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Living in the shadows: the persistence of secrecy in young people living with HIV on antiretroviral therapy, a qualitative study of the BREATHER Plus trial

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1. Introduction

Globally, public health programmes have been implemented over decades, with an increased focus on antiretroviral therapy (ART) to suppress HIV and support the health of adolescents. However, despite these efforts, stigma continues to be a significant barrier to maintaining HIV care (Joint United Nations Programme on HIV/AIDS, 2021; Stackpool-Moore et al., 2022; World Health Organization, 2021). HIV prevalence is high in South Africa and Uganda, and both of the countries together accounted for 29 % of the 1.3 million adolescents living with HIV in sub-Saharan Africa (SSA) in 2023 (United Nations International Children's Emergency Fund, 2024). Young people living with HIV (YPLHIV) in South Africa and Uganda still face persistent HIV stigma and discrimination, which profoundly impact their health, wellbeing, and willingness to disclose their status (Govindasamy et al., 2020; Nabunya et al., 2020).

Life-long daily ART, helps maintain the physical health of YPLHIV but requires them to navigate complex psychosocial challenges, including managing the fear of stereotypes and stigma associated with their condition and taking ART (Bond et al., 2019; Johnson-Peretz et al., 2022; Kimera et al., 2020; Madiba & Josiah, 2019; Stangl et al., 2019). Their fear of discrimination, social rejection and loss of social support may encourage them to keep their status a secret (Dlamini & Mtshali, 2023; Galano et al., 2017; Hardon & Posel, 2012; Jones et al., 2020; Mackworth-Young et al., 2020). While secrecy can protect YPLHIV from stigma, it also creates barriers to optimal care and support and can result in delayed or inconsistent healthcare access, reduced ART adherence, and exacerbated mental health issues (Bruce et al., 2020; Crowley et al., 2019; Dlamini & Mtshali, 2023; Kalichman et al., 2019; Maseko & Madiba, 2020).

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In 2023 in South Africa and Uganda, there were 300 000 and 85 000 YPLHIV aged 10–19 years, respectively (United Nations International Children's Emergency Fund, 2024). In these contexts of high HIV prevalence, misconceptions about HIV transmission can fuel fear and discrimination leading to social exclusion and a reluctance to speak about living with HIV (Burns et al., 2020; Fielden et al., 2011; Mackworth-Young et al., 2020; Steenberg, 2020). YPLHIV have been described as promiscuous, contagious, irresponsible, immoral, of low social status and less deserving of opportunities (Govindasamy et al., 2020; Kabunga et al., 2024; Kimera et al., 2020). Religious and cultural beliefs can both exacerbate, through moral judgments, and mitigate stigma through supportive community networks (Burns et al., 2020; Mackworth-Young et al., 2020). The social perceptions of ART and the requirement to adhere to a strict schedule of doses, can pose significant obstacles during adolescence when youth are developing their sense of self and identity (Crowley et al., 2019; Johnson-Peretz et al., 2022; Nabunya et al., 2020). Several authors have identified secrecy as contributing to anxiety, loneliness, isolation, hopelessness, self-hate, confusion and a reluctance to seek help, linking it to psycho-social and emotional challenges for YPLHIV in addition to suboptimal adherence (Mackworth-Young et al., 2020; Maseko & Madiba, 2020; Ngwenya et al., 2024; Nsibandze et al., 2021; Steenberg, 2020).

Secrecy has been defined as an "embodied practice" established in the social context (Hardon & Posel, 2012). Understanding it involves an analysis of the body both as a subject that experiences living with HIV and as an object influenced by the threat of stigma and discrimination (Bruce et al., 2020; Hardon & Posel, 2012; Mackworth-Young et al., 2020; Steenberg, 2020). Applying this definition secrecy is viewed as a social and relational practice that exists along a continuum. It is not inherently negative, but rather helps YPLHIV cope with stigma, discrimination and navigate potential impacts to their relationships, support and social status. In countries of high prevalence of HIV stigma, youth may adopt it to navigate their treatment-taking relationship within their context because it fulfils a subjective functional purpose.

The findings from research in SSA have observed that YPLHIV have to be vigilant about being seen with medication, fear exposure, and often choose to withhold their HIV status in relationships (Bond et al., 2019; Dlamini & Mtshali, 2023; Johnson-Peretz et al., 2022; Madiba & Josiah, 2019). Individuals in their households, communities, schools, and healthcare environments, if aware or communicated to about the positive HIV status of young people, may maintain secrecy to 'help protect' them from stigma and discrimination (Burns et al., 2020; Crowley et al., 2019).

In this study, we explore secrecy in YPLHIV taking lifelong ART within their everyday lives. We provide insights into the notion of secrecy from the perspectives and experiences of YPLHIV on ART, as well as the perspectives of their caregivers, and healthcare providers. The inclusion of caregiver and healthcare provider perspectives move beyond an individual-level analysis of YPLHIV (Brittain et al., 2023; Burns et al., 2020; Crowley et al., 2019; Kabunga et al., 2024; Kimera et al., 2020), to provide a comprehensive understanding of secrecy. The data are drawn from the social science component of the BREATHER Plus trial − a randomised open-label 2-arm controlled trial evaluating the efficacy, safety and acceptability of short cycle (5 days on, 2 days off) dolutegravir/tenofovir-based triple ART in adolescents aged 12–19 years in SSA (ISRCTN: 85058577; PACTR: 202103692694276; CTA: 27505/0005/001-0001).

2. Methodology

2.1. Study sites

This study was conducted in three trial sites in clinic settings. This was Durban International Clinical Research Site/Enhancing Care Foundation site in eThekwini in South Africa and Baylor College of Medicine Children's Foundation and Joint Clinical Research Centre (JCRC) sites both in Kampala in Uganda. All sites provide paediatric health care services, including HIV care and treatment, to YPLHIV from households across low-to-middle income socio-economic backgrounds.

2.2. Study participants and sampling

Longitudinal data were collected from December 2022 to July 2024 using in-depth interviews (IDI's) and focus group discussions (FGDs) in South Africa, and FGDs in Uganda (See Tables 1 and 2).

To be eligible for inclusion in the study YPLHIV had to be virologically suppressed for 12 months at enrolment, on ART for ≥1 year with no previous treatment failure resulting in regimen change, lived in South Africa and Uganda for the study duration and were willing to disclose information about their HIV status and taking ART to the research teams. Non-trial patients who met these criteria were participants in other clinical trials (previous and current) and/or attending the site HIV clinic. Most adolescent participants (trial and non-trial) were unmarried, and two were parents (one in South Africa and one in Uganda) of which one (in Uganda) was in a traditional marriage.

Caregivers participating in FGDs were immediate or extended family members who lived with the child, participated in the child's daily care, and knew about the child's ART. These were family members of trial participants in both trial arms. The health professionals for the FGDs were drawn from the BREATHER Plus trial site clinical teams. They had experience in the management of care for adolescents living with HIV and were involved in participant care from trial inception.

