Background

The People Living with HIV Stigma Survey UK 2015 is a collaborative community-led initiative that captures the feelings and experiences of living with HIV today.

A total of 1576 people were recruited from 120 community organisations and 47 HIV clinics throughout the United Kingdom (UK) and completed an anonymous online survey. Responses were stored securely and analysed at PHE with community engagement.

Here, we examine the lived experiences of the 378 women (including 19 trans women) focusing on the last 12 months.

Results

Women living with HIV in the UK continue to experience HIV-related stigma and discrimination.

Figure 1 shows the proportion of women who worried about treatment, avoided situations or experienced negative treatment in the last 12 months.

Compared to men who have sex with men (MSM), fewer women had experienced rejection by a sexual partner due to their HIV (11% vs 27%, p<0.001), while more trans women reported worrying about verbal harassment (47% vs. 22%, p<0.001) and exclusion from family gatherings (37% vs. 18%, p=0.008) than other women.

Despite similar levels of disclosure in primary healthcare settings, women were more likely to report lower control over disclosure of their status (aOR 1.65, 95% CI 1.05, 2.59) and lower levels of support following disclosure (aOR 1.99, 95% CI 1.23, 3.21) compared to men after adjustment for demographics. 47% (8/19) of trans women reported being treated differently to other patients at their GP of 14% (49/359) of other women: almost half (7/19) reported negative comments from a healthcare worker about their HIV status or people living with HIV compared to 15% (54/359) of other women.

Conclusions

- Women living with HIV in the UK report worrying about and experiencing negative treatment, and avoiding interactions in relation to their HIV infection in a variety of settings.
- Trans women experience disproportionate levels of negative treatment in healthcare settings.
- We ask for interventions to increase sensitivity and support for women and particularly within the healthcare and faith settings.

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