

Nepal PLHIV Stigma Index Survey 2.0

Background

People living with HIV (PLHIV) often experience stigma and discrimination that can significantly affect their emotional well-being and mental health. HIV-related discrimination is not only a human rights violation but also has an impact on people’s ability to access HIV testing, care, and treatment. United Nations’ 2016 High-Level Meeting on Ending AIDS included “elimination of HIV-related discrimination” as one of three critical targets to achieve by 2020, along with reducing the number of new HIV infections and people dying from AIDS-related causes to under half a million.

The PLHIV Stigma Index 2.0 aimed to address stigma and discrimination relating to HIV while also advocating for eliminating key barriers and issues perpetuating stigma, a key obstacle to HIV prevention, care, and treatment.

The People Living with HIV Stigma Index 2.0 was implemented in Nepal under the leadership of the PLHIV networks; NAP+N and NFWLHA and with the technical and financial support from Save the Children, Global Fund and facilitated by an independent research organization; the Center for Research on Education Health and Social Science (CREHSS).

Methodology

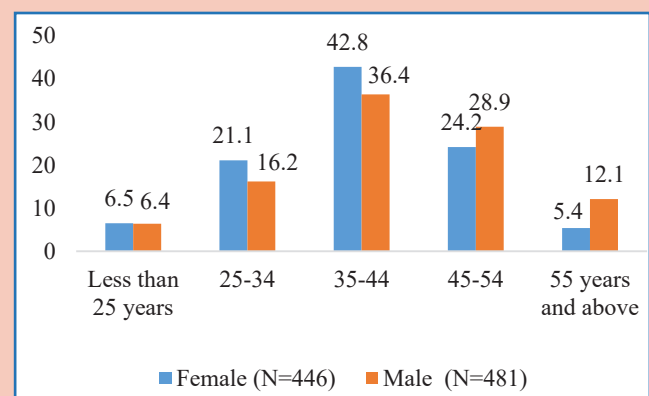
The PLHIV Stigma Index 2.0 is a nationally representative study based on a cross-sectional study design. This study covered 927 respondents aged 18 and above (446 females and 481 males) from 21 districts (3 from each Province). Furthermore, a total of 21 case stories (3 from each Province) were covered as a part of the qualitative study. The questionnaire and methodology used in the study were that developed by The Global Network of People Living with HIV (GNP+), The International Community of Women Living with HIV/AIDS (ICW), and The Joint United Nations Programme on HIV/AIDS (UNAIDS). The respondents were recruited using a combined approach of venue-based sampling and limited chain referral sampling. Data were collected digitally by trained enumerators who were PLHIV. SPSS software was used for quantitative data analysis. Univariate and Bivariate analyses (chi-square test) were performed for the key indicators.

Key Findings

Background characteristics: A higher proportion of the respondents were aged 35–44 years (female 43% and male 36%), followed by those who were 45–54

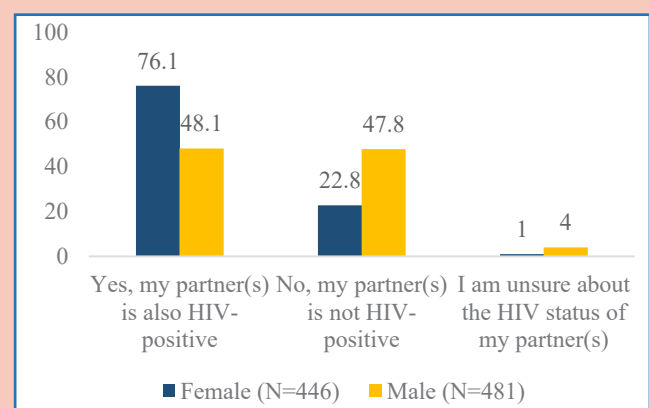
years (female 24% and male 29%). The mean age was 39.6 years for females (SD± 9.7) and 42.2 years (SD±10.8) for the male respondents.

Figure 1 Age group of the respondents by the sex assigned by birth



Almost three-fifths of the respondents (59%) were currently in an intimate/sexual relationship, and among them, a higher proportion were males (72%) compared to females (44%). A higher proportion of female respondents (76%) than male respondents (48%) have a partner that also lives with HIV.

Figure 2 Partner’s HIV status



More than three-fourths of them (77%) had only primary or less education, while one-sixth of them (17%) had completed secondary education/high school. Likewise, respondents came from diverse economic backgrounds: 15 percent were unemployed, 18 percent were involved in full-time work as an employee; (males=23% and females=13%), 21 percent were working full-time but not as an employee (self-employed or business owner), and 14 percent were casual or informal part-time work.

