EXPLORING THE INFLUENCE OF INTERSECTIONAL STIGMA ON UPTAKE AND RETENTION IN ART PROGRAMMES FOR SELECTED YOUNG KEY POPULATIONS IN MALAWI

Findings from a Mixed Methods Analysis

Report Summary

Background and Rationale

Over the last decade, the national, multi-sectoral HIV/AIDS response in Malawi has prioritised the inclusion of all population groups, including key populations, as essential to the country's efforts to end HIV and AIDS as a public health threat by 2030. Within the country's definition of key populations are men-having-sex-with-men (MSM) and, more recently, transgender people, along with other groups. Current HIV programmes for MSM and transgender women in Malawi place an emphasis on a range of tailored strategies for encouraging individuals living with HIV to come forward for diagnosis and to subsequently enrol on ART. They also contain a component to strengthen retention and adherence, and to achieve and maintain viral suppression. All of this occurs in a challenging social context for these individuals 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 for MSM or transgender women is relatively unknown, 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 an exploratory, 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 Malawian 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 Malawi 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 Malawi 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, and including similar studies in Zambia and Zimbabwe. The project 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 transgender women, all self-disclosed as HIV-positive and currently on ART. Data was collected in secure confidential settings (including on the premises of a donor-funded Drop-in Centres managed by the Centre for the Development of People) by trained research assistants, some of whom were themselves members of the study population.

At total of 48 young people (14 from Blantyre; 14 from Lilongwe; 14 from Mzuzu and 6 from Mangochi) agreed to participate, gave informed consent, and completed both the questionnaire and the in-depth interview. All participants were offered MWK8,200 at the end of the encounter to support transport costs. Interviews were recorded and subsequently transcribed and translated by research assistants (participants spoke a mix of English, Chichewa or Tumbuka). Questionnaire results were loaded to Kobo Connect and transcripts to Nvivo 12 pro. Data analysis used both qualitative and quantitative techniques and relied on a flexible, dialogic approach to triangulation to build c0mplementary, reflexive links between the two types of results (quantitative and qualitative).

This study was approved by the Research Ethics Committee of the Kamuzu University of Health Sciences and the Biomedical Health Research Ethics Committee of the University of KwaZulu-Natal.

Findings

Participant Characteristics

Of the 46 participants, 54% identified as MSM and 46% as transgender women. In terms of self-assigned gender, 52% defined themselves as male, 11% as female, and 17% as transgender. With regard to sexual orientation, 43% of participants described themselves as gay, followed by 24% as bisexual. A further 33% indicated that they were transgender women with primarily male sexual partners. The median age of the participants was 22 years. Just over half of all participants (57%) had completed a secondary school level of education (48% for the MSM group and 67% for the transgender group). Almost one third (30%) of participants had completed post-secondary level education, with this proportion being slightly higher among MSM (32%) than among transgender women (29%).

With reference to employment status, 26% indicated that they were unemployed (43% of transgender participants) and 30% indicated they were self-employed. The median monthly income of the study participants (for those that received any) was MWK50,000 (US$49). Regarding other characteristics, 33% of participants were living with family and 39% were living on their own; 52% were single, and 93% described themselves as Christians. These proportions did not differ substantially between the MSM and transgender groups.

Overall, 43% of participants (40% for MSM and 48% for transgender women) indicated that they had known of their HIV status for five years or longer. Four participants indicated that they had acquired HIV at birth. For ART, 46% indicated they had been on ART for five or more years. Three-quarters (74%) were diagnosed at government facilities (68% for MSM and 81% for transgender women); however, only 59% (68% for MSM and 48% for transgender women) indicated that they were also receiving their ongoing care at these facilities. Most other participants (28% of MSM, for example) had been diagnosed in non-governmental facilities and were also receiving their HIV care there (35%). Two participants (transgender women) were receiving care from facilities operated by the Christian Health Association of Malawi (CHAM) and one participant (transgender woman) was receiving care from a private provider.

From the data analysis, four over-arching themes emerged: 1) intersectional identities; 2) experiences and effects of intersectional stigmas; 3) coping and resilience; and 4) influences on ART adherence.

Intersectional Identities

At the start of each interview, participants were asked to describe their *sexual orientation or gender identity*, and to reflect on their degree of acceptance and comfort with who they were in their social

contexts (their affect). With regard to these identities, participants gave a range of descriptions, but most were 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.

