






RESEARCH ARTICLE

# Predictors and consequences of HIV status disclosure to adolescents living with HIV in Eastern Cape, South Africa: a prospective cohort study

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## Abstract

**Introduction:** The World Health Organization recommends full disclosure of HIV-positive status to adolescents who acquired HIV perinatally (APHIV) by age 12. However, even among adolescents (aged 10–19) already on antiretroviral therapy (ART), disclosure rates are low. Caregivers often report the child being too young and fear of disclosure worsening adolescents' mental health as reasons for non-disclosure. We aimed to identify the predictors of disclosure and the association of disclosure with adherence, viral suppression and mental health outcomes among adolescents in sub-Saharan Africa.

**Methods:** Analyses included three rounds (2014–2018) of data collected among a closed cohort of adolescents living with HIV in Eastern Cape, South Africa. We used logistic regression with respondent random-effects to identify factors associated with disclosure, and assess differences in ART adherence, viral suppression and mental health symptoms between adolescents by disclosure status. We also explored differences in the change in mental health symptoms and adherence between study rounds and disclosure groups with logistic regression.

**Results:** Eight hundred and thirteen APHIV were interviewed at baseline, of whom 769 (94.6%) and 729 (89.7%) were interviewed at the second and third rounds, respectively. The proportion aware of their HIV-positive status increased from 63.1% at the first round to 85.5% by the third round. Older age (adjusted odds ratio [aOR]: 1.27; 1.08–1.48) and living in an urban location (aOR: 2.85; 1.72–4.73) were associated with disclosure between interviews. There was no association between awareness of HIV-positive status and ART adherence, viral suppression or mental health symptoms among all APHIV interviewed. However, among APHIV not aware of their status at baseline, adherence decreased at the second round among those who were disclosed to ( $N = 131$ ) and increased among those not disclosed to ( $N = 151$ ) (interaction aOR: 0.39; 0.19–0.80). There was no significant difference in the change in mental health symptoms between study rounds and disclosure groups.

**Conclusions:** Awareness of HIV-positive status was not associated with higher rates of mental health symptoms, or lower rates of viral suppression among adolescents. Disclosure was not associated with worse mental health. These findings support the recommendation for timely disclosure to APHIV; however, adherence support post-disclosure is important.

**Keywords:** HIV; adolescents; ART adherence; viral suppression; disclosure; mental health

Additional information may be found under the Supporting Information tab of this article.

**Received** 19 November 2021; **Accepted** 26 April 2022

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## 1 | INTRODUCTION

In 2020, there were an estimated 1.75 million adolescents (aged 10–19 years) living with HIV (ALHIV), of whom nearly 90% lived in sub-Saharan Africa (SSA) [1]. Despite declines in the number of new HIV infections among adolescents, increased access to antiretroviral therapy (ART), resulting in improved survival of children with perinatally acquired HIV,

has led to a growing population of adolescents with perinatally acquired HIV (APHIV) [2, 3]. Recent estimates from surveys in Southern African suggest that as many as two-thirds of ALHIV acquired HIV perinatally [2].

Levels of ART adherