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Perceptions of community and family level IDU and HIV related stigma, disclosure decisions and experiences with layered stigma among HIV positive injection drug users in Vietnam

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Abstract

This paper explores how perceived stigma and layered stigma related to injection drug use and being HIV positive influence the decision to disclose one's HIV status to family and community and experiences with stigma following disclosure among a population of HIV positive male injection drug users (IDUs) in Thai Nguyen, Vietnam. In qualitative interviews conducted between 2007 and 2008, 25 HIV positive male IDUs described layered stigma in their community but an absence of layered stigma within their families. These findings suggest the importance of community level HIV prevention interventions that counter stigma and support families caring for HIV positive relatives.

Keywords

injection drug use; Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome; layered stigma; disclosure; Vietnam

Introduction

The HIV/AIDS epidemic in Vietnam remains concentrated among high-risk groups, especially injection drug users (IDUs). In 2009, nearly a fifth of IDUs in Vietnam (18.4%) were infected with HIV and in some provinces between a third and a half of IDUs were HIV positive (Viet Nam 2010 Country Progress Report, 2010). In countries like Vietnam, where the HIV/AIDS epidemic is concentrated among socially marginalized persons, stigma towards people living with HIV/AIDS can be higher than in generalized epidemics.(Genberg et al., 2009) When HIV positive individuals perceive stigma towards those infected with HIV, they are less likely to disclose their status (Simbayi et al., 2007; Smith, Rossetto, & Peterson, 2008) and those who do not disclose their status have diminished HIV risk reduction behavior.(King et al., 2008)

The experience of IDUs in Vietnam reflects the convergence of the interrelated components of labeling, stereotyping, separation, status loss and discrimination, that Link and Phelan propose (Link & Phelan, 2001) lead to stigmatization. Drug use has been labeled a "social evil" since the post-American war era (Luong, 2006) and IDUs are stereotyped as thieves

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and liars with mental problems (Thi et al., 2008). IDUs experience rejection and isolation in their community and family (Wolfe & Malinowska-Sempruch, 2004) and, at any given time, as many as a quarter of the total population of IDUs in Vietnam may be forcibly detained in detoxification centers (DTCs) for periods of between two and five years.(Hammett et al., 2008) State sanctioned separation, loss of status and discrimination of IDUs lead inevitably, as Link and Phelan suggest, to stigmatization.

Mahajan et al. (2008, p. S77) observe that when there is “pre-existing stigma”, “vulnerable individuals” are likely to experience a higher degree of HIV/AIDS stigma and that “laws and policies in many countries” can also “exacerbate pre-existing stigma and discrimination associated with at-risk groups”.(Mahajan et al., 2008) In Vietnam, the government’s 2001 decision to merge its National AIDS Committee with the Department for Social Evils Prevention underscored connections between HIV and injection drug use (Hong, Anh, & Ogden, 2004; Team, 2004). Public health campaigns from this period presented disturbing images of emaciated figures and skeletons linking social evils, such as injection drug use, to illness and death from HIV infection (Thi, et al., 2008). While the Vietnamese government has since recognized the negative impact of HIV-related stigma and has legislated efforts to protect people living with HIV/AIDS (PLWH) from stigma and discrimination (National & Assembly, 2006), stigma towards PLWH remains (Gaudine, Gien, Thuan, & Dung, 2009; Thi, et al., 2008) at the community and family level (Hong, et al., 2004; Team, 2004; Thi, et al., 2008)

In Vietnam, then, HIV positive IDUs may face layered stigma, where HIV stigma is “layered on top of pre-existing stigmas” (Nyblade, 2006). Layered stigma, which has also been conceptualized as “double stigma” (Grossman, 1991), “co-stigmas” (Chan, Yang, Zhang, & Reidpath, 2007), and “layering stigmas” (Lee, Kochman, & Sikkema, 2002; Reidpath & Chan, 2005) may impact an individual’s inclination to disclose their HIV positive status. Hong and colleagues suggest, for example, that the burden of layered stigma may make HIV-positive IDUs particularly reluctant to disclose their disease status (Berger, 2004; Hong, et al., 2004).

