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The People Living with HIV Stigma Index 2.0: Preliminary results from the Dominican Republic

Project SOAR

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The People Living with HIV Stigma Index 2.0: preliminary results from the Dominican Republic (Updated November 2019)

Stigma and discrimination among people living with HIV contribute to poor quality health care, coercion and violence, job loss, and exclusion from social gatherings. Given its impact on the HIV epidemic, addressing stigma affecting people living with HIV is a global priority.

In 2008, the Global Network of People Living with HIV (GNP+), the International Community of Women Living with HIV (ICW), the International Planned Parenthood Federation (IPPF), and UNAIDS launched the People Living with HIV Stigma Index (Stigma Index) to provide evidence on stigma and discrimination that can be used to advocate for the rights of people living with HIV. The Stigma Index is a survey instrument used to document stigma and discrimination experienced by people living with HIV. As of November 2017, more than 100,000 people living with HIV had been interviewed in over 50 languages by 2,000 trained people living with HIV interviewers. The Stigma Index is a data collection tool, an advocacy tool, and an empowering intervention for both the interviewers collecting data and the interviewees who are sharing their experiences of stigma.

The Stigma Index was recently updated through a participatory process to reflect shifts in the HIV epidemic, growth in the evidence base on how different populations are affected by stigma, and changes in the global response to HIV—particularly given the recommendation of early initiation of treatment. Based on pilot testing in Cameroon, Senegal and Uganda, the Stigma Index 2.0 was finalized in 2018 for use around the world.

This brief describes preliminary key results from using the Stigma Index 2.0 in the Dominican Republic.

KEY MESSAGES

- Despite high treatment levels, only half knew if they were virally suppressed.
- Many participants use drugs, but they do not receive the clinical and social support that they need.
- Participants reported high levels of internalized and external stigma from other individuals, as well as in health care settings.

METHODS

Alianza Solidaria para la Lucha Contra el VIH y SIDA (ASOLSIDA) and Red Dominicana de Personas que Viven con VIH/SIDA (REDOVIH)—the two largest networks of people living with HIV in the Dominican Republic—led the implementation of the Stigma Index 2.0. ASOLSIDA and REDOVIH also led implementation of the original Stigma Index in 2008, when the Dominican Republic was the first country where this methodology was fielded.

Under Project SOAR, the Population Council provided technical assistance along with a local research advisory committee made up of Consejo Nacional para el VIH y Sida (CONAVIHSIDA), Programa Conjunto de las Naciones Unidas sobre el VIH/Sida (ONUSIDA), Dirección General de Control de las Infecciones de Transmisión Sexual y Sida (DIGECITSS), and Servicio Nacional de Salud (SNS).



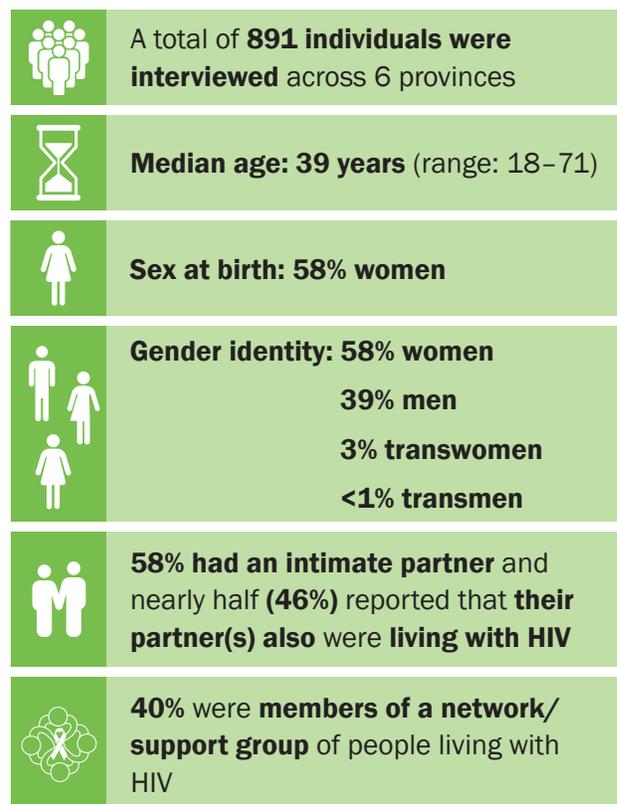
Fieldwork was conducted from November 2018 to January 2019. The interviewers, who were living with HIV, were recruited and trained by ASOLSIDA and REDOVIIH. They in turn recruited participants through their peer network and on-site at service delivery sites (Table 1).

