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ORIGINAL RESEARCH

Stigmas intersecting with antiretroviral adherence in young key populations living with HIV in Zambia

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Abstract

Introduction: Limited research has been conducted on the experiences of ART adherence among young HIV-positive men who have sex with men (MSM) and transgender women (TGW) in Zambia. This study aimed to address this evidence gap through elucidating the manifestations of stigmas intersecting with antiretroviral adherence in young key populations living with HIV in Zambia.

Methods: This study used a mixed-methods design. In-depth interviews collected qualitative data, and a questionnaire collected quantitative data. We used thematic analysis for qualitative data. Qualitative data were descriptively analysed using Stata. ART adherence was defined as ever missing an ART dose (yes/no). Frequencies and percentages were generated for ART adherence by socio-demographic characteristics and stigma indicators.

Results: We recruited 56 participants from three sites: Lusaka, Chipata and Solwezi districts. Participants' mean age was 23 years. Half of the participants reported ever missing an ART dose, with equal proportions among MSM (50%) and TGW (50%). Missed doses were more frequent among participants who experienced HIV related stigma (59.4%) compared with those who did not (37.5%). Missed doses were more prevalent among those living with family (88.9%) compared to those not living with family. Stigma related to sexual orientation or gender identity (SOGI) showed mixed patterns, with no consistent differences in missed doses. Variations in adherence were observed across age, education, employment, living arrangements and care settings, however, there were no clear patterns that had emerged due to the small sample. The emergent themes were sexual orientation and gender identity–based stigma, negotiating self-identity amid uncertainty, stigma experiences in the family and ART adherence, sexual orientation, HIV ART adherence and disclosure challenges, as well as restarting ART.

Conclusion: The study provides evidence of how stigmas intersect with antiretroviral therapy (ART) among young key populations. Meanwhile, most of the stigma that affected adherence to ART was related to HIV. Supporting adherence to ART among adolescents and young people, including sexual minority groups, may require tailored approaches that address their lived experiences.

Keywords: ART, adherence, stigma, community systems, young, HIV, Zambia

Abstract in Español at the end of the article

INTRODUCTION

Sub-Saharan Africa is one of the regions most severely affected by the HIV epidemic, and Zambia bears a high burden [1]. Globally, young people aged 15–24 years, particularly, are disproportionately impacted by HIV [2,3]. Key populations accounted for about 46% of new HIV infections across Southern Africa in 2022 [4,5]. In 2021, Zambia's HIV prevalence in the adult population (15-49 years) was among the highest globally (11.1%, a slight drop from 12.1% in 2019) [1]. HIV prevalence in key populations was almost double that in the general population [1]. As of 2020, for example, the estimated population of men who have sex with men (MSM) was 114,852, and the prevalence of HIV was 21% among MSM and 22% among transgender women (TGW) [6].

MSM and TGW tend to be the least targeted by HIV treatment programs despite experiencing various physical and sexual violence, which negatively interact with important HIV-related health outcomes [7–9].These outcomes include uptake and retention in HIV programmes and medication adherence [7–9]. Anxieties about the future as well as adoption of risk behaviors also affect HIV health outcomes [1,10]. Challenging contextual stigmatization, discrimination, and violence linked to criminalization, socio-cultural and religious attitudes and practices regarding sexual or gender diversity also affect coverage and acceptability and adoption of ART programs in these groups [1,9]. In addition, Zambian law criminalises same-sex sexual contact and does not embrace gender diversity [1,11].

Region-specific knowledge about how to address risks that affect uptake and retention on ART for HIV-positive MSM and TGW is beginning to emerge but remains inadequate [1,9]. This study, which used a mixed-methods design, aimed to address this evidence gap through elucidating the experiences of ART adherence challenges in a small group of young MSM and TGW living with HIV in Zambia in Lusaka, Chipata and Solwezi districts. The study contributes to evidence for addressing risks that affect uptake and retention on ART for HIV-positive MSM and TGW by documenting intersecting stigmas that affect ART adherence.

METHODS

Study site and population

The study was done in Chipata, Lusaka and Solwezi districts. These sites were selected because they are among those with the highest HIV cases [1]. We included young gay, bisexual or other MSM and TGW, all self-disclosed as HIV-positive and self-identifying as being currently on ART [1]. The young key population (YKPs) were aged 18 to 24 years; self-identifying as gay, bisexual or MSM, or TGW or female with a gender at birth being male [1].

Study design

The study used a mixed-methods design (quantitative survey and in-depth interview), which involved the collection of qualitative data (phenomenological study design) and quantitative data (cross-sectional study design) from the same study sample. We adopted a mixed-methods design as it allowed for triangulation and a richer analysis of the complex phenomena underlying factors that shape ART adherence in YKPs living with HIV in Zambia [1,12,13]. This study is part of the study on exploring influence of intersectional stigma on uptake and retention in ART programmes for selected MSM and TGW groups in three Southern African Development Community (SADC) countries: Malawi, Zambia and Zimbabwe [1].

