection by their family members and the local community. One unmarried 34-year-old participant, who had disclosed to no one, recalled when he was given his test results, “I felt depressed and inferior. Thinking about the positive results, I was scared and sad … I fear most that other people will distance themselves from me. It is unavoidable.” Many participants reported that those with HIV in their community used separate personal items, such as eating utensils, and that neighbors and family members threw away cups and dishes after a person suspected to have HIV used them. Therefore, some participants worried that they would also experience this form of discrimination. “I would be sad if I was required by family to eat with a separate bowl and chopsticks,” said a unmarried 38-year-old who had disclosed to no one.

In addition to explicit concerns about discrimination and physical abandonment, many participants experienced fears of imminent loneliness and emotional abandonment as evidenced in the following quote.

I was very worried. First my life expectancy would be shorter, don’t know when to die. Secondly … I was afraid of people’s stigma and abandonment, especially close family members, my neighbors … Firstly, what my family, relatives will think about me. Secondly, what friends and neighbors will think about me. I don’t think that they will stay away from me but I think their emotions and feelings for me will not be the same, so I am very scared.” – married 37-year-old who had not disclosed to his wife

As indicated in the previous quote, the majority of participants also thought about death resulting from HIV infection. Regardless of disclosure status, many feelings about death reflected an underlying concern for the economic and social well-being of the participants’ immediate family, especially for their wives and children. One 37-year-old man, who had not disclosed to his wife, explained:

I felt irritated, sad, and uncomfortable. The disease was already within my body. At that moment, I felt physically normal. But mentally, I was depressed … I don’t know when I may die. This is a concern … I worry about how long I can live and about wife, children and family economy.

Although participants feared an early death (because of the economic and social responsibility they felt for their family), none discussed fear of the process of death. The
theme of family extended beyond initial responses to learning their HIV status and became a dominant theme throughout the discussion of their first years coping with their HIV status.

**SELF-STIGMATIZING BEHAVIORS DUE TO FEAR OF TRANSMISSION**

In addition to their social and economic family responsibilities, participants felt responsible for their families’ health. For the vast majority of participants, concern about transmission led to self-stigmatizing behaviors such as isolation. Some participants who had not disclosed provided alternative rationale to their families for their self-isolation. One unmarried 32-year-old who had disclosed to no one explained:

As I had a room of my own, I took everything, even the smallest thing, into the room with the reason that I was addicted and risky … I learned from a meeting that I attended that old people’s immunity is very weak. Since my parents are old, I wanted to protect them from illness. I did not tell them that I have HIV, but I said that I have an addiction, which sometimes leads to illnesses like liver disease. As a result, I wanted to separate myself to avoid getting my parents sick.

Even participants who had disclosed and had support from family chose to isolate themselves, thereby engaging in self-stigmatization to protect their family. One man described how he altered his behaviors to avoid accidental transmission.

Now if I have a scratch on my hands or legs, I will not give my children a bath. I use a separate set of bowls and chopsticks. I have my own private teacup too, but share the teapot. Only my teacup is put in a separate place as are my bowls and chopsticks, towel, toothbrush and other things. Everything.” (married 38-year-old who had disclosed to his wife and father)

Feelings of inferiority and fear of rejection also led a few participants to engage in self-imposed isolation from their family, friends, and neighbors. “Due to my inferiority, I have to give attention to talking to other people. I cannot talk normally like others” reported a married 34-year-old who had disclosed to his wife and mother.

Several participants discussed taking extreme measures to protect their family from HIV infection. For example, one 37-year-old man, who had disclosed to his wife, divorced her when he learned that she and his child were not infected. “I am infected,” he said, “and wanted to liberalize my wife and children [from the impact of my HIV], and to prevent infection in my children [through divorce].”

A married couple who were both HIV-positive chose to have an abortion to prevent transmission to their unborn child. Another married couple who were both HIV-infected took their daughter to live with her grandmother to prevent transmission.