Disclosure

HIV Status Disclosure

HIV status was commonly disclosed to intimate partners (67%), other family members (64%), children (56%), and friends (40%). As expected, disclosure was less common among employers (17%), classmates (15%), and teachers (9%). Similarly, a considerable proportion of the respondents mentioned that disclosing their status took place without their consent (status disclosed without consent among neighbors; 34%, friends; 27%, children; 20%, co-workers; 22%, partners/wife/husband; 15%).

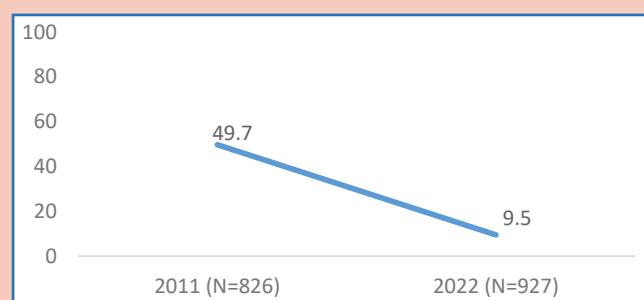
Table 1 Disclosure of HIV status without consent

| Status disclosed without consent to... (Yes %) | Female | Male | Total (%) |
|---|--------|------|-----------|
| Husband/wife/partners | 15.1 | 15.0 | 15.0 |
| Children | 18.3 | 20.9 | 19.4 |
| Other Family members | 28.1 | 20.8 | 24.3 |
| Friends | 30.1 | 23.8 | 27.2 |
| Neighbors | 34.8 | 33.8 | 34.4 |
| Employer | 21.1 | 19.5 | 20.3 |
| Co-workers | 24.1 | 19.7 | 21.8 |
| Teachers/School administrators | 22.4 | 25.8 | 23.8 |
| Classmates | 20.5 | 21.5 | 21.0 |
| Local leaders | 23.4 | 22.2 | 22.8 |
| Authority figures (e.g., police, judges, law enforcement, etc.) | 41.9 | 33.3 | 37.9 |

External Stigma and Discrimination

Experience of external stigma and discrimination (at least one event of stigma and discrimination within the 12 months) has markedly decreased over the years, from 49.7 percent in 2011 to 9.5 percent in this study (2022).

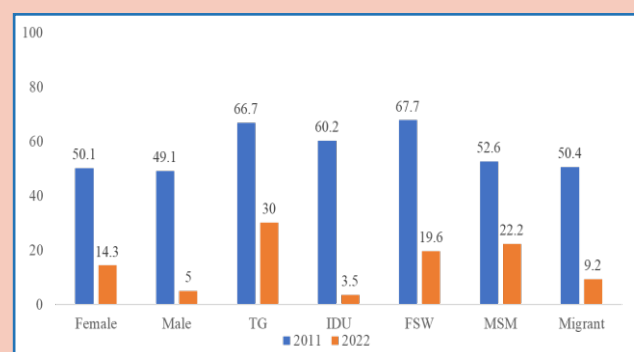
Figure 3: Experience of at least one event of stigma and discrimination due to HIV during the past 12 months



The most common experience of stigma and discrimination faced by the respondent was discriminatory remarks or gossiping by people other than family members (5%), followed by discriminatory remarks or gossiping by own family members (4%) and verbal harassment (4%).

Experience of stigma and discrimination has decreased in all the KP groups compared to the past; however, the prevalence of stigma and discrimination is notably high among TG (30%), followed by MSM (22%) and FSW (20%).

Figure 4: Experience of at least one event of stigma and discrimination due to HIV during the past 12 months: 2011-2022



Internalized Stigma

Almost one-third of the respondents (32%) reported having felt internalized stigma due to their HIV status, the proportion being two times higher ($p < 0.001$) among the female respondents (43%) than males (22%). Internalized stigma was found higher ($p < 0.05$) among the youth aged below 25 years (38%) than in other age groups.

