EXPLORING THE INFLUENCE OF

INTERSECTIONAL STIGMA ON UPTAKE AND RETENTION IN ART PROGRAMMES FOR SELECTED YOUNG KEY POPULATIONS IN ZAMBIA

Findings from a Mixed Methods Analysis

Report Summary

Background and Rationale

Since 2017, the national, multi-sectoral HIV/AIDS response in Zambia has prioritised the inclusion of all population groups, including key populations, as essential to the country's efforts to end HIV and AIDS as public health threats by 2030. Within the definition of key populations are men-having-sex-with-men (MSM) and transgender people, along with other groups. HIV programmes for MSM and transgender women in Zambia place an emphasis on a wide variety of modalities for encouraging individuals living with HIV to come forward for diagnosis and to subsequently enrol on ART. They also contain a number of strategies to encourage ART retention and adherence and to achieve and maintain viral suppression. All of this occurs in a challenging social context for these individuals, one that is characterised by a high risk of stigma, discrimination and violence, as well as other forms of marginalisation and exclusion across personal, social, economic, cultural and professional domains. The extent to which these risks affect uptake and retention on ART is relatively unknown, in particular for younger individuals who may face additional vulnerabilities, due to limited experience with ART, for example, or having fewer personal or social resources than their older peers to resist the influence of stigma.

This study attempted to contribute to closing these knowledge gaps. It used a mixed-methods approach to arrive at a multi-dimensional view of the experiences of young (18-24 years), HIV-positive MSM and transgender women and their successes and challenges to sustain themselves on ART and to achieve well-being in the Zambia context. The conceptual framework for the research drew on emerging trends in theory and practice for research on stigma, including the concepts of minority stress, intersectionality and intersectional stigma. Young HIV-positive MSM and transgender women in Zambia may find themselves at the intersection of stigma related to their sexual or gender diversity and their HIV status. Understanding how these influences manifest themselves in the lives of these young people, and how they affect their health seeking behaviours – particularly retention in HIV services – is critical to designing and sustaining effective public health interventions for these priority groups.

The Zambia study was part of a regional research project led by the Health Economics and HIV/AIDS Research Division at the University of KwaZulu Natal, Durban, South Africa. The project includes similar studies in Malawi and Zimbabwe. It is funded through the HIV Special Fund Round III initiative of the Southern African Development Community.

Study Design and Methods

The study followed a mixed-methods, parallel design with simultaneous collection of qualitative and quantitative data from the same study sample. The qualitative component involved semi-structured, in-depth interviews; the quantitative component involved a self-administered, confidential questionnaire. The study population included young (18-24 years) gay, bisexual or other men who have sex with men, and young transgender women, self-disclosed as HIV-positive and currently on ART. Data was collected in secure, confidential settings by trained peer research assistants, some of whom were themselves members of the study population.

At total of 56 young people agreed to participate and completed both the questionnaire and the in-depth interview. There were 29 from Lusaka, 14 from Chipata and 13 from Solwezi. All participants were offered 100 Zambian Kwacha (US$6) at the end of the session to support transport costs. Interviews were recorded and subsequently transcribed and translated by trained transcribers (participants spoke a mix of English, Nyanja, Bemba and Lozi). Questionnaire results were loaded to Kobo Connect. Data analysis used both qualitative and quantitative techniques and relied on a flexible, dialogic approach to triangulation to build complementary, reflexive links between the two types of results (quantitative and qualitative).

This study was approved by the Research Ethics Committee of the University of Zambia and the National Health Research Authority. The study was also approved by the Biomedical Health Research Ethics Committee of the University of KwaZulu-Natal.

Findings

Participant Characteristics

Of the total number of participants, 64% (36) initially identified as MSM and 36% (20) as transgender women. With regard to sexual orientation, over half of the participants (55%) described themselves as gay; eight participants (14%) described themselves as bisexual. The remainder (31%) identified themselves as transgender women with primarily male sexual partners. Just over half of participants (52%) had completed a secondary school level of education, and one third (32%) had completed post-secondary education, with this proportion being higher among MSM (36%) than transgender women (25%). With reference to employment status, 43% indicated that they were unemployed. The median monthly income of the study participants, for the only 55% who recorded any income, was ZMW1,150 (US$59). Regarding other characteristics, 46% of participants were living with family, 52% were single, and 95% described themselves as Christians. These proportions did not differ substantially between the MSM and transgender groups.