Study sample

To recruit participants, we used snowball sampling, an approach in which an interviewee or participant recruiter provides the name of at least one more potential interviewee; in turn, this interviewee recommends other potential interviewees [14]. We needed this approach because same-sex sexual contact is criminalised and the law does not embrace gender diversity in Zambia [1,10,11]. Further, this approach was vital, given the lack of previous research experience with the study population [1,10]. The study included a total of 56 YKP; they completed both the questionnaire and the in-depth interview. This sample was arrived at considering the lack of a sampling frame for MSM and TGW in Zambia, the safety and confidentiality considerations as well as feasibility and ethical issues related the study's exploratory objectives.

The participants were 29 from Lusaka, 14 from Chipata and 13 from Solwezi. Refer to our previously published article for the characteristics of the study participant [1]. Our first publication on this topic describes the sampling process [1].

As shown in Table 1, majority of the participants had been diagnosed with HIV within the past three years. Overall, 23.2% of participants had been diagnosed less than one year before the survey, while 21.4% and 26.8% had been diagnosed one year and two years prior to the survey, respectively.

With regards to place of diagnosis, most of the participants were diagnosed at NGO HIV testing and counselling centres (39.3%). MSM were more likely be diagnosed through the NGO centres where as TGW were evenly distributed across government and NGO services. Furthermore, 25% of the participants had been on ART for less than one year, and long-term ART use (five years or more) was reported only among MSM (17.5%). The most common source of ART services was the private sector for both MSM (50%) and TGW (50%) followed by church mission facilities (37.5%). On the other hand, government facilities accounted for only 3.6% of ART service delivery.

Table 1. HIV-related characteristics of the participants.

HIV diagnosis and ART service	MSM N(%)	TG N(%)	Total N(%)
**Time since diagnosis (years) **			
<1	9 (22.5%)	4 (25%)	13 (23.2%)
1	9 (22.5%)	3 (18.6%)	12 (21.4%)
2	10 (25.0%)	5 (31.3%)	15 (26.8%)
3	4 (10.0%)	2 (12.5%)	6 (10.7%)
4	1 (2.5%)	2 (12.5%)	3 (5.4%)
5	7 (17.5%)	0 (0.0%)	7 (12.5%)
Place of diagnosis			
Government general health clinic, hospital	6 (15.0%)	4 (25.0%)	10 (17.9%)
Government HIV testing & counselling center	12 (30.0%)	4 (25.0%)	16 (28.6%)
Born with HIV	0 (0.0%)	1 (6.3%)	1 (1.7%)
NGO HIV testing & counselling centre	18 (45.0%)	4 (25%)	22 (39.3%)
Outreach/mobile testing	2 (5.0%)	2 (12.5%)	4 (7.1%)
Time on ART (years)			
<1	10 (25.0%)	4 (25.0%)	14 (25.0%)
1	8 (20.0%)	3 (18.8%)	11 (19.6%)
2	10 (25.0%)	6 (37.5%)	16 (28.6%)
3	4 (10.0%)	1 (6.3%)	5 (8.9%)
4	1 (2.5%)	2 (12.5%)	3 (5.4%)
5	7 (17.5%)	0 (0.0%)	7 (12.5%)
Place of ART service			
Public/government facility	1 (2.5%)	1 (6.3%)	2 (3.6%)
Church mission facility	18 (45.0%)	3 (18.6%)	21 (37.5%)
NGO/CBO facility	1 (2.5%)	4 (25.0%)	5 (8.9%)
Private hospital/clinic	20 (50.0%)	8 (50.0%)	28 (50.0%)

Data collection

Quantitative and qualitative data were collected in secure and confidential settings. Information in the tools included SOGI, socio-economic characteristics, living arrangements and relationships status, length of time living with HIV, preferred providers for HIV services, self-reported ART adherence and knowledge of viral suppression [1]. The data collection tools and consent forms were translated into the Njanya and Bemba languages for all participants to easily understand the questions. These settings were approved by representatives of sexual minority organisations consulted during the study design. Each participant was screened according to the eligibility criteria before they could be invited to participate in the interviews. Upon meeting the inclusion criteria, the participants were asked to complete informed consent form. The interview process started with the quantitative survey, followed by a short break and then an in-depth interview. The whole interview process took approximately 1 and half hours. The multiple-choice and closed-ended items in self-administered survey or quantitative questionnaire and also the topics in the qualitative interview guide have been described previously [1].