> *"I was born a gay person and one can't lie, saying I started it as I was growing. No, I was born like this and maybe other people they might see me as a trans person. That's my sexuality. I am not the person that people can see me as, but inside me, the way I was created, I am a person belonging to LGBTQI+ community."* MSM, 23 years, Mangochi

> *"l describe myself as a trans woman, known as transgender. So, on gender identity, l was born male, and l have a dick. But myself, inside me, the feeling l have is a feeling of a woman. l feel like a woman and I am proud of it that. l feel the way l am like a woman, like what every woman does. It's the way l am."* Transgender woman, 22 years, Lilongwe

From the questionnaire, 96% of participants agreed or strongly agreed that they were comfortable with their identities; a slightly lower proportion (89%) agreed or strongly agreed that they would not wish to change their identities. These proportions did not substantially differ between the two groups of participants.

> *"I am very comfortable because this is how I am, that is how God created me. It's not just a choice of lifestyle, but it's something that is within me, that is how I feel, it's nature."* MSM, 22 years, Mzuzu

> *"The reason like I am comfortable is because I am the image of God. It's the reason I am comfortable. Because if I am not comfortable, with the way I was born, it's like I am against with God."* Transgender woman, 24 years, Blantyre

There was a similar variety of views amongst the participants about being *a person living with HIV (PLHIV)*, from highly affirming, to more doubtful.

> *"As I am living with HIV, I take it as how everyone normally lives."* MSM, 23 years, Mzuzu

From the questionnaire results, some participants found it more difficult to be so confident and assured about their HIV status compared to their sexual orientation or gender identity. For example, 26% of study participants agreed or strongly agreed that they felt ashamed about their HIV status (29% for transgender women). More than half (59%) hid their HIV status from others (72% for transgender women). One-third (33%) sometimes felt worthless, and a further one-quarter (26%) thought less of themselves because of being HIV-positive. Transgender participants generally had a more negative self-regard as PLHIV than their MSM peers.

> *"Sometimes it's hard, it's a disease and you stay believing that one day you will die. I complain sometimes because I think, where did I get the disease? Was I born with it, or I got it because I have sex with my fellow men? I don't know. Or I got HIV when I was taking care of someone sick? I don't know the actual way I got HIV and I am disappointed mostly."* MSM, 24 years, Blantyre

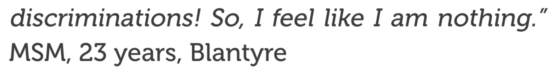
In comparison to the results for affect regarding sexual orientation or gender identity, a greater proportion of participants were struggling to find a similarly positive and accepting view of their health status.

Experiences and Fears of Intersectional Stigma

The presence of stigma and its influence became more evident as participants interacted with their social environment, through processes of disclosure of their sexual orientation and gender identity, or their health status, and what may or may not have transpired when such information began to circulate in social settings, whether within families, among sexual minority peers and other friends, or in the community more generally.

Encounters with stigma soon intensified to influence most aspects of daily social interaction. There were numerous interrelationships between stigma related to sexual orientation, gender identity, and health status, that manifested themselves on a frequent basis, either as things to be endured and recovered from, with or without the assistance of others, or as experiences to be feared and avoided, sometimes at a significant cost to self-confidence and self-esteem.

> *"It is very difficult because one, we are already MSM being discriminated against in communities, and two, if you are also positive, you are also to be discriminated. So, a lot of*



discriminations! So, I feel like I am nothing." MSM, 23 years, Blantyre

The findings further demonstrated that, in Malawi, 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.

> *"The moment I disclosed it to my parents [being gay], and my friends, at first they were running away from me, failing to chat with me, meaning I was staying alone. Even my parents were saying I am not a human. Even my brother said that this is a bad choice, and you are not supposed to be my friend, my relative, whatever. So, it was such a bad thing to me because I was feeling alone, nobody was there to help me to overcome the situation."* MSM, 18 years, Lilongwe

> *"At first when I got to the hospital and explained that I am a transgender but also HIV positive, the doctor said, 'You have sex with fellow men and you are also HIV positive? Why can't you stop? Where will this lead you?' This discouraged me."* Transgender woman, 24 years, Blantyre

In the midst of intersectional stigmas, participants revealed both vulnerabilities and remarkable strengths in the way that they found, evolved, and expressed their identities, in terms of sexual or gender diversity and health status. These young people became 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 were 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.

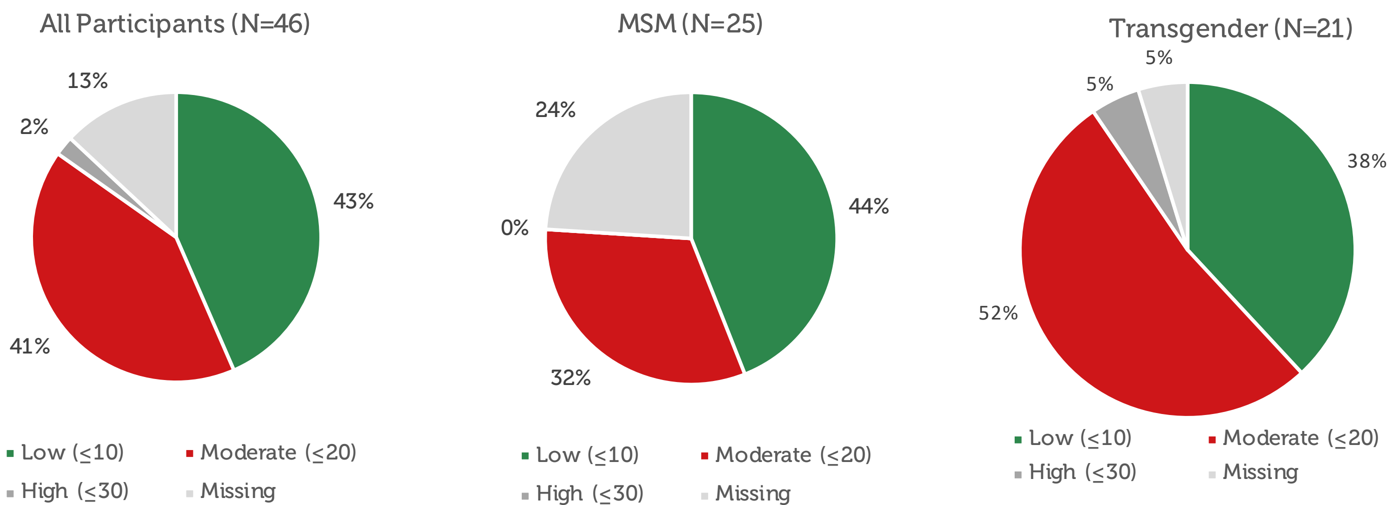
Effects of Stigma

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

> *"I can say I am affected, mentally, because I do Isolate myself on the issue concerning being HIV positive and the way that I look, being a gay. I just feel guilty because where I stay, I say I am a gay, and at the same time I am HIV positive, so people do laugh at me, saying it's a punishment from God. And when I combine all these things, I don't feel good because the community judges me with the condition I am in, the way that I do things. So, I don't feel comfortable and mentally I am disturbed a lot."* – MSM, 18 years, Lilongwe

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 CESD-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. From the responses, 43% of participants had a score <10, indicating that they had only low to minimal symptoms of depression (44% for MSM and 38% for transgender participants). However, an equal proportion (41%) had moderate to significant symptoms, reaching 52% for transgender participants.

The study found that 63% of all participants had never contemplated suicide. For the remainder, 37% had ever contemplated suicide and 33% had done so in the past year. Very few participants (6 or 13%) had disclosed these thoughts to anyone. Finally, 11% (1 MSM and 4 transgender participants) indicated that it was likely they may still attempt suicide at some point in the future.

"When I am in bad mental health especially, I am used to being alone with those things. Sometimes, I don't take food and even I would decide not to take any medication because I feel like I am nothing, I am useless... Sometimes I decide if I can die today, I can rest. So, a lot of things come into my mind when I am disturbed." MSM, 18 years, Lilongwe

Coping with the Effects of Stigma

The study's participants had different ways that they coped with and responded to the effects of stigma, including poor mental health. These ranged from some more problematic practices, such as high levels of alcohol or drug use. The study used the Alcohol Use Disorders Identification Tool (AUDIT) to examine the frequency of consuming alcohol for the 79% (44/56) participants that consumed alcohol (*Figure B*).