More than two-thirds (69%) of participants indicated that they had been diagnosed with HIV within the past two years. One transgender participant indicated that she had acquired HIV at birth. Almost three-quarters (72%) indicated they had been on ART for two years or less. Almost half of participants (47%) were diagnosed at government facilities and a similar proportion (50%) indicated that they were also receiving their ongoing care at these facilities. Most other participants (39%) had been diagnosed in non-governmental facilities, including those operated by the Churches Health Association of Zambia and were also receiving their HIV care there (38%). A higher proportion of transgender participations (20%) than MSM participants (3%) were using private health care.

From the data analysis, five over-arching themes emerged: 1) intersectional identities; 2) experiences and fears of intersectional stigmas; 3) stigma and mental health; 4) coping and resilience; and 5) influences on ART adherence.

Intersectional Identities

With regard to their identities as MSM or transgender women, participants gave a range of descriptions during the interviews with most anchored in a strong sense of understanding and acceptance that their sexual orientation or gender identities were a fundamental and enduring part of who they were as persons, as in these examples.

> *"I am gay and I love who I am, because it's something I didn't just come up with, but it's something that I feel is in me and I was born with it...So, I feel okay with it myself."* MSM, 24 years, Chipata

> *"Being a TG, it is not something that you just wake up today and just say, 'I am a TG.' No, it is about the way you feel yourself. The way I feel myself, it is important. I feel like a woman; I see the woman in me. So, it is very important to me."* Transgender woman, 22 years, Lusaka

From the questionnaire, 75% agreed or strongly agreed that they are comfortable with their identities and would not wish to change them. As for the proportion of participants who were less assured, the interviews indicated that these doubts largely arose from the difficulties of the social context.

> *"Mostly... some of the reasons that I am [only] slightly comfortable, mostly stigma. We have a lot of stigma against, you know, homosexuality, being gay, just being different. When you are different people don't understand. So yeah."* MSM, 23 years, Lusaka

There was a similar variety of views amongst the participants about being a person living with HIV (PLHIV).

> *"How it feels like [living with HIV]? Ah, one doesn't choose to have HIV, but when you are found with it, you just need to start taking medication and continue being the way you were before. Don't start to fold your arms and start looking sad or feeling sorry for yourself, or even stop moving around assuming people will smell the medicine on you. So, you just need to be the way you were a long time ago."* MSM, 19 years, Chipata

From the questionnaire results, a number of participants found it more difficult to be confident and assured about their HIV status compared to their sexual orientation or gender identity. For example, 45% strongly agreed or agreed that they occasionally felt worthless because they were HIV-positive; whereas close to a third of participants (31%) strongly agreed or agreed that they were ashamed that they were HIV positive. Further, 27% of participants (30% of MSM and 20% of Transgender women) agreed or strongly agreed with the statement "I think less of myself because of my HIV status." In comparison to their sexual orientation or gender identity, a greater proportion of participants were struggling to find a similarly positive and accepting view of their health status, as in this example.

> *"In general, this HIV that I am living with it is a talk of the community. It is a type of disease or an illness that is painted with a lot of backlash on it because people feel that these people that have HIV have been doing bad things and involving themselves into sexual activities. Yeah, they have been doing immoral activities. That is the reason why they are living with HIV. So, I feel it's not something that is really straight sitting with me because of that...What I mean is what people say literally brings a lot of emotions."* Transgender woman, 22 years, Solwezi

Experiences and Fears of Intersectional Stigma

While traces of stigma emerged in how participants described themselves (as sexual minorities, and individuals living with HIV, and the degree to which they accepted these things about themselves) the influence of stigma became more prominent as they expressed themselves in their social environments, beginning with who they told about themselves, what they disclosed and why. Anxieties about, or experiences of stigma influenced these disclosures and sometimes led to complex arrangements for managing who could know what about them, whether about their sexual orientation, gender identity or health status. And once information began to circulate in this wider social context, whether initiated by the participants themselves, or happening despite their efforts to conceal or keep these things hidden, the influence of stigma and the fear surrounding it intensified.

