

## Perceived Discrimination among People Living with HIV in Nepal

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### ABSTRACT

**Background:** HIV is one of the major public health problems in Nepal, fuelled by several socio-economic factors. The objective of this study was to explore perceived discrimination among people living with HIV in their own family, society and health facilities.

**Methods:** A qualitative descriptive cross-sectional study was conducted with semi-structured face-to-face in-depth interview of 18 people (10 men, 8 women) living with HIV in four districts of Nepal.

**Results:** Perceived discriminations among people living with HIV were found among family, society and health facilities. In families, the major forms of perceived discrimination were restriction to go outside, exposure to media and use of different utensils for eating purpose. Female HIV positive perceived more violence at household level than males. Financial restriction was also found imposed upon some respondents by the family for being HIV positive. Similarly, restriction to participate in social work, restriction to buy from shops, social harassment and insult were the main forms of discrimination. Perceived discrimination experienced in the health facility yielded very bitter experiences to some respondents, while many had refused treatment because of their HIV status.

**Conclusions:** People living with HIV faced different forms of perceived discrimination within family, society and health facility which are thought to be crucial in supporting a person at the time of crisis. Intensive programs that can reduce social stigma and discrimination faced by people living with HIV are a must.

**Keywords:** discrimination; family; health facilities; HIV; society.

### INTRODUCTION

Discrimination towards People Living with Human Immunodeficiency Virus (HIV) (PLHIV) ranges from unconscious gestures, neglect, to conscious rejections, which even results to harassment and hostility.<sup>1</sup> In many settings worldwide, PLHIV have experienced a significant level of discrimination.<sup>2-5</sup> There is also some empirical evidence that discrimination may contribute to an increase in HIV-related risk behaviours among PLHIV.<sup>6,7</sup>

In Nepal, HIV infection is concentrated to key populations at higher risk population such as sex workers, migrants and person who inject drugs.<sup>8</sup> The spread of HIV is fuelled by stigma and discrimination.<sup>9</sup> However, very little

research has been conducted to find out discrimination faced by PLHIV in the context of Nepal and most of them were done using quantitative methods. This study aimed to identify perceived discrimination among PLHIV in Nepal by using qualitative method.

### METHODS

The study was exploratory, formative and qualitative using a convenience sample to assess social stigma and discrimination among 18 (10 men and 8 women) PLHIV. Data were gathered by in-depth face-to-face interviews conducted among PLHIV in four districts of Nepal. The corresponding author administered the interviews.

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Participants were recruited with the help of organizations working for the PLHIV. The interviews ranged from 30 minutes to 90 minutes and all the information were recorded through notes. Interviews were translated and transcribed from Nepali to English. Data were coded using preliminary codes, and the analysis was done based on respondents' experiences related to perceived discrimination in family, society and health facility.

The interview guide included three questions on the discrimination in the family. They were: restrictions to go outside home, economical support from family and physical and social restriction within family such as use of separate utensils, use of separate toilet and isolation. Questions concerning discrimination in the society included: disclosing the HIV status in community, restriction to participate in social activities, discrimination at work place, threat, assault, insult and harassment by other community members. The information on discrimination in health care setting was collected by questions on the procedure of counselling, behaviour of health worker when visiting health facility, and history of refusing treatment by health facilities.

Participation of respondents was completely voluntary and no incentives were provided. Verbal consent was taken from the participants. In order to protect the identity of participants, no identifying information was collected. Ethical approval was obtained from Research Unit, Institute of Medicine, Tribhuvan University, Nepal.