Table 2 Background characteristics of respondents by internalized stigma (Yes%)

| | | % | N |
|---|-----------------------------|------|-----|
| Both Sexes | | 31.9 | 927 |
| Sex assigned at birth (Chi-square 45.0, $p = 0.000$) | Female | 42.6 | 446 |
| | Male | 22.0 | 481 |
| Age group (Chi-square 9.9, $p = 0.043$) | Below 25 | 38.3 | 60 |
| | 25-34 | 34.9 | 172 |
| | 35-44 | 35.2 | 366 |
| | 45-54 | 25.5 | 247 |
| | 55 and above | 25.6 | 82 |
| Name of Province (Chi-square 92.7, $p = 0.000$) | Province 1 | 38.5 | 96 |
| | Madhesh | 22.1 | 136 |
| | Bagmati | 35.6 | 222 |
| | Gandaki | 14.9 | 148 |
| | Lumbini | 57.9 | 107 |
| | Karnali | 9.9 | 91 |
| Type of KP+ | Sudurpaschim | 44.9 | 127 |
| | Sex workers | 35.3 | 51 |
| Type of KP+ | IDU | 11.8 | 85 |
| | Transgender | 40.0 | 20 |
| | MSM/Gay | 22.2 | 27 |
| | Migrant workers | 24.5 | 98 |
| | Partners of migrant workers | 30.6 | 111 |
| | Bi-sexual | 85.7 | 7 |
| None of the above | 35.7 | 597 | |

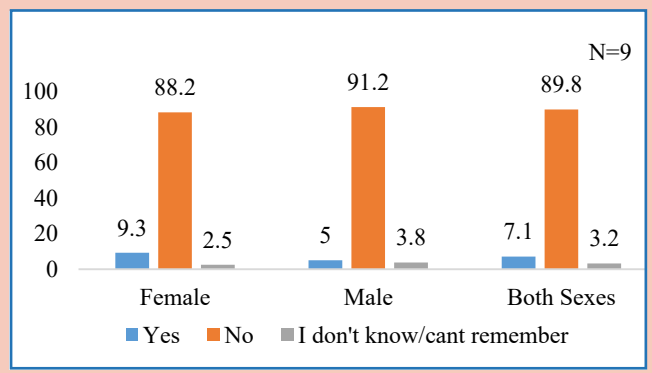
Almost two-fifths of them (37%) felt dirty about being HIV positive (female=42%, male=32%). Likewise, less than a third of them (30%) reported a feeling of worthlessness (a higher proportion of them having such feelings were females; 34% than males; 26%). Moreover, more than half of the respondents (56%; similar proportions for males and females) reported hiding their HIV status from other people. Likewise, one in three respondents (33%) expressed feeling guilty for being HIV positive; the proportion is higher for males (38%) than females (28%).

Resilience (an ability to withstand self-stigma) was also examined. Nearly half of the respondents mentioned that their self-confidence (45%) and self-respect (46%) had been positively affected by their HIV status over the past 12 months; the proportion is similar for males and females. Half of the respondents (51%) mentioned that their ability to respect others had been positively affected by their HIV status, with a similar proportion among males and females.

Interactions with healthcare services

Only two-thirds of the respondents (65%) took an HIV test voluntarily/by their own choice. Three out of five respondents (60%) took about six months or less to decide to get an HIV test. More than a quarter of the respondents (27%) hesitated to get tested due to fear of other people's (e.g., family, friends, employer, or community) reaction to their positive tests results. A fourth of the respondents (25%) reported that they immediately went for treatment (on the same day of diagnosis) after being diagnosed with HIV. On the other hand, it is notable that one in five respondents delayed the ARV treatment for more than two years (19%). Among those who had ever initiated ART, 7 percent of the respondents had interrupted/stopped ART in the last 12 months.

Figure 5 Ever interrupted or stopped HIV (Antiretroviral) treatment



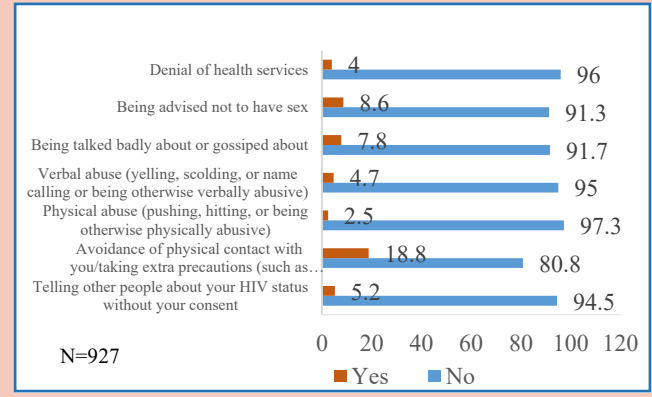
The reason for the interruption of treatment as mentioned by the respondent was because they were

worried that their HIV status would be disclosed (32%) and they were not ready to deal with their infection (12%); while 5% were worried that health workers would mistreat them or disclose their HIV status without their consent.