To be included in the study, study participants had to be 18 years of age or older, living with HIV for at least a year, able to give informed consent, and speak Spanish or Haitian Creole. The study was designed to insure inclusion of men who have sex with men, female sex workers, and persons of Haitian origin.

Table 1 Study sites

Province	Site
La Altagracia	Hospital Nuestra Señora de la Altagracia
Barahona	Hospital Regional Universitario Jaime Mota
Puerto Plata	Centro de Promoción y Solidaridad Humana (CEPROSH)
	Clínica móvil
	Hospital Ricardo Limardo
La Romana	Clínica de Familia
	Hospital Provincial Francisco A. Gonzalvo
Santiago	Centro de Salud Juan XXIII
	Clínica móvil
	Hospital Regional Universitario José María Cabral y Báez
Santo Domingo	Centro de Orientación Integral (COIN)
	Centro Sanitario
	Instituto Dominicano de Estudios Viroológicos (IDEV)
	Lotes y Servicios

WHO WERE THE STUDY PARTICIPANTS?



RESULTS

Participants were primarily motivated by health concerns to get tested, but it was not always their decision.

A majority (85 percent) said getting tested was their decision. However, 9 percent said it was not their decision and 6 percent were pressured by others.

Ninety-eight percent of the participants were on ART, yet slightly more than half knew they were virally suppressed.

Figure 1 ART and knowledge of viral suppression



Participants reported high levels of internalized stigma.

The most common forms of internalized stigma were having difficulty telling others about being HIV positive (85 percent) and hiding their status from others (69 percent) (Figure 2).

