Stigma-Related Challenges for People Living With HIV and Gaps in Patient Advocacy Group Responses: Perspectives From HIV Organizational Personnel

THPED312

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Key Takeaways

- HIV stigma remains deeply embedded across systems and settings, with respondents reporting frequent observation of discrimination in multiple environments, including healthcare
- Organizational preparedness is uneven, with gaps in confidence, policies, and stigma-reduction policies, suggesting that many settings are not fully equipped to address HIV-related stigma effectively
- Stigma continues to shape lived experiences of people living with HIV, undermining comfort in care settings, limiting access to services, and contributing to mental health and psychosocial burden
- These findings emphasize the need for stronger training, clearer messaging, and more systematic dissemination to support stigma reduction

Plain Language Summary

- HIV stigma persists despite high awareness and acceptance of the concept of Undetectable = Untransmittable (U=U)
- It remains common in healthcare settings, affecting mental health and access to care
- Stronger training, health system interventions, and wider U=U dissemination may help reduce stigma and improve care

Introduction

- Patient advocacy groups (PAGs) are key partners in HIV care, providing education, support, service linkage, and advocacy for people living with HIV
- As frontline providers of care, support, and advocacy, they offer unique insights into organizational preparedness to manage HIV-related stigma, barriers to care, and stigma-reduction strategies
- Although most HIV stigma research has focused on people living with HIV, few multinational studies have examined the perspectives of HIV organization personnel
- Understanding these perspectives can identify opportunities to strengthen HIV stigma reduction efforts, improve patient support, and build organizational capacity to address HIV-related stigma across healthcare and community settings

Methods

- We analyzed interim data from the Positive Perspectives survey of HIV organizational personnel in 29 countries (n=357)
- Respondents reported on experiences of stigma within the HIV community, comfort discussing sensitive topics, organizational activities, and adherence support
- Data were summarized descriptively as well as with multivariable logistic regression analysis, adjusting for age, gender and self-reported viral load

Results

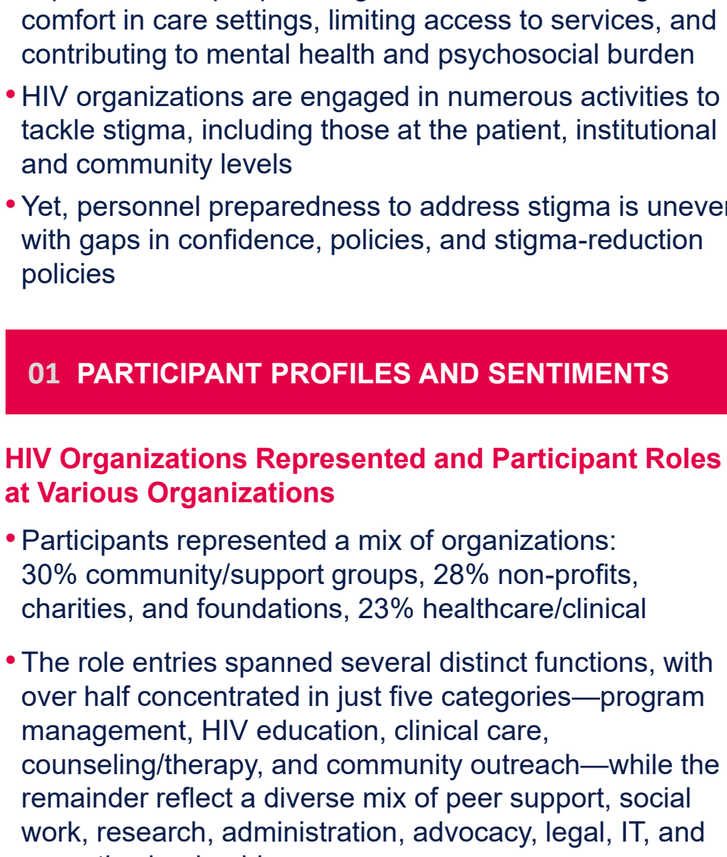
- Findings showed that stigma continues to shape lived experiences of people living with HIV, undermining comfort in care settings, limiting access to services, and contributing to mental health and psychosocial burden
- HIV organizations are engaged in numerous activities to tackle stigma, including those at the patient, institutional and community levels
- Yet, personnel preparedness to address stigma is uneven, with gaps in confidence, policies, and stigma-reduction policies

01 PARTICIPANT PROFILES AND SENTIMENTS

HIV Organizations Represented and Participant Roles at Various Organizations

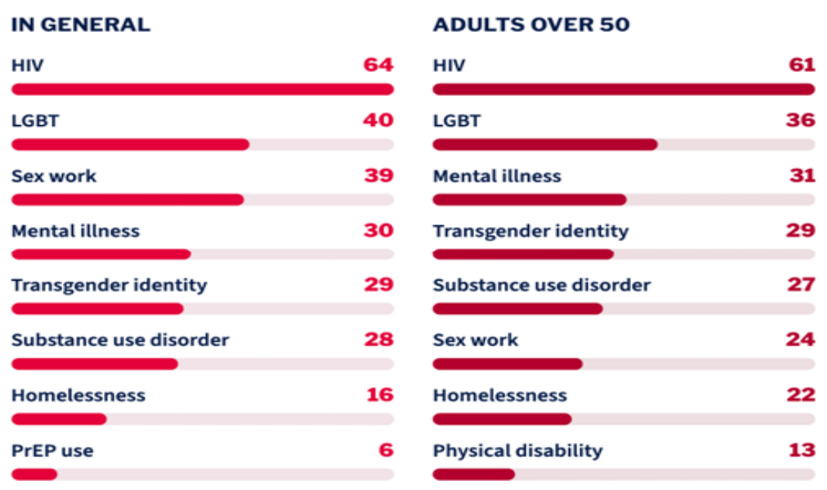
- Participants represented a mix of organizations: 30% community/support groups, 28% non-profits, charities, and foundations, 23% healthcare/clinical
- The role entries spanned several distinct functions, with over half concentrated in just five categories—program management, HIV education, clinical care, counseling/therapy, and community outreach—while the remainder reflect a diverse mix of peer support, social work, research, administration, advocacy, legal, IT, and executive leadership

Figure 1. Sentiments and Experiences Towards Stigma



02 PERCIEVED EXTENT OF HIV STIGMA

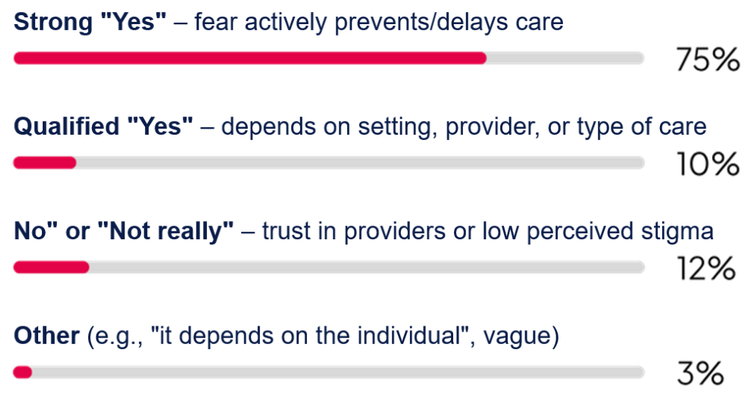
Figure 2. Ranking of Conditions and Identities Perceived to Carry Greatest Stigma in the Community Overall and Among Adults Aged 50 Years and Older



03 STIGMA IN GENERAL HEALTHCARE SETTINGS

Figure 3. Impact On Access To Non-HIV Care

Across 14+ languages, the overwhelming consensus is that stigma-induced fear—rooted in the need to share HIV status against one's will with uninformed providers (especially dentists/GPs)—significantly deters people from seeking non-HIV healthcare



Most frequent translated themes (in order of appearance):

- Fear of having to share HIV status with non-specialist doctors/dentists
- Previous negative experiences (rude treatment, refusal of care, gossiping staff)
- Concern that non-HIV symptoms will be blamed on HIV or dismissed
- Fear of being seen entering HIV clinics (community recognition)
- Intersectional stigma (sex work, LGBTQIA+, people who inject drugs)
- Internalized shame and anticipated rejection

Minority "No" rationales (translated):

- Stigma is lessened in large academic/university hospitals
- Patients have established, trusted HIV physicians who coordinate all care
- Perceived improvement over the last 5–10 years (U=U awareness)

04 STIGMA PREVENTION IN HIV SETTINGS

Figure 4. Self-efficacy Towards Tackling Stigma

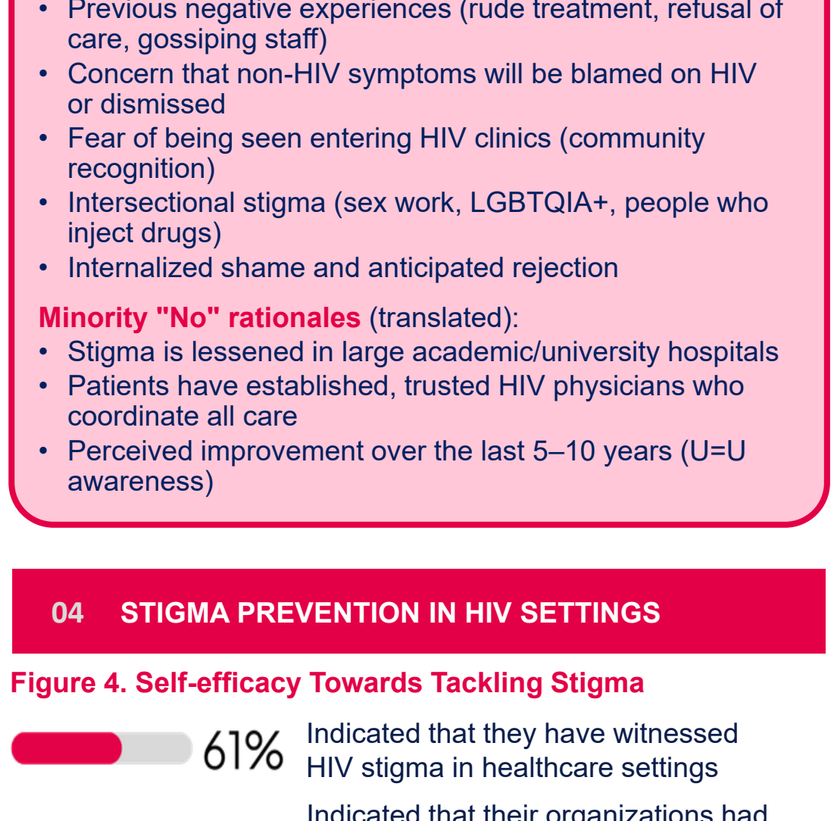


Figure 5. What PAGS Are Doing to Address HIV Stigma

Figure 6. Sentiments Towards U=U In Addressing Stigma

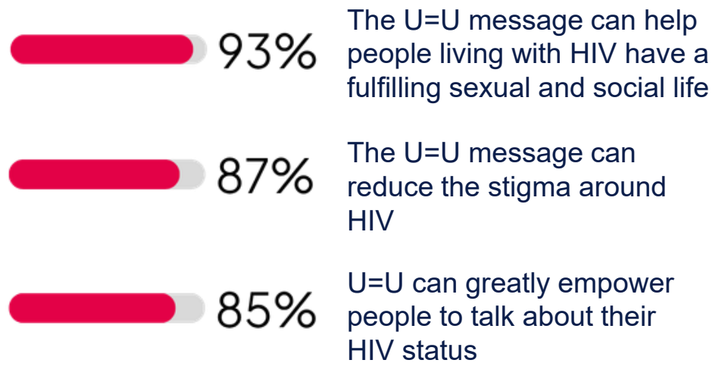
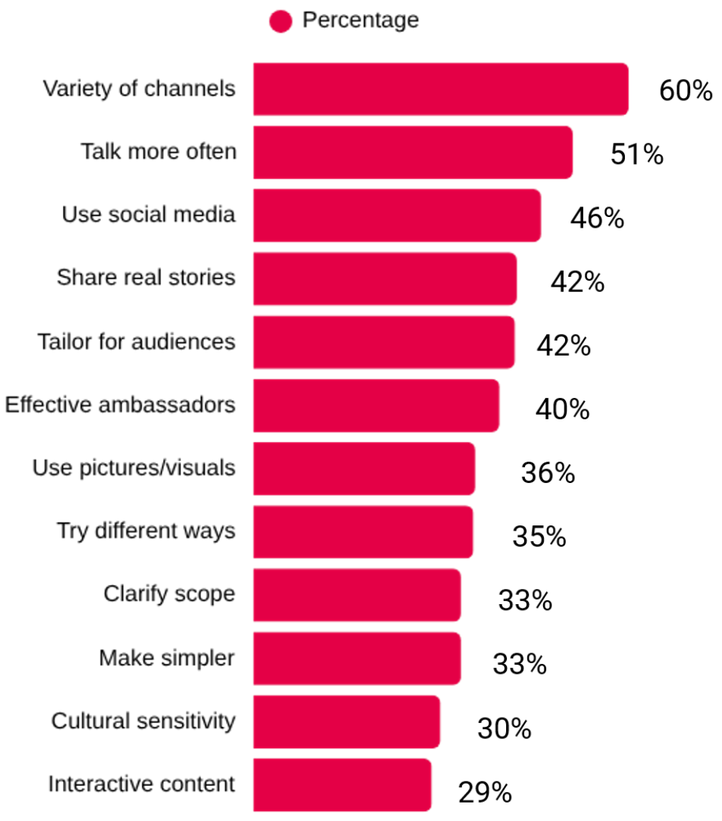


Figure 7. Perceived Opportunities to Improve Communication About the Concept of Undetectable = Untransmittable (U=U)



Compared to Those Who Had Not Received Any Training, Organization Staff Who Had Received Stigma-Related Training Were...

3X More confident about addressing stigma (AOR=3.36, *P*=0.015)

2X More comfortable discussing various key health issues with people living with HIV, including mental health issues (AOR=2.29, *P*=0.012) and substance use (AOR = 1.99, *P*=0.045)

Limitations and Conclusions

- These data are cross-sectional and cannot yield causal inferences because of their observational nature
- Nonetheless, the findings show that PAGs are engaged in different activities to tackle stigma and that providing training to staff can increase their self-efficacy to better help people living with HIV
- Stigma-related fears continue to deter people living with HIV from accessing non-HIV healthcare, highlighting gaps in stigma training among non-HIV healthcare professionals
- Despite the benefits of U=U in reducing stigma, empowering people to talk about their HIV status, and helping people living with HIV have fulfilling sexual and social life, limited personnel training on U=U represents an important gap in current responses
- These findings emphasize the need for stronger training, clearer messaging, and more systematic dissemination to support stigma reduction

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