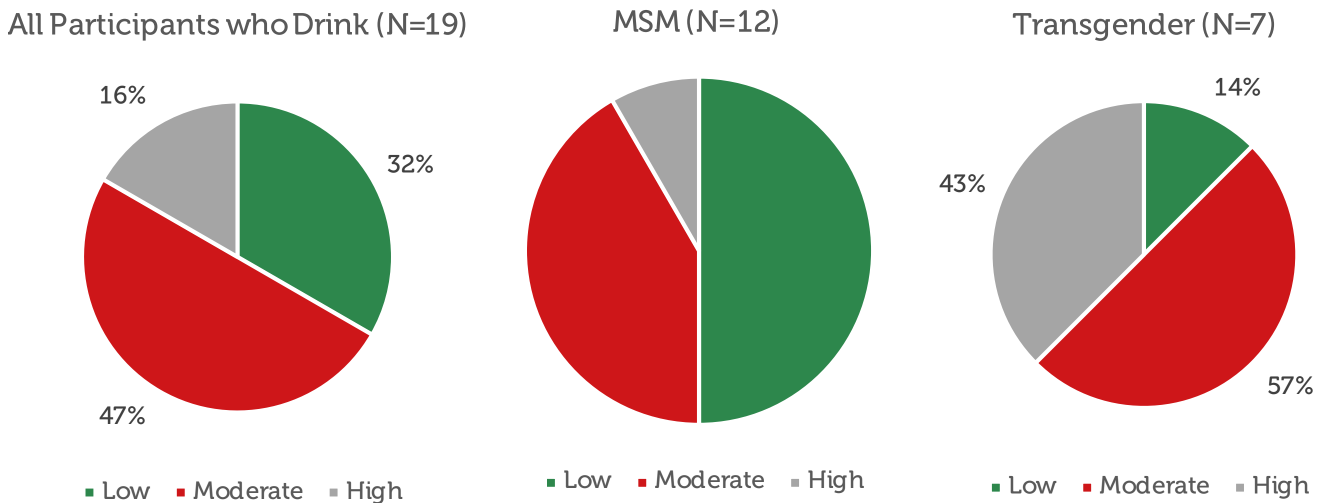


Figure B: AUDIT results

Overall, 19 or 43% of all participants (12 or 48% for MSM and 7 or 33% for transgender women) indicated that they consumed alcohol on a regular basis, ranging from monthly to daily consumption. One-third (32%) of participants (50% for MSM and 14 % for transgender women) indicated a *low* level of alcohol consumption (monthly or less). A greater proportion (47%) had *moderate* consumption (monthly or weekly) reaching 57% for transgender participants. Of the participants who consumed alcohol, only four (one MSM and three transgender participants) were *high* or frequent users at levels symptomatic of addiction.

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.

> *"I chill with people, I go for football, I go for netball, and it heals me, to give away or to take away that stress that I'm having."* MSM, 23 years, Blantyre [MWI-BT-DK-MSM-12]
> *"I like listening to music. It eases me. It is something that puts me at ease. Maybe I am angry, I am frustrated, I think of things that cannot change, I just sit down, put myself down, and listen to music to cool myself, and maybe talking to someone. Over time, the things can go, and I feel a kind of relief."* Transgender woman, 19 years, Lilongwe [MWI-LL-MM-TG-P11]

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 (rarely) mental health professionals in order to unburden themselves and to seek support.

> *"The moment I go to the hospital to get medication, they counsel me on how I can handle myself, how to avoid stress. So, when I go there, those people do help me, saying this is not the end of life, you can do everything, anything you can do. So, that kind of encouragement makes me to feel comfortable, saying I am a human and I can do everything as a person."* MSM, 18 years, Lilongwe

Those participants who had access to these services reported that they were 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 have accepted it [being on ART] and the fact that I am HIV positive, it's now another chapter. So, I decided to live as normal. The other side is taking my treatment as a daily hope."* MSM, 22 years, Lilongwe

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.