> *"As I said to you, being gay is not easy. And being gay plus being HIV positive is something that makes you crazy because people will just say, 'Whatever they were doing, it caught them in their act!' ...So, it's something that is so difficult to keep up with."* MSM, 24 years, Chipata

The findings further demonstrated that, in Zambia, social characteristics linked to sexual or gender diversity and HIV status, were either devalued or at constant risk of such devaluation for the individuals that possessed them. For the young participants, intersectional stigma was indeed a potent force in their contexts; one that was flourishing although with intricate variations in its forms, manifestations, intensities, and effects across a range of socio-ecological zones, from the private, interior world of the individual to the public and institutional.

> *"It's not easy I am telling you. I don't just come out in open and tell people that I am HIV positive. I don't. I do hide myself, the reason being I am scared of the society, that they will start laughing at me, pointing fingers at me. So, it's like I am living like a private lie where I have to be hiding for who I am. It's like I just*

can't come out and tell people that I am HIV positive, I am gay." MSM, 23 years, Solwezi [ZAM-SOL-WC-MSM6]

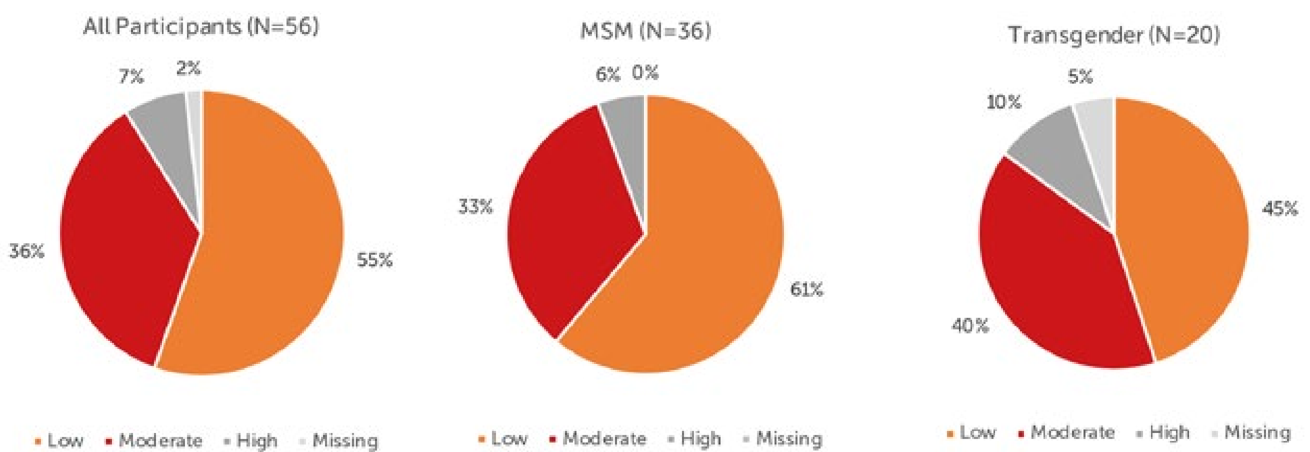
In the midst of this, the participants revealed both vulnerabilities and remarkable strengths in the way that they find, evolve, and express their identities in terms of sexual or gender diversity and health status. These young people become adept at managing their outward-facing identities through various strategies for disclosure and concealment, being a person living with HIV in some contexts, being a member of the sexual minority community in others, but rarely being both at once. While it would appear that the study participants are more able to manage their experiences and risks of HIV-related stigma, they had a stronger vulnerability to stigma related to their sexual orientation or gender identity, particularly if their HIV status was also used to devalue them.

Stigma and Mental Health

There were a range of stigma-related effects on the participants, arising from actual experiences or from fears and anxieties about stigma and discrimination, whatever their source or object. These effects included a negative influence on mental health as well as causing a range of other emotional, social, or physical harms, and increasing participants' anxiety about recurrent experiences in the future.

The study used the Centre for Epidemiological Studies Depression Scale – 10 Item Version (CES-D-10) to measure the presence of depression symptoms in participants (Figure A).

