

A Qualitative Study of Stigma and Discrimination against People Living with HIV in Ho Chi Minh City, Vietnam

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Abstract Stigma and discrimination against people living with HIV/AIDS (PLHIV) are a pressing problem in Vietnam, in particular because of propaganda associating HIV with the “social evils” of sex work and drug use. There is little understanding of the causes and sequelae of stigma and discrimination against PLHIV in Vietnam. Fifty-three PLHIV participated in focus group discussions in Ho Chi Minh City. Nearly all participants experienced some form of stigma and discrimination. Causes included exaggerated fears of HIV infection, misperceptions about HIV transmission, and negative representations of PLHIV in the media. Participants faced problems getting a job, perceived

unfair treatment in the workplace and experienced discrimination in the healthcare setting. Both discrimination and support were reported in the family environment. There is a need to enforce laws against discrimination and provide education to decrease stigma against PLHIV in Vietnam. Recent public campaigns encouraging compassion toward PLHIV and less discrimination from healthcare providers who work with PLHIV have been encouraging.

Keywords Stigma · Discrimination · HIV/AIDS · Vietnam · Southeast Asia

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Introduction

An estimated 260,000 people are living with HIV in Vietnam (UNAIDS 2007). In Ho Chi Minh City, the largest city in the country and one of the epicenters of the HIV epidemic in Vietnam, the number is estimated to be more than 70,000 (Analysis and Advocacy 2006). The HIV epidemic has been primarily driven by injection drug use, due in part to Vietnam’s proximity to the “golden triangle” of opium production (Myanmar, Thailand, and Laos). By 2005, an estimated 53% of all HIV infections in the country had been acquired through injection drug use (Vietnamese Administration for HIV/AIDS Control 2006). Commercial sex work also drives the epidemic, and increasingly sex workers are using illicit drugs. Female sex workers are estimated to account for 4% of all HIV infected individuals (Vietnamese Ministry of Health 2005). The majority of other HIV infections are attributed to sexual transmission (Analysis and Advocacy 2006). It is estimated that homosexual transmission is responsible for less than 10% of new infections (Analysis and Advocacy 2006).

A survey that focused on at-risk populations, conducted in Ho Chi Minh City from October 2005 to June 2006, found that the HIV prevalence was approximately 30% among injection drug users and 11% among street sex workers (Vietnamese Ministry of Health 2007). More recently, however, HIV has been spreading to the general population. There is also increasing awareness that men who have sex with men are at risk for HIV (Colby 2003), and surveillance in this population in 2006 showed HIV prevalence to be 5% in Ho Chi Minh City and 9% in Ha Noi (Vietnamese Ministry of Health 2007).

At the time of this study in 2004, few treatment or care and support programs for people living with HIV (PLHIV) had been established in Vietnam. Treatment was available at one public hospital on a fee-for-service basis: patients could buy antiretroviral medications at market prices, and no free antiretroviral medications were provided. There was a small number of self-support groups for PLHIV in Ho Chi Minh City, named “Friends Helping Friends” clubs, providing social and psychological support. However, because these clubs included a number of current or former drug users, non-drug users often chose not to join.

In Vietnam, drug use, sex work, and crime have been identified by the government as “social evils” to be eradicated. Various bureaus and ministries, including the police, have been tasked to prevent and deal with these problems. In the first years of the HIV epidemic in Vietnam, the linkage with injection drug use and sex work added to the stigmatization of PLHIV. A study in 2004 demonstrated that two main causes of stigma and discrimination were fear of becoming infected through casual contact, and moral judgments against PLHIV related to the association between HIV and drug use and prostitution (Hong et al. 2004). Another study conducted in 2004 by UN Vietnam, demonstrated that these perceptions extended to the workplace; about 30% of workers interviewed held a strong belief that an HIV-infected person should be dismissed from the job, and 80% agreed with immediate public disclosure of PLHIV identified in the workplace (United Nations Country Team Viet Nam 2004). Fear of transmission has been strongly felt among health care providers as well, despite the fact that they are generally more knowledgeable about the modes of HIV transmission (Nguyen et al. 2004).

