The 2014 Stigma Index Survey: experiences of people with HIV

The Stigma Index measures the level of stigma and discrimination experienced by People living with HIV (PLHIV), and is a survey undertaken by nearly 50 countries, worldwide. *Allanise Cloete et al* describe the 2014 PLHIV Stigma Index Survey conducted earlier this year in all nine provinces of South Africa.

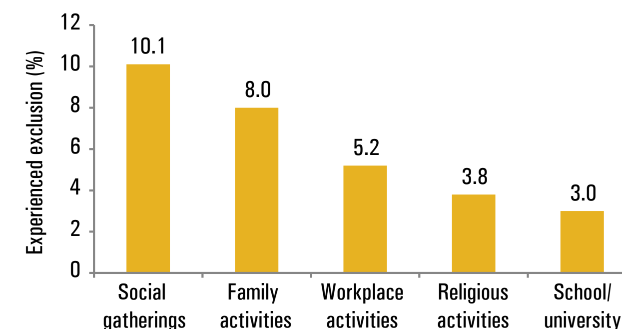
Historically, the Stigma Index was a joint initiative of several organisations: the Global Network of People Living with HIV/AIDS (GNP+), the International Community of Women Living with HIV/AIDS (ICW), the International Planned Parenthood Federation (IPPF) and the Joint United Nations Programme on HIV/AIDS (UNAIDS), who worked together to develop the survey. Under the greater involvement of people living with AIDS principle, the benefits of the index, particularly for those conducting it, go further than just collecting needed evidence.

The process of implementing the index is intended to be empowering PLHIV, their networks and local communities. The 2014 South African PLHIV Stigma Index was commissioned by the South African National AIDS Council (SANAC) and undertaken by the Human Sciences Research Council in collaboration with three NGOs belonging to the SANAC PLHIV sector, namely, the National Association of People Living with HIV and AIDS (NAPWA), the Treatment Action Campaign (TAC), Positive Women's Network and UNAIDS.

Overall, the majority of PLHIV who took part in the survey were female. Almost half of respondents reported living with an HIV-positive diagnosis for five years or more. The mean age of the study sample was 36 years. Half were sampled from small towns or villages and most were in a relationship. Two-thirds were unemployed. Of concern is that more than half of the respondents reported having gone without food during the last 12 months.

The study found that PLHIV had experienced moderate levels of external stigma (stigma from others), such as exclusion from family activities and other social gatherings because of their HIV positive status (Figure 1).

Figure 1: Experiences of stigma and discrimination involving exclusions from social situations reported by respondents



Source: 2014 South African PLHIV Stigma Index

Experiences of external stigma were not extended to services such as health care services, for example only a few survey respondents reported that they had been denied access to health care, or had lost their jobs or income because of their HIV status. Nevertheless over one quarter (27.5%) of the respondents believed that health care professionals had breached confidentiality and one-third (35.3%) believed that their records would not be kept completely confidential.

There is evidence of internalised stigma (self-stigma) among the PLHIV that were interviewed, with some expressing feelings of shame, guilt, self-blame, low self-esteem and feeling suicidal (Table 1).

Table 1: Self-reported internal stigma among respondents in the survey

Feelings experienced	%
Ashamed	28.7
Guilty	28
Blaming oneself	30.5
Blaming others	19.1
Having low self-esteem	22.2
Should be punished	11.1
Suicidal	11.2

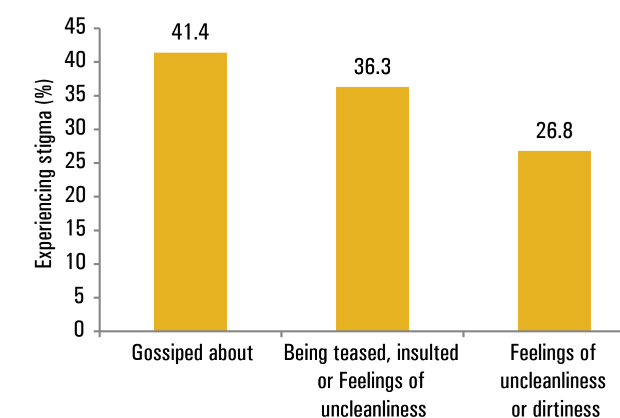
Source: 2014 South African PLHIV Stigma Index

Regarding internalised stigma, 28.7% felt ashamed, 28.0% had feelings of guilt, 30.5% blamed themselves, and 19.1% blamed others and had low self-esteem (22.2%).