To provide insight into the potential effects of stigma on an individual's well-being, including health, participants completed the CESD-10 (symptoms of depression) and SBQ-R screening tools (thoughts and experiences of suicide) [15–17]. A detailed analysis of intersectional stigma, depression and suicidal thoughts for selected young key populations living with HIV in Zambia has been published previously [1].

Data analysis

Qualitative data

Qualitative analysis started with audio recordings being transcribed verbatim by trained research team members. This was followed by reading and reviewing the transcripts and comparing them with the audios to assess accuracy of the transcription process. The data were analysed using thematic analysis [18]. The two lead investigators first developed a coding manual in line with the topics in the interview guide. Initially, two researchers (JMZ and RA) independently coded four transcripts. These codes were reviewed by a third researcher for clarity and consistency (PN). The code book and all transcripts were subsequently loaded into Nvivo (12 pro) to finalise the coding process. Once coding was complete, the codes were merged into themes. The data collection and analysis processes reached data saturation, the stage when no additional new information can be obtained. The data collection and analysis teams discussed and validated that outcome [19].

We promoted trustworthiness during analysis by paying attention to issues of credibility, transferability and dependability. Credibility was promoted through triangulating data sources. Transferability was enhanced through thoroughly transcribing data and adding quotes from a variety of respondents. Finally, dependability was achieved through thoroughly documenting the research process including recruitment, as well as data collection and entry processes [20].

Quantitative data

This study analysed data using Stata (version 18). The analysis was descriptive in nature as it aimed to explore patterns of HIV care experiences, stigma and ART adherence among MSM and TGW. Participants in the study were categorised based on their self-reported sexual orientation. Individuals who identified as gay/homosexual or bisexual were classified as MSM, while those who identified as transgender were classified as TGW. The sample comprised of a total of 56 participants (40 MSM and 16 TGW).

Individual level factors

Respondents were asked "In which year did you receive your HIV diagnosis?" and "In which year did you start taking ARVs?" The questions were recoded as time since diagnosis (years) and "Time on ART" respectively. These variables were categorised as >I year, 1 year, 2 years, 3 years and 5 years and above.

Respondents were asked about the place of HIV diagnosis (government general health clinic, hospital, government HIV testing and counselling centre, born with HIV, NGO HIV testing and counselling centre, outreach/mobile testing); place of ART service (public/government facility, church mission facility, NGO/CBO facility, private hospital/clinic); age group (19–20, 21–22, 23–24); highest level of education completed (primary, secondary, post-secondary); employment status (not employed, employed, self-employed, full-time student); and living arrangement (not with family, with family, other).

Stigma-related variables included any experience of SOGI-related discrimination (no, yes); fear or anxiety related to SOGI (no, yes); fear or anxiety related to HIV status (no, yes); and any experience of HIV-related stigma (no, yes).

Outcome variable

The outcome variable was ART adherence. ART adherence was defined as a binary variable indicating whether the respondent had ever missed a dose of ART, with "no" coded as 0 and "yes" coded as 1.

Statistical analysis

Descriptive statistics were generated for all variables, stratified by MSM and TGW. Cross tabulation variables, stratified by MSM and TGW. Cross tabulations were used to examine the distribution of ever missed an ART dose across socio-demographic characteristics, HIV care related variables and stigma related variables (SOGI & HIV). No inferential statistics tests or multivariate models were performed given the small sample size. Instead, results are presented as descriptive patterns intended to inform hypothesis generation and interpretation

Ethics

Ethical approval to conduct the study was sought from the Research Ethics Committee of the University of Zambia, the University of KwaZulu-Natal and the National Health Research Authority in Zambia (Reference number 1070-2020). To promote confidentially, we worked with a mobiliser (a member of the MSM community), members of the peer interview team, and organisations providing services to key populations to recruit study participants within their social networks [1,10]. Verbal informed consent to collect and publish data was sought before participants could participate in either qualitative or quantitative interviews. We adopted verbal consent because same-sex sexual contact is criminalised in Zambia. Confidentiality was ensured by not collecting any personal identifying information.

RESULTS

This section presents results on experiences of ART adherence among young HIV-positive men who have sex with men and transgender women in Zambia. The results are organized around the following headings: distribution of missed ART dose among respondents by background characteristics, determinants of missed ART dose, sexual orientation and gender identity stigma, stigma experiences in the family, and restarting ART.

Distribution of missed ART dose among respondents by background characteristics

Table 2 shows the prevalence of participants that had ever missed an ART dose. Overall, 28 out of 56 participants (50%) reported ever missing an ART dose with similar proportions among MSM 50% (n=20) and transgender women 50% (n=8). Further, missed doses were more prevalent among participants aged 23 to 24 years (58.6%) and this was more prevalent amongst MSM in this age group (66%). Missed doses were more prevalent among those living with family (88.9%) compared to those not living with family (47.4%).