Figure A: CES-D-10 results



According to the CES-D-10 methodology, a score of <10 indicates low to minimal symptoms of depression, a score from 10-20 indicates moderate to significant symptoms of depression, whereas a high score from 20-30 is symptomatic of major depression, potentially in need of urgent clinical intervention. From the responses, over half of the participants (55%) had a score <10, indicating that they had low to minimal symptoms of depression. This proportion was higher for the MSM participants (61%) compared to the transgender participants (45%). It was also observed that a greater proportion of transgender participants had moderate to significant symptoms of depression (40%), or major depression (10%) compared to the MSM participants (at 33% and 6%, respectively).

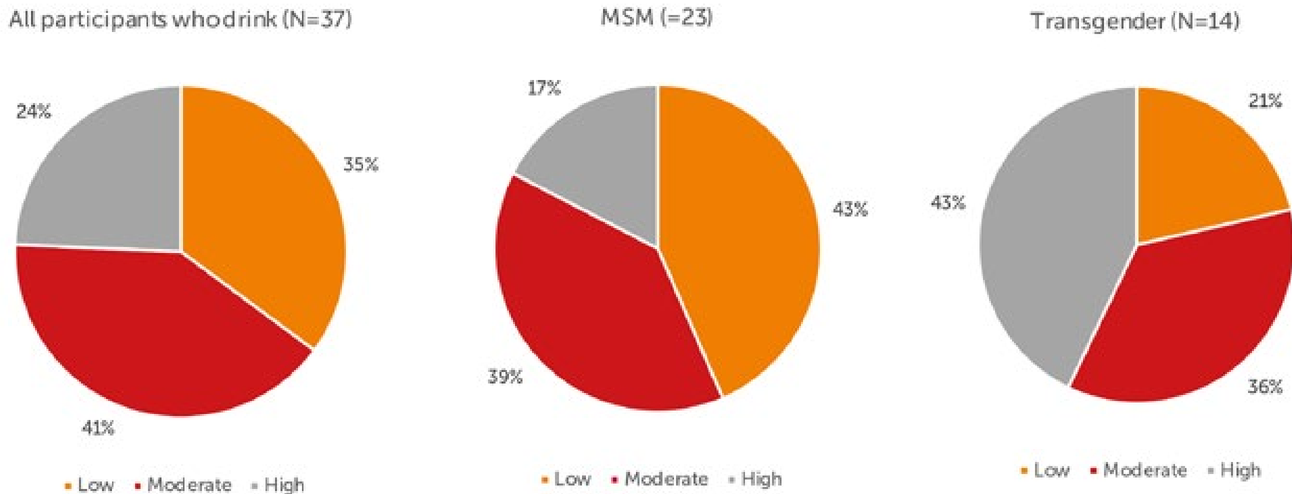
The study found that 57% of all participants had never contemplated suicide. Of the remainder, 36% had contemplated suicide at least once, and 13% had done so in the previous year. Transgender participants had contemplated suicide more than their MSM peers. Very few had disclosed such thoughts to others (18% for all participants, 25% for transgender women). Finally, four (7%) of the young participants (three MSM and one transgender woman) indicated that it was likely they may still attempt suicide at some point in the future.

Coping with Stigma

The study's participants coped with and responded to the effects of stigma, including poor mental health, in different ways. These included some

problematic practices, such as high levels of alcohol or drug use. The study employed the Alcohol Use Disorders Identification tool (AUDIT) to examine the frequency of taking alcohol for the 66% (37/56) that drank (Figure B).

Figure B: AUDIT results



One-third (35%) of participants (43% for MSM and 21% for Transgender women) indicated a low level of alcohol consumption (monthly or less). A greater proportion (41%) had moderate consumption (monthly or weekly). One quarter of participants (24%) were high or frequent users of alcohol, including levels symptomatic of addiction. This was highest (43%) for transgender participants.

Aside from alcohol or drug use, the young participants had other ways of coping with the effects of stigma. These included exercise (sports, walking, swimming), meditation and prayer, reading, having sex, or just keeping busy. Focussing on positive or purposeful activities relieved stress or lifted the burden of poor mental health for these young people, as in these examples.