She stays with her grandmother all the time, since she was three … She lives there, never lives here. She eats and sleeps there. We rarely give [her] a bath and, only wash her head, she has to bathe herself. (married 33-year-old who had disclosed to his wife)

For many participants, this self-imposed isolation removes sources of encouragement, support, and love and may augment emotional burden. As evidenced in the above quote, self-stigmatizing behaviors also limit the role of HIV-positive IDUs as fathers, husbands, and sons.
CONCERN ABOUT PSYCHOLOGICAL EFFECTS ON FAMILY MEMBERS

In spite of isolation potentially diminishing a man’s role in his family, participants continued to want to act as protectors. Almost every participant expressed concern about the emotional effects of their HIV infection on their wives, children, or parents.

I didn’t want to make my family miserable, didn’t want to be a burden to my family. At that time I thought I wanted to die soon, quickly to release the burden, so that my parents, wife and children didn’t have to worry about me.” (married 32-year-old who had disclosed to his wife and other family members)

Although he eventually decided to disclose, other participants chose not to disclose for similar reasons.

Initially, I was also sad … Family members will be even more worried with the disclosure. I don’t even talk about it to my wife. With the disease, I may worry. But family members will be dozens of thousands of times more worried. Therefore, it would be best not to disclose it … Parents are old. Wife and children will be scared from what they have heard about this irreparable disease. Accordingly, I don’t want to disclose it. (married 37 year-old who had not disclosed to his wife)

Other participants expressed fear that family members, especially mothers and wives, would become physically ill due to the shock of such devastating news.

Participants were also concerned about psychological effects on their extended family (siblings, nieces, and nephews), as well as on immediate family from whom they were physically separated. One man explained that he did not want his son and daughter who had left the community to know about his HIV because it would devastate them.

I am afraid if I tell [my son] he will be shocked. He just got a permanent job last November, so I am afraid that he will be depressed and quit the job. It will be the same with the one in Taiwan, I am afraid that she will be depressed, she will not work, she will be worried about me. (married 47-year-old who had disclosed to his wife and other family members but not to his children)

Participants also worried about lifelong psychological effects on family. One married 39-year-old man, who had not disclosed to his wife or family, worried that his child would feel inferior her entire life because her father has HIV, saying: “When my child grows up people will know that she is not infected, then it does not matter but she will still feel inferior herself and inferior to her friends.” Furthermore, concerns about the emotional burdens to their family extended beyond psychological consequences to include subsequent physical and economic tolls.

CONCERN ABOUT STIGMA DIRECTED AT FAMILY MEMBERS

Participants not only worried about physical, psychological, and economic costs stemming from the emotional burden of knowing a family member has HIV, they also shared worries about the effects of discrimination from the community on their family’s economic well-being and mental health.

My younger siblings all have houses for rent which provide their incomes. I am just afraid that if the tenants know I have HIV they will not stay. (married 39 year-old who had not disclosed to his wife or to his family)

Several informants were afraid that if their HIV status were known, their children would not be able to go to school. Like the participant whose daughter lived with her grandmother to prevent accidental transmission, another participant sent his child to live with the grandmother to protect against stigma.
My child lives with maternal grandmother because the mother is abroad. I am just afraid that if my child stays with me, my child will be affected—affected such as stigma. I am not afraid of the child’s getting infection because I know the way [to prevent infection]. Here I am afraid that when the child goes to school, they know that the child is of an addict, HIV-infected. (divorced 37-year-old who had disclosed to his ex-wife)

Similar to their concerns about lifelong psychological effects on their children, some interviewees discussed lifelong effects of stigma on their children.

His [my son’s] getting married will be difficult, if the village knows. If they know that parents are HIV-infected then their children don’t dare to get married to him, even when taking a test and holding the test result paper, it will be difficult. (married 47-year-old who had disclosed to his wife and other family members)

Secondary stigma is a profound concern, as it has the potential to extend well beyond the participant spatially and temporally. The weight of this realization may in turn greatly influence how an HIV-positive IDU responds to his infection and to his duty to protect his family.