We purposively recruited 87 YPLHIV, 15 caregivers, and 16 health professionals from both trial sites (See Tables 1 and 2). The rationale for the sample size and number of participant groups was to understand changes YPLHIV experienced over time and gain insights from diverse perspectives of people in their lives. There were three refusals from trial participants. The reasons given were lack of interest from child and/or parent (n = 2) and time constraints (n = 1). Two trial participants from phase I declined participation in phase II because of time constraints.

All caregivers in South Africa and Uganda were females and this also reflected the participation of female's as primary caregivers of participants in the trial. The caregivers in the FGDs were aged 30–60 years, with younger mothers among participants in Uganda. Three male caregivers from the trial participants were contacted during recruitment in South Africa and agreed to participate but when subsequently contacted, one did not answer and two said that they were not available.

Twelve health professionals were recruited in South Africa (11 female, 1 male) and four in Uganda (2 female, 2 male) representing different cadres (See Table 2). Some health professionals in South Africa representing senior medical cadres declined to participate because of time constraints (n = 7). The health professionals that participated were qualified to provide clinical, counselling, recruitment, data and administrative services (Table 2). Researchers contacted each potential participant in the groups at least three times before accepting a non-response and contacting the next person.

2.3. Recruitment and data collection

Embedded in the clinical trial, participant recruitment for IDIs and FGDs was conducted in the trial sites. Participants were recruited and scheduled according to their availability and convenience after trial procedures and during weekends and school holidays.

We sought separate permissions for audio recordings and anonymized notetaking using appropriate informed assents and consents for

Table 1
In-depth interviews sample overview, South Africa.

Phase	No	Female	Male	Median age (years)
I	29	15	14	17
II	27	14	13	17

Table 2
Focus group discussions sample overview, South Africa and Uganda.

Group	Site	Number	Composition	
			Age range (years)	No. (female: male)
Trial (9)	SA*	1	18–19	4 (4:0)
		1	14–17	3 (0:3)
	UG	2	18–19	12 (6:6)
		1	15–19	5 (5:0)
		2	15–17	11 (6:5)
		2	12–14	12 (6:6)
Non-trial (3)	SA	1	18–19	5 (3:2)
	UG	2	15–19	12 (6:6)
Caregiver (3)	SA	1	42–59	4 (4:0)
	UG	2	30–60	11 (5:6)
Health professional (2)	SA	1	24–68	12 (11:1)
	UG	1	–	4 (2:2)

- SA, South Africa. UG, Uganda.
- Trial participants. SA*: 6/7 young people living with HIV (YPLHIV) who participated in in-depth interviews, participated in the focus group discussions.
- Non-trial patients. SA: YPLHIV participating in clinical trials other than BREATHER Plus. UG: YPLHIV previously participated in clinical trials and/or attended the site HIV clinic.
- Caregiver: mother (immediate family) and aunt and grandmother (extended family).
- Heath professional cadres represented: patient administration, medical, clinical, health promotion, and data in HIV treatment and care services (SA). Medical, clinical and health promotion in HIV treatment and care services (UG). “-”: unknown.

participant groups (trial, non-trial, caregivers and health professionals) and ages (12 to $\geq$ 18 years). This was obtained for phase I and phase II IDIs and FGDs. Consent was collected by a member of the local social science team in each site (LS, SN). Data were collected after the respective written informed assents and consents were obtained.

2.3.1. In-depth interviews

We conducted longitudinal IDIs by following up the same participants in two phases at different times in the trial (Table 1). For phase I, the first IDIs in South Africa trial participants were informed about the social science component of the trial at the clinics. If interested, they with their parents’ and guardians’ permission were then referred to the interviewer (LS). The interviewer contacted the potential participants, and parents and guardians of the potential participants (18–19 years and <18 years) by telephone, informed them about the study and invited them to meet to complete the written informed consent and/or assent document and participate in an IDIs that was then scheduled. First IDIs in phase I, were scheduled and conducted with 29 YPLHIV (median age, 17 years), and 27 s IDIs in phase II (27 YPLHIV, median age 17 years). See Table 1. Phase I was conducted in the first six months of the trial and phase II on average 15 months into the trial which assisted in determining experiences of YPLHIV over time. This approach facilitated the establishment of familiarity and rapport between the interviewer and the participants. In the second phase of the IDIs in South Africa the interviewer (LS). The process used for recruitment, assent and consent, and data collection in Phase I was followed.

2.3.2. Focus group discussions

For the FGDs with trial, non-trial patient and caregiver groups the study teams coordinated the sessions with support from the site trial teams who assisted with referral and recruitment. The FGDs were conducted over the first 18 months into the trial. In each site, the FGDs were facilitated by at least two team members. All trial and non-trial FGDs were organised by gender and age (Table 2). In South Africa, information on the study was shared over the phone with trial participants (18–19 years) and the parents and guardians of trial participants (<18 years) and they were invited to an informed assent and consent meeting. If they signed a written assent and/or consent they were scheduled for and participated in the respective FGD. In Uganda, information about the social science component of the trial was shared directly by the trial team at the clinic. If interested, with their parents’ and guardians’ permission the YPLHIV were referred to the facilitator (SN) who then informed them about the study and invited them to a meeting for written informed consent and/or informed assent processes. They then participated in a scheduled FGD in their respective age groups (12–19 years). For the caregiver FGDs, this process was followed directly with the parents and guardians of the trial participants.

Potential health professional participants were met in person. The social science team briefed all health professionals involved in the trial who were interested in participating in the FGDs and informed them about the study. They were invited to provide written informed consent, and FGDs were scheduled at a convenient time in each site.

2.4. Data management and processing

The semi-structured guides used for data collection were informed by literature on YPLHIV focused on their perceptions and experiences related to ART adherence and disclosure and probed the topic of stigma from various perspectives. The guides were developed in English and translated into local languages (isiZulu in South Africa, Luganda in Uganda). Graduate-level researchers (LS and SN), experienced in qualitative methods and trained in interviewing and facilitation skills, conducted the IDIs and FGDs in participants’ preferred languages. In-depth interviews averaged 35 min and FGDs lasted approximately 1 h. In South Africa, all the IDIs and most FGDs were conducted in isiZulu, with one FGD in both isiZulu and English. In Uganda, five FGDs were in Luganda, four in English, and three in both languages. Audio recordings were transcribed and translated into English. Three authors (TCS, SN, and LS) reviewed transcripts to ensure translation quality and accuracy.

2.5. Data analysis

The IDIs and FGDs transcripts included data on participants enrolled in both arms of the BREATHER Plus trial. This data analysis included all days on which the trial participants were supposed to adhere to ART. For non-trial patient participants, the focus on the FGD transcripts were on days (during the data collection period or previously) in which they were to adhere to once-daily oral ART. The FGD transcripts included data from caregivers of trial participants in both trial arms and health professionals involved in the trial overall that referred to days of adherence for trial participants, and keeping HIV and ART a secret.

Employing thematic data analysis (Braun & Clarke, 2021), team members (TCS and SN) familiarised themselves with the transcripts and discussed phenomena and concepts. The first author (TCS) developed the initial coding framework from topic guide themes and the data, then refined this collaboratively with the teams across both sites (See supplementary data file). Emerging codes were synthesised into overall themes and a codebook was created for definitions and meanings to facilitate data rigor. The authors (TCS and SN) iteratively read and discussed transcripts, exchanging notes and interpretations until consensus was reached. The IDI transcripts from both phases were compared to follow changes in participant perceptions and experiences over time (TCS). For this study, themes and concepts focused on secrecy in the lives of YPLHIV were identified and the initial five transcripts from IDIs and FGDs were coded, discussed and the codebook updated (TCS and SN). The remainder of the transcripts were coded in each country independently. NVivo 13 (2020, R1) was used to organise the data and then data were copied into Microsoft Excel 2024 to sort themes and sub-themes for sharing across sites.

2.6. Ethics approval

The necessary ethical and access approvals for our study were received. In the trial site in South Africa, ethical approval for the protocol was obtained from the University of KwaZulu-Natal (UKZN) Biomedical Research Ethics Committee (BREC Ref No: 4160/2022). In the trial site in Uganda, ethical approval for the protocol was obtained from the Joint Clinical Research Centre Ethics Committee no number (reference JCRC-IRB/REC) and the Uganda Council for Science and Technology. BREATHER Plus is registered with PACTR, number 202103692694276; ISRCTN number 85058577 and CTA number 27505/0005/001-0001.

All written informed assents and consents were received from minors and parents and legal guardians before participating in the study. The audio recordings were safely stored in a password-protected computer and downloaded by team members (SN, LS, and TCS) for study transcription and translation, data processing and data analysis purposes. To protect the participants' confidentiality their names and identifiers were removed from the transcripts before qualitative data analysis and unique identification numbers were assigned.

3. Results

In this sample, 27 of 32 YPLHIV enrolled in the trial participated in both Phase I and II IDIs. Two participants in Phase I declined to participate in Phase II (See Table 1). There was an even gender distribution in trial and non-trial groups in IDIs and FGDs (See Tables 1 and 2). Most adolescents acquired HIV through vertical transmission. In both South Africa and Uganda sites, female caregivers were mothers and extended family members who were aunts and grandmothers of the trial participants. There were more female health professionals in South Africa than in Uganda.

We interpret the findings using three predominant themes derived from the data. Secrecy was evident among most participants across sites. Although in-depth narratives from the IDIs with YPLHIV in the trial in both phases in South Africa, in addition to the FGDs in South Africa and Uganda are presented, the subsequent narratives when trust was built provided the most updated and nuanced experiences and perceptions of secrecy.

3.1. Motivations to maintain secrecy

3.1.1. Fears and stigma

As described by participants in South Africa and Uganda, in social situations YPLHIV **avoided being asked questions by people** they were with. Youth described strategies to avoid situations to prevent feelings of inferiority and shame when reacting to questions that they anticipated would be asked about their HIV status and ART. This navigation was a dominant concern in their narratives about their home, religious, cultural, school and clinic environments in which they described their fear of being exposed and need to remain unidentifiable and conceal their ART. Participant 1, a 19-year-old male from the South Africa site shared that he does not tell his peers in his community when he goes to the clinic, to discourage them from accompanying him. In this excerpt, he explained:

> *"In my neighbourhood people like accompanying each other. They would ask me where I am going, and I would not want to tell them … When people see me going to the clinic, they want to come with me, when I come back with the pills making a loud sound, someone who does not know is going to ask me what the pills are for, they will be shocked when I tell them, I just tell people that the pills are not mine, they sent me to get them at home."*

Fearing unintended disclosure, he denied that the medication was his, using a family member's illness as an alibi. He had a scenario in mind and did not want to invite unnecessary questions and evaded further conversation about HIV.

Some participants in both settings described their environments, particularly schools, as unsupportive, and so secrecy was deployed to protect them against the **fear of rejection**. Participant 2, a 50-year-old mother from the Uganda site, in a FGD with female caregivers of the similar age group, expressed that she feared that *"… they (YPLHIV) may be discriminated against and abused in school."* Caregivers feared that their children might be ostracised for being contagious and socially devalued. For example, participant 3 a non-trial patient, aged 15 years in a discussion with males (15–19 years) in Uganda stated: *"I don't want my friends to know my status because they [friends]may refuse to play with me thinking that I might infect them."* He feared that if his friends knew his status, they would apply the misconception that HIV was contagious.

Most participants from both adolescent (trial and non-trial) and caregiver groups in South Africa and Uganda had **concerns about "…*gossip*" and third-party disclosure**. Their narratives conveyed a need to uphold secrecy by being cautious of whom they were willing to tell in fear of their own emotional response to the reaction. Participant 4, a young female (15 years) in South Africa shared*:*

> *" …. I run away from peoples' talk because I'm sympathetic and I'm quick to get upset. I don't like someone else to talk badly about the situation I am in, the situation I am facing."*

She felt vulnerable and unable to cope with a potentially shameful experience of "..*gossip*". Her anticipated distressed response highlights how fear of exposure was based on an assumption that they could perceive her negatively if they knew of her positive HIV status, which in turn would adversely influence her own self-perception. Female and male participants in South Africa and Uganda feared that the siblings they lived with and peers and relatives living outside their household would "..*gossip*" about them. Participant 5, a male (15–19 years) non-trial patient in Uganda shared being confronted by his younger brother about why he was "*always taking medicine and was not getting better,*" refused to tell him that his medication was HIV treatment. In this FGD with his peers, he explained his reason for maintaining secrecy: "… *the way I see him (younger brother he lived with); he will gossip about me to the entire village."*

Caregivers across sites were equally concerned and believed that **third-party disclosure** would be harmful. Some youth in both sites reported that their mothers told them to maintain their secret. They were guarded about how they would be treated by people in school and extended family members. Participant 2, a caregiver (50 years) from the Uganda site expressed concern for younger adolescents. She stated: *"These children are young so nothing good can come out of them disclosing their status to peers because they will not be able to help them in anyway."* In South Africa caregivers feared criticism from extended family members if their medication was found in their bag. Participant 6, a mother (42–59 years) whose children were trial participants from the South Africa site expressed: *"… I also don't bother myself by saying they (children) must go, because someone might open the child's bag and be on your case about it."* They withdrew from socialising with relatives and discouraged their children from visiting and staying over.

Concerns about third-party sharing extended into digital spaces, where several YPLHIV in South Africa, reported fearing stigma from their HIV status **"*trending*" on social media.** Participant 7, a young male (14 years) in South Africa shared that if secrecy was not maintained he *"… would find himself trending on social media."* Posts usually *"trend"* because the content about the person is negative. Youth were anxious about this, aware of how their HIV status could become increasingly visible online and among peers who were social media users. Participant 8, an older (18 years) female also in the South Africa, rationalised: *"People do talk on social media and what they say becomes offensive especially from people you know … Why do they look down on it (HIV)? Because we did not make ourselves like this, and it wasn't [our] parent's intention to pass it on, so a person must think before saying something because they don't know how the affected person will feel."* She resolved that the posts were unempathetic and harmful, both to them as individuals and to their caregivers, reflecting erroneous judgements about presumed acquisition and transmission behaviour.

Most youth across sites adopted a stance to protect themselves from their **fear of anticipated stigma** and discrimination because of what they had previously observed or had been told, despite not having experienced stigma directly. For example, participant 9, an 18-year-old male from the Uganda site, in a discussion with 15–19-year-old males, when asked about their experiences explained: *"No it is just my way of thinking. I think they can do that; I have heard stories about such things from people. They said that in the past people living with HIV faced a lot of discrimination even from family* members.*"* When asked about how this made him feel, he responded: *"Bad, which is why I don't want others to know my status."* This information from others mediated secrecy and negative feelings of inferiority.

In South Africa, there was fear of **recrimination from stereotypes about sexual promiscuity**, associated with horizontal infection. Participant 5 (15 years) in South Africa, who previously reported her fears of third-party disclosure, shared about being told by her friend's mother, an elderly lady in her community, that she should: *"… distance from her child because I love boys, I am the bad child, and boys will sleep with me …"* Her friend's mother associated living with HIV with promiscuity and immoral sexual behaviour, and reasons for her child to ostracise her. Participant 10, an 18-year-old female also from South Africa, reported overhearing older women in her community saying: *"… She is HIV positive, and she will infect other children with the virus because she is not even taking treatment."* This reflected the fear of discriminatory attitudes equating YPLHIV on ART to adolescent irresponsibility.

3.1.2. Managing relationships

An experience that was commonly illustrated within the data was that YPLHIV **helped keep their mothers' secrets from their fathers**. Participant 11, a young (16 years) female in South Africa, who lived with her mother and visited her father and stepmother, maintained the code of secrecy. Recounting how she took her HIV treatment whilst her father was in the next room she described: *"I take them, hide them, and go out with them … I put them (ART) in plastic (carrier packet)..Just a little plastic [bag] … I take the container and put them in a plastic bag and take them out, I go to drink them at the door."* Her mother arranged for her stepmother to assist her. Echoing a similar experience a mother of a male YPLHIV from the same site, participant 12 (42–59 years) in South Africa shared her approach with caregivers. She explained: *"When he (her husband) leaves for work, I was making him (her son) take the pills, whenever he would be there, he is not taking them, you see that life of hiding …"* She managed her son's ART schedules to fit around his uninformed father's presence and this helped her to keep his HIV status from his father.

The mother-child secrecy extended to other family members of YPLHIV. Male participants (trial and non-trial, 12–19 years) in Uganda described their HIV-positive status as a secret shared only with their mothers, who were also living with HIV. Participant 13, a male (12–14 years) from Uganda explained: *"..at home, every weekend we get visitors (relatives) yet taking the medicine is a secret between me and my mother, so it became hard for me to take the medicine, so I joined the study (trial) to have a break on the weekend while we have visitors at home*."

There was an interaction between **viral load literacy and perceived security**. Participants' understanding that viral suppression eliminated onward transmission was considered to both motivate ART adherence and justify the lack of risk in maintaining their secret. Participant 14, a male non-trial patient (18–19 years) in South Africa in a FGD with YPLHIV on ART in his peer group maintained that he would not tell his sexual partners of his HIV status regardless of the consequences of condom failure. When discussing his relationships with his girlfriends he explained: *"Also, the doctor said there are low chances of infecting others because the virus is suppressed. So, there's no need to tell them …"* His perceived sense of security of having an undetectable viral load minimised his concern about telling his girlfriends. Some YPLHIV used this as autonomy to maintain secrecy.

3.2. Mechanisms for practising secrecy

3.2.1. Covert medication storage, discreet use

Most participants were concerned that their ART would be discovered and so invested considerable thought in navigating where and how to **store their treatment covertly**. Young study participants in South Africa stored their ART in hard-to-reach places at home or in their caregivers' bags or vehicles when away. Being the only one living with HIV at home, participant 15, a 16-year-old male from South Africa used a *"… safe place away from people"* by storing his ART in his room and applied a double barrier of a "*… bucket and then put another bucket on top of another"* making it difficult to access if found. Other participants combined their ART with their parents' or grandparents,' in bags that were typically used to store medication for their conditions, rather than separately. Participant 16, another 16-year-old male also in South Africa stated: *"I too put them (ART) there (fathers' bag), for them (his siblings) not to touch them because that bag no one touches it, because they know that our father's bag … stores [his] pills."* This method made it difficult for his family members to tell medications apart and determine that it was his medication if it was accidently discovered.

Some youth expressed a preoccupation with needing their ART to be kept *"safe"* so that it could not be discovered, even if someone was looking. This was often particularly pronounced when needing to surreptitiously store their ART when away from home. Participant 17, a young female (18 years) in Uganda, who attended boarding school, was afraid that learners that she shared a dormitory with would accidently discover her ART if they opened her suitcase and so would carry it around with her to ensure its concealment and discrete consumption. In a FGD with 18–19-year-olds, she shared: *"I move [around] with my medicine in the bag so when it is time to take it, I put it in the hand, and I put it in the mouth."* Adopting an alternative method to storing ART on hand in the same site, participant 9 the male participant (15–19 years) also in Uganda who had heard about the stigma experiences of others in his community, explained in an FGD that his preference was to store his ART at work rather than at home. He maintained: *"I keep it (ART) at work so if you come to our home and start snooping around, you will not find anything. I have a locker at work, and I can lock it up."* He perceived his room as a space where people could intrude.

Like participant 11, a 16-year-old in South Africa who discreetly took her ART in a room away from her father, male and female YPLHIV in the same age group and older sought secluded areas when in public in school, work, religious and social environments. They described physically leaving public social situations for **discreet ART use** in restrooms, outdoors, and locker spaces away from peers, congregations and colleagues. They used ART in spaces where fewer people were present, and the medication was easy to access. Participant 9, the young male (15–19 years) in Uganda employed these diversionary tactics with his colleagues at work, in a FGD, described:

> *"… I never take [ART] in public. I go to my locker then pretend..[I] am looking for something while looking around to make sure no one sees me. If my colleagues are near the locker area, I will start a silly conversation so that we can laugh so much, then when I realise that it's getting past the time when I am supposed to take my medicine I will ask them if they don't have work to do and everyone will go to do their work, then I can quickly take the medicine."*

The excerpt shows that using several steps in managing the situation, under pretence including spatial manoeuvring to be in a quieter and discreet place, and initiating and maintaining arbitrary diversionary interactions, he created an opportunity to efficiently consume his tablets without his peers seeing. He from the Uganda site, further explained this and his method of discreet use for ART adherence: *"I make sure that I stand next to my locker in a way that doesn't allow them to see what I am doing. So, during the conversation, I open it (the bottle) and hold my pills in* *my hand. I usually prepare my water in advance so that as soon as they go away, I quickly swallow the medicine."*

Some youth in South Africa who attended church were concerned that religious leaders would learn about their HIV status and others chose not to take their medication in front of the church congregation. Participant 18, an 18-year-old from the female South Africa site, misled her peers at a church camp, showing them that she was fetching something from her bag without revealing that it was medication. She explained her method of inconspicuously 'dry ingesting' her ART tablet: *"We were divided, at first everyone was in the tent and those who wanted to attend were attending but my friends were in the tent. I walked in[to] (the tent) like I wanted to take something from my bag and took my pills, I no longer drink the pills with water, I just swallow it."* Her method avoided attention and questions from her friends about where she was going (pretending to remove something from her bag which was not usual) and what she was doing (not fetching water to take her ART).