This paper aims to explore perceptions of and experiences with IDU related stigma, the influence perceptions of IDU and HIV layered stigma can have on the decision to disclose HIV positive status and experiences with layered stigma among a group of HIV positive male IDUs in Thai Nguyen, Vietnam. Stigma as expressed through labeling, stereotyping, separation, status loss and discrimination (Link and Phelan, 2001) and layered stigma are considered in both a community and family context given the central importance of both of these groups to the social organization of life in Vietnam. Understanding the connection between layered stigma and decisions surrounding disclosure of HIV positive status could guide development of HIV prevention interventions and policies that effectively combat stigma.

Methods

Study site

This qualitative research was conducted in Thai Nguyen, a semi-rural mountainous province in the northeast region of Vietnam, which lies along trafficking routes from the “Golden Triangle”, one of the most extensive opium-producing areas in Asia. In the last decade, Thai Nguyen has experienced a rapid increase in injection drug use which has been associated with Vietnam’s transition to a market economy and a related increase in the availability of heroin. In 2004, an estimated 6,450 IDUs lived in Thai Nguyen, a province with approximately a million residents (unpublished data). The primary treatment option for IDUs in Thai Nguyen, as is the case throughout Vietnam, is forced detainment in a DTC.

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Study enrollment

Participants in this qualitative study were 25 HIV positive heterosexual male IDUs, residents of Thai Nguyen. Males were recruited given formative work for a large randomized controlled trial where 97% of 1,432 IDUs surveyed were male (unpublished data). Participants reported injecting drugs in the last year, had learned of their HIV positive status within the last two years via voluntary counseling and testing (VCT) and had given written informed consent to participate. Twelve IDUs who had disclosed their HIV positive status to their primary sexual partner as well as 13 IDUs who had not disclosed their HIV positive status to their primary sexual partner participated. Participants who had disclosed their HIV positive status to their primary sexual partner were purposively selected from a group of 499 individuals who had been screened for another research project but found ineligible because they were HIV positive. This project recruited participants under the purview of a “Men’s Health Study” to protect against the possibility of HIV related stigma. Participants who had not disclosed their HIV positive status to their primary sexual partner were purposively recruited through VCT centers in Thai Nguyen which provided information about the study to clients. Interested clients approached the study about participating. Participant confidentiality was ensured through the use of personal identifying numbers and password-protected secure computers.

Qualitative In-Depth Interviews

Prior to interviewing participants, ethnographers completed an intensive one-week training on qualitative interview techniques (e.g., probing, framing, summarizing, checking) and several weeks of field training. One on one semi-structured interviews were conducted in private rooms at a health center near the participants’ homes. Participants were asked to recount personal narratives on a variety of topics including: their experiences with learning that they were HIV positive, their decision-making process around disclosure, family reactions to disclosure, perceptions of IDU and HIV stigma within their community and family and their experiences with stigma from their community and families. Interviews took between one and two hours, were audio-taped, transcribed in Vietnamese, translated into English, and entered into Atlas TI (Muhr, 2004). Transcripts were reviewed for major themes related to stigma and disclosure. Coded text was organized into matrices to facilitate comparisons. Themes that emerged are described in detail below.

The research plan, interview guides, and consent forms were reviewed and approved by the Johns Hopkins University Bloomberg School of Public Health Committee on Human Research and the Institutional Review Board for the Centre for Preventive Medicine in Thai Nguyen, Vietnam.

Findings

The average age of participants was 34 (range: 27–47). Six participants were single (average age 33.7), 16 were married, and 3 were divorced. While single men tended to live with their parents, married men who reported on their living conditions and family structure were equally likely to be the head of household as to be living with their parents. The majority of participants reported having injected heroin and/or opium for at least 5 years. Of the 13 participants who had not disclosed to a primary partner, 11 had not disclosed their HIV status to anyone and 2 had disclosed only to injection partners. Of the 12 participants who had disclosed to a primary partner, 10 had disclosed to family members (including their primary sex partner) and 2 had disclosed to both family members (including their primary sex partner) and friends in the community. Sixteen participants had one or more children and one-third had received vocational training or education beyond high school. Participants

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who were employed worked as farmers, laborers, vendors and small business owners. Nineteen participants were unemployed.