**SUICIDE TO PROTECT FAMILY FROM STIGMA**

Fear of the impact on one’s family is so great that several participants discussed suicide.

I did not fear for me, but I did for my family members, wife, and child. I am responsible for my disease, but I was scared for my family and for the bad reputation for my family … Because suicide is not related to disease, I wish to die by committing suicide to prevent people from thinking that I died from AIDS. (divorced 32-year-old who had not disclosed to his ex-wife, discussing several suicide attempts)

One participant wanted to commit suicide before becoming visibly sick with an AIDS-related illness. This informant was worried that his family would not be able to find someone willing to carry his coffin or that those who did carry his coffin would demand that his family cover the coffin in paper to prevent HIV transmission.

My friends died with skinny bodies and lumpy faces. Therefore, I said to myself that before I am too weak, I must commit suicide. Now, I am still big and fat. But when I am too thin, it is too scary to others to look at my face … I said [to my wife], “It is best to die together, otherwise, we wait until I die with physically destroyed body, nobody would carry me. If they do, they will have to use a piece of paper to cover their hands before carrying me.” In general, when young people died without proof of dying from HIV or not, people used paper to cover their hands. They feared transmission. I don’t know, but how can the transmission possible through the coffin. (married 28-year-old who had disclosed to his wife)

Notably, interviewees suggested that suicidal thoughts were not a consequence of depression, but rather a means to prevent the community discovering their disease. Participants wanted to die before physical characteristics of AIDS became evident to prevent community stigma directed at their family and the public consequences of death from HIV/AIDS.

Another participant described how he attempted suicide because he did not want to suffer the life of a person with AIDS.

My wife encouraged me a lot because I thought that we should not live just to become more miserable. I used to dissolve rat poison and inject the solution into
the body, but didn’t die. (married 47-year-old who had disclosed to his wife and other family members)

This quote hints to what many other informants who had disclosed to family stated—family members provided an important source of care, encouragement, and support.

**FAMILY SUPPORT**

Many IDUs who had disclosed were eventually able to overcome their depression, reduce high-risk behaviors, seek medical treatment, and go on with life normally, which they attributed to the care and love of their families.

> [After discovering my HIV infection] They [parents] loved me more, in general … previously, they kept the food to themselves, but since they learned about my HIV, they reserved or shared the tasty food with me by bringing it to my house. (married 28-year-old who had disclosed to his wife and parents)

> She [wife] loves me more too. [We] think more about each other now. The goal is to live with each other better. (married 27-year-old who had disclosed to his wife and mother)

Nevertheless a few participants shared that some family members reacted negatively.

> Even when I came to visit, my family members were afraid, when sitting for a drink, it was the same, when smoking tobacco with a waterpipe, I did see people acting differently. (married 47-year-old who had disclosed to his wife and other family members)

> Another participant who had not explicitly disclosed his HIV status to his wife at the time suspected that his wife left him after discovering that he was infected.

> When I wanted sex, she just lay showing disinterest in it. Initially, she said she wanted to go back to her own house for a bath. Then the separation was followed by quarrels, and she came back to her own house … She said she went back to her own house for a bath and no more sex. She seemed unhappy complaining about this and another. Then she went back to her house permanently without saying that it was due to my disease. (married 32-year-old who had disclosed to his first wife, second wife, and mother)

**DISCUSSION**

Our findings illustrate the importance of family to an IDU during the first 2 years after learning of HIV seropositivity, regardless of whether he disclosed his HIV status during that time. Our research expands on previous investigations, which tend to characterize secondary stigma as a subset of broader stigma and have not specifically addressed the importance of family and the impact of secondary stigma from the perspective of PLWH. Participants expressed both fear of family reaction to their status and fear of consequences to family.