Participant 7's mother from the South Africa site recruited people to assist younger adolescents aged 14-17-years-old to discreetly take their ART. This extended to other caregivers in both South Africa and Uganda sites. For example, in South Africa a grandmother and an aunt 'assisted' 14- and 15-year-old females, respectively in using stealth approaches to adhere to ART when they were with people. Participant 19, a female (14years) in the South Africa site who attended a ritual with similarly aged females revealed: *"..one of the women who do virginity testing knows that I take pills … she would call me aside and then I would take them (ART) … My mom (grandmother) saw that I like to attend the reed dance (a cultural practice) so she decided to tell her."* These adults covertly stored and administered ART within the young person's social-cultural settings.

3.2.2. Carrying medicines, avoiding suspicion

YPLHIV did not want to be seen with ART and adjusted their daily lives and routines by **not carrying medication** with them when leaving home. Most participants choose to leave their ART at home when socialising with peers or spending time with romantic partners and to return to use ART there. Participant 20 a younger, 14-year-old male in South Africa who played soccer with other young males in his community in the nearby sports grounds on weekends, explained: *"… When I realised what time it is, I would then run home and take the pills."* Although this delayed the scheduled time and inconvenienced him, he and participants in trial and non-trial groups, used ART where it was stored among family members and used partial secrecy when explaining. This included explaining to family members who knew that they were taking medication or attending the health facility because they were living with an unspecified condition i.e. described as being *"sick."*

Activities were disrupted by the need to return home or hide when taking medicine. In addition to missing routine sporting events, participants mentioned missing playtime, leisure activities, and interactions with family and relatives. This may have emotional and developmental implications. Participant 21, a female health professional in South Africa, expounded during an FGD from a provider perspective on the reluctance of YPLHIV to carry ART when mobile: *"..they would rather leave the medication at home and then go – that interferes with their adherence. So, I can say taking medication can change some aspects of your life."* For YPLHIV in care, not carrying ART and returning home, provided an additional step to taking ART and was at the expense of treatment adherence.

For some YPLHIV in Uganda who carried their medicines when travelling, the possibility of missing ART doses was greater when away from home than when at home. Participant 22, a 15-year-old, female in Uganda, who was a cook, chose to miss her doses when travelling away from home for work. In a FGD with15–19-year-old females, she compared: *"..So, when I am with people who do not know me, I fear to take my treatment and sometimes I end up missing [doses]; when I am at home, I take my medicine, but I miss [doses at work] because I don't want those people to know about me."* Her work involved meeting unfamiliar clients who she cooked for and the uncertainty around them discovering her HIV status prevented her from using the ART she had packed. This finding in YPLHIV Uganda was also evident among other trial participants in South Africa, where YPLHIV who packed their medication with them when staying overnight or at social events and skipped doses when they were around people.

Most YPLHIV in the sites **prioritised reducing suspicion around their ART** by altering their treatment schedule. They adopted temporal management strategies by looking for opportunities when the 'coast was clear' or vigilantly monitoring and planning their scheduled ART time. Participant 23, a 17-year-old male in Uganda who was attending boarding school adopted a passive approach to using ART by waiting for an opportunity. In the FGD with 15–17-year-old males, he explained: *"I would wait for everyone to leave the dormitory and while they were in the bathroom, I would take my medicine."* When spending time with romantic partners, young women preplanned by taking ART before they left home or when they returned. Participant 24, an 18-year-old female in South Africa who was a parent to an infant, when with "… [her] *baby's father [who] doesn't know anything about [her] status"* shared her approach to planning for times to return home to use her ART there, instead of carrying it with her, in fear of him finding out. In the IDI she stated: *"… I would leave the baby (at the fathers house) and go, and we are also close to each other, I would estimate here is home and over there it his home."* Carrying ART was risky and created concerns about how to use it discreetly.

In responding to their fear, in their scheduled time to take ART, YPLHIV removed themselves from the people they were with, to reduce the possibility of their HIV status being exposed. Participant 25, a male (17 years) in Uganda withdrew from his friends to adhere to ART. In the 15-19 year-FGD with non-trial patients, he elaborated:

> *"I stopped being comfortable around my friends and even feared that they might find out that I was taking HIV treatment. Whenever we were playing, I had to leave for some time to go and take my medicine then come back and play. Once I found out that I had HIV I had to cut down on [the] time I spent with friends so that when it gets to time when I am supposed [to take] treatment, I am already at home to avoid raising any suspicion."*

In the excerpt, he perceived that decreasing his time with his peers would make his routine schedule for medication less obvious, reducing the likelihood of unintended disclosure. In the process, he withdrew from daily social activities like many other participants across the sites. In this site, the mother of a younger adolescent decided to remove her from boarding school and place her in day school, for fear that her daily ART schedule would expose her status. Participant 26, a female (15 years) also in the Uganda site detailed this among her 15-19-year-old peers. She stated: *"… when I was in secondary school, my mother could not take me to boarding school because I had to take my medicine every day and I didn't want everybody to know about it. Because I wanted to be safe by not telling them."* There was a fear of harm from inadvertent disclosure and a need to stay "safe" to protect her mother and herself from anticipated stigma.

Most participants across the sites, had concerns about carrying ART when mobile, because of the **noise the tablets made**. They feared that the conspicuous rattling sound would lead to suspicion and questions about their HIV status. Participant 27, a male (18 years) from the South Africa site, when asked about his treatment during an IDI stated: *"No, they (people) hear the noise in my bag when I enter the taxi, or when I'm walking, they always going to make noise."* To avoid people physically present when they were moving around from hearing this sound, some YPLHIV chose to decant doses. He said: *"I don't carry the container; it depends whether I put in the tissue or plastic. I don't like to take the whole container because it makes a lot of noise. You can hear that there are pills in here."* Participant 18, a female of the same age also from the South Africa site, when preparing to attend the church camp decanted her doses into a small plastic bag to prevent her fellow peers from hearing the noise. She shared: *"I packed enough for the days that I was at the camp, which is Thursday, Friday, [and] Saturday. I had packed a pill for Sunday as well* *because I knew that I was going to return home at night."* She took care to include an additional dose from the container to adhere to ART on her travel day.

