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POSTER #25

Language Matters in Healthcare – Understanding the Frequency and Impact of Stigmatizing Language among Cisgender and Transgender Women and Non-binary Adults Living with HIV in the United States

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BACKGROUND

Stigmatizing language in healthcare settings has been widely documented as a barrier to care and well-being for people living with HIV. Language reinforcing stereotypes or implying blame can reduce willingness to engage in care, increase anticipated and internalized stigma, and harm mental health. The Well Project (a non-profit organization with the mission to change the course of the HIV pandemic through a comprehensive focus on women and girls across the gender spectrum) sought to understand the experiences and impact of stigmatizing language in healthcare settings among women and nonbinary adults living with HIV.

To read the full report, scan the QR code

METHODS

Using a cross-sectional survey design, The Well Project developed a web-based survey consisting of multiple-choice, Likert-scale, ranking, and open-ended response items to obtain quantitative and qualitative data. An IRB-approved, cloud-based survey platform was used and tracking of respondents' internet protocol addresses was disabled. Descriptive statistics were used to summarize survey responses using counts and proportions.

This analysis focuses on 182 US respondents self-identifying as cisgender women (93%), transgender women (4%), and nonbinary adults (3%) living with HIV. The sample was diverse across race/ethnicity, sexual orientation, age, type of health insurance used, and number of years living with HIV. Geographically, the greatest percentage of respondents lived in the Southeast US, with others spread fairly evenly throughout other regions of the US.

RESULTS

In total, 131 (72%) respondents reported experiencing stigmatizing language in healthcare settings from a variety of healthcare providers and staff (Table 2.1).

Of the 68 respondents who reported experiencing stigmatizing language from a medical doctor, 59 described specific types of medical doctors (Table 2.2).

72% **of respondents** *(n=131)* reported **experiencing stigmatizing language in the healthcare setting**

"I have seen providers who have been in their role for a long time say stigmatizing language because they have never been corrected. They are not current on the new language and have no interest in learning." – *Survey respondent*

Table 2.1

Experiences of Stigmatizing Language by Type of Professional[1]	
Nurses	57%
Medical Doctors	52%
Medical Office Staff	44%
Emergency Department Personnel	30%
Dentists	28%
Physician's Assistants	24%
Social Workers	22%
Case Managers	17%
Home Health Workers	15%

[1]A total of 131 respondents reported experiencing stigmatizing language in the healthcare setting. Prevalence reflects this denominator.

Table 2.2

Experiences of Stigmatizing Language by Type of Medical Doctor[1]	
Primary Care Provider	71%
HIV Clinician	47%
Obstetrician/Gynecologist	44%
Pediatrician	24%

[1]A total of 59 respondents reported experiencing stigmatizing language from a specific medical doctor. Prevalence reflects this denominator.

Among 131 respondents who reported on the impact of stigmatizing language:

65% **of respondents** *(n=131)* reported that the use of stigmatizing language from a healthcare provider impacted their **self-esteem and mental health**

> *"Hearing stigmatizing language from a healthcare provider, someone who is supposed to be a source of support, is uniquely damaging. It can **internalize shame**, making me feel defined by my status and 'less than' others. It directly undermines my self-worth and can lead to **increased anxiety, depression, and isolation.**"*

54% **of respondents** *(n=131)* reported that **delaying, avoiding, or missing healthcare appointments** as a result of stigmatizing language from a healthcare provider

> *"There have been times when the dread of encountering a specific provider's judgmental tone or being subjected to awkward, stigmatizing questions **made me reschedule an appointment**. The mental and emotional energy required to prepare for potential stigma is exhausting. It creates a barrier where the short-term relief of avoiding a negative interaction feels heavier than the long-term benefit of the appointment, **leading to delays in seeking care.**"*

52% **of respondents** *(n=131)* reported the use of stigmatizing language had an impact on their **overall well-being or quality of life**

> *"[Stigmatizing language at least partially] led to the use of substances for quite some time. ... How I was treated affected my mental health and **made me feel useless and disgusting.**"*

39% **of respondents** *(n=131)* reported finding it **difficult to take antiretroviral medications** as a result of stigmatizing language from a healthcare provider

> *"There were times when **harsh words** from providers made me **lose my motivation to stay consistent with my treatment.**"*

"Sometimes, a healthcare provider has used terms like 'HIV-infected person' in a way that made me feel like my condition defined me, rather than focusing on my overall health. Other times, casual questions about my lifestyle felt judgmental, even if unintentional." – *Survey respondent*

Respondents were asked to rank specific terms using a scale of "Not at all stigmatizing"; "Slightly stigmatizing"; "Neutral"; "Moderately stigmatizing"; or "Very stigmatizing." Table 3 shows the ranking of the top ten most stigmatizing terms (reported as "Very stigmatizing" and "Moderately stigmatizing") identified by respondents.

"Doctors and nurses should avoid labels like non-compliant or 'risky' and instead use supportive language such as 'working on adherence' or 'support needed.' This would show empathy in their tone and words which makes a big difference." – *Survey respondent*

Table 3

Top 10 Most Stigmatizing Terms Ranked by Respondents (n=170)
1. AIDS victim
2. Clean/Dirty
3. Full-blown AIDS
4. AIDS patient
5. HIV carrier
6. Promiscuous
7. HIV infected
8. Treatment failure
9. Risk (as in "risk for HIV" or "high risk")
10. Survivor

This survey also addressed several solutions to decrease stigma in the healthcare setting, including using person-first language. Person-first language puts the person before the condition or label and describes who they are, not what they have been diagnosed with.

Respondents ranked the top three types of support they would like to see increased to address HIV-related stigma:

1. **Education and awareness campaigns**
2. **Training for healthcare providers to reduce stigma**
3. **More support groups for women living with HIV**

77% **of respondents** *(n=166)* agreed that **person-first language improves communication and reduces stigma in healthcare settings**

CONCLUSION

The Well Project undertook this project to augment anecdotal evidence with quantifiable data to further illuminate the impact of language. We would like to acknowledge the community members, clinicians, researchers, and others who have been at the forefront advocating for and implementing person-first language. The results demonstrate that hearing stigmatizing language can negatively affect not only mental health, self-esteem, and quality of life, but also individuals' willingness to attend healthcare appointments and take medications as prescribed.

The Well Project ***encourages allies in the healthcare and research sectors to help "call in" their peers when stigmatizing language is utilized, to lessen the burden on community members and other advocates to do so - especially in settings where community members are not adequately represented.***

This research underscores the clear need for increased education and training around person-first language for healthcare professionals, which has the potential to improve provider engagements and health outcomes for women living with HIV.

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