The occurrence of missed doses was mostly common among participants receiving ART from private clinics (53.6%) and church- run facilities (52.4%) than those accessing care from public facilities (0%) or NGO/CBO run facilities (40%). With regards to HIV related stigma and adherence to ART, more than half (59.4%) of those who reported HIV related stigma had ever missed a dose compared with those who reported no HIV – related stigma (37.5%). On the other hand, the patterns by SOGI related discrimination were less consistent with the high missed does prevalence observed both among those with or without reported SOGI discrimination.

Table 2. Proportion of participants who reported ever missing an ART dose by background characteristics among MSM and transgender women in Zambia (n = 56).

Category	MSM n (%)	TGW n (%)	Total n/N (%)
Age group (years)			
19–20	0 (0.0%)	2 (66.7%)	2/5 (40.0%)
21–22	7 (38.9%)	2 (50.0%)	9/22 (40.9%)
23–24	13 (65.0%)	4 (44.4%)	17/29 (58.6%)
Highest education completed			
Primary	8 (53.3%)	1 (33.3%)	9/18 (50.0%)
Secondary	3 (42.9%)	0 (0.0%)	3/9 (33.3%)
Post-secondary	9 (50.0%)	7 (63.6%)	16/29 (55.2%)
Employment status			
Not employed	4 (57.1%)	3 (75.0%)	7/11 (63.6%)
Employed	4 (66.7%)	3 (42.9%)	7/13 (53.8%)
Self-employed	1 (14.3%)	0 (0.0%)	1/8 (12.5%)
Full-time student	11 (55.0%)	2 (50.0%)	13/24 (54.2%)
Living arrangement			
Not with family	12 (48.0%)	6 (46.2%)	18/38 (47.4%)
With family	7 (87.5%)	1 (100.0%)	8/9 (88.9%)
Other	1 (14.3%)	1 (50.0%)	2/9 (22.2%)
Place of HIV care			
Public/government facility	0 (0.0%)	0 (0.0%)	0/2 (0.0%)
Church mission facility	9 (50.0%)	2 (66.7%)	11/21 (52.4%)
NGO/CBO facility	1 (100.0%)	1 (25.0%)	2/5 (40.0%)
Private hospital/clinic	10 (50.0%)	5 (62.5%)	15/28 (53.6%)
Any experience of SOGI-related discrimination			
No	7 (77.8%)	2 (66.7%)	9/12 (75.0%)
Yes	13 (41.9%)	6 (46.2%)	19/44 (43.2%)
Fear/anxiety related to SOGI			
No	20 (54.1%)	7 (53.8%)	27/50 (54.0%)
Yes	0 (0.0%)	1 (33.3%)	1/6 (16.7%)
Fear/anxiety related to HIV status			
No	0 (0.0%)	1 (100.0%)	1/3 (33.3%)
Yes	20 (52.6%)	7 (46.7%)	27/53 (50.9%)
Any experience of HIV-related stigma			
No	6 (33.3%)	3 (50.0%)	9/24 (37.5%)
Yes	14 (63.6%)	5 (50.0%)	19/32 (59.4%)

Note: Percentages represent the proportion of participants within each category who reported ever missing an ART dose. For MSM and TGW columns, percentages are calculated within each subgroup. For the Total column, values are presented as n/N (%), where N is the total number of participants in each category (MSM and TGW combined). Only the "Yes" (ever missed dose) category is presented.

Sexual orientation and gender identity–based stigma

Participants gave a range of descriptions regarding sexual orientation and gender identity. Although some experienced stigmatisation that affected ART adherence, others had developed 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. This is how one young participant described himself:

> "*I was born like this and there is a purpose as to why I am like this. So, whatever people might say about me is not what or who I am. I am who I am today.* (MSM, 21 years, Lusaka, Zambia [ZAM-LSK-CW-MSM5])"

This young person's sexual orientation has a "purpose" that is given at "birth," and this anchors his confidence and assurance:

> "*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 [ZAM-CHP-MB-MSM8])"

Transgender participants had a similar level of confidence, as in this example:

> "*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 [ZAM-LSK-NN-TG3])"

Negotiating self-identity amid uncertainty

For participants who were less assured, the interviews provided some insights. Their doubts largely arose from the difficulties of the social context, or simply as a result of being young and not wanting identities to be too fixed before exploring different possibilities. On the influence of the social context, this young person described its effects:

> "*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 [ZAM-LSK-MB-MSM6])"

Stigma has a corrosive effect on self-assurance about one's sexual orientation. This young person also had difficulties because of the risks in her social environment:

> "*Sometimes it makes me feel bad [being transgender].... Like the way I mentioned when people say bad things about me, that one feels like a woman, talks like a woman. I always say, "Me, I am me."* (Transgender woman, 24 years, Lusaka [ZAM-LSK-NN-TG-02])"