Most participants developed a hyperawareness around their HIV status exposed from the sound of their tablets in the container. YPLHIV who chose to carry their containers adopted noise-reducing techniques when preparing for a trip. Most adolescents in trial and non-trial groups insulated their tablets with material to prevent the noise from the tablets colliding onto the container. Participant 28, a male (19-year-old) in South Africa when visiting his friends, explained: *"I would bring the whole container and if I have not used plastic, it would be the tissue then I would open the container and take out the tissue then I take the pill and return the tissue back and put it back in my bag then I go to drink it (tablets) and return to them … I am avoiding the jiggle noise."* The tablets colliding in the container created this noise. This auditory marker of their HIV status became a source of HIV disclosure anxiety among his friends. Participant 16, a male, younger in age (16 years) from the South Africa site, who carefully stored his ART at home was also cautious when packing to travel to his family members and relatives who lived in a village. He described that when packing his luggage bag to minimise its noise and visibility when mobile, he would: *".. go with a bottle of it (container of tablets) and maybe I put some tissue in the middle to make it not make noise, then I put them in a bag and sink them to the bottom so that I start with them at the bottom and then I put the clothes on top so that I take them well."*

Perceived as an indicator of anticipated stigma from inadvertent disclosure, noise reduction strategies and methods were used to dampen the sound. This was among friends, non-household family members and relatives of YPLHIV. Health professionals and caregivers described helping manage this. Concerned about stigma, participant 29, a female health professional in South Africa provided some guidance to a trial participant. She outlined:

> *"… I told her to take a few (tablets) out and put [it in] the pill container … that our old people use (pill box organizer) so nobody will hear when she clicks it and picks it up, but I also told her to put something inside like cotton wool or tissue, so when she topples it you are not going to hear that noise."*

She further explained that this was done to assist her as a learner studying with her peers in a communal living space. Caregivers also adopted this approach, intended to make the containers less threatening and stigma-avoidant for YPLHIV to travel without being concerned about their HIV status being accidently disclosed.

3.2.3. Avoidant communication

Youth as participants in trial and non-trial groups in both sites communicated using language **avoiding direct references to ART and HIV,** positioning these away from themselves. They used linguistic evasion referring to ART as *"pill"* when participating in IDIs and FGDs. They discussed experiences when they used ambiguous language to describe their medicine when responding to a family member, peer, or stranger in a communal setting. In participant narratives, HIV was obscured through euphemisms e.g. *"sick," "the situation I am in/facing," "deep issue,"* and *"bad 'condition'"* – terms averting responsibility from stereotypes associated with self-blame for acquiring HIV. Participants described symptoms *"coughing,"* weight loss, not feeling *"good"* and hospitalisations, concealing their identity of living with HIV. The masking effect communicated the impact on their wellbeing without revealing the condition.

Some participants **used spontaneous or believable explanations** to avoid revealing the actual purpose of their medication. Although some YPLHIV in South Africa and Uganda expressed that efforts to construct alternative explanations about their ART to employers for being absent and people they commuted to and from the clinic with made them feel uncomfortable and unpleasant, they did not reveal their HIV status. When asked about their medication they spontaneously responded using more socially acceptable 'cover stories' e.g., *"heart problem," "stomach-ache"* and *"lung"* illnesses as reasons. Participant 30, an 18-year-old male in South Africa, shared an incident when travelling from school when he responded to taxi drivers' questions about what his medication was for. He stated: *"I do tell them (taxi drivers), but I don't tell them the truth I tell them that this treatment is for my lungs because I have [a] lung disease since I was a child."* Participant 31, another male, aged 17 years, in South Africa, when seen taking medication by family members who he lived with explained that he crafted a 'story' about having a *"headache,"* tailored to fit in with what they already knew about him.

3.3. Secrecy implications for youth living with HIV

3.3.1. Limiting support

Limited support was an unforeseen circumstance for YPLHIV and could worsen feelings of loneliness and isolation for some who reported having inadequate perceived support to manage HIV. For example, observing and 'hearing about' members of the communities they lived in *"fighting"* with and *"gossiping"* about each other and *"abuse"* in school. In maintaining secrecy, YPLHIV deny others the opportunity to offer support for living with HIV and adhering to ART. This emotional, social and physical support could be from romantic partners, neighbours in communities, learners in schools, and immediate or extended family members who were willing to help. 'Help-providing' behaviours were evident from caregivers, health professionals and family members. In addition, in maintaining secrecy there was an overreliance on selected family members to provide physical support through medication and clinic reminders and being accompanied to the clinic.

The **nature of the secret** may place limits on the type of support received. Through partial secrecy peers at school and family members were disclosed selected information about participants HIV status and medication, by their caregivers or the YPLHIV themselves. Participant 32, a male (14–17 years) in South Africa in a FGD explained: *"He (a classmate he sits next to in school) doesn't know what we are attending for, but just that we attend the hospital only."* Within their households in South Africa, several participants were uncertain of their siblings' awareness of their status and understanding of the purpose of their medication. Although it is uncertain if these individuals would choose to support the YPLHIV, the nature of support from a learner at school, uninformed father or misinformed family member will be limited and not specific to HIV management.

3.3.2. Taking a toll

Relationships were strained, and YPLHIV reactions to secrecy were emotionally challenging linked to shame for both females and males, and for some young females connected to the blame associated with interparental secrecy. For example, the female participant 11 in South Africa who was sustaining her mother's secret from her father who she visited, when asked how she handles this expressed: *"It makes me sad because he should also know that his child is taking pills."* Her social bonding experiences with her father had been disrupted. Participant 32, an female (18 years) in South Africa, resented her mother who had told her that her dead father was to blame for her acquiring HIV because he had been 'unfaithful.' In an IDI she explained: *"… I feel like I am tortured because of the sins of my parents. I said, well, I don't see a reason to live because it's not my fault, it's their fault."* She feared that she would use ART to overdose and in times of intense emotional distress, chose not to adhere to prevent this. Secrecy negatively impacts trust, sense of belonging, security and connection to family members.

Cognisant of the cost to their relationships, **self-isolation would be less demanding** and more appealing in managing HIV. In South Africa and Uganda sites, some participants shared that they disengaged from activities with peers in schools and communities. Participant 33, a female (18-19-years) in South Africa in a FGD with peers stated: *"… I wasn't going out and playing with my friends anymore, I'm always at home. One day mom asked me why I was not going, I said: I don't like it anymore because there is something they will see on me."* She withdrew from her friends in her community, feeling emotionally distressed that her concealable HIV status was visible to them. In both sites, female and male participants described withdrawing from social activities with their peers. For these participants, with internalised stigma and feelings of shame, secrecy could perpetuate stigma.

