

“The clinic was brutal...all the nurses stigmatized her”: An exploratory descriptive qualitative study of intersectional stigma experienced by people living with HIV

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Background

Key and vulnerable populations have difficulty maintaining in care and being adherent to treatment if HIV+.

Overall aim of the study:

To explore the factors that drive or facilitate HIV-related stigma and its manifestations in various institutions in society and what the outcomes are for affected populations and institutions in the 3 provinces with highest prevalence of HIV-related external and internal stigma (i.e., KwaZulu-Natal, Mpumalanga, and the Free State) in South Africa.

Interview guide design and sample questions

Informed by the Health Stigma and Discrimination Framework developed by Stangl et al. (2019)

1st Domain: Factors that drive or facilitate health-related stigma

How are HIV and AIDS seen in your community?

2nd Domain: Manifestations

Do people make remarks in your presence that indicate that they are aware of your HIV status?
Probes: What kinds of remarks? How do these remarks make you feel?
How has your family been after finding out about your HIV status? Your friends? Your sex partners?

3rd Domain:

Outcomes for affected populations
Outcomes for organizations and institutions

What are some of the difficulties in accessing HIV medications, counselling and other services at health care facilities?

Can you describe your relationship with your providers?

Social dimensions (e.g., family and romantic partners); and;

They are treating us... those people treat use differently. Because in family's people cannot talk, even if they are positive, people cannot talk. Because they are scared that they are going be judged, sworn and other bad things.

Results
HIV-related stigma manifests in multiple sectors in which key and vulnerable populations living with HIV interact

They would: "Whoa, we don't know where he contracted this thing, you brought a disease at home and even when you walk by on the street you will find people talking about you, why you have HIV, and they will start distancing themselves from you. Because you are going to infect them, they do not know that HIV can infect anyone. Within families, they will start choosing, they no longer use for example you're eating bowl or spoon. Even today these things are still happening (FSPNLGBTI01)

In my community HIV AIDS is seen as a disease that has not been accepted; people haven't accepted that it is a disease we live with because they criticize us, as soon as a person knows that you are like this; it seems as if they have to look down on you, you get my point, they call you names so I can say that HIV in my community is.... If you have it seems as if you are nothing (MPPNPLHIV33)

HIV has impacted my life in a way that many things had to change. In a way that some of the friends I had - I lost some friends. I lost friends. And in terms of boyfriends, relationships and what-what. These days there's no one who wants to be with someone who has this disease and everything. So, it is not easy for me to be in a relationship. But in school I can say it is okay. Ya, it is okay. Because it is not all people who look down at me (MPNCPLHIV02)

Structural (e.g., healthcare and social protection services).

They called us and we had to go and intervene in a case where a trans woman was sent returned to go back where she came from get medication where she comes from, I had to intervene because the clinic was brutal and all the nurses were stigmatizing her, we had to get in as a trans community to say why if you can assist this one you can't because she is also human. (MPNVLGBTI01)

Conclusion

These data reveal how already stigmatized groups are subjected to acts of prejudice and discrimination when accessing treatment, counselling and care for HIV. This emphasizes the importance of using an intersectional lens, thus moving beyond a 'single-axis framework' to understand the complexities and nuances of HIV-related stigma. Thus, intersectional stigma is a way of understanding how social inequalities shape the multiple dimensions of the experiences of key and vulnerable populations living with HIV and possesses the potential to uncover and explicate previously unknown inequalities.

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Study Findings: Socio-demographic characteristics

An **exploratory descriptive qualitative** design is particularly relevant where information is required directly from those experiencing the phenomenon under investigation and where time and resources are limited

Purposive sampling was used to identify and select participants to take part in the study in the provinces of KwaZulu-Natal, Mpumalanga and the Free State

Interviews were conducted remotely (i.e., telephonic) and once COVID-19 restrictions were lifted, face to face interviews were conducted by a trained interviewer who volunteers for Positive Women's Network (PWN)
All COVID-19 regulations were strictly followed during in person interviews.

Study Population

All persons living with HIV (16 years and older) who were:

Linked to an NGO/CBO that provides services to people living with HIV and who lives in the 3 participating provinces

Key informant interviews (N=52) were conducted with people living with HIV from various backgrounds
Managers of support groups and lay healthcare personnel (n=5)

Community Sector

Adolescents living with HIV
Sex workers
People living with HIV (18 years and older)
Sexual and gender minority groups
Persons who inject drugs

Public Sector

Public health care workers (nurses, medical doctors) (rural/urban)
Community health workers
Managers of community based support groups

Civil Society Sector

AIDS activist
Youth activist

HIV-related stigma manifests in multiple sectors in which key and vulnerable populations living with HIV interact:

Young women and female sex workers living with HIV are blamed for spreading the virus and are described in stigmatizing terms in the community in which they live as well as when accessing healthcare.

Study participants attributed stigmatizing behaviors of healthcare workers to cultural and religious beliefs.

RESULTS

Intersecting stigma

HIV-related stigma is layered over other forms of social inequalities such as:

Sexual orientation and gender identifications (SOGI),

It is so difficult, especially in my area because of the woman lesbian nè, they do not expect you to have HIV. They will be questioning you how did you get that HIV being, so it is very, very difficult as a lesbian woman to accept. Even the nurses, they ask you so many questions at the end of the day, a lot of my community, the LGBTQI community, we then do not go to go the clinic because even the nurses are charging you how are you, you are sleeping with other... They say during the day you are a lesbian but at night you change, that is why you then get this HIV thing. You understand? That stigma is there (MPACAIDS01)

Race, age, sex work

Actually it was difficult at first, you know, where I live, you know, it is a black like rural and stuff. So when you say you are HIV positive they see you like you will lose... So it is very difficult for my family, but my mom supported me from the start (MPNCPLHIV01)

Yes, when you get there, they look at you, when you produce your card, they look at you with that "and then this one?" they give you the pills at the pharmacy right?! They look at you like "look at that kid fetching so many pills" some other time you have to go for a check up or produce your blood, the look like "wow, indeed she is fetching the pills for herself" they look at you in an awkward way (MPNCPLHIV06)

Just for instance here in my area, people heard that I am sex worker and I do not know how. So, when they are drunk, they would say, "I am here, I am here if you need me, you can come for me here" They think that I am just a tool for them to use when they are drunk. When you try to talk in public, they would denounce me and say, "who are you, you are just nothing" and not take me seriously. There is still stigma surrounding my profession, so we find ways to hide pretending to people that you have found work and so you wake up in the morning like everyone else and go to work but it all a ploy to lie or hide. But you simply get no respect in this profession of ours (KZNVSW01)