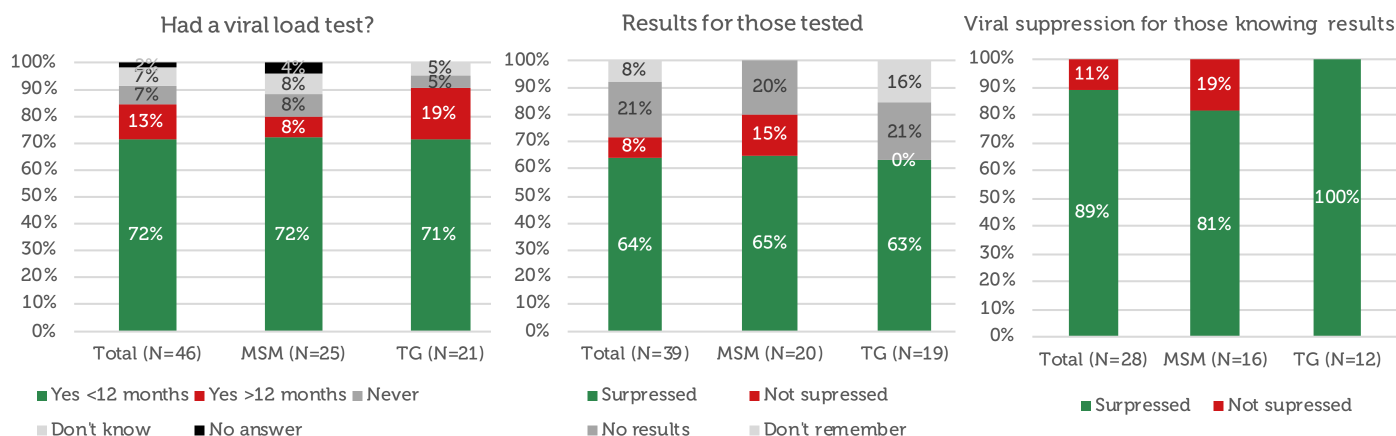
One quarter (25%) of participants had missed ART doses at least once (28% for MSM and 24% for transgender women). Most indicated it was because they 'simply forgot.' Other reasons were being away from home, not wanting others to see them with the medication, being drunk or being depressed. Some described how they had missed doses only once, while others had stopped taking their medication for many days or weeks.

> *"The moment I am in a bad situation, I decide not to take the drugs because I feel like taking the drugs, it's nothing. And I don't see any importance of taking the drugs at that moment because I decide that I am useless, I am nothing. So, when I am disturbed, I feel like I am nothing. I don't even recall that I should take the drugs at this time. As you know, we are told to have a specific time for taking the drugs."* MSM, 18 years, Lilongwe

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, the study asked participants about their viral load (*Figure C*).

Figure C: Self-reported results for viral suppression



Self-reported viral suppression was 64% for all participants who were tested (65% for MSM and 63% for transgender participants). However, when those who received no results or couldn't remember the result are excluded, the level of self-reported viral suppression improves significantly at 89% overall (81% for MSM and 100% for transgender women).

Fortunately, for those participants who had stopped or interrupted treatment at some point, were individuals or events that encouraged them to restart and to overcome whatever influences were leading to the interruption.

> *"Sometimes when you are stressed, when you are depressed, really you just feel like, let me stop this, let me just die. But you realise that I still have life to live, I still have to do this! You end up still taking the ARVs. So, the issue of mental health, it's really hard. You sometimes feel tired, feel stressed and at the same time, you need to take the ARVs. But, yeah, you just have to do it."* Transgender woman, 21 years, Lilongwe

Discussion

The study set out to explore the concept of intersectional stigma and how it can manifest itself

and affect the lives and experiences of young HIV-positive MSM and transgender individuals in the Malawian context. It also set out to explore pathways between manifestations and experiences of intersectional stigma, linked to sexual orientation or gender identity and HIV-status, and their influences, especially ART adherence.

What the findings have illustrated is that there is a convergence of multiple stigmatised identities and experiences amongst the young participants, linked to their sexual orientation, gender identity and HIV status, something that has not been comprehensively described previously, at least for Malawi. This convergence has a significance influence on their mental, emotional, and physical health which, in turn, affects ART adherence for at least the one quarter of participants who reported missing ART doses (many more could be at risk of such occurrences, however, according to their own accounts).

In response, the young participants, many of whom were still dependent on their families for their well-being, needed to find and adopt multiple strategies to avoid or endure such risks, many by hiding or disguising what they felt to be their true selves. Such efforts were a burden to the extent that it could lead to self-doubt, and the more corroding effects of self-stigma, on their sense of security about and acceptance of their sexual orientation or gender identities, and their health status. Fortunately, a number of participants had found themselves with accepting and supportive siblings, parents, social networks, and even health care providers. Such accounts were encouraging, if still too small in number, and a sign that, for Malawi, more tolerance and acceptance is emerging for these young people in all of their diversity.

