

# Prevalence of HIV status disclosure among young adolescents on antiretroviral therapy in Johannesburg, South Africa

Mhakakora, T.<sup>1</sup>, Mapungwana, P.<sup>1</sup>, & Chadyiwa, M.<sup>2</sup>

<sup>1</sup>University of Johannesburg, Johannesburg, South Africa

<sup>2</sup>Sefako Makgatho Health Sciences University, Ga-Rankuwa, Pretoria, South Africa

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### Correspondence to:

Dr. Pheyiye Mapungwana  
[pheymaps@gmail.com](mailto:pheymaps@gmail.com)

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## ABSTRACT

### Introduction

Disclosure of HIV status is crucial for effective management and support among adolescents on antiretroviral therapy (ART).

### Purpose

This study aimed to assess the prevalence of HIV status disclosure and its associations with various factors among adolescents aged 10–14 years on ART.

### Methods

This quantitative, descriptive study analysed secondary data from 281 adolescents aged 10–14 years on ART across thirteen public clinics. Participants were selected using convenience sampling. Key variables included disclosure status, gender, age, ART duration, attendance at support groups, clinic adherence, and viral load. Data were analysed using IBM SPSS (version 25), employing chi-square tests and t-tests, with a significance level set at  $p < .05$ .

### Results

The findings revealed that only 26.3% of participants had fully disclosed their HIV status. Full disclosure was significantly associated with clinic adherence ( $p = .002$ ) and support group attendance ( $p < .05$ ). However, no significant correlation was found between disclosure and viral load suppression ( $p = .886$ ).

### Conclusion

The low prevalence of full HIV status disclosure underscores the urgent need for targeted interventions to enhance disclosure practices. Strengthening caregiver training and aligning health policies with the psychosocial development of adolescents are critical steps to improve health outcomes and provide effective support for this vulnerable population.

## INTRODUCTION

Adolescence is a critical developmental stage characterised by significant physical, emotional, and cognitive changes, during which individuals are particularly vulnerable to engaging in risky health behaviours that can have lasting implications for their well-being (Dick & Ferguson, 2015). The World Health Organization (WHO) identifies adolescents as a key population at risk for HIV/AIDS, underscoring the necessity for targeted interventions that address their unique health needs (World Health Organization [WHO], 2010).

In South Africa, where the HIV epidemic poses a substantial public health challenge, the Prevention of Mother-to-Child Transmission (PMTCT) programme has made notable progress in reducing the incidence of HIV among newborns (National Department of Health [NDoH], 2016a; UNICEF, 2017). However, as these children transition into adolescence, the critical issue of HIV status disclosure becomes increasingly relevant, as it is essential for promoting treatment adherence and improving health outcomes.

WHO and national guidelines advocate for age-appropriate HIV status disclosure to adolescents receiving antiretroviral therapy (ART), emphasising its importance in enhancing treatment adherence and overall health (WHO, 2011). These guidelines recommend that caregivers and healthcare providers engage in open and supportive communication with adolescents about their HIV status, thereby fostering a sense of agency and responsibility regarding their health (Sirikum et al., 2014; Cluver et al., 2015).

Despite these recommendations, research indicates that a significant number of young adolescents remain unaware of their HIV status, which poses substantial barriers to effective treatment adherence (Brown et al., 2011; Haberer et al., 2011; Vreeman et al., 2014). This lack of awareness is particularly concerning given that the mortality rate among adolescents living with HIV in South Africa has doubled, even as mortality rates in other age groups have declined (Dick & Ferguson, 2015).

The complexities surrounding HIV status disclosure are compounded by various factors, including cultural beliefs, stigma, and the emotional readiness of both caregivers and adolescents to engage in such discussions (Mavhandu-

Mudzusi & Khoza, 2015). Furthermore, the absence of standardised protocols for disclosure within healthcare settings can lead to inconsistencies in practice, further exacerbating the challenges faced by adolescents and their families (Haberer et al., 2011).