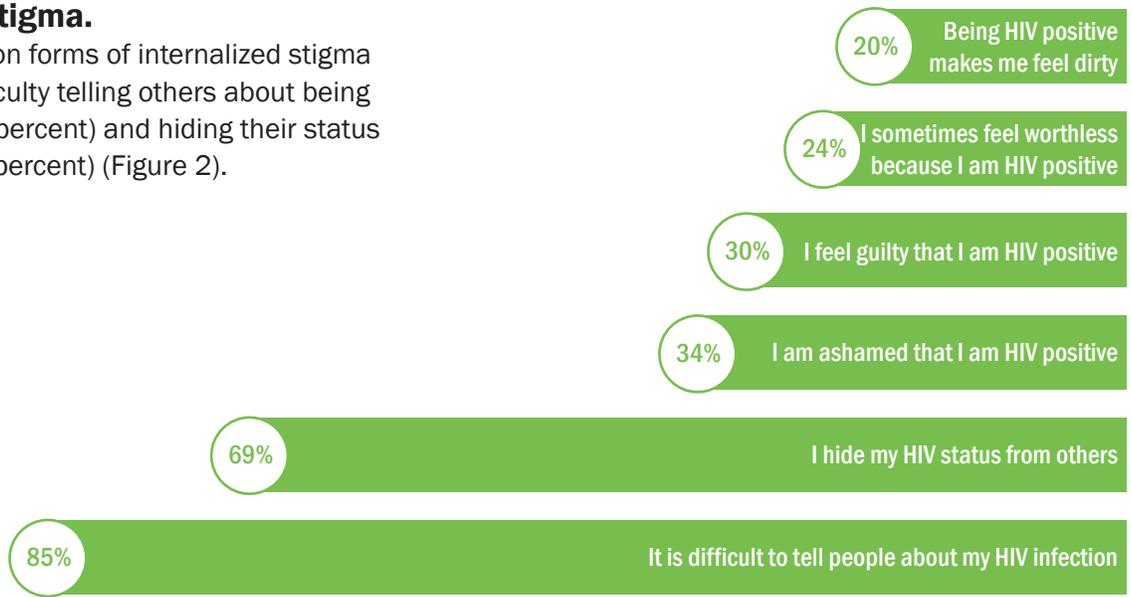


Figure 2 Internalized stigma

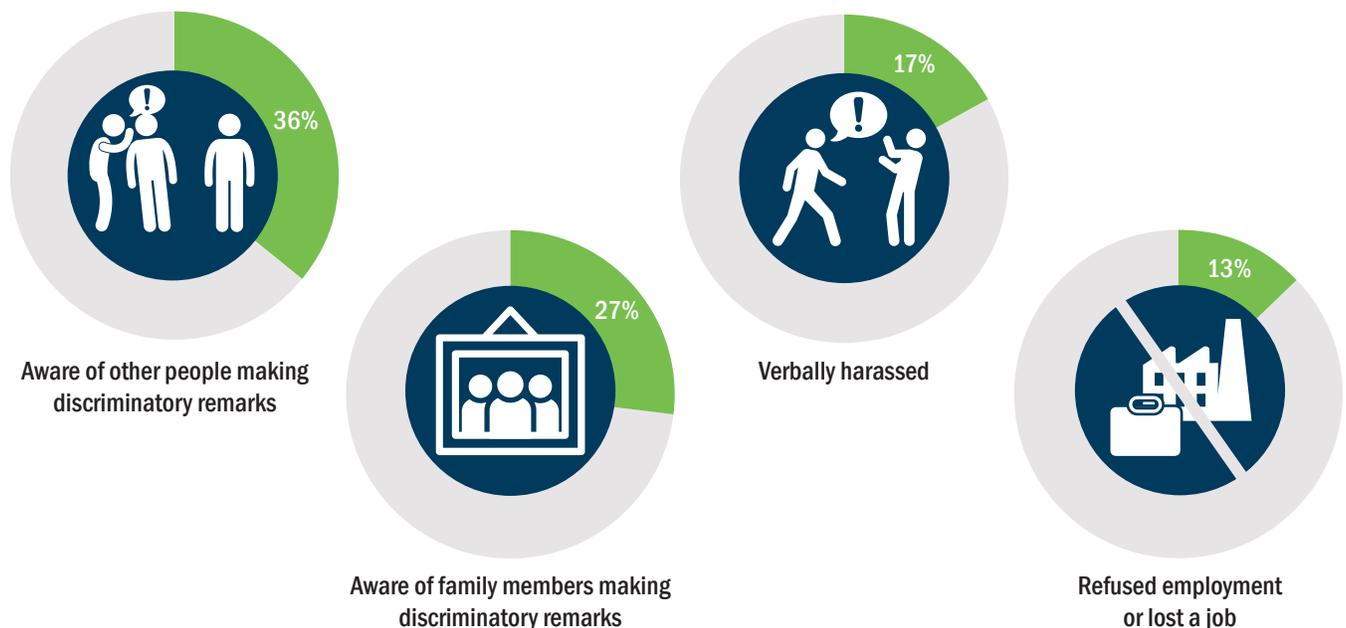
External stigma was also common among participants.

More than a fourth (27 percent) experienced negative comments made about their HIV status from family members in the past 12 months, and 36 percent reported hearing negative comments about them from other individuals (Figure 3).

In the last 12 months, 14 percent had experienced at least one form of stigma while using HIV services.

The most common forms were negative comments (7 percent), gossip (7 percent), and verbal abuse (5 percent).

Figure 3 External stigma due to HIV status



Providers advised participants not to have children.

Some participants reported that providers had advised them not to have children. Among women, 8 percent reported being advised not to have children, compared to less than 2 percent among men.

A substantial proportion of the participants have used drugs, yet few belonged to a drug user support group.

Eleven percent had injected or habitually used drugs like heroin, cocaine, or methamphetamines. Among them, only 8 percent were part of a support network or group for drug users.

CONCLUSIONS

Stigma remains a problem among people living with HIV in the Dominican Republic and manifests internally as well as externally from different people and in different contexts, including the health care setting. The study also shows that a high proportion of participants do not know if they are virally suppressed, and some participants reported that providers advised them not to have children. Also of interest is the notably large number of participants who report using drugs. This community has typically not been prioritized in the country as a “key population” by donors, policymakers, and programs, but this study suggests their distinct needs should be addressed.

The study demonstrates the feasibility and acceptability of using the People Living with HIV Stigma Index 2.0 in getting people living with HIV to talk openly about their experiences of stigma. Their responses are valuable for helping to pave the way for stigma reduction efforts.

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