results brief

The People Living with HIV Stigma Index 2.0: Results from pilot testing in three countries

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. 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 both a data collection tool and an empowering intervention for both the interviewers collecting data and the interviewees who are sharing their experiences of stigma.

Since the Stigma Index was launched, 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—have highlighted the need to update and strengthen the Stigma Index as a measurement and advocacy tool. In October 2015, with support from USAID/PEPFAR, Project SOAR established a small working group (SWG) with representatives from GNP+, ICW, UNAIDS, USAID, and several experts within and external to SOAR. The SWG outlined a process for evaluating and updating the Stigma Index that would be transparent and incorporate as many perspectives as possible in the process. The updated draft survey was then formally pilot-tested before being finalized and disseminated in late 2017. This brief describes key results of pilot-testing the Stigma Index 2.0 in Cameroon, Senegal and Uganda.

MAIN CHANGES BETWEEN THE ORIGINAL STIGMA INDEX AND THE STIGMA INDEX 2.0

Topical

- Adapted questions/response options to distinguish experiences by gender identity, population, and individuals born with HIV
- Added new questions to examine more in depth the varied experiences of sex workers, men who have sex with men, lesbians, transgender individuals, people who use drugs
- Expanded the healthcare section with an emphasis on the HIV care continuum
- Incorporated existing, validated scales to measure internal stigma and mental health
- Created new scale to measure resilience

Methodological

- Framed questions to ask about the last 12 months to better track over time
- Streamlined structure to reduce administration time
- Reduced open-ended questions

METHODS

Project SOAR researchers from the Population Council and Johns Hopkins University provided technical assistance to local country partners in Cameroon (Metabiota in collaboration with RéCAP+), Senegal (Enda Santé and RNP+), and Uganda (National Forum for People Living with HIV [NAFOPHANU]) in pilot testing the draft Stigma Index 2.0. To be eligible, respondents had to have been living with HIV for at least one year,

18 years or older, and able to provide informed consent (written or verbal, depending on setting). Respondents were recruited from people living with HIV networks, community-based organizations serving key populations, antiretroviral therapy (ART) clinics, and through snowball sampling. Survey data were collected on tablet computers (Senegal and Cameroon) or mobile phones (Uganda) in multiple languages. The target sample size was 400 respondents per country. In addition, 20 people per country participated in qualitative, cognitive interviews. The study was approved by local ethics committees in each country, and by the Institutional Review Boards of the Johns Hopkins School of Public Health (Baltimore, USA) and the Population Council (New York, USA).

RESULTS

Participant characteristics

A total of 1,207 people living with HIV participated in the pilot study. The majority of participants were in their mid-30s, female, and had known their HIV status for more than six years. Although nearly everyone was on ART, only 61 percent in Cameroon and Senegal and 42 percent of respondents in Uganda reported being virally suppressed (Table 1).

Figure 1 Prevalence of internalized stigma by country

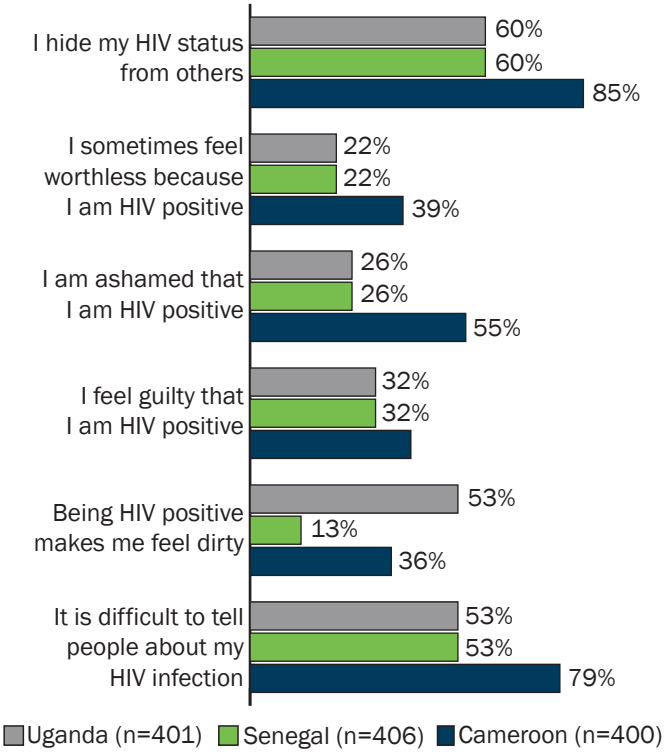


Table 1 Who were the study participants?