In light of these challenges, it is imperative to understand the current state of HIV status disclosure practices among adolescents enrolled in ART. This understanding is crucial for developing effective strategies that can enhance treatment adherence and ultimately improve health outcomes for this vulnerable population.

This study therefore aims to conduct a situational analysis of the prevalence of HIV status disclosure among young adolescents aged 10 to 14 years enrolled in ART at public healthcare facilities in Johannesburg. By examining existing practices and barriers to disclosure, the research seeks to inform the development of targeted interventions that promote effective communication about HIV status, thereby supporting adolescents in taking an active role in managing their health.

## METHODS

### Design

This study employed a quantitative, descriptive, and contextual design. It involved quantitative analysis of routinely collected ART monitoring secondary data from healthcare clinics, focusing on a cohort of young adolescents enrolled in the ART programme. The ART monitoring data were obtained from thirteen public healthcare clinics in the City of Johannesburg, Region A sub-district.

The key variables measured included:

- i. HIV disclosure status
- ii. Gender
- iii. Current age
- iv. Period on ART
- v. Support group attendance
- vi. Clinic adherence
- vii. Viral load count

### Setting

The research was conducted in public healthcare clinics located in the City of Johannesburg, Region A sub-district.

### Participants

The study included a sample of 281 young adolescents (females and males aged 10–14 years) who were enrolled in ART as of January 2018. According to the Johannesburg District Health Information System, a total of 466 young adolescents were enrolled in ART across the targeted clinics by the end of June 2018.

### Sampling

A convenience sampling method was employed to select participants. This method was chosen due to the accessibility of data from the healthcare clinics. However, this sampling method may limit the generalisability of the findings, as it does not ensure a representative sample of the broader population of young adolescents living with HIV. The rationale for using this method was based on the need to quickly gather data from available records, which is particularly useful in resource-constrained settings.

### Data Collection

Data were collected from the Johannesburg District Health Information System, which provided summary information on the total number of young adolescents enrolled in ART per region, sub-district, and healthcare clinic. The HIV disclosure statuses and support group attendance records were located in the ART files at the healthcare clinics. A disclosure stamp was routinely used by healthcare workers to record and update the HIV disclosure status in adolescents' ART files.

Demographic information, clinic adherence, period on ART, and viral load count for each young adolescent were accessed on the Tier.net system. Tier.net is a real-time electronic system on which ART history and records of every patient are captured and stored directly from the ART files. The Tier.net system was deemed more reliable than ART files, as some important pages from the clinics' ART records were often missing. Patient information was linked from the ART files to the Tier.net system using unique identifiers such as file numbers. The data were captured and coded in an Excel spreadsheet.

### Analysis

The collected and coded data were quantitatively analysed using IBM Statistical Package for the Social Sciences (SPSS, version 25). The analysis aimed to determine the prevalence of HIV status disclosure among the sample of young

adolescents enrolled in ART and to evaluate the correlation between HIV disclosure status and viral load count.

Continuous variables (current age, period on ART, and viral load count) were presented in tables, and figures were converted into percentages, frequencies, summary statistics, and measures of central tendency (mean and median). Pearson's chi-square tests of independence were used to measure associations between HIV disclosure status and other variables (gender, support group attendance, clinic adherence, current age, period on ART, and viral load count). A *p*-value below .05 was considered statistically significant.

### Ethical Considerations

The study adhered to ethical principles of informed consent, ethical research clearance, privacy, and confidentiality. Informed consent from the parents or caregivers of adolescents was obtained through the NDoH's Index-Patient consent form and the HIV services consent form. Ethical clearance was granted by the University of Johannesburg's Research Ethics Committee. Privacy and confidentiality were maintained by not using adolescents' names or identity numbers. The sample data were de-identified, and unique codes were used to link the data from ART files to the Tier.net database and the Johannesburg District Health Information System. Data were stored in a password-protected folder on a password-protected laptop.