Participants feared rejection, discrimination, and abandonment by the community but especially by their family. At the same time, thoughts of an early death and secondary stigma prompted fear about the social and economic well-being of their surviving relatives. Many worried that their disclosure would cause psychological stress to their parents, wives, and children. In the midst of this desire to protect their families from the consequences of HIV and stigma, participants also expressed the importance of family support. This attention to family seems to reflect the precedence of family within the sociocultural context of Vietnamese society and supports other study findings that family is the principle source of support for those with HIV/AIDS in Vietnam (Thi et al., 2008).
Of primary concern for many participants was preventing transmission and reducing the emotional, social, and economic burden to family. In an attempt to protect family members, some participants engaged in extreme behaviors such as divorce, avoiding contact with children, or sending children to live with relatives, highlighting the need to educate both those with HIV and the community about mechanisms of HIV transmission. Most participants resorted to some form of self-isolation. As part of the same culture and society engaged in stigmatizing IDUs and those with HIV, an HIV-positive IDU may adhere to those morals and values and believe he deserves an inferior position and discrimination (Ogden, 2005). Indeed, some participants stated they were inferior. Internalization of community and family attitudes may contribute to the tendency to use self-isolation in the coping process to protect others. In addition to self-isolating behaviors, this internalized stigma may result in depression, despair, shame, low-self-esteem, withdrawal from loved ones, and reduced contact with the community (Hong et al., 2004; Thi et al., 2008).

Almost all participants indicated they experienced at least one of these consequences associated with internalized stigma at some point after receiving their HIV test results—a time when IDUs need emotional and instrumental support. Engaging in self-isolation and withdrawing from loved ones may be particularly destructive for an IDU and his ability to cope with HIV. Depression and lack of social support have been shown to increase injecting and sexual risk behaviors among HIV-positive IDUs (Latkin & Mandell, 1993; Williams & Latkin, 2005). In our study participants reported that family support aided in reducing risk behaviors such as injection drug use and in obtaining medical treatment. In addition to impacting individual risk reduction, self-isolation impacts disclosure, which in turn prevents negotiation of condom use and needle sharing between sexual and injecting partners, respectively.

Self-isolation may further limit family and community support for two reasons. First, withdrawal and unusual behavior validate suspicion of injection drug use (Rounsaville, Weissman, Crits-Christoph, Wilber, & Kleber, 1982). Because IDUs in Vietnam are often assumed to be HIV infected, suspected drug use leads to injection drug use and HIV stigmatization in the community (Hien et al., 2000; Maher et al., 2007). Second, self-isolation may exacerbate negative attitudes because an HIV-infected IDU cannot live up to his traditional family duties. Social isolation of an individual, whether by his own choice or by the community, affects the social and economic status of his relatives because he can no longer contribute the expected level (Hong et al., 2004). Moreover, because of drug use and suspected HIV status, many IDUs already cannot meet society’s expectations. Social and economic hardship for the family was another consistent concern of participants, though most participants focused on secondary stigma as the primary source of this suffering.

To avert secondary stigma, several participants contemplated suicide. Suicidal ideation and attempted suicide to protect families have been found in other studies. PLWH in Ho Chi Minh City reported suicidal thoughts due to fear of burdening their families and fear of physical changes associated with AIDS (Thi et al., 2008). When the drive to protect one’s family from social stigma, emotional burden, and economic hardship are coupled with depression, decreased self-worth, and isolation, an increased tendency toward suicidal ideation may result. Many participants who had disclosed in our study credited their ability to overcome depression, shock, and suicidal thoughts and to eventually live more healthily to the love and support of family. Even within the family, discrimination and moral judgments about PLWH are significant barriers to disclosure (Clark et al., 2003; van der Straten et al., 1998), making the decision to test and disclose complicated.