Although it is well recognized that PLHIV have many unmet needs in Vietnam, their voices and efforts are often not strong enough to gain adequate attention from the community, and there has been little research to understand the causes and sequelae of stigma and discrimination against PLHIV. This research was conducted in order to more clearly identify the problems faced by PLHIV in Ho Chi Minh City. Our goal was to gain insights on the causes, manifestations and impact of stigma and discrimination.

We provide recommendations aimed at raising awareness and increasing access to social support services for those who are infected or affected by HIV.

Methods

The study was conducted from October to November 2004 in Ho Chi Minh City. Qualitative research methods were used to elicit in-depth descriptions about experiences of stigma and discrimination from study participants, without the constraints of a closed-ended questionnaire. All focus group discussions and key informant interviews took place in private rooms at the Anonymous HIV Testing Site (ATS), the first free voluntary counseling and HIV testing site in Vietnam.

Participants were recruited by HIV counselors and peer educators at the ATS, a “Friends helping Friends” club, and other peer-support groups for PLHIV. Study participants were self-identified to be HIV-positive. Participants were divided into seven groups based on gender, age, and common risk characteristics, as follows: male injection drug users 18–25 years old, male injection drug users age over 25 years, female sex workers 18–25 years old, female sex workers age over 25 years, men who have sex with men (MSM), other men, and other women. These divisions were made in order to understand differences in stigma and discrimination between groups believed to be at higher risk (MSM, injection drugs users, commercial sex workers) and lower risk of HIV (men and women not in the above categories). In addition, based on our counseling experiences, we felt that the experiences of older drug users and sex workers (age >25 years) would be different than those who were younger.

A total of seven focus group discussions were conducted, one for each of the identified groups. Each focus group had seven to eight participants. The focus groups were led by two Vietnamese interviewers and followed a semi-structured interview guide. An additional note-taker was present at each focus group discussion. At the beginning of every focus group, participants completed anonymous forms with basic demographic information including age, marital status and occupation. The discussions focused on experience with stigma and discrimination, and participant opinions regarding their causes and effects in four sectors of their lives: the health care setting, the workplace, the family, and the community.

Following each focus group discussion, one or two individuals were invited to participate in individual in-depth interviews. Interview participants were selected using purposeful sampling, a procedure by which information-rich cases are strategically selected in order to gain maximum information relevant to the research goals

(Coyne 1997; Patton 2002). The interviews were intended to create a private space in which participants could discuss any sensitive issues that they were afraid to disclose during the focus groups, and share potential disagreements with opinions raised during the focus groups. A total of 12 individual interviews were conducted. Interviewers were the same study staff who facilitated the focus group discussions. A semi-structured interview guide was developed and edited for use during the interviews to reflect emerging topics from the focus group discussions.

The research study was reviewed and approved by the Institutional Review Boards at UCSF and the Ho Chi Minh City AIDS Committee. Focus group participants used aliases to hide their identity. The participants were able to withdraw from the conversation at any time and to refuse to answer any questions. Focus group discussions and interviews were conducted in Vietnamese, and all participants, facilitators and interviewers were Vietnamese nationals.

Discussions and interviews were recorded and transcribed. Opencode software (Umea University, Sweden) was used for coding and analyzing the data. Analysis was conducted in Vietnamese. The major goal in analyzing the data was to identify common themes and variations in themes across groups. Data collected from individual interviews was cross-checked with data from the focus group discussions to identify inconsistencies. Contradictions or different information between various sources of information were analyzed in more detail.

Results

A total of 53 PLHIV participated in focus group discussions, including 29 men and 24 women. The mean age of participants was 31 years (range 18–57). Most participants (70%) had a secondary school education or higher. Forty percent of participants were single, 39% were married, 15% were divorced, and 6% were widows or widowers.