## RESULTS

### Discrimination within the Family

A number of respondents experienced different forms of discrimination resulting from their family's anxiety over fears of loss of social standing in their community due to a HIV-positive person in the family. One woman described her experience as follows:

"When I was diagnosed as HIV positive, my mother-in-law said: 'You will die soon. But we have to live for a long time. If others know about your condition, it would be hard to live for us also. So please stay inside the home and never talk about yourself to outsiders.'" (Infected through sexual transmission from HIV positive husband, female, 24 years, Chitwan)

Some individuals decided to isolate themselves from their family and community to protect siblings and parents. One individual described his feelings:

"My family loves me very much. I am the only son. They have high expectations from me. If I tell them that I was infected, they surely will reduce their love towards me. They may refuse to stay in the same house. They may

get frustrated and develop psychological problems. So I am afraid of telling my own family about my condition." (Infected through needle-sharing, male, 32 years, Chitwan)

Many respondents had assumed that telling their families about their HIV status would bring about big obstacles. Reactions were not necessarily negative. Fourteen respondents had good family support. The family support changed, especially in case of daughter-in-law, often after the death of the son. One respondent shared her feelings:

"After the death of my husband due to HIV, my mother-in-law refused to give me the family property and said that I was free to go anywhere. She said: 'You killed my son', so why should I keep on providing you food and clothes.'" (Infected through sexual transmission with HIV positive husband, female, 25 years, Bara).

It was found that most of the economic support of the family was related to gender. All male respondents said that the economic support from family was very good. The quote below gives an example:

"My wife knows I am HIV positive, she never say anything bad to me and is never angry with me. Instead, she weeps alone and does not show any tears to me. She loves me very much though I am a great fraud." (Infected by having sex with sex workers, male, 33 years, Chitwan).

The conditions of female PLHIVs were not as good as the males. Only three out of eight female PLHIVs lived with their families; the remaining left their home and went to live in their parental house. Most of them shared feelings that they were discriminated against in their own house after the death of their husband.

### Discrimination in Society

Among 18 people interviewed, only nine had exposed their HIV status in the community. The rest did not tell due to the fear of discrimination. Four respondents told their family only while the other four told their family, close neighbours and close relatives. One respondent only disclosed his HIV status to the health personnel. Eight out of nine respondents who told their status in the community experienced no refusals in participation in society gatherings. However, one HIV positive respondent was denied participation in social event. Respondents were skeptic to disclose their HIV positive status. One respondent expressed:

"Now I have a normal social life. Everybody respects me. If I told them, they would change their behaviour. It may hamper my life, wife and children. So why should I expose?" (Infected by syringe sharing, male 36 years Makawanpur).

One respondent who ran a vegetable shop in her community shared her bitter experiences and said:

“When my neighbours knew I was infected by HIV, they did not buy anything from my shop.” (Infected by sex with husband, female 37 year, Chitwan).

Ten respondents said that they had experienced some discrimination in the work place. The discrimination was not only limited to other organizations but, occurred in the HIV related organization, too. President of AIDS organization in Makawanpur, an organization established by PLHIV, said:

“Staff of organizations working in the HIV field behaves well when they are in seminars or meetings. When they depart, they treat us like unknown persons and they are not ready even to shake hands with us.” (Infected by syringe sharing, male 34 years Makawanpur).

Discrimination could happen also among the PLHIV themselves as experienced by a respondent working as a secretary in a PLHIV established organization. The discrimination based on HIV also happened among close friends. One respondent shared:

“After he knew I was infected with HIV, a very close friend with whom I stayed, said, “I was close with you, I might develop that disease. You transmitted HIV to me.” But he refused to accept that staying together does not transmit HIV. Then I took him to have his blood test which reported negative. He still did not believe and we went for reconfirmation. I was deeply shocked by my friend’s behaviour. (Infected by sex with HIV positive women, male, 33 years, Chitwan).

One PLHIV shared his bitter experience about discrimination in a jail:

“When I was arrested by police for drug use, they kept me in a separate room, prepared separate meals for me, gave separate utensils to eat and used sharp words. (Infected by syringe sharing, male 34 year, Makawanpur)

Discrimination in the community existed in various forms. Two respondents said that they had bitter experiences of threat; and three respondents said that they were insulted due to their HIV status; furthermore, four respondents were harassed for being HIV positive.

