

WORDS MATTER: The Impact of Stigmatizing Language in the Healthcare Setting Among Cisgender and Transgender Women and Nonbinary Adults Living with HIV in the US

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BACKGROUND

Stigmatizing language in healthcare settings remains a persistent barrier to care. To understand its impact for women and nonbinary adults living with HIV, The Well Project (a non-profit organization) conducted a national survey exploring their experiences in healthcare settings. The IRB-approved web-based survey consisted of multiple-choice, Likert-scale, ranking, and open-ended response items to obtain quantitative and qualitative data. Although quantitative survey items captured the frequency of reported impacts of stigmatizing language, open-ended responses provided more insight into how language shaped participants’ experiences.

To learn more about this project, scan the QR code



METHODS

This descriptive-interpretive qualitative analysis examined open-ended survey responses from 182 US respondents living with HIV that self-identified as cisgender women (93%), transgender women (4%), and nonbinary adults (3%). The study sample was diverse across race/ethnicity, sexual orientation, age, type of health insurance used, and number of years living with HIV. Survey responses were coded inductively to identify recurring concepts, experiences, and recommendations. Codes were organized into sub-domains and mapped to five analytic domains: • *Mental Health and Self-Esteem* • *Healthcare Engagement* • *Well-Being and Quality of Life* • *Taking Medication as Prescribed* and • *Solutions, Recommendations, and Affirming Care Practices*. Quantitative survey responses were used descriptively to contextualize findings, while the primary focus of this analysis remained on participants’ qualitative narratives.

RESULTS

In total, **131 respondents (71%) reported experiencing stigmatizing language in healthcare settings** from a variety of healthcare providers and staff. Respondents reported that stigmatizing language in healthcare settings resulted in:

- Impact on **mental health and self-esteem (65%)**
- Delaying, avoiding, or missing **healthcare appointments (54%)**
- Effects on **overall well-being or quality of life (52%)**
- Finding it **difficult to take their HIV medication as prescribed (39%)**

Participants who reported these experiences were also asked to describe, through open-ended text responses, the specific events with stigmatizing language and how it affected them. These qualitative responses provided deeper insight into the ways stigmatizing language influenced participants’ lives and informed the **conceptual model presented below**.

“Hearing stigmatizing language from a healthcare provider, someone who is supposed to be a source of support, is uniquely damaging....It directly undermines my self-worth and can lead to increased anxiety, depression, and isolation.”
- Survey respondent

“There were times when harsh words from providers made me lose motivation to stay consistent with my treatment.” - Survey respondent