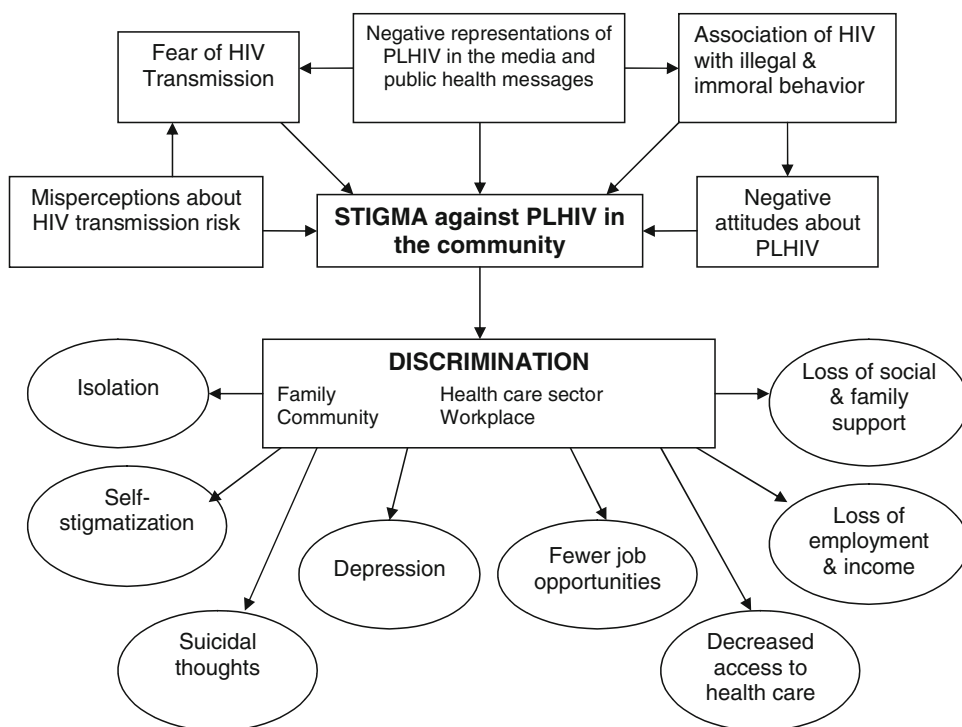
Information obtained during the 12 individual interviews mostly confirmed our findings from the focus group discussions. However, the interviews provided an opportunity to validate and expand upon the findings from the focus group discussions.

Three main themes relating to stigma and discrimination emerged: (1) attitudes, misperceptions, and negative media representations led to stigmatization of PLHIV; (2) acts of discrimination occurred within various sectors of Vietnamese society, including the family, the community, the healthcare sector, and the workplace; and (3) stigma and discrimination resulted in negative effects on PLHIV. These themes can be organized into a framework as shown in Fig. 1.

Causes of Stigma and Discrimination

Fear and misperceptions about the risks and methods of HIV transmission were noted by participants as principle causes of stigma and discrimination. Family members’

Fig. 1 Schematic diagram of stigma and discrimination against PLHIV in Ho Chi Minh City: causes, effects and relationships



beliefs that HIV could be transmitted through casual contact led to discriminating behavior within the home:

He treats me well as a father; however, he separates my items from the rest of the family. My bowls and chopsticks are carefully put aside, and my father always takes a bath before me because there is only one bathroom in the house. Whenever I take a bath before him, he cautiously cleans the bathroom with boiling water to ensure no virus can survive. (32-year-old female sex worker)

When I sit down on a certain chair, nobody has the courage to use it. (24-year-old female sex worker)

Fear of HIV and people infected by HIV was, in part, fostered by public health campaigns that used negative images of death and disease to try to scare people into avoiding high-risk behavior. Associating HIV with the government's "social evils" program to eliminate illegal drugs, prostitution and crime further stigmatized PLHIV as "bad people" because only those engaging in social evils would become infected:

Do you remember a few years ago? There were hundreds of posters and banners depicting images of death, skeletons, syringes and metaphors for sex work. These images and metaphors are rooted in the minds of the community. They automatically link HIV/AIDS with drug users and sex workers. They automatically think drug use and sex work will lead to unavoidable death. (29-year-old male IDU)

Stigma and Discrimination in the Health Care Setting

Discrimination in healthcare facilities was frequently reported by participants. Manifestations included non-verbal actions such as being ignored or stared at with disapproving facial expressions, and treated with unfriendly attitudes. Some participants also reported being verbally abused or being refused routine services.