Our study has several limitations. Inferences about disclosure may be biased. Participants who disclosed on average knew their HIV status for 7 months longer than those who did not.
disclose, simply giving them more time or opportunity to disclose. Additionally, nondisclosing and disclosing participants were different in ways other than disclosure status. Because disclosure was defined in terms of disclosure to sexual partner and not disclosure to another family member or friend, those who disclosed were required to have a sexual partner. Consequently, a larger percentage of those who disclosed were married, which may have created some bias in response and affected generalizability to other HIV-positive IDUs in Vietnam. Because data were collected cross-sectionally through self-report, our ability to make inferences about temporality is limited, and self-reporting bias may be present. Conclusions from data are limited in that although the focus was secondary stigma and family role in coping, we did not collect detailed information on family structure of information about stigma directly from family.

Nevertheless, our aim was to document and describe reactions to HIV-positive test results and to determine the role family plays in behaviors related to the coping process. For sensitive topics such as HIV disclosure and stigma experiences, qualitative methods are useful and can yield generalized principles, which may be incorporated into meaningful interventions. Other research comparing stigma experiences across African and Asian settings found, as did we, that family members likely provide a large portion of support for PLWH (Ogden, 2005). Following these findings, we believe that some of the results from our research may be applicable to non-Vietnamese contexts in terms of the role of family in HIV intervention, prevention, support, and stigma reduction.

Although the Vietnamese government has begun anti-stigma campaigns to increase compassion for PLWHs (Hong et al., 2004), currently those living with HIV in Vietnam have many unmet needs in terms of treatment and support, especially in the broader community context (Thi et al., 2008). Interventions for HIV-positive individuals have tended to focus on those living with HIV; however, our study underscores the importance of considering the sociocultural context of “self.” In Vietnam, if they are to work, in addition to educating those with HIV about transmission, sustainable interventions must acknowledge the importance of family in individual decisions about HIV health-seeking behaviors and disclosure. Programs should add counseling for PLWH to reduce self-blame or guilt for secondary stigma; provide guidance on disclosure to sexual and injecting partners as well as to those who could provide emotional and instrumental support; and offer family counseling and support groups to encourage family to more actively provide support for PLWH and to teach family members how to deal with secondary stigma. Likewise, community stigma reduction campaigns should address not only stigma directed at HIV-infected individuals but also secondary stigma directed at those associated with the stigmatized primary individual.

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References


TABLE 1

Study Population Demographics

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</tr>
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<td>Marital status</td>
<td>34 (range: 27–47)</td>
</tr>
<tr>
<td>Single (never married)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Married</td>
<td>11 (91.6)</td>
</tr>
<tr>
<td>Divorced</td>
<td>1 (8.4)</td>
</tr>
<tr>
<td>Children</td>
<td>3 (25.0)</td>
</tr>
<tr>
<td>0</td>
<td>6 (46.2)</td>
</tr>
<tr>
<td>1</td>
<td>6 (46.2)</td>
</tr>
<tr>
<td>2</td>
<td>1 (7.8)</td>
</tr>
<tr>
<td>Education level</td>
<td>3 (23.1)</td>
</tr>
<tr>
<td>Secondary school</td>
<td>9 (39.1)</td>
</tr>
<tr>
<td>High school</td>
<td>6 (26.1)</td>
</tr>
<tr>
<td>Vocational training</td>
<td>5 (21.7)</td>
</tr>
<tr>
<td>College, university</td>
<td>2 (8.7)</td>
</tr>
<tr>
<td>Currently employed</td>
<td>6 (25.0)</td>
</tr>
<tr>
<td>Yes</td>
<td>3 (27.3)</td>
</tr>
<tr>
<td>Currently injecting</td>
<td>9 (69.2)</td>
</tr>
<tr>
<td>Yes</td>
<td>15 (60.0)</td>
</tr>
</tbody>
</table>

<sup>a</sup> Among the disclosed participants, one man was married to his second wife and the divorced man was living with his current primary sexual partner. One man with no children was expecting his first child. Two participants were missing education level, and one participant was missing information about his employment.

<sup>b</sup> No p values or tests of statistical difference are given as the numbers come from a purposefully selected sample used for ethnographic research. When qualitative methods are used, the implied denominator is often inaccurate and therefore is not appropriate to use to draw statistical inference.