The risk of being 'noticed' or 'found' is a persistent anxiety ("what if…what if"), even as he knows himself and his sexuality. Another participant had struggled with her identity for some time before coming to accept it:

> "*How I feel about myself? Ah let me just explain a bit about this. I don't know when it was, but I remember it was in grade 8, I just felt that in me to say, ah, it's like outside I am a man, a full man, but inside of me there is something wrong [laughs]. So, I tried my level best to pray over that.* (Transgender woman, 23 years, Chipata [ZAM-CHP-NN-TG5])"

Stigma experiences in the family and ART adherence

Participants had a range of views and experiences, from open disclosure to complete secrecy. For some participants, it was more important to miss doses than to risk being seen taking the medication or otherwise known to be on ART. Although the reasons and circumstances for sharing or not sharing information differed, they were difficult for some participants and still carried real or feared risks of different types of harm linked to stigma.

Being HIV-positive, including being on ART, is something that other family members "need to know" so that they can provide assistance when needed. For this young participant, disclosure was linked to adherence support:

> "*Since it's [taking ART] something that I have to do every day, I decided to tell them so that they can be reminding me just in case I forget, and also for them to push me into taking the medication.* (MSM, 24 years, Chipata [ZAM-CHP-MB-MSM4])"

For this individual, disclosure led to finding out another family member was also HIV-positive and on ART:

> "*I saw that she was also on the drugs. I told her that I do see you with these drugs most of the time, what are they? She was, like, no, these are drugs for HIV. Then I was, like, are you living with HIV? And she said, yeah. And I was, like, okay, same applies to me. She was, like, oh, so we are two of us in the house.* (MSM, 21 years, Lusaka [ZAM-LSK-WC-MSM5])"

The quality of participants' experiences with ART, and how this created risks for missed doses, was also affected by the process of disclosure (or non-disclosure), including whom to tell and not to tell and why, as well as how to avoid being found with or seen taking medication. Being on ART was clearly information to be carefully managed. Other participants had more negative experiences, however. Others had experienced rejection or isolation following disclosure of being on ART, as did this participant:

> "*I disclosed it to someone I had met, who I thought we would be together forever. I decided to let them know that I insist on using condoms because I am on medication. The person didn't take it well. He said, "Ah, okay, but we just have to part ways."* (MSM, 22 years, Lusaka [ZAM-LSK-WC-MSM10])"

One participant stated that he stopped taking medication because of being forced to disclose his HIV status when his family found medication:

> *"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 [ZAM-LSK-MB-MSM5])"

Some participants made determined efforts to maintain the secrecy that they were on medication even to family because of concerns about rejection or isolation, as in this example:

> *"I don't want my family or my friends to know that I am on medication. I don't want people to know. That's why I hide, even when I am going to the hospital.* (MSM, 23 years, Lusaka, Zambia [ZAM-LSK-WC-MSM1])"

Not wanting family members to know that they were on medication also made some stop taking ART. This could happen for someone living in a big family setting or not wanting to carry drugs when travelling to visit family members, as in this example:

> *"It's because I never wanted my family members to know that I was on medication. And I just felt I was tired of taking this medication. ...I stopped taking my medication for 2 months and the reason was I had gone to the farm, my grandmother's farm. We had gone with my cousins, aunties, there were a lot of people there.* (Transgender woman, 23 years, Lusaka [ZAM-LSK-TC-TG1])"

Interviews showed that some individuals had disclosed their HIV status to no one because of stigmatisation. This included avoiding disclosure or the risk of disclosure, as in this example:

> *"Challenges [of living with HIV] are there. You find that you go to the hospital to collect the medication. You find that you start feeling shy or maybe the people who are giving the medication at the hospital are your friends. So, you will start feeling shy and decide to go back [home].* (MSM, 19 years, Chipata [ZAM-CHP-MB-MSM3])"

Having to take ART is clearly an added dimension of living with HIV. It is something that can be seen by others and can reveal one's status in a very public way. The daily risk compounds the difficulty for some. For a number of participants, fear of being seen taking the medication itself by the family was another negative aspect of being on ART, as in this example:

> *"Taking ARVs every day is not an easy thing. It's not an easy thing, I just have to tell you that. It's something difficult. You know, let's talk from my experience, let's say like myself, I take the ARVs at 21 hours. Then in that 21 hours you receive some visitors. Then those visitors, they don't even know your status. And you can't start taking those drugs in front of them.* (MSM, 23 years, Solwezi [ZAM-SOL-WC-MSM6])"

Sexual orientation, HIV ART adherence and disclosure challenges

The responses to their disclosing being on ART were influenced by stigma linked to their HIV status, their sexual orientation or gender identity, or both. Disclosing to others was taking a risk of such negative reactions, according to this individual:

> *"Some [family members and friends] were just like, "HIV, it's something that can be so scary, but you need to just keep on taking the drug." Others were mocking me, "You don't listen [you sleep with men], no wonder you are like this." Different reactions.* (MSM, 23 years, Chipata [ZAM-CHP-MB-MSM9])"

'Like this' implies both his health status and his sexuality. Disclosing being on ART may indirectly lead to disclosing other things, potentially one's sexual orientation, as in this example:

> *"I wouldn't even dare to tell my uncle. He is too tough. He might just ask me, "I have never seen you with a girl, so where did you get this from?"* (Transgender woman, 24 years, Lusaka [ZAM-LSK-NN-TG8])"

Several insisted that they could only disclose their HIV status and SOGI with other MSM who were also HIV positive for fear of being discriminated.

> *"So, I maintain I simply discuss my HIV status or sexuality with people that I am close to, like men who have sex with men who I know I have been sexually involved with and who may also be positive.* (MSM [ZAM-SOL-WC-MSM-02])"

Some of the respondents reported that SOGI related stigma led to frustration and, at times, denial of their HIV status. They noted that a combination of frustration and denial sometimes resulted in missed medication as noted below.

> *"Yeah it does because when you look at certain situations where you would you have something that is running in you, and you tend to do things without thinking straight, like when people talk about your sexuality, so you would go out frustrated, forgetting about your HIV status… you tend to forget your medication.* (Transgender woman [ZAM-CHP-NN-TG01])"

Stigma associated to sexual orientation or gender identity also triggered mental stress and subsequently contributed to missing ART:

> *"Things like when I am walking in the road, and people start talking about me that I walk like a girl, and I am gay. That hurts and gets to me. I end up sleeping and forgetting to take my medication.* (Transgender woman, 23 years, Lusaka [ZAM-LSK-TC-TG1])"

Mental health challenges, including reacting to stigma and rejection, could lead to stopping to take ART, as in this example.

> *"It affects me sometimes because, if people reject you, you feel like stopping to take the medication. "Maybe am just wasting my time, let me just die." It affects me a lot.* (MSM, 24 years, Lusaka [ZAM-LSK-MB-MSM8])"

Restarting ART

For those participants who had stopped treatment, fortunately individuals or events encouraged them to restart and to overcome whatever influences were leading to the interruption. This advice and encouragement came from a variety of sources, including friends, families, health workers and the individuals themselves:

> *"It's because I realized that I was punishing myself, and that even if people laugh at me, it's not them who have the problem but it's me who needs help.* (MSM, 24 years, Chipata [ZAM-CHP-MB-MSM7])"

For this next individual, health workers helped him work through his challenges with stigma, including self-stigma:

> *"At the beginning I never used to think properly because sometimes I used to wish that I can kill myself. But after some time, I have been thinking properly because of the advice that I got from the hospital. I now take my medication on time and do everything that I was advised to do.* (MSM, 24 years, Chipata [ZAM-CHP-MB-MSM2])"

Despite the problem of stigma, one still has to manage living with HIV; and, to do this, taking ART is essential. Support from friends and peers on ART also encouraged some to restart treatment:

> *"The same support the guys gave me, words, the encouragement, it just kept me going… they told me their situation to say, "I have been on treatment for such, such years, and I am okay nobody can tell."* (MSM, 24 years, Chipata [ZAM-CHP-MB-MSM8])"

For others, family members assisted, either directly or indirectly. In this example, the influence was direct:

> *"My mom found out that I wasn't taking medication. She was very upset with me. She was, like, you want to kill yourself? Yeah, so she told me to start taking my medication. Then again, I had to start.* (Transgender woman, 24 years, Chipata [ZAM-CHP-NN-TG2])"

Finally, participants had also been encouraged to restart with support from KP-friendly CSOs, as in this example:

> *"There's an organisation that deals with this. That's where somebody explained to me what happens when you stop taking the drugs. So, that's how I started again, yah.* (Transgender woman, 23 years, Lusaka [ZAM-LSK-TC-TG3])"

DISCUSSION

The study showed that a convergence of multiple or different stigmatized experiences within MSM and TGW, was not only a social challenge, but as a critical and compounding barrier that affected HIV disclosure and ART adherence health behaviors. Although some respondents reported experiencing acceptance and support and had disclosed their HIV status, many experienced stigma from their families. Meanwhile, data showed that most of the stigma that affected adherence to ART was related to HIV. Having more individuals fear stigma related to HIV rather than SOGI is an interesting finding in a country where the latter is criminalised and morally unaccepted. The qualitative findings further showed that HIV or SOGI stigma also contributed to mental distress including frustration, which subsequently contributed to treatment interruption. Regarding family stigma, respondents reported they had difficulties maintaining privacy when taking HIV medication, as they lived in crowded households (sharing a room with many others). Fear that other people in the house might learn their HIV status from seeing them take ART, and that they might experience rejection or isolation from the family, made MSM and TGW either hide or stop taking medication.