3.3.3. Adherence challenges

Aware of spatial and temporal factors that challenged adhering to ART doses, YPLHIV prioritised **alleviating suspicion over adherence** resulting in a stealth form of treatment adherence. Hiding medication led to forgetting doses. Participant 28, an older male in South Africa who did not want his friends who he visited to find out about his status and insulated his tablets because of the sound explained why he, and others like him, may forget to take pills: *"… sometimes it will be because of their storage site and is not a visible place where you will be able to see and remember to take the pill, it could be the place where they are hiding them, that's why they are not taking them correctly."* Some youth stored their medication out of plain sight and away from items of routine use to avoid discovery but then that made it difficult for them to remember, leading to missed doses.

The **tension between concealment and visibility** demonstrates the complex terrain YPLHIV navigated. Practising secrecy challenges remembering ART schedules through elusive and covert storage, not carrying it or being seen using it. There were risks for YPLHIV in both the South Africa and Uganda sites. This increased the likelihood of missing doses, especially when they had limited physical reminders. YPLHIV managed their number of decanted doses by packing extra doses on travel days and there was a possibility of these being insufficient. There was also a risk to their adherence health and wellbeing in mistakenly taking incorrect medication because of elusive storage site of their ART with the *"pills"* of other family members in their household. YPLHIV developed alternative techniques e.g. ingesting tablets without drinking water to reduce suspicion and inadvertent disclosure. They also delayed, skipped or missed consecutive doses when in social environments.

In managing the situation of not carrying their medication to prevent suspicion and questions, stealth ART adherence strategies would be employed and in striving to adhere family members provided forms of 'physical support.' Participant 34, a female (15 years) in South Africa, discouraged by her aunt who feared their mutual relatives would enquire when she visited, did not carry her medication. When she stayed at her aunt's house her grandmother administered her cousin's doses. She stated: *"It (ART) was my cousin's because … I thought she already knew, but at night my grandmother called me, and she gave it to me secretly."* Sharing ART doses to prevent the trial participant from missing doses may have led to fewer available doses for her cousin. Like other YPLHIV in both South Africa and Uganda sites, she did not tell anyone about the practical challenges of taking ART.

4. Discussion

YPLHIV in trial sites in South Africa and Uganda practiced secrecy in their everyday lives when taking life-long ART to navigate the complexities of living with HIV. Secrecy, identified in both sites is a manifestation of local stigmas, shaped by social, relational, and cultural dynamics. For YPLHIV HIV is inextricably linked to their ART and is a complex source of inadvertent disclosure and stigma. Despite living with HIV for several years and being stable on ART, youth in this study exist in a state of liminality (Turner et al., 2017), adopting secrecy in the face of fears of being identified as living with HIV and stigma.

Contrary to "truth-telling" which equates silences, partial truths and non-disclosure with treatment 'non-compliance' and 'deviant' adolescent behaviours, in this study. Secrecy fulfils a subjectively functional purpose supporting stigma management. In line with previous work (Bernays et al., 2017; Fielden et al., 2011; Hardon & Posel, 2012; Mackworth-Young et al., 2020; Madiba & Josiah, 2019), we posit that secrecy serves as resistance to activities that risk unintended HIV status disclosure in YPLHIV experiencing internalised stigma.

Our findings show that YPLHIV fear questions and reactions about their medication and HIV status, typically occurring in situations of being found out, which often leads them to conceal their medication to prevent inadvertent disclosure and protect themselves. For example, they fear perceived and anticipated stigma, social rejection, "*gossip*" and third-party disclosure in-person and via social media which motivates them to maintain secrecy.

Challenges related to family secrets have been found in research on YPLHIV in SSA and the global North (Daniel, 2015; Dlamini & Mtshali, 2023; Galano et al., 2017; Namukwaya et al., 2017). Congruent with this, we found that secrecy functions as a collective family practice, adopted by caregivers. If the secret of their HIV status was to be revealed it has implications in family relationships. YPLHIV experiencing internalised stigma expressed shame and sadness. When following intraparental and family patterns of secrecy. In this study, narratives were shared about keeping secrets from fathers by female YPLHIV, however caregivers who were mothers to sons and daughters shared this. Although caregivers were limited to the available female voices, because males would not take part, similar patterns of secrecy in families affected by vertical transmission emerged across sites with caregivers expressing an unwillingness for their child's status to be revealed, suggesting that fundamental challenges of managing HIV stigma transcend national boundaries. Further research to explore gender dynamics would be useful.

In this study, managing perceived stigma was inscribed in bodily practices and sensory awareness manifested through strategies such as spatial manoeuvring, temporal management and avoidant communication in the social context. It extends previous findings regarding the covert storage of ART, vigilance about being seen with medication and the associated noise of ART in its packaging found in research in SSA (Brittain et al., 2023; Burns et al., 2020; Kimera et al., 2020; Madiba & Josiah, 2019), by providing information on the role of caregivers and health professionals. The avoidant communication about HIV and ART demonstrates the social navigation required when living with internalised HIV stigma. These language adaptations have been observed in previous studies of YPLHIV including the previous BREATHER social science study in Uganda (Bernays et al., 2017; Burns et al., 2020; Daniel, 2015; Fielden et al., 2011; Gittings et al., 2022; Mackworth-Young et al., 2020; Steenberg, 2020).

Temporal management, spatial manoeuvring, and avoidant communication were mechanisms that may have been useful to help strive for less-than-perfect ART adherence, providing short-term solutions and relief. However, for YPLHIV experiencing internalised stigma, it might unintentionally perpetuate the view that living with HIV is discreditable and must be concealed at all costs. Decanting and packing ART doses found in this and other studies (Muiruri et al., 2020; Ramadhani et al., 2018), is one such example. Although research has found that self-packaging has been discouraged because of its negative association with treatment adherence and viral suppression (Muiruri et al., 2020), internalised stigma, and its pathway to maintaining secrecy and the tension between ART concealment and visibility is less clear.

There is a network of people who support or encourage secrecy. While this network was intended to create a barrier for YPLHIV from stigma, it may unintentionally reinforce feelings of shame. The protecting effect of secrecy would therefore be miscarried. In youth who feared the shame from "*gossip*", judgement and third-party disclosure this could create a compounding effect. They may experience psychological and emotional strain from maintaining secrets in relationships, extreme concern about being identified, and hypervigilance about their ART being discovered.

As in other studies (Brittain et al., 2023; Burns et al., 2020; Kimera et al., 2020; Madiba & Josiah, 2019), the current study found that secrecy can impact treatment management for ART adherence; and has immediate consequences for the wellbeing of YPLHIV. The burden of internalised stigma combined with the need to maintain perfect adherence can hinder their mental health, social development and emotional regulation. The constant effort to keep their HIV status and ART regimen secret can lead to heightened HIV disclosure anxiety, fear of being identified, and hypervigilance. The toll of secrecy has been previously linked to social isolation, anxiety, depression, negative self-concept and exacerbating existing mental health conditions and suicidality (Govindasamy et al., 2020; Mackworth-Young et al., 2020; Maseko & Madiba, 2020; Ngwenya et al., 2024; Nsibandze et al., 2021; Steenberg, 2020).