The study targeted both disclosed and undisclosed young adolescents enrolled in ART. A waiver on the requirement for adolescents' assent was sought and granted by the University of Johannesburg's Research Ethics Committee to eliminate the risk of accidental disclosure for undisclosed young adolescents. The adolescents and their caregivers were not direct participants in the study, the study only utilised secondary data.

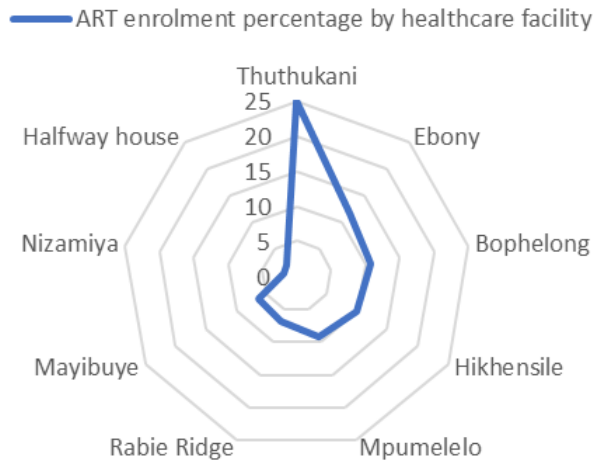
## RESULTS

The following key variables were analysed: HIV status disclosure, gender, support group attendance, clinic adherence, current age, period on ART, and viral load count.

According to **Figure 1**, the healthcare clinics with the highest percentages of young adolescents enrolled on ART

were Thuthukani (25%), Ebony (11.7%), Bophelong (10.7%), Hikhensile (10%), Mpumelelo (9.2%), Rabie Ridge (6.8%), and Mayibuye (6.4%). Conversely, Nizamiya (1.8%) and Halfway House (2.1%) had the lowest enrolment percentages.

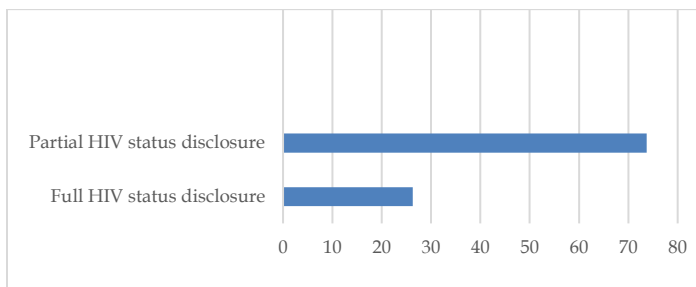
**Figure 1:**  
ART enrolment percentage by healthcare facility



**HIV Status Disclosure**

As shown in **Figure 2**, the prevalence of full HIV status disclosure among the sample of young adolescents was relatively low at 26.3%. The majority (73.7%) were found to be only partially disclosed.

**Figure 2:**  
HIV status disclosure among young adolescents

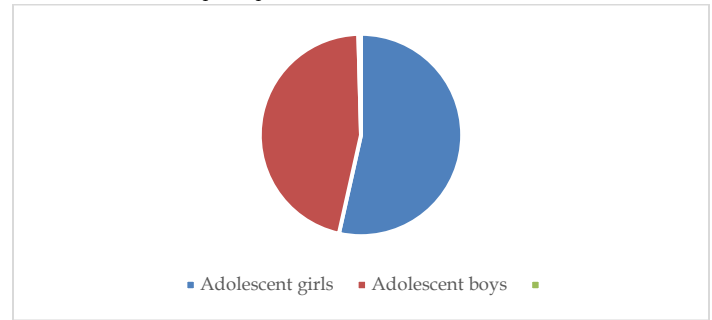


**Gender Distribution**

**Figure 3** presents the gender distribution of the sample. Out of the 281 adolescents, 151 (53.7%) were girls and 130 (46.3%) were boys.