Female participants reported frequent episodes of discrimination in obstetrics/gynecology hospitals. In one hospital, HIV-positive women were placed in a separate room marked with a sign outside the door as reserved for HIV-positive patients. Women reported that hospital staff refused to do routine work such as changing bed sheets or the covers on exam tables, forcing the patients to do these tasks themselves.

When I was hospitalized for an abortion at 5 months of pregnancy, I had to stay in a delivery room specifically designed for HIV-infected mothers. I stepped up to the delivery table and laid there by myself. Eventually, I "gave birth" without help. I was in labor for a while, and then the baby came out.

Only after that a midwife came and gave me a piece of cloth. She told me to clean myself up. I had to step down from the delivery table and get in the wheelchair with no support. (18-year-old female)

Study participants reported that discrimination from nurses and orderlies was more common than from physicians. Lack of adequate knowledge about HIV and fear of contracting HIV may contribute to the way these health care workers treated PLHIV:

[A nurse] placed the intravenous bottle in front of me and said, "Tell someone you know to do it for you!" She feared holding the needle to stick it under the skin into my vein. (57-year-old male IDU)

However, participants also reported abusive behavior from physicians. Some physicians' treatment of patients demonstrated a lack of knowledge about HIV disease as well as discriminatory practices:

I entered an examination room in a city hospital and was met by a doctor. The doctor asked me how long had I been infected. I answered that I had been infected over a year earlier. The doctor then said, "Do you know how long you will live? Only one more year." ...I was so shocked that I couldn't eat any food for a week. (25-year-old female sex worker)

I asked the doctor who advised me to get an abortion, "What will happen to my baby if I give birth?" and she answered, "You are not even able to take care of yourself, what are you thinking about, taking care of your baby?" (24-year-old female)

Some participants felt that there was a recent reduction in discriminatory attitudes and behavior in the health care sector. Experiences related to discrimination seemed to be occurring less frequently, and health care providers in HIV clinics in particular were noted to treat patients with more respect.

One doctor I know is very helpful. He is non-judgmental toward IDUs. I brought a couple of friends to him for an operation. He was more than willing to do it, and he even refused the operation fee. (50-year-old male IDU)

HIV/AIDS specialists treated us normally, but those who were not experts dreaded providing services to us. They must have considered us monsters. (25-year-old male IDU)

Stigma and Discrimination in the Workplace

Almost half (47%) of study participants were unemployed. The main reason given for not working was poor health,

and secondarily lack of funds for transportation. Those who had sought employment faced discrimination in their job searches. One participant shared his experiences in applying to work as a waiter in a restaurant:

I was denied the job due to my infection status. I'm sure of it since the employer spoke about it to the person who introduced me. The employer said they were fearful of HIV transmission. If I worked as a cook's assistant, I might hurt or cut myself with the knives, and the chance of transmission is high. But it shouldn't matter if I work as a waiter. Taking orders or carrying dishes are not at all risky. Learning from my previous experience, the third time I looked for a job I kept silent about my [HIV] status. Then I got the job. (25-year-old male IDU)

Some participants decided to quit their jobs because their employers or co-workers treated them differently after their HIV status became public. One participant noted:

In my workplace, everyone knows that I'm living with HIV. Some treat me well, yet the others are afraid of me. They stay away from me for fear of infection. (31-year-old male)

Stigma and Discrimination in the Family

Many participants reported that they were often isolated within the family, as their relatives avoided physical contact or sharing meals, kitchen utensils, or a bathroom.