Interviews with participants revealed some universal themes about stigma and decisions about disclosing HIV positive status. Perceived and experienced injection drug use and HIV related stigma at the community and family level and layered stigma were among the topics discussed.

Stigma from community and family towards injection drug use

Perceived stigma from the community was intensely felt by most participants. IDUs felt they were stereotyped and labeled as "useless, wasteful, unemployed, sick and injection [injecting] all day" and distrusted,

> They feared that if I went to their houses, I would steal something.... They were vigilant upon my visit.

Some IDUs internalized stigma from the community:

> In the past, I injected a lot, and thus people did not like me … How could they like me?

While community members stereotyped and discriminated against IDUs and their families, family members engaged with IDUs, voicing disappointment and anger. One participant described his mother's reaction:

> You are so stupid. [I don't care] whatever you spend on, whatever you destroy, what I hate most is that you destroy yourself.

Family members actively tried to change the injecting behaviors of their IDU relatives:

> My parents scolded me, cursed me, did prohibit me to use, didn't allow me to go out, took control of my money.

Participants perceived stigma related to injection drug use from the community in the form of stereotyping and discrimination. Within the family, anger and frustration were expressed towards IDUs and IDUs lost status in terms of financial independence and physical freedom.

Perceived HIV-related stigma in the community

Participants also perceived stigma, manifested through separation and discrimination, within the community, towards HIV positive individuals:

> They don't want them [HIV infected people] to come visit or have meals. Even when they have a marriage reception party, they don't invite them.

> …even if that person sells goods, no customers will buy anything … people don't dare to come visit.

Concerns about stigma and the financial impact of discrimination discouraged individuals from revealing their HIV positive status to the community:

> They would stigmatize me if they knew it and boycott my shop. It would be harder for me to earn my living. I don't disclose it as it is my life.

In general, participants expected that they would experience stigma from their communities if their HIV positive status was known:

> If they know they will … not sympathize.

Most respondents perceived HIV-related stigma in their community. Several respondents noted that they would suffer financially if their HIV status were known in the community.

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Consequently, most respondents avoided publicly disclosing their HIV status to avoid separation and discrimination.

Layered stigma in the community after disclosure

Fears of experiencing additional stigma for being HIV positive were realized for IDUs whose HIV positive status became known to the community:

> When I was addicted, the community hatred was 5. When I got HIV, the hatred was 1–2 times more.

> When they [the community] learned about my addiction, the intimateness reduced. When they learned about my HIV infection, the intimateness decreased further… They did not like me as previously….

For these participants, pre-existing stigma for injection drug use was magnified by an additional layer of HIV related stigma. Individuals experienced a palpable negative shift in separation and discrimination from members of the community.

Perceived HIV-related stigma among family members and its impact on disclosure

While IDUs universally perceived HIV related stigma in their community, expectations of stigma from families varied. In some instances, concerns about stigma and separation discouraged participants from disclosing their HIV positive status to their families:

> I was afraid of people's stigma and abandonment, especially close family members... [I] kept hiding and suffered myself, honestly.

> The most important [thing] to me is to have someone to comfort me to overcome difficulties. But I am too afraid to disclose it, and thus, I suffer alone.

Other participants did not fear stigma from their families and decided to disclose with the hope of receiving support from their loved ones:

> I think I need the support from the family, and thus, should tell them.

> I talked to them to have their sympathy and support.

Fears of stigma and separation which marked the reluctance of IDUs to reveal their HIV positive status to the community also characterized the worries of many IDUs about revealing their status to family members. These fears, however, were tempered by the desire for support and comfort that family members might offer.