In YPLHIV who perceived inadequate support, it may further challenge forming authentic relationships and barriers to help-seeking. The withdrawal and self-isolation raise concerns about loneliness and shame associated with internalised HIV stigma and have been found in other studies in SSA (Nabunya et al., 2023; Ngwenya et al., 2024). Internalised negative stereotypes such as those related to sexual immorality and responsibilisation (Viljoen et al., 2021), played a role in facilitating secrecy. This was evident in the narratives of YPLHIV in South Africa who faced accusations of promiscuity and non-adherence and were exposed to these stereotypes, regardless of the mode of acquiring HIV. This dynamic provides some insight into stereotypes YPLHIV live with, perpetuating shame.

Further research is needed to investigate secrecy and its long-term impact on the health and wellbeing of YPLHIV, including the long-term effects of mechanisms for stealth treatment adherence in youth living with vertically and horizontally acquired HIV. Examining the complex interplay between stigma, secrecy, and ART adherence will provide insights into why interventions to support treatment adherence and prevent onward HIV transmission are unsuccessful; individuals such as caregivers, family members or peers who help keep their HIV status and ART a secret could provide insight. Research on appropriate interventions that respond to local stereotypes, internalised primary and secondary stigma would be useful.

The advent of other treatment simplification interventions for adolescents, presents an opportunity to reduce the harmful consequences of maintaining secrecy. Less frequent dosing as a result of using a long-acting injectable form of ART or being able to take ART less frequently could minimise the risks of questions and reactions about their medication and the risks of being “found out” which YPLHIV and their caregivers were concerned about. The BREATHER Plus trial short cycle (5 days on, 2 days off) compared to daily ART arm (every day without any breaks in treatment), removes the need to practice secrecy, on “weekends off,” i.e. days when youth are typically more social. Investigating the impact that short cycle compared to daily ART has on stealth ART forms of stigma in YPLHIV and their secrecy network, and, if found to be effective and made available beyond the trial in the countries health systems, will assist in development of these interventions.

Long-acting regimens could reduce the need for the mechanisms, methods and strategies YPLHIV employed to maintain secrecy in their everyday lives A study with older Ugandan women found that long-acting injectables may reduce "pill stigma" by eliminating visible medication containers (Odongpiny et al., 2022). Long-acting injectable ART would free YPLHIV from medication transportation concerns, repackaging requirements, and risky storage practices that compromise adherence. The concerns about and support for this from caregivers and healthcare providers found in our study could potentially decline. Monthly or bimonthly injections could provide relief from the psychological and emotional toll of taking daily oral ART and the frequent HIV status reminders that may reinforce internalised stigma. There may also be less ongoing strain and tensions related to medication reminders and adherence monitoring by caregivers and within families with bimonthly, or even less frequent, injections or pills. Access to such regimens holds promise for YPLHIV to face fewer barriers to participation in social activities.

However, long-acting regimens may create different secrecy challenges for YPLHIV depending on the social context including relational and systemic factors (Bruce et al., 2020; Hardon & Posel, 2012; Mackworth-Young et al., 2020; Steenberg, 2020). While injection visits replace collecting ART, they still risk HIV status exposure when attending health facilities (Bond et al., 2019; Odongpiny et al., 2022), and require explanations for absences from work and school. The clinical administration of ART injectables may also reinforce rather than reduce stigma. However, from this study secrecy appears to be tied to issues of stigma and shame; changing the medication modality alone may not address these underlying issues. Social stigma is likely to persist, raising ethical concerns for implementation in South Africa and Uganda where prevalence is high (Ekusai-Sebatta et al., 2025).

Beyond this, programmatic and policy decision-makers are challenged to consider how to develop interventions that respect the choices of YPLHIV, comprehensively respond to stealth ART adherence, and create less judgmental environments, where maintaining secrecy becomes less necessary. Given the study implications, interventions that provide integrated psychosocial support and emotional literacy should be considered. The demonstrated creativity of YPLHIV in care and their adaptability if properly supported could also form the basis for developing HIV management skills.

4.1. Limitations

The study was not designed to investigate secrecy from the onset. The longitudinal data enabled an examination of how youth navigate living with HIV, ART adherence and disclosure across two Eastern and Southern African geographies contributing to a conceptualisation of secrecy in local contexts. The two-phase IDIs with trial participants and FGDs with participant groups contribute to the depth and breadth of our findings. These methods enabled us to generate data on sensitive topics over time from YPLHIV, alongside caregiver and provider perspectives. However, the varying methodologies limit cross-site comparisons. We offered some insights into participant ages; however, we did not conduct a rigorous analysis based on age. Although IDIs were conducted in South Africa providing more nuanced quotes as examples, data drawn from the FGDs in Uganda were described and common themes between sites were presented. Data collected from YPLHIV in treatment and care in trial sites in geographical areas in South Africa and Uganda may have limited generalisability. However, the sample facilitated access to various secrecy perspectives. While caregivers included immediate and extended family members only available female perspectives were captured. There was a focus on the perspectives of mothers, aunts and grandmothers of the trial participants in the caregiver FGDs in South Africa and Uganda sites, and not on male caregivers who were not contactable or available to participate in the study. Health professionals were limited to those providing trial services. However, these findings may be transferable to routine HIV care settings of first-line once-daily ART regimens.

4.2. Conclusion

This study examines secrecy among YPLHIV receiving ART in a trial setting in South Africa and Uganda. The notion of secrecy represents a complex adaptation to perceived and anticipated stigma within the social context, serving a functional purpose. By reframing non-disclosure, this study provides insights into the need for stigma reduction interventions in managing HIV disclosure and psychosocial and emotional support for youth in HIV care.

Notes.

1. We use the terms “adolescent,” “youth,” and “young people living with HIV” (YPLHIV) interchangeably to refer to study participants living with HIV and on ART.
2. The names of all study participants have been anonymized and we applied the term “participant” in chronological order. The references collected, sex, age and site are indicated. If no participant group is indicated e.g. non-trial, caregiver and health professional, the quote

comes from an in-depth interview or focus group discussion with a trial participant.

CRediT authorship contribution statement

Tamlyn Carmin Seunanden: Writing – review & editing, Writing – original draft, Validation, Software, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Nothando Ngwenya:** Writing – review & editing, Supervision, Methodology. **Stella Namukwaya:** Writing – review & editing, Validation, Formal analysis, Data curation. **Londiwe Shandu:** Data curation. **Moherndran Archary:** Writing – review & editing. **Cissy Kityo Mutuluuza:** Writing – review & editing. **Sarah Lilian Pett:** Writing – review & editing. **Adeodata Rukyalekere Kekitiinwa:** Writing – review & editing. **Sarah Bernays:** Writing – review & editing, Conceptualization. **Janet Seeley:** Writing – review & editing, Supervision, Methodology, Conceptualization.

Data availability statement

The data generated and/or analysed during the study are not publicly available to maintain participants' privacy, but the data upon which this study is based are available from the corresponding author upon reasonable request.

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Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix B. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ssmqr.2025.100560.

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