We used to be a close family, but upon learning of my infection with HIV, they started to change. They never touched or used any items that I had put my fingers on. For example, the glasses were placed in a tray. Once I picked up one glass from the tray, they completely refused to use the other glasses in that tray. (30-year-old male IDU)

Two participants reported being separated from their children by other family members:

I was not allowed to take care of my child. My child was taken away from me by my mother-in-law. She said she did that to prevent the transmission [of HIV] to him. (27-year-old female)

My wife also discriminates against me. She looks down upon me and hurts me deeply with her words. She shouts at me and prevents me from holding my child, whom I love dearly. (36-year-old male)

In extreme cases, PLHIV have been forcibly ejected from their homes:

No sooner did my husband die [of AIDS] than my mother-in-law told me to move out of her house. She

said, "Get out of my house! If you remain here, you will transmit the virus to all of us." She kept hitting my children, yelling at them: "You have HIV-infected parents!" Little could I do but move out of her house. (25-year-old female sex worker)

Two female participants reported physical and sexual abuse by their male partners:

...After he got drunk, he started causing trouble. As he is a man, when he is sexually aroused, he tries to get me into bed. But then he scolds me "Fuck you! You bring bad luck to me. Because of you, I don't have any children but the disease!" Then he hits me. I rarely answer back. (32-year-old female)

Every time he wants sex, he gives me a beating. I have to submit to him and do what I am told to do. (47-year-old female sex worker)

However, some participants received support from their families. In particular, several participants reported being cared for by their mothers:

My mom cares for me. She loves me dearly. There were times when I was too weak to move, so my mom took my dirty clothes and washed them for me. She is the only one who is willing to wash my clothes. (36-year-old male)

Stigma and Discrimination in the Community

Experience with stigma and discrimination in the community varied among the participants. Because they had not revealed their HIV-positive status to non-family members, most reported no discrimination from their neighbors and friends. The fear of the stigmatization and discrimination that might follow was enough for most PLHIV to actively hide information about their infection from anyone other than their immediate family and their closest friends.

For those PLHIV whose infection status was known in their neighborhoods, stigma and acts of discrimination were commonly reported. Neighbors did not want to say hello when they passed PLHIV in the street, would not touch or shake hands, and would either stare at them or avoid eye contact.

There is a food-stand near my house. When I went there to buy a bowl of noodles, the owner was reluctant to serve me: she asked me to go back home and she would bring the food to me later. She didn't want me to hang around there for fear of transmission. I was so ashamed. (24-year-old female sex worker)

In some cases, other family members were also shunned by the community because of their relation to a PLHIV:

Some of my neighbors did not allow their children to play with mine. They assumed I had HIV/AIDS. (36-year-old male)

Differential Stigma and Discrimination Between Subject Groups

Most participants agreed that IDUs were the most heavily stigmatized group because people in the community presumed that IDUs were thieves, liars, or had mental health problems.

You will be discriminated against being an IDU, let alone being a person who is HIV-positive. It's in the minds of people that an IDU must be a thief. (25-year-old male IDU)

Members of the MSM focus group felt that they faced double stigmatization due to their homosexuality and their HIV infection. Many cited ignoring the behavior of neighbors as the only way to cope with the discrimination they faced.

...over time everyone in my apartment building knew that I was infected. They looked at me with contempt because I was a drug user and HIV infected. My homosexuality only made it worse. Every time I leave the house, I am so sad because people look at me like I am abnormal. (21-year-old MSM)

Due to fear of stigma and shame associated with sex work, the majority of sex workers in the study kept their work a secret from family, neighbors and friends. We therefore were not able to assess whether sex workers suffered more or different discrimination than other women infected with HIV. Most HIV-positive sex workers in our study continued to work as sex workers, noting that they needed to support themselves and their families.