*Disclosure by Gender:* The prevalence of full HIV status disclosure was higher among girls (55.4%) compared to boys (44.6%). However, the chi-square test indicated no statistically significant association between gender and HIV status disclosure,  $\chi^2(1, N = 281) = 1.54, p = .215$ .

**Figure 3:**  
Gender distribution of participants



**Support Group Attendance, Clinic Adherence, and Viral Load Count**

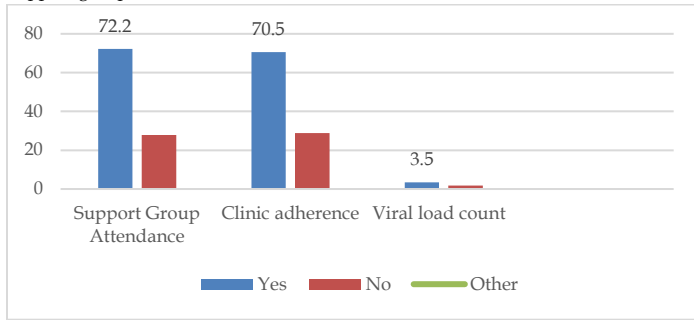
**Figure 4** depicts support group attendance, clinic adherence, and viral load count among the participants.

*Support Group Attendance:* A majority (72.2%) of young adolescents attended support groups, while 27.8% did not. Among those who attended, the prevalence of full HIV status disclosure was significantly higher (83.8%) compared to those who did not attend (16.2%). The chi-square test showed a statistically significant association,  $\chi^2(1, N = 281) = 9.47, p = .002$ .

*Clinic Adherence:* Overall, 70.5% of adolescents adhered to clinic appointments, while 28.8% defaulted. Among those adhering, 70.3% were fully disclosed, while 29.7% were not. The chi-square test indicated no statistically significant association between clinic adherence and disclosure,  $\chi^2(1, N = 281) = 0.28, p = .598$ .

*Viral Load Count:* Updated viral load records were available for 93.6% of adolescents, while 6.4% had missing or outdated records. The mean viral load count was 13,292.42 copies/mL (SD = 52,641.51), with a median of 119 copies/mL. Only 24.7% of participants had suppressed viral load counts (<20 copies/mL). An independent samples t-test comparing mean viral load counts between partially disclosed (M = 13,155.79, SD = 51,876.34) and fully disclosed adolescents (M = 13,589.20, SD = 54,081.27) revealed no statistically significant difference,  $t(279) = 0.14, p = .886$ .

**Figure 4:**  
Support group attendance, clinic adherence, and viral load count



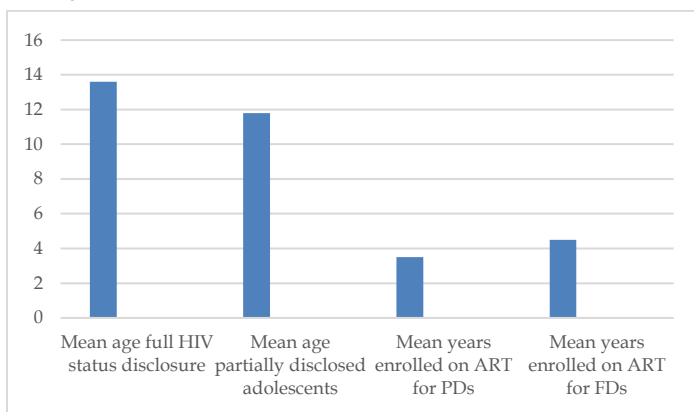
*Age and Period on ART*

**Figure 5** presents the mean age of disclosure and the average period on ART.

*Mean Age of Disclosure:* The mean age of full HIV status disclosure was 13.6 years, compared to 11.8 years for partially disclosed adolescents. An independent samples t-test indicated a statistically significant difference,  $t(279) = 2.14, p < .05$ .