Quantitative data also showed that participants who lived with their families were more likely to have a missed ART dose than those who did not live with their families. Stigma from the family included enacted (experienced) stigma such as forced disclosure, anticipated stigma which included not disclosing HIV status or SOGI for fear of being disowned, as well as internalized or self-stigma such as feeling shy. Drawing on the Minority Stress/Strengths Model, the findings show that these stigmas are linked to broader social stress processes that shape the lives of MSM and TGW [21]. For example, stigma from the family such as forced disclosure can be conceptualized as distal stressors, external forms of prejudice and experiences of discrimination that undermine the ability to adhere to ART and live health lifestyles. Whereas internalized or self-stigma such as feeling shy maybe conceptualized as proximal stressors which arise from a socialization process in which MSM and TGW learn to reject themselves for being LGBT or develop expectations to be stigmatized or rejected due to awareness of prevailing social stigma [21]. These findings support other studies which show that HIV-related stigma may not only be a manifestation of fears related to the health condition itself but also reflect negative attitudes regarding behaviors and identities originally associated with HIV transmission, including sexual orientation [22–24]. We there note that these different forms of stigma which affect ART adherence are a public health problem that should be considered in intervention development and policy design.

Stigma from the family can affect ART adherence, as it can trigger mental health challenges such as depression and stress, which often affect adherence to health interventions, including medication [10,25]. At an individual level, stigmatizing language, behaviors, and attitudes from the family could potentially lead to divide family members into “us” and “others” [26], which can trigger mental distress and many other negative coping behaviours such as alcohol abuse. In addition, fear of losing support negatively impacts health behavior, given the high levels of poverty in Zambia, including limited employment or business opportunities and inadequate socioeconomic support from the Government [27].

The findings suggest existence of a structure at the family level that constrains the ability of young HIV-positive MSM and TGW to freely take and adhere to ART. This limitation could affect their ability to engage in safe sexual practices [1]. We note, like other studies on minority and vulnerable groups, that this discriminatory family structure could limit the agency of MSM and TGW to confidently define, understand and accept their HIV-positive identity and live positively [1]. Overall, this discrimination might make MSM and TGs living with HIV view themselves as inferior members of the family, and later the whole community or society [1].

Although community-level interventions are vital, special attention should be paid to household-level dynamics, as the family was the most significant factor that complicated ART adherence among young HIV-positive MSM and TGW in this study. Thus, there is need to develop and implement family centred approaches to improve ART adherence including interventions for strengthening family relationships [28]. Studies, mainly done in the general population, have emphasized the role that the family plays in providing social support, and how this support enhances ART adherence among young people [24,29]. This support includes providing nutrition, helping with collecting medication, reminding people living with HIV to take medication and providing emotional support [30]. We have also previously documented the role that relational implementation strategies play in promoting uptake of health services or positive behavior change in communities and families [31–34]. These strategies are vital as they enhance shared communication, understanding of health problems, and foster increased commitments toward addressing the problems [31–34].

Meanwhile, the findings highlight that others had developed a strong sense of understanding and acceptance that their sexual orientation or gender identities as a fundamental and enduring part of who they were as persons. This suggests the presence of identity resilience or self-confidence within the stigmatising environment. Literature suggests that such resilience is vital as it might facilitate development of adaptive copying mechanisms as well as act as a buffer against adverse psychosocial outcomes [35–39]. In the context of ART, such confidence might assist in promoting positive health outcomes including ART adherence and safer sexual practices [35–37,39].

Given the current reduction in funding for HIV, especially for key populations, it important to sustain gains made in HIV programming by prioritizing stigma reduction interventions that simultaneously address interpersonal (family level) drivers of stigma while strengthening individual-level coping mechanisms. This proposal is in line with the Minority Stress/Strengths Model, which notes that the identification of family as a source of stigma creates an opportunity or entry point for affirming supportive family relationships which may buffer the harmful effects of stigma and promote ART adherence [21,35–37,39]. To ensure development of appropriate family-based interventions, it is important to consider adopting a co-production approach, which involves having interventions jointly produced by the affected population [1,40]. Thus, we recommend that more research should be done on developing participatory interventions that simultaneously address interpersonal or family-based stigma and individual level coping mechanisms.