Effects of Stigma and Discrimination

Fear of stigma and discrimination among PLHIV often led to self-isolating behavior and/or low self-esteem. Participants reported avoiding contact with friends or family members, staying at home, and not accessing public services or seeking employment:

...whenever having lunch at work, I avoid sharing meals with my colleagues because of my HIV infection. (31-year-old male)

.... I have seen some job announcements for hairdressers. I would like that work, but I dare not apply because I don't think people will accept a sickly person like me. (24-year-old female sex worker)

Some participants reported avoiding health care services due to past experiences of discrimination in health facilities. Many noted that they would only seek health care for extremely severe conditions.

Every time the nurse passed by me, she stared at me in a bad way. I was so embarrassed. I did not know how to hide my face. I curled myself in the corner of the bed most of the time. After 2 days of intensive care in the hospital, I insisted on going home, even though I knew my condition was still critical. From then on, I never set foot in the hospital. If I'm sick now, I treat myself. (23-year-old male IDU).

Many participants reported past or current thoughts about suicide, such as planning suicide when they developed symptoms of AIDS. The reason for this was the fear of becoming a burden for their families and fear of the "disfiguring features" associated with the later stages of AIDS:

When my disease progresses to the last stage of HIV/AIDS, as I see people on TV or at the infectious disease department in the hospitals, it will be too hard to accept. You know, the figures are deformed and skinny. I imagine I won't even have the courage to look at myself in the mirror. How can I let my family see me? I discussed it with my husband, and we agreed that we will kill ourselves when we approach the last stage [of AIDS]. (27-year-old female)

Discrimination against PLHIV and their families can have negative economic consequences for those who own their own businesses. One participant noted that neighbors avoided his mother's store after they knew that he was infected:

I was living with my mother when I was seriously ill, which was a period of about 6 or 7 months, and very few people came to our food store. My neighbors told my mother, "Your hands are used to clean up your son, and he is HIV infected." As a result, we had to eat the food that we were supposed to sell. (25-year-old male IDU)

Discussion

Almost all of the PLHIV that we interviewed had experienced discrimination. Root causes of stigma and discrimination appeared to be fear of HIV infection, misperceptions about HIV transmission, and negative representations of PLHIV in the media. Previous research in Vietnam has shown that fear of HIV infection leads people to avoid contact with infected persons (Hong et al.

2004). Poor knowledge about HIV transmission may cause people to overestimate the risk of acquiring HIV infection through casual contact. Other studies have found that many people believe they can get HIV through casual contact such as hugging, eating together, or sharing a bathroom (Bain Brickley et al. 2005; Hong et al. 2004). Better public health education about the modes of HIV transmission would help people to correctly understand that HIV cannot be acquired through casual contact and may alleviate some of the isolating behavior that PLHIV in Vietnam commonly report.

The Vietnamese government campaign against “social evils” has been cited as a contributing factor to stigma and discrimination against PLHIV (Hong et al. 2004). For many years, prominently displayed public health posters linked HIV and AIDS with illegal drug use and prostitution. Skeletons and emaciated figures were used to demonstrate the consequences of behaviors deemed socially unacceptable, leading people to believe that disease and death were the inevitable outcome of HIV infection. By linking HIV infection with social evils, these campaigns promoted the message that all PLHIV were engaging in illegal and morally corrupt behavior. Newer public health campaigns in Vietnam encourage people to show compassion for PLHIV, but many of the older posters and the ideas that they fostered remain in the minds of the population.

This study found that stigma and discrimination were commonly encountered in public health care facilities. The experiences related by the PLHIV we interviewed indicated that many health workers feared HIV transmission from patients and overestimated the risk of occupational transmission of HIV. The fact that discrimination was encountered more often from nurses and orderlies than from physicians supports a conclusion that lack of training and poor knowledge underlie the poor treatment that many PLHIV experience in health care settings.

