

"My attitude towards my own HIV journey changed the way others see me and treat me"

Insights from Coach Mpilo on challenging and changing stigma



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Background

HIV-related stigma and discrimination remain significant barriers to achieving the UNAIDS 95-95-95 targets and maximizing the health and well-being of people living with HIV (PLHIV). Among healthcare workers living with HIV, there is a complex and multi-layered intersection of both external and internalized stigma, particularly among community health workers and peer navigators who work closely with communities.

Methods

We explored the experiences and perceptions of male peer navigators living with HIV (known as "coaches"), with the aim of understanding how they have addressed stigma in their personal and professional lives. We employed a qualitative design involving individual semi-structured in-depth discussions with 45 coaches across five provinces of South Africa.

Lessons learned

Stigma remains a significant barrier to PLHIV health and well-being

Coaches described numerous experiences of stigma and discrimination in their relationships with partners, family, friends, and the wider community. They also noted that even the anticipation of stigma can be debilitating, particularly anticipated rejection by potential sexual partners.

Some family members indicated that they won't stay with me as I was HIV-positive and taking treatment.

[I felt] shame and guilt for the wrong decisions I made, especially when people ask for details on how and where I contracted the virus.

[I experienced] being treated badly, giving up on my survival, and being blamed for bringing this upon myself.

Stigma is often rooted in fear

Coaches reported that internal stigma was generally rooted in fear of sickness and death, particularly due to a cause many initially viewed as shameful. Fear of 'social death' was another common theme—i.e., fear of rejection by partners, family, friends, and community. Coaches also talked about the fear of loss experienced by their family members.

Your future is doomed. They start mourning you and lose hope in you.

Death is the first thing that comes to the mind of family when you disclose.

[You would experience] pity and avoidance once you were discovered to be living with HIV.

Some feel sympathy for you as [they believe] your life has been cut short.

Self-acceptance is internally empowering

Coaches felt that letting go of internal stigma and accepting oneself and one's HIV status was an essential precondition for coping effectively with external stigma.

Self-acceptance is the first step to healing and setting the tone on how others will treat you.

Stigma will always be there from lack of information, but we move on, and now we are comfortable in our own skin.

Unfortunately, people will always have something to say, but I am comfortable talking about my status and educate them in the process.

Living openly and confidently with HIV is externally powerful

Coaches also reported reducing external stigma in their communities by living openly and confidently with HIV, thereby showing people that someone can be living with HIV and also be strong, healthy, and psychologically well-adjusted.

In our door-to-door campaigns, people do not believe when we indicate that we are living with the virus. They say we are lying, that we are paid to say that just to get them to test.

Initially I would hear snide comments from people who heard me on the radio, calling me names and trying to put me down. Now that is almost non-existent.

People do not believe when I disclose my status during my campaigns because I am healthy and confident.

Coaches are reframing their HIV status as a strength

Many coaches reported reframing their experience of HIV as a resource for advising and supporting other men living with HIV. Coaches noted that many people retain an outdated and distorted mental image of someone with HIV and that seeing someone with HIV who looks and feels well quickly changes that image. They said the best way to change stigma in the community was to talk about HIV as much as possible.

I counselled and supported him, and he did disclose, and his partner accepted him. Now they are living a good life...It makes me happy that I changed someone's life and not him alone but also the family.

I feel powerful, and I am ready to bring change to my community. I am glad that this program has turned my bad story into a great story that will help other men.

Finding out I was to be a coach gave me so much courage. I know there is so much light after the diagnosis. I hope to share this light with others.

Conclusions

The Coach Mpilo model demonstrates that empathetic disclosure from a healthcare worker can reduce stigma and encourage others to seek care.

By finding purpose in their HIV status, embracing it publicly, and countering outdated notions of what it means to be living with HIV, coaches have been able to reduce both internal and external stigma and encourage clients to start and stay on treatment.

This suggests that greater visibility of PLHIV could be a significant element of an effective stigma reduction strategy.

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The Coach Mpilo model

Coach Mpilo is a reimagined peer navigator or case manager model, employing men living openly and confidently with HIV who are stable on treatment as coaches of newly diagnosed men and other men struggling with barriers to linkage, disclosure, adherence and viral suppression.

Coaches work one-on-one with men to break the isolation and paralysis that many men feel at diagnosis and give them a safe and relatable source of support. Coaches also serve as role models in their communities, changing the image of what it means to be a man living with HIV.

Coaches are recruited within their communities and complete a one-week training, after which they are linked to a clinic and deployed in their communities. The clinic then refers newly diagnosed men and men who have disengaged from treatment to the coach. Coaches also engage men proactively via community outreach.

Coaches generally provide support for a period of six months, up to the point of viral suppression and decanting, but remain available as needed.