#### **Discrimination in Health Facility**

The health care setting is an important place from which PLHIV expects good care, support and treatment. Five respondents said that they did not get any counselling after receiving their HIV positive report.

Six respondents said that they had experiences of health institutions refusing treatment to them due to their HIV

status. These institutions included government hospital, medical college and private clinics. The other two respondents had bitter experiences in health institutions and remaining had not visited health institution till the time of the data collection. A respondent shared:

“When I was diagnosed as HIV positive in a private medical college, the doctor directly said to me, “You are infected with HIV and treatment may contaminate instruments which may infect us.” He refused to treat me and quickly discharged me. He even refused to touch me. I felt like injecting the same syringe in his body. Though, I controlled myself, the discriminating behaviour of the doctor still makes me feel stigmatized.” (Infected by syringe sharing, male, 32 years, Chitwan)

Most of the respondents expressed that the behaviour of the staff of the government hospital was not good and said, “They do not give priority to us and look in a different way when we go there.”

A respondent was dissatisfied with the mentioning of her HIV status on her prescription. She added:

“Though the behaviour of nurses and doctors is good at private hospitals, it is not good to mention ‘HIV positive’ on the prescription. When medicine-seller asked, “Are you HIV positive?” it stigmatized me. (Infected by sex with HIV positive husband, female, 27 years, Chitwan).

#### **DISCUSSION**

In this study among PLHIVs in Nepal, discrimination against the PLHIVs was found in family, society and health care setting. Family, the basic unit of social life, is the major safety net for an individual. PLHIVs were anxious of losing the family support, care and love, and hurting expectations and trust of family by disclosing their HIV-positive status. As found in other studies in the region, stigma has caused those infected and affected with HIV to feel guilty and ashamed, hesitate to express their views, and feel fearful that they will not be taken seriously.<sup>10</sup> Meanwhile the family also feared to lose social reputation and acceptance for having an HIV positive family member. The findings of the study are in line with findings from South Asia suggesting that stigma and discrimination is routinely faced by PLHIVs and their families.<sup>10</sup> In this study, family support for PLHIV was gendered in the study area. Most of the male PLHIV found their families and wife supportive and non-discriminating. In contrast, female PLHIVs felt verbal violence, threat of losing parental property of husband and even losing support for their basic needs. These results confirm that HIV further reinforces stereotypes and fuels the already existing gender-based discrimination against girls and women in the South

Asian region as warned by UNICEF and UNAIDS.<sup>10</sup> Family was found as a major discrimination place in Lagos study as well.<sup>3</sup>

Society in Nepal still provides a safety net for individual at times of crisis and need. This study found that PLHIVs feared to lose the respect and care of the society. PLHIVs were also afraid that their daily economy would be adversely affected if they disclosed their HIV positive status. This led to non-disclosure of HIV status in some cases. Perception of HIV as 'bad man's disease' and considering the disease as a question about morality have further complicated the situation of non-disclosure of HIV positive status in Nepal.<sup>11</sup> PLHIVs who received support from their family felt less social discrimination. PLHIVs also reported discrimination from their fellow PLHIVs, indicating the presence of hierarchy among PLHIVs themselves. Though there is no criminalization of PLHIV status in Nepal, discrimination happened also in law enforcement institutions. This was shown by cooking and providing meals to PLHIVs using separate utensils at police custody. This is in line with a study among Metis (transgender) in Nepal.<sup>12</sup>

Discrimination at health facility by well-trained health service providers can be linked with lack of empathy and inadequate law enforcement on the rights of PLHIV. Behaviour and attitude of the health care staff reflected low awareness among them. They were found non-sensitive to the needs of PLHIVs. A study also anticipated that this situation is aggravated by the service providers' voluntary decision making on providing services.<sup>13</sup> Such discrimination was a demotivating factor in seeking sexual health services.<sup>14</sup> Lack of confidentiality, discrimination and negative attitudes held by health care provider are the major barriers in seeking health care services by female sex workers, occupying a significant proportion of the total number of PLHIVs in Nepal.<sup>14</sup> Though Nepal is said to achieve a significant progress in policy and human rights for PLHIVs,<sup>15</sup> enforcement is yet to be strong.