Substandard medical care and an atmosphere of stigmatization led some PLHIV to avoid health care facilities altogether. More and better training on HIV transmission and blood-borne pathogen exposure prevention is needed for health workers in Vietnam. Our own collective experiences in providing training to Vietnamese health workers since 2001 has been that stigmatization and discrimination in health facilities rapidly declines as staff become more knowledgeable and experienced in providing services to PLHIV. Study participants themselves suggested that the availability of low-cost or free antiretroviral medications, along with improved attitudes of health care providers, would decrease discrimination against PLHIV. Another suggestion was to create a center for HIV-infected or -affected children and a center for people in the last stages of AIDS.

For those participants who were working or had sought employment, stigma and discrimination in the workplace was a common occurrence. They reported that their co-workers and employers treated them differently by staring at them or avoiding them because of their HIV status. PLHIV have also been denied employment because of being HIV-positive. Vietnamese law states that employers cannot discriminate against PLHIV in hiring and cannot fire an employee because of HIV infection (Law on HIV/AIDS Prevention and Control 2006). Furthermore, HIV tests cannot be required of prospective employees, with the exception of air flight crews and military personnel (Government of Vietnam 2007). These laws need to be enforced, and workplace trainings on HIV transmission and relevant laws will help decrease stigma and discrimination against PLHIV.

In the home, most participants experienced some level of stigma and discrimination from their family members. Manifestations ranged from isolating behavior to hostile words. Discrimination within the family was particularly upsetting to PLHIV because family bonds in Vietnam are traditionally strong and for most people the family is their sole means of support. Counseling for family members of PLHIV could help them to better understand HIV infection, and training could improve their homecare skills while minimizing the risk of transmission.

Two female participants in our study reported being victims of sexual violence from a partner or spouse. This may or may not have been related to their HIV status. We did not have enough data on this topic to come to conclusions, but further research is needed regarding domestic and sexual violence against PLHIV and women in general in Vietnam.

Study participants agreed that IDUs faced the greatest stigma because of the additional stigma of being an IDU, a “socially evil” behavior in Vietnam. One stigma study in Ho Chi Minh City found that both IDUs and sex workers faced stigma and discrimination long before they were diagnosed with HIV (Hong et al. 2004). MSM also felt that they faced a double stigma due to their HIV infection and their sexual orientation. To our knowledge, there has been no research which has compared discrimination among homosexuals with and without HIV in Vietnam, so it is difficult to determine the extent that the stigma they experience is due to their HIV status or to their perceived risk behaviors.

Stigma and discrimination have direct negative effects on PLHIV in Vietnam. When stigma is highly prevalent in the community, PLHIV can internalize the negative attitudes and beliefs about HIV infection, leading to self-stigmatization, low self-esteem, and depression. Some study participants even mentioned considering suicide. Our group has launched a pilot study to document PLHIV’s

recognition of symptoms of depression and their health-seeking behaviors from the public and private sectors. Study participants in the current study felt strongly that outreach and support services for PLHIV, such as HIV counselors and self-help and support groups, were critical to their living “positively”. Female participants also expressed a need for all-female support groups, in which they would feel freer to discuss their personal issues and where they could receive emotional comfort from their peers.

Our research had a number of limitations. Because of the small sample size and the purposeful sampling methodology, the results may not be generalizable to the broader population of PLHIV in Ho Chi Minh City. Other community members, such as health care providers and family members of PLHIV, were not included, so the sources of information were limited. Nevertheless, the findings reflect the voices of those who participated, and point to measures that can be taken to decrease stigma and discrimination against PLHIV in Ho Chi Minh City.

On a more optimistic note, we are encouraged by recent signs of reduction of stigma and discrimination against PLHIV in Vietnam today. Public health campaigns now encourage sympathy and compassion for PLHIV, and prevention messages focus on routes of transmission rather than blaming specific groups of people for spreading the disease. Furthermore, according to study participants, as more health workers are trained and gain experience in caring for PLHIV, the level of discrimination in healthcare settings appears to be decreasing. Certain rights of PLHIV are now protected by Vietnamese law. However, stigma and discrimination remain a constant in the lives of PLHIV in Vietnam, and continuing efforts are needed to ensure that the gains made are reinforced and not lost.

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