*Period on ART:* The mean period on ART for fully disclosed adolescents was 6.1 years, compared to 5.6 years for partially disclosed adolescents. The difference was statistically significant,  $t(279) = 2.29, p = .023$ .

**Figure 5:**  
Mean ages of disclosure and period on ART



**DISCUSSION**

This discussion interprets the results within the context of a typical cohort of young adolescents enrolled on ART in South Africa. The analysis is based on the selected sample and secondary ART monitoring data, along with demographic information of 281 adolescents enrolled on ART at public healthcare clinics in the City of Johannesburg, Region A.

Clinics with higher percentages of adolescents on ART were located in Ivory Park and near Tembisa, communities characterized by high population density and large informal settlements. As highlighted in the literature, urban informal settlements in South Africa present increased risks of HIV exposure, contributing to high prevalence rates (SANAC, 2016; National Department of Health, 2016a). Conversely, the clinics with the lowest adolescent enrolment were situated in Midrand, a lower-density suburban area.

*Gender Distribution and Disclosure*

Girls made up the majority of adolescents on ART, which aligns with previous findings indicating that South African ART cohorts of HIV-infected adolescents generally contain more girls than boys (National Department of Health, 2016a). Kranzer et al. (2017) reported that gender distribution is relatively balanced among children below age 10 due to perinatal infection. However, among adolescents, the proportion of girls increases due to sexual transmission risks.

Although this study found that girls had higher rates of full disclosure compared to boys, the chi-square test indicated no statistically significant association between disclosure and gender,  $\chi^2(1, N = 281) = 1.54, p = .215$ . This suggests that gender alone does not significantly influence disclosure outcomes, despite psychosocial differences in adolescent maturity noted in prior studies (Vreeman et al., 2014).

*Support Group Attendance and Disclosure*

A significant association was found between support group attendance and disclosure,  $\chi^2(1, N = 281) = 9.47, p = .002$ . Adolescents attending support groups were more likely to be fully disclosed (83.8%) compared to those not attending (16.2%). Support groups typically separate adolescents based on their disclosure status, creating safe spaces for discussion and peer support (Right to Care, 2018). These findings align with South African disclosure guidelines (National Department of Health, 2016a, 2016b) and WHO recommendations that disclosure should occur before age 12 (WHO, 2011).

Despite these policies, this study confirms that most adolescents remain unaware of their HIV status, echoing findings from Vreeman et al. (2014), Atwiine et al. (2015), and Madiba (2012). These studies consistently report low

rates of full disclosure among children and adolescents on ART in low- to middle-income countries.

#### *Clinic Adherence*

This study confirmed that support group attendance was closely linked to clinic adherence, as both activities usually occurred on the same day. Among participants, 70.5% adhered to clinic appointments, while 28.8% defaulted. However, no significant association was found between disclosure status and adherence,  $\chi^2(1, N = 281) = 0.28, p = .598$ . This suggests that adherence may be driven more by caregiver involvement than by adolescents' knowledge of their status.

#### *Age and Disclosure Status*

The mean age of full disclosure was 13.6 years, significantly higher than the mean age of partially disclosed adolescents ( $M = 11.8$  years,  $SD = 1.51$ ),  $t(279) = 2.14, p < .05$ . This suggests that disclosure is more likely to occur when adolescents are older, even though national and international guidelines recommend disclosure before adolescence (Madiba, 2012; Pinzón-Iregui et al., 2013).

#### *Period on ART and Disclosure*

Adolescents who were fully disclosed had been on ART slightly longer ( $M = 6.1$  years,  $SD = 3.86$ ) compared to those partially disclosed ( $M = 5.6$  years,  $SD = 3.31$ ). This difference was statistically significant,  $t(279) = 2.29, p = .023$ , although the effect size was small. The results suggest that duration on ART has only a minor influence on disclosure.