> *"I work out, I go to the gym, I do a bit of meditation, I read certain books that usually sharpen my mental faculties."* MSM, 24 years, Chipata

> *"I worship my Lord, and I know that everything is possible with Him by my side."* Transgender woman, 24 years, Chipata

> *"I keep my mind off things that are making me feel bad and I do different kinds of chores around the house, to remove the pressure I have."* Transgender woman, 24 years, Lusaka

In addition to their own strategies for coping with the stress of stigma or poor mental health, participants had relied on peer counsellors, or peer promoters or navigators, and KP-friendly health workers, and more rarely mental health professionals in order to unburden themselves and to seek support.

> *"I handle my issues on my own. I do not like to involve too many people because they can look down on me that, every day, I have issue, like I'm always having the same issues, every day. So, you will find that I handle my issues on my own in whatever situation I am in. Unless when the issue is too big that is when I can go to a counsellor."* MSM, 20 years, Lusaka

Those young participants that could access these services found them greatly beneficial. Participants also relied on family members, friends, or romantic partners when they felt overwhelmed.

Effects of Stigma on ART

Being on ART had specific meanings and significances for the participants. For some it was empowering and life affirming.

> *"I live happy because I have accepted it [taking ART] and I don't have that feeling to say, let me stop this because maybe I am in this situation, or because I am a transgender, or anything. And I can't stop taking it unless*

I stop breathing!" Transgender woman, 23 years, Chipata, Zambia

However, a number of participants had mixed views about taking ART, much of it linked to fears or experiences of stigma. This fuelled an additional layer of risk that led some individuals to prefer missing doses, occasionally or over more prolonged periods, rather than endure actual or feared social, emotional, or physical harms linked to being 'found out' as someone living with HIV and taking ART.

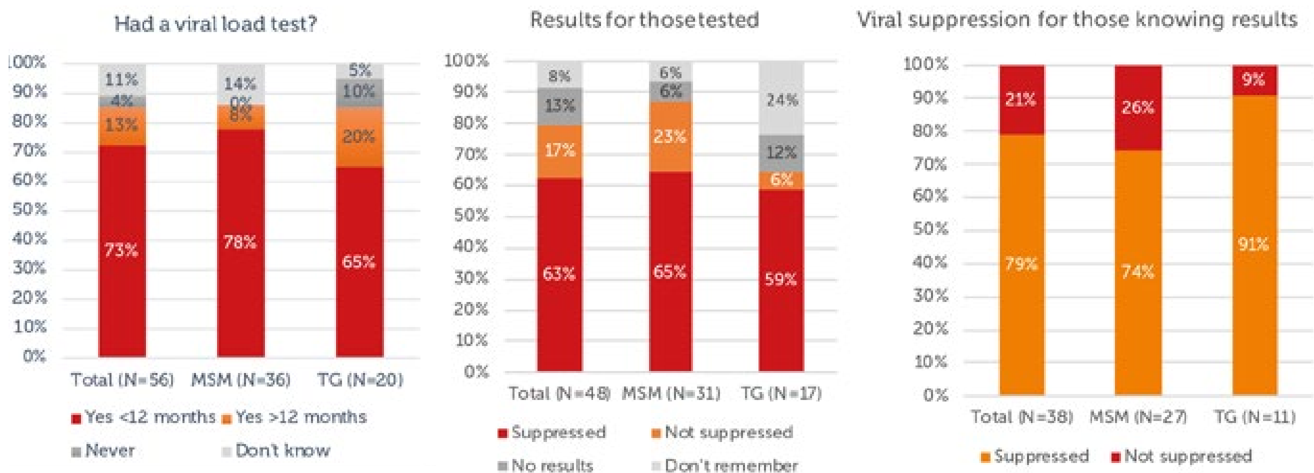
Overall, 50% of participants had missed doses at least once since starting ART (the proportions were the same for MSM and transgender groups). How fears about or experiences of stigma led to missing doses of ART was explained by a number of participants, including this one:

"At some point I had stopped. I really, really had stopped because when somebody who was closely related to me found them [the medication] and then exposed me in the house, so I was like, anyway, I just had to throw them, like, away. Let me just die. Everybody knows now and I am embarrassed, so let me just stop taking them." MSM, 24 years, Lusaka

Some described how they had missed doses only once, while others had stopped taking their medication for many days or weeks. Several factors contributed to missing doses, including simply forgetting that they were on medication, being depressed, forgetting to carry medicines when travelling, lack of food, or consuming too much alcohol. Mental health challenges, including loneliness, depression, reacting to stigma and rejection, and suicidal thoughts could all lead to stopping ART.