Strengths and limitations

Successfully conducting this study in a context that criminalises MSM and TGW is one of the major strengths of this study. Thus, it provides useful evidence on the roles of stigma and family in shaping ART adherence in young key populations, as well as data collection processes in similar contexts. Further, adoption of a mixed study design facilitated triangulation of data, allowing us to develop a comprehensive account of experiences with ART adherence among young MSM and TGW living with HIV [1]. However, drawing our findings from a small sample, 56 participants, limited the generalization of the results to the whole country. Another limitation of the study is that we selected individuals currently on ART while this study was about challenges in adhering to ART. This inclusion criterion was adopted in consideration of the legal and social environment that criminalizes MSM and TGW. Further, inclusion of only two participants who had accessed ART from public health facilities due to legal and social environment restrictions denied us the opportunity to learn more regarding the experiences of accessing services from such facilities. Such information is vital considering recent funding cuts affecting public health systems.

Conclusion

Most young HIV-positive MSM and young HIV-positive transgender women experienced various forms of stigma that affected their ability to adhere to ART. Participants who lived with their families were more likely to have a missed ART dose than those who did not live with their families. Meanwhile, qualitative data showed that most of the stigma that affected adherence to ART was related to HIV. This stigma is rooted in legal, historical, cultural, religious and socioeconomic contexts which shape attitudes and behaviors by family members towards young HIV-positive MSM and TGW. It is thus important that strategies for addressing poor ART adherence should address family and sexual orientation and gender identity stigma. This implies addressing various community, interpersonal and societal-level factors that influence how stigma is constructed and experienced in families, as well as how young HIV-positive MSM and TGW respond to such acts.

DECLARATIONS

Competing interests

The authors declare that they have no competing interests.

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Author contributions

JMZ, MZ, PN, KG and RA contributed to the design of the study, including the data collection tools and collecting data. JMZ, MZ, PN, BW, HB, AM, DK, PN and RA participated in analysing the results of the study. All the authors contributed to revision of the results, the draft manuscript, and approved the final manuscript.

Data availability

The datasets collected and/or analysed during the current study are available from the corresponding author on reasonable request.

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ABSTRACT IN SPANISH

Estigmas que se entrecruzan con la adherencia al tratamiento antirretroviral en poblaciones clave jóvenes que viven con VIH en Zambia

Introducción: Existe poca investigación sobre las experiencias de adherencia al tratamiento antirretroviral (TAR) entre hombres jóvenes que viven con VIH y que tienen sexo con hombres (HSH) y mujeres transgénero (MT) en Zambia. Este estudio tuvo como objetivo abordar esta brecha de evidencia mediante la elucidación de las manifestaciones del estigma que se entrecruzan con la adherencia al tratamiento antirretroviral en poblaciones clave jóvenes que viven con VIH en Zambia.

Métodos: Este estudio utilizó un diseño de métodos mixtos. Se realizaron entrevistas en profundidad para recoger datos cualitativos y se aplicó un cuestionario para recoger datos cuantitativos. Para el análisis de los datos cualitativos se utilizó un análisis temático. Los datos cuantitativos se analizaron de forma descriptiva utilizando Stata. La adherencia al TAR se definió como haber omitido alguna vez una dosis (sí/no). Se generaron frecuencias y porcentajes de adherencia al TAR según características sociodemográficas e indicadores de estigma.

Resultados: Se reclutaron 56 participantes en tres sitios: los distritos de Lusaka, Chipata y Solwezi. La edad media de los participantes fue de 23 años. La mitad de los participantes reportó haber omitido alguna vez una dosis de TAR, con proporciones iguales entre HSH (50%) y MT (50%). Las dosis omitidas fueron más frecuentes entre los participantes que experimentaron estigma relacionado con el VIH (59,4%) en comparación con aquellos que no lo experimentaron (37,5%). La omisión de dosis fue más prevalente entre quienes vivían con su familia (88,9%) en comparación con quienes no vivían con ella. El estigma relacionado con la orientación sexual o la identidad de género (OSIG) mostró patrones mixtos, sin diferencias consistentes en la omisión de dosis. Se observaron variaciones en la adherencia según edad, educación, empleo, arreglos de vivienda y entornos de atención, aunque no emergieron patrones claros debido al pequeño tamaño de la muestra. Los temas emergentes fueron: estigma basado en la orientación sexual e identidad de género; negociación de la identidad personal en contextos de incertidumbre; experiencias de estigma en la familia y adherencia al TAR; orientación sexual, adherencia al TAR y desafíos en la revelación del estado serológico; así como el reinicio del TAR.

Conclusión: El estudio aporta evidencia sobre cómo los distintos tipos de estigma se entrecruzan con la terapia antirretroviral en poblaciones clave jóvenes. La mayor parte del estigma que afectó la adherencia al TAR estuvo relacionada con el VIH. Apoyar la adherencia al TAR entre adolescentes y jóvenes, incluidos los grupos de minorías sexuales, puede requerir enfoques adaptados que aborden sus experiencias vividas.

Palabras clave: TAR, adherencia, estigma, sistemas comunitarios, jóvenes, VIH, Zambia

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