#### *Viral Load and Disclosure*

Most adolescents (93.6%) had updated viral load records. The mean viral load was 13,292.42 copies/mL ( $SD = 52,641.51$ ), with only 24.7% achieving viral suppression (<20 copies/mL). However, no significant association was found between disclosure status and viral load,  $t(279) = -0.14, p = .886$ . This finding reflects earlier studies highlighting that adolescents may struggle with ART adherence due to developmental, behavioral, and psychosocial challenges, even when fully disclosed (Jaspan et al., 2009; Sawyer et al., 2012; Hanghøj & Boisen, 2014).

WHO (2013) and UNAIDS (2017) also report persistent challenges with viral suppression among South African adolescents, underscoring gaps in long-term treatment adherence and retention in care.

#### *Summary of Comparison with Existing Literature*

The findings of this study are consistent with prior research showing that many adolescents on ART remain unaware of their HIV status (Madiba, 2012; Vreeman et al., 2014; Atwiine et al., 2015). The low disclosure rates highlight ongoing challenges in achieving targets set by South African disclosure guidelines (National Department of Health, 2016a, 2016b).

#### *Implications*

Delayed or partial disclosure may hinder treatment adherence and result in poor health outcomes. The high prevalence of unsuppressed viral loads (75.3%) in this study indicates an urgent need for improved disclosure practices and adolescent-centered support systems. Support groups, in particular, play a crucial role in facilitating disclosure and promoting treatment literacy.

#### *Potential Social and Psychological Consequences*

Delayed disclosure can have negative psychosocial consequences, including isolation, anxiety, and depression, exacerbated by the stigma surrounding HIV. A lack of disclosure may also hinder adolescents' ability to form supportive relationships and engage in healthy behaviours, compromising overall well-being.

#### *Study Limitations*

This study relied on secondary data, which may not reflect the full context of adolescents' disclosure experiences. Convenience sampling further limits generalizability, and qualitative dimensions of disclosure—such as emotional and psychological impacts—were not explored.

#### *Recommendations for Future Research*

Future studies should:

1. Conduct full surveys of ART-enrolled adolescents to verify disclosure records and establish accurate baseline data.
2. Identify barriers that prevent caregivers and healthcare workers from adhering to national disclosure guidelines.
3. Develop and evaluate capacity-building interventions for healthcare workers and caregivers, ensuring alignment with existing guidelines (National Department of Health, 2016b).
4. Explore longitudinal impacts of disclosure on adherence and outcomes.

- Conduct qualitative research into adolescents' experiences of disclosure to capture psychosocial dynamics.

## CONCLUSION

This study found a low prevalence (26.3%) of full HIV status disclosure among young adolescents on ART in South Africa. While disclosure was associated with age and support group attendance, no significant relationship was observed with viral load suppression. This suggests that disclosure alone does not guarantee improved treatment outcomes.

The findings highlight the need for comprehensive interventions combining disclosure with psychosocial support, caregiver training, and structured community-based programmes. School-based initiatives embedded in life-skills or health education curricula may also reduce stigma and support disclosure.

Ultimately, improving disclosure practices is essential for enhancing treatment literacy, autonomy, and adherence among adolescents living with HIV. Policymakers must prioritize caregiver and healthcare worker training, while researchers should continue investigating the long-term effects of early and structured disclosure.

**Ethical Approval:** Ethical clearance was obtained from the University of Johannesburg's Research Ethics Committee (REC-01-63-2018). Permission to access healthcare clinics and the District Health Information System was granted by the Johannesburg Health District Research Committee (DRC Ref: 2018-10-004). The study was registered on the South African National Health Research Database (NHRD Ref. No: GP\_201810\_019).

**Conflicts of Interest:** None declared.

## ORCID iDs:

Mhakakora, T.<sup>1</sup>: Nil identified  
 Mapungwana, P.<sup>1</sup>: <https://orcid.org/0000-0001-7351-9936>  
 Chadyiwa, M.<sup>2</sup>: <https://orcid.org/0000-0001-6263-4402>

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