Conclusion and Recommendations

The study has shown that while important progress has been made in Malawi to diagnose, reach, and retain young HIV-positive MSM and transgender women on ART in HIV care, challenges remain related to the influences of intersectional stigma linked to sexual orientation and gender identity, and HIV status. The findings suggest the following areas for further action to address the different individual, interpersonal, community, health system and societal factors and influences that drive and shape the experiences of stigma and discrimination among young HIV-positive MSM and transgender women in Malawi, and that affect their efforts to maintain themselves on ART. These include the following:

Individual interventions

- Through different strategies and modalities, create more awareness and support for positive coping behaviours, such as sports, artistic endeavours, and other similar pursuits to build and sustain personal coping and resilience.
- Create accessible resources for personal mental health support, including approaches based on positive psychology or mindfulness which have been shown to be effective in other contexts.
- Create accessible resources to assist young key populations to understand intersectional stigma and to recognise and reduce its negatives effects.
- Develop and scale-up differentiated approaches to support individuals, with a specific emphasis on tailored approaches for transgender individuals and their diverse needs.
- Create more pathways towards economic upliftment so that young MSM and transgender people living with HIV can be more autonomous.

Interpersonal and community interventions

- Design and implement education and awareness campaigns, through different strategies and modalities, including social media, to build knowledge and skills for individuals who are key populations to recognize and address mental health challenges.
- Scale up interventions within LGBTQI+ spaces (including DICs) to reduce and eliminate HIV-related stigma, particularly at the interpersonal and community levels, with a specific emphasis on topics such a shared disclosure and mutual caring and solidarity regardless of one's health status.
- As part of supporting young key populations living with HIV and on ART, reinforce components addressing self-acceptance and strategies for safe disclosure of their health status, including in sexual and romantic partnerships.
- Design or strengthen mechanisms for supporting young MSM and transgender people living with HIV to manage family and community dynamics, including for safe disclosure of their social identities and health status.
- Create more pathways (including scaling up Parents and Friends of LGBTQI+ Individuals [PFLAG] initiatives) for parents, family members, friends, and others to seek out and address their own stigmatising attitudes, beliefs and practices regarding sexual orientation and gender identity, and HIV status.

Improving health services

- Urgently address the critical gap in mental health support for young key populations living with HIV, with due regard to their diverse needs, particularly transgender people. This should be done across a continuum of strategies and modalities from improving the accessibility, availability, affordability, and acceptability of clinical mental health services to creating innovative interventions for MSM and transgender people themselves to follow and be confident in 'self-help' modalities.
- Urgently develop and incorporate a comprehensive component of mental health support in the existing service packages for key populations in Malawi, including through DICs, as part of outreach services, and as a component of support groups.
- Urgently develop and implement crisis response mechanisms for young key populations contemplating or attempting suicide.
- Create friendly and supportive pathways for young key populations to recognise and address problematic alcohol or drug use, including addiction.
- Intensify and expand current interventions and efforts to support ART adherence for young key populations, including components addressing safe and effective strategies for disclosure, and for building and maintaining supportive social networks amongst their families, friends, and HIV-positive peers.
- Expand the content of the training of 'KP-friendly' health service providers to have more emphasis on the needs of HIV-positive key populations on ART, with a particular emphasis on recognising and responding to mental health needs.
- Create more 'safe spaces', physical or virtual, for MSM and transgender people on ART to know and support each other, and to identify and become resilient to the effects of intersectional stigma.

Addressing structural barriers

- Use the results of the study, and its implications for population health, to bolster efforts towards decriminalisation of sexual and gender minorities in Malawi. At a minimum, use the results to maintain and reinforce the moratorium.
- Find innovative strategies to create or reinforce protective provisions in laws and policies to better promote and protect the health and human rights of young sexual minorities.
- Continue to engage parliamentarians, religious and cultural leaders, and other opinion leaders at all levels to recognise the negative effects of stigma and discrimination linked to sexual orientation, gender identity and health status, and to reduce and ultimately end attitudes and practices that are drivers of such stigma, and that limit the effectiveness of the HIV response, as well as spoiling the quality of life of young sexual minorities, including those living with HIV.

Finally, the study's findings suggest some additional areas for research, including the following:

- How do intersectional identities linked to gender, religion, and social economic status impact on the experiences of stigma and retention on ART among MSM and transgender people living with HIV?
- What are the most effective strategies for addressing mental health and substance use disorders among MSM and transgender people living with HIV?
- What are the best practices for developing culturally sensitive and responsive interventions to reduce stigma and to improve retention in HIV care among MSM and transgender people living with HIV?
- How do other sexual minorities living with HIV, such as lesbian, bisexual, and non-binary women and transgender men, experience intersectional stigma and how does this affect their uptake and retention on ART?

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