Service Delivery Experiences

Almost one in five respondents (19%) reported that health workers avoided physical contact/took extra precautions such as wearing double gloves when they had contact with them. Similarly, around one-tenth of the respondents (8%) stated that health workers talked badly or gossiped about them because of their HIV status. Likewise, 5 percent reported that the health service providers disclosed their HIV status without their permission. In the same way, 4 percent of the respondents reported that they had experienced denial of health services because of their HIV status. Moreover, 3 percent of the respondents reported having experienced physical abuse (pushing, hitting, or being otherwise physically abusive) from the health workers in the past 12 months.

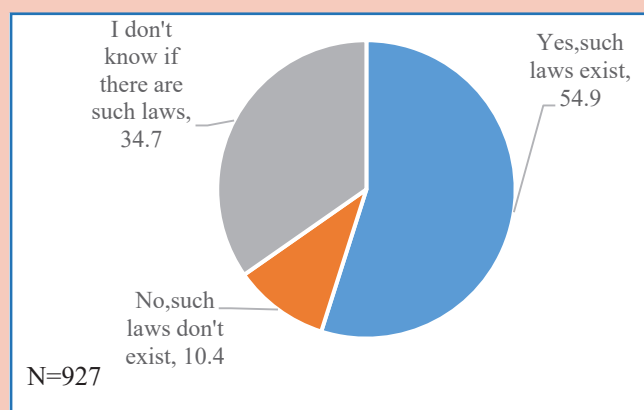
Figure 6 Experiences when receiving care from health workers in the past 12 months



Human Rights and Effecting Change

The most common experience of rights violation as reported by the respondents within the last 12 months was being forced to get tested for HIV or disclose their status to get medical insurance (26%) and forced to get tested for HIV/disclose their status in order to get health care services (20%). More than half (55%) of the respondents were generally aware of the laws protecting them from discrimination, while more than one-third (35%) did not know if such laws existed.

Figure 7 Knowledge of Laws that protect people living with HIV from discrimination



Stigma and discrimination experienced for reasons other than HIV

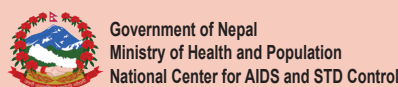
Among the KPs, stigma, and discrimination were higher among transgender people (35%), followed by MSM/Gay (19%) and sex workers (16%) due to their sexual orientation regardless of their HIV status.

Conclusion and Recommendation

- ◆ Disclosure is very crucial to preventing HIV transmission. However, HIV disclosure among the PLHIV was substantially lower. Almost a third of the respondents reported not disclosing their HIV status even among their nearest family, and disclosure is uncommon among peers, classmates, and employers. Therefore, an intensive awareness intervention is required for the PLHIV group so that all of them understand the sensitivity of their status disclosure and readily disclose their status, and protect the general population from getting HIV.
- ◆ Compared to 2011, external stigma and discrimination among the PLHIVs have sharply decreased; figure 4 (from 49.7% in 2011 to 9.5% in 2022). Still, the prevalence is considerably high. One in 10 respondents have experienced at least one event of stigma and discrimination due to their status during the past 12 months. Thus, educational activities need to be held in various settings, including communities, health facilities, social and mass media platforms, and formal education systems. Social and mass media platforms can reach a much wider audience. Influencers in social media who promote educational activities related to HIV/AIDS may help reduce broader external stigma related to HIV/AIDS.
- ◆ Stigma and discrimination were found higher among the youth below 25 years (20%) than in

other age groups. Therefore, interventions that focus on the prevention of stigma and discrimination, especially awareness campaigns, should target the youths so that self-stigma can be minimized among the youths who are PLHIV. In addition, their self-confidence needs to be strengthened to live their lives to the fullest.

- ◆ Stigma and discrimination by the health service providers at the health facilities have decreased by almost half compared to 2011 (denial of health services because of HIV status has decreased to 4% in 2022 from 7.3% in 2011). Still, considerable proportions of the PLHIVs are facing discrimination from the providers as well as they have issues with confidentiality of their status disclosure during service delivery. These complaints are evident in the case studies of the PLHIVs as well. Thus, evidence-based interventions to reduce provider stigma and discrimination, such as training programs for health professionals, need to be conducted regularly to sensitize them toward the diverse needs of the PLHIVS.
- ◆ The findings also showed that the experience of stigma and discrimination among the PLHIV is high because they belong to a key population group. For instance, within the last 12 months, 35% of the transgender, 18.5% of the MSM/Gay and 15.7% of the sex workers have experienced stigma and discrimination for reasons other than HIV. Therefore, advocacy of the rights of the KP groups, especially MSM/Gay and transgender people, and equal treatment to them irrespective of their sexual orientation is essential to protect them from stigma and discrimination.



Save the Children



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