

Experiences of HIV stigma among Blue Sky Trust (BST) members: A service evaluation



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Background

- HIV stigma, defined as negative attitudes and beliefs held about people with HIV, is one of the biggest current challenges in the response to HIV (CDC, 2022).
- Stigma is linked with depression, less social support, lower adherence to antiretroviral medication, and poorer physical health (Rueda et al., 2016).

Methods

- This collaborative project was approved by the Blue Sky Trust (BST) advisory board & registered with Newcastle upon Tyne Hospitals (NuTH) as a service evaluation.
- Surveys (N = 20) and interviews (N = 6) were used to collect demographic data, experiences of stigma, and ideas about how BST could respond.
- Thematic Analysis (Clarke et al., 2015) was used to analyse qualitative data.

Aims

- To gather examples of HIV stigma from BST members.
- To identify settings where stigma occurs.
- To find out what members think BST can do to support them after experiences of stigma, and to tackle stigma.

Participants

Of 20 people who took part, most were White British (85%), aged between 50-59 years (55%), male (65%), and had lived with HIV for more than 10 years (55%). Half identified as heterosexual.

"A lot of people act as if HIV is the be all and end all, it's like the worst thing that could happen, so they've always used the phrase "oh at least it's not HIV," which isn't exactly nice to hear when you're diagnosed with it"

"When you tell people for instance, it's a weight off your head, and I think it's made me a lot more open to people" "I found that the attitude to HIV amongst the gay population in the North East is, I find it very negative"

My cannula removed during the night, and blood was gushing out of my hand. I pressed the buzzer and a male nurse came, but he wouldn't help me. When another nurse came to help me, he told her that she should be careful with my blood"

"Provide support to allow victims of stigma to use that experience as a tool to educate others about the facts around living with HIV in 2022"

"Just concentrate on building resilience to train [HIV] positive people to put up with the shit they will face" "I think we need to keep on going and focus on helping HIV positive people in dealing with their own stigma" "Anger was a big factor, not only because my employer terminated my employment, but they went on to sack my partner at the time for unfounded professional misconduct (guilt by association)"

"...and the words they used just, you know, made me feel dirty"

Survey Results

- HIV stigma had been experienced by 85% of participants. Dating apps (53%), workplace (47%), dating (41%) and in healthcare (41%) were the most common sources.
- Stigma caused people to feel mentally (88%) and physically (77%) worse, embarrassed (48%) and socially isolated (47%). Some people felt stronger (18%) and more resilient (35%) because of stigma, but most did not agree with this.
- Promotion in public places (28%), education (22%), training (17%), and sexual health education in schools (11%) were suggestions for tackling stigma (see word cloud). The general public, healthcare professionals and police were suggested targets of interventions.



Interview Findings

Four main themes were identified from interviews with six participants. Themes: 1) diagnosis and disclosure, 2) source and type of stigma, 3) the impact of stigma, and 4) Living well and responding to stigma. See quotes below.

"I've been put at the bottom of dental appointment lists and hospital lists in the past too"

"I lost family and friends. It has been financially devastating, and made recovery 100 times more difficult"

References

Centers for Disease Control and Prevention. (2021). *HIV stigma and discrimination*. <u>Facts about HIV Stigma | HIV Basics | HIV/AIDS | CDC</u> Clarke, V., Braun, V., & Hayfield, N. (2015). Thematic analysis. Qualitative psychology: A practical guide to research methods, 222, 248. Rueda, S., Mitra, S., Chen, S., Gogolishvili, D., Globerman, J., Chambers, L.,&Wilson, M., Logie, C.H., Shi, Q., Morassaei, S., Rourke, S. B. (2016). Examining the associations between HIV-related stigma and health outcomes in people living with HIV/AIDS: a series of meta-analyses. BMJ open, 6(7), e011453.