Hence there is evidence of internal stigma experienced by a sizeable proportion of PLHIV who took part in the study. Of note is that experiences of internal stigma were found to be higher than experiences of external stigma reported by respondents in the last 12 months. Of concern is that one in ten of the respondents felt that they should be punished as a result of their HIV-positive status (11.1%) and one in ten felt suicidal in the last 12 months (11.2%).

In this study, TB-related stigma was also measured as experienced by PLHIV. During the project initiation phase, the steering committee made a decision to include items that relate to TB-related stigma in South Africa because of the high co-morbidity of TB and HIV (SANAC, 2014a). The study found moderate levels (26.8%-41.4%) of TB-related stigma.

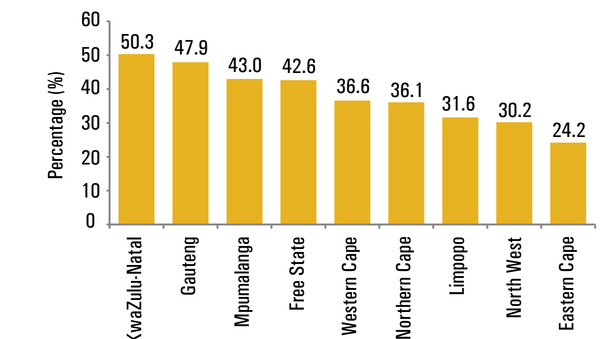
Figure 2: Experiences of TB-related stigma and disclosure reported by respondents in the study



Source: 2014 South African PLHIV Stigma Index

Differences between provinces were also striking with regard to external, internal - HIV related stigma and TB-related stigma. For instance, with regards to internal stigma, proportionately more respondents from Mpumalanga, KwaZulu-Natal and Free State (which have the highest HIV prevalence) had felt some internalised stigma than Eastern Cape and North West.

Figure 3: Experiences of feeling internalised stigma by province



Source: 2014 South African PLHIV Stigma Index

In terms of sexual reproductive health and human rights, 92.6% of respondents indicated never being coerced into sterilisation by a healthcare professional following their HIV-positive diagnosis. However it is of concern that 7.4% of respondents reported forced sterilisation. It is recommended that further investigation be conducted into forced sterilisation by the National Department of Health.

Concerning work, health and education services, 5.3% of respondents reported having changed their place of residence or that they were denied access to rental accommodation, nearly half of whom (48.6% of 5.3%) indicated that their HIV-positive status was the reason, or part thereof, for being forced to change their place of residence or being denied access to rental accommodation. Forty percent of those who reported having lost a job indicated that their HIV-positive status was either directly or indirectly responsible for having lost a job or another source of income during the preceding 12 months. Importantly, over 90.0% of respondents reported never having experienced discrimination in health care settings.

Disclosure of HIV-positive status to spouses and partners was found to be 89.4%. This was also the case with disclosure to other older family members (84.6%). High rates of disclosure of HIV-positive status were found in this study. This was expected because we recruited PLHIV who belong to support group structures. In the workplace however it was found that most respondents in the study indicated that their employers and/or bosses (51.5%) were not aware of their HIV-positive status. Of concern is that over one quarter (27.5%) of the respondents believed that health care professionals had breached confidentiality and one-third (35.3%) believed that their records would not be kept completely confidential.

Results of the survey demonstrate that although South Africa made some good progress in the management of HIV-related stigma, in particular within the health care sector, about one-third of PLHIV who took part in the study reported some form of external stigma while there was evidence of internalised HIV-related stigma and stigma-related to TB. There is therefore an urgent need to develop both national policies and evidence-based stigma reduction programmes to address HIV-related stigma and discrimination in South Africa. ■

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