A number of factors associated with this study prevent the generalization of these findings to the PLHIVs in Nepal. This qualitative research using a small convenience sample was conducted in Central Terai Region of Nepal. The findings may reflect local experiences and conditions only. Further, the PLHIVs interviewed may have distinct risks associated with their geographic locality, including engagement in risky behaviours. However, all the interviews were done by corresponding author, which enhanced the data quality. Despite these limitations, these data do fill a gap in the literature of a perceived discrimination among PLHIV in Nepal that may serve to justify and inform future prevention efforts.

## CONCLUSIONS

In Nepal, HIV-related discrimination is occurring in a wide range of settings: family, friends, PLHIV themselves, community and health care institutions. Thus, a wide scale societal awareness campaigns and more focused local interventions are needed, with special emphasis on HIV positive women and families of the HIV infected.

## CONFLICTING INTEREST

We declare no conflict of interest

## Name of department to which the work attributed

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## REFERENCES

1. Desclaux A. Stigmatization and discrimination: What does a cultural approach have to offer in HIV/AIDS Stigma and Discrimination: An anthropological approach: UNESCO; 2002.
2. Surkan PJ, Mukherjee JS, Williams DR, Eustahe E, Louis E, Jean-Paul T. Perceived discrimination & stigma toward children affected by HIV/AIDS & their HIV-positive caregivers in central Haiti. *AIDS Care*. 2010;22(7):803-15.
3. Akinbami A, Wright K, Adeyemo T, Dada M, Dosunmu A. HIV-Related discrimination reported by people living with HIV in Lagos. *Journal of Medicine*. 2010;11(1):39-41.
4. Elford J, Ibrahim F, Bukutu C, Anderson J. Sexual behaviour of people living with HIV in London: Implications for HIV transmission. *AIDS*. 2007;2007(Supp1):PS63-S70.
5. Parette-Watel P, Spire B, Obada Y, Moatti J. Discrimination against HIV-infected people & the spread of HIV: some evidence from France. *PLOS One*. 2007;2(5):e411.

6. Chesney M, Smith A. Critical delays in HIV testing and care: the potential role of stigma. *Am Behav Scientist*. 1999;42(7):1162-74.
7. Botnick M. Fear of contagion, fear of intimacy. *J Homosexual*. 2000;39:77-101.
8. Government of Nepal, United Nations. Nepal Millennium Development Goals Progress Report 2010. Kathmandu: UN Country Team Nepal; 2010.
9. Suvedi BK. Transition of HIV epidemic in Nepal. *Kathmandu Univ Med J (KUMJ)*. 2006 Jan-Mar;4(1):115-8.
10. UNICEF, UNAIDS. HIV/AIDS related discrimination & stigma in South Asia: A violation of human rights. South Asia High Level Conference; Kathmandu: UNICEF, UNAIDS; 2003.
11. Wasti SP, Simkhada P, Teijlingen ER. Antiretroviral treatment programmes in Nepal: Problems and barriers. *Kathmandu Univ Med J (KUMJ)*. 2009 Jul-Sep;7(27):306-14.
12. Wilson E, Pant SB, Comfort M. Stigma and HIV risk among Metis in Nepal. *Cult Health Sex*. 2011;13(3):253-66.
13. Jha C, Madison J. Barriers to Utilization of Sexual Health Services by Female sex workers in Nepal; . *Global Journal of Health Science*. 2009;1(1):12-22.
14. Ghimire L vTE. Barriers to Utilization of Sexual Health Services by Female Sex Workers in Nepal. *Glob J Health Sci*. 2009;1(1):12-22.
15. UNAIDS. UNGASS Country Progress Report (Jan2006-Dec 2007). Nepal; 2008.