Given the frequency of missed doses, it was not surprising to find that self-reported viral suppression was not optimal for all participants (Figure C).

Figure C: Self-reported results for viral suppression



Viral suppression was lower for MSM participants who knew their results (74%) than for transgender participants (91%). Some of this is no doubt linked to missing doses; however, the study could not firmly establish these links. For those participants that had stopped or interrupted treatment at some point, fortunately, there were individuals or events that encouraged them to restart and to overcome whatever influences were leading to the interruption.

Discussion

The findings have shown how stigma emanating from "multiple socially devalued characteristics" – being MSM or transgender, HIV-positive and on ART – are "mutually constitutive" and "synergistic" in their forcefulness. This was very evident, for example, in the many complex strategies the young participants adopted to manage disclosure (and non-disclosure) about their sexual orientation, gender identity, and their health status, depending on the social settings in which they found themselves, whether it was being amongst siblings or partners, other sexual minority peers, other friends, health workers, or members of the community at large. Few and far between were the opportunities or spaces where

the participants did not have to feel vigilant about inadvertently revealing something about their 'true' identity or their health status, including taking ART.

All of this effort was maintained, it appeared, to anticipate or avoid stigma. These efforts also had a considerable toll on the young participants, in the form of mental health challenges, and problematic coping behaviours, such as heavy alcohol use, that could lead, eventually, to missed doses of ART, or at least elevated risks of such things. Very few participants appeared to have reached a state where, through open disclosure, supportive social networks, access to counselling and mental health support, and a highly evolved self-assurance, they had become resistant and resilient to such negative forces and were not at risk of negative consequences, including missed doses.

Conclusion and Recommendations

The study findings were proof enough that more needs to be done on multiple fronts and levels. Long-term ART adherence remains a global challenge for all groups and requires layered, multi-pronged interventions at multiple levels, from the individual to the structural. Older adolescents and young people on ART, including those who are members of sexual minority populations, may require more focussed approaches.

With the socio-ecological framework in mind, the findings suggest the following areas for further action to address the different community, interpersonal, health system and societal level factors and influences that drive and shape the experiences of stigma and discrimination among young HIV-positive MSM and transgender women and their efforts to maintain themselves on ART:

Individual interventions: Conduct life-skills training and support economic empowerment, including microcredit support and mentorship. There is also a need to promote positive coping behaviours in response to stigma experiences, modelling those participants that adopted reading, singing, exercising, and to support the development of safe spaces and support groups for MSM and transgender women living with HIV.

Relationship/interpersonal interventions: Provide life-skills training; supportive, inclusive, and comprehensive health services; and strengthen social support through partner engagement and peer-to-peer discussions.

Community interventions: Provision of life-skills training, and opportunities for critical reflection and gender awareness to community members.

Health systems interventions: Train health workers in critical reflection and gender awareness. There is also a need to link safe spaces for young HIV-positive MSM and transgender women to mental health support and ART services, including KP-friendly, trusted, and caring health facilities. Further there is need to develop community health systems and strategies that take into account appropriate community-based health promotion channels that are compatible with and trusted by the MSM and transgender people living with HIV.

Societal interventions: Strengthening implementation of laws and policies that provide a favourable environment for MSM and transgender women living with HIV, including stigma reduction policies that consider multiple intersecting stigmas. Finally, there is a need to reflect on the value of sustaining criminal laws against sexual and gender diversity when their consequences are so harmful, both to young people in Zambia, and to the national effort to end HIV and AIDS as public health threats by 2030.

For the *full report*, see: Zulu JM, Armstrong R, Nyamaruze P. Exploring the Influence of Intersectional Stigma on Uptake and Retention in ART Programmes for Selected Young Key Populations in Zambia: Findings from a Mixed Methods Analysis. Durban: HEARD, University of KwaZulu-Natal; 2023. Available at: www.heard.org.za