Absence of layered stigma in the family after disclosure

Interestingly, several HIV positive IDUs who had initially faced separation and a loss of status from family members because of their drug use experienced a reduction in stigma from family members when they disclosed their HIV status:

> I was not isolated any more by my family.

> They even love me more.

> Even they care about me more, sympathize with me more, create better conditions for me than before

IDUs who disclosed their HIV positive status to family members generally received support and care and even a reduction in stigma experienced previously.

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Discussion

Interviews with male HIV infected IDUs in Thai Nguyen revealed qualitative differences in community and familial responses to both injection drug use and HIV positive status and that layered stigma was present in the community after disclosure, but not necessarily in families. IDUs explained that responses from the community with regard to injection drug use and HIV positive status were routinely negative. Members of the community distrusted and avoided IDUs. For individuals whose HIV positive status was public, community level stigma, manifested through separation and discrimination was magnified.

Alternatively, familial responses to revelations of injection drug use and HIV positive status were generally characterized by concern. While family members reacted to an individual's drug use harshly, this reaction was often driven by fear for the IDU's well-being and a desire to prevent further injection drug use. Responses to disclosure of HIV positive status were also largely driven by concern. Those family members who learned of an IDU's HIV positive status typically embraced their infected family member, providing care, encouragement, and support. Unlike the layered stigma which IDUs either observed within or experienced from the community, participants who decided to disclose to their families found acceptance of their HIV positive status and a seeming reduction in their experience of stigma related to their injection drug use. This may be due to a perception that as compared to HIV negative IDUs who can control their behavior, HIV positive individuals are seen as ill and in need of care (Chan, et al., 2007). Interviews with this cohort of HIV positive IDUs suggest then that while layered stigma is expected and experienced in the community, in families where disclosure takes place stigma is not layered and stigma related to injection drug use appears to be marginalized in the context of life threatening illness.

The stigma our participants observed in their community is consistent with previous work in this region (Hammett et al., 2005; Hong, et al., 2004). In the presence of observed layered stigma, then, and with the possibility of severe social consequences, only two participants explicitly disclosed their status to community members. Community-based programs that dispel myths about HIV transmission, delink HIV from the social evils, and promote images of PLWH as productive members of society are needed to create an environment in which HIV-positive IDUs can reveal their status.

There are limitations with our analysis. Results from the small sample size and purposive sampling methodology of this qualitative research, may not be generalizable to all HIV positive IDUs in Vietnam. In particular, our participants, who each had a primary sexual partner, may be more likely to have family members they can rely on for support. The primary sexual partner may be a spouse or it may be that an individual who is able to maintain a primary sexual relationship is also more skilled at maintaining other intimate relationships. In addition, participants who disclosed to family and had the positive experiences we report may have been confident before they disclosed that family members would be supportive. It is possible that those who did not disclose to family may not have because they did not expect to receive support and if they had disclosed would have experienced less support and more stigma than participants discussed in this paper. Additionally, our participants' perceptions of and experiences with stigma from the community or within their families may have been impacted by other stigma drivers, such as divorce or unemployment. Finally, the support male IDUs might expect to receive from their family and in particular female family members can not be generalized to what HIV positive female IDUs might experience especially within the context of gender roles in Vietnam.

Access to anti-retrovirals (ARVs) and care for opportunistic infections (OIs) may also impact disclosure decisions. In our study, none of the men who had not disclosed their HIV

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status reported taking ARVs or receiving treatment for OIs while several of the men who had disclosed were involved in some form of treatment or care. It is not clear whether treatment and care spur disclosure or are a consequence of disclosure.

Despite these limitations, our rich qualitative data provide valuable insights into the very real and powerful layered stigma which exists towards HIV positive IDUs in a semi-urban community and the equally powerful care and support families may provide for these same individuals. It is the anticipation of this care and support which can encourage HIV positive IDUs to disclose their status to their families. Indeed, disclosure of HIV positive status to families does not seem to increase stigma and may in some cases mitigate injection drug use related stigma. Our findings suggest the need for stigma reduction interventions aimed at the larger community and for interventions which support the role of families in providing care for HIV-positive IDUs.

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