	Cameroon (n=400)	Senegal (n=406)	Uganda (n=401)
Mean age in years (range)	38 (18–69)	42 (18–70)	36 (18–81)
Mean years knowing HIV status	7.8	6.6	6.8
Sex by birth			
Male	30%	23%	40%
Female	70%	77%	60%
Key populations			
MSM/Gay	14%	14%	9%
Lesbian	<1%	<1%	2%
Transgender female	5%	3%	6%
Transgender male	<1%	<1%	1%
Female sex worker (incl. trans females)	24%	20%	29%
Male sex worker (incl. trans males)	5%	4%	<1%
Using drugs	1%	2%	5%
Currently on ART	99%	97%	97%
Report viral suppression	61%	42%	61%

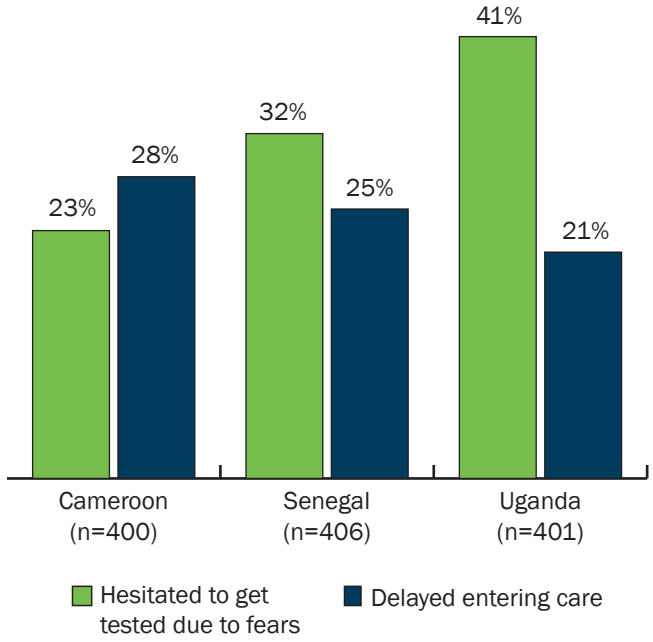
More than half of respondents reported at least one form of internalized stigma.

The validated six-question AIDS-related Stigma Scale (IA-RSS)[1] that was added to the Stigma Index 2.0 indicated high rates of internalized stigma, with the highest rates in Cameroon for five of the six items, as shown in Figure 1.

Stigma leads to delays in seeking testing and engaging in care.

As many as 4 in 10 respondents in Uganda delayed getting tested for HIV because of fears about how other people would respond if they tested positive. More than a fourth in Cameroon delayed entering care for numerous reasons, including being worried that others would find out their status, being afraid health workers would treat them

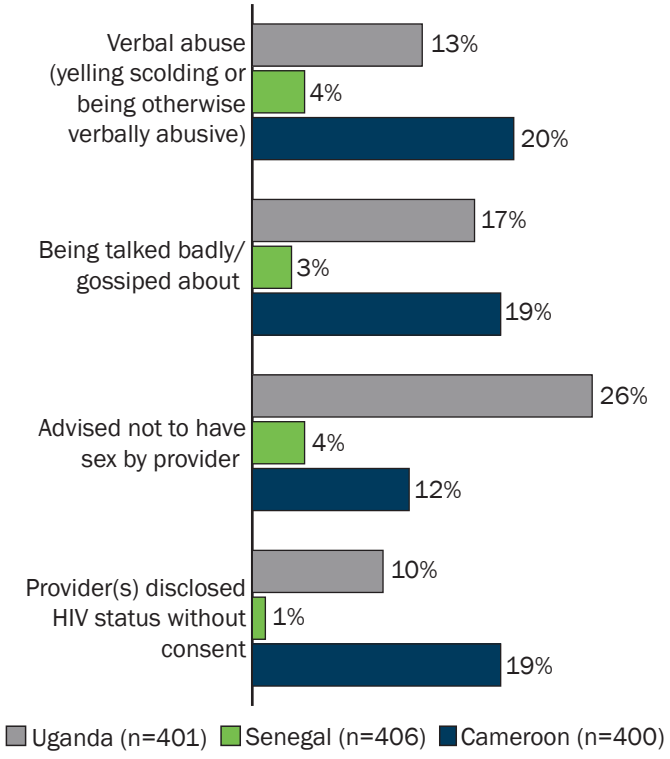
Figure 2 Delays in seeking care by country



badly or disclose their status without their consent, or because they had had a bad experience with a health worker previously (Figure 2).

Up to one quarter of participants in each country experienced at least one form of stigma in a healthcare setting (Figure 3).

Figure 3 Experiences of healthcare stigma by country



New questions reveal high rates of stigma and violence against key populations living with HIV.

For example, forced sex was reported by more than half (53 percent) of sex workers in Cameroon, 40 percent in Senegal, and 32 percent in Uganda. For men who have sex with men, nearly a third (30 percent) in Senegal reported forced sex compared to 23 percent in Cameroon and 16 percent in Uganda (Table 2). Reports of discriminatory remarks from family members were higher in Cameroon than the other two countries for these two population groups.

Table 2 Stigma and violence experienced by men due to being gay or having sex with other men

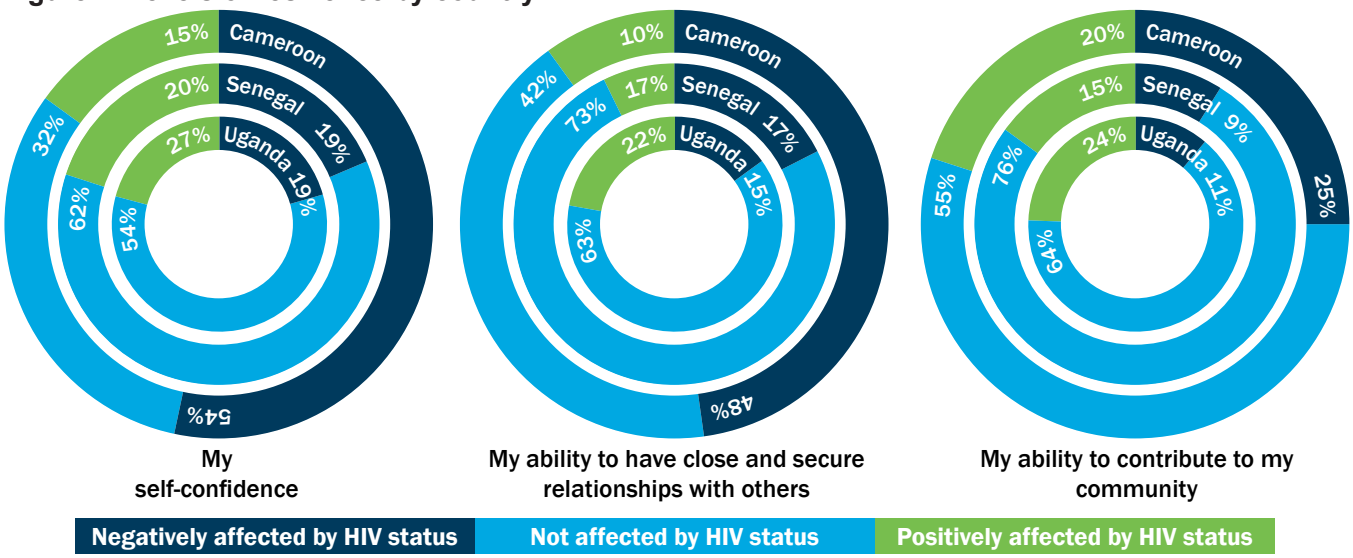
	Cameroon (n= 53)	Senegal (n=46)	Uganda (n=37)
Excluded from family activities	68%	17%	11%
Family members made discriminatory remarks	85%	37%	24%
Verbally harassed	89%	44%	32%
Blackmailed	73%	33%	27%
Physically harassed	58%	28%	19%
Forced to have sex	36%	30%	16%

Despite their HIV status, many participants reported resilience in meeting their needs.

The resilience scale we tested performed well as validated by factor analysis.[2] There was good variability in scores, which ranged from -11 (HIV status negatively affecting the ability to meet needs) to +11 (HIV status positively affecting the ability to meet needs).

Overall, the mean composite scale score in Cameroon was -2.9 compared to 0.34 in Senegal and 0.69 in Uganda, indicating those in Cameroon were least resilient and those in Uganda most resilient. This is further illustrated by Figure 4 which shows how participants responded to three of the 11 items in the scale.

Figure 4 Levels of resilience by country



CONCLUSIONS

The updated Stigma Index 2.0 performed well in these pilot studies in sub-Saharan Africa that included a broad cross-section of people living with HIV in the three participating countries.

The expanded healthcare section showed that many respondents delayed testing for HIV or entering care due to fears of how they would be treated, which was borne out by their reports of stigma and discrimination experienced in the healthcare setting.

Although respondents reported high rates of HIV-related stigma—and internalized stigma, in particular—the updated Stigma Index also indicated that many people living with HIV are resilient in the face of their HIV status.

High rates of stigma and violence were found among MSM, transgender individuals, sex workers and people injecting drugs. Further analyses are needed to explore the impact of disclosure patterns on stigma, as well as the intersectionality of HIV-related stigma and stigma due to key population membership.

NEXT STEPS

- Countries are encouraged to incorporate implementation of the Stigma Index 2.0 into Country Operational Plans (COPs) to be supported by PEPFAR.
- As of February 2018, countries have begun planning implementation of the Stigma Index 2.0, including through Global Fund grants and PEPFAR COPs.

REFERENCES

[1] Kalichman, SC et al. 2009. "Measuring AIDS stigmas in people living with HIV/AIDS: the Internalized AIDS-Related Stigma Scale" *AIDS Care*. 21(1): 87–93.

[2] Gottert, A. et al. "The People Living with HIV (PLHIV) Resilience Scale: Development and validation in three countries in the context of the PLHIV Stigma Index" (manuscript in preparation).

CONTACT US

GNP+ (with the International Partnership) is fielding and coordinating all questions about the Stigma Index 2.0 and its implementation. GNP+ can be contacted at plhivstigmaindex@gnpplus.net.

For questions related to US Government support of the Stigma Index, contact Alison Cheng, USAID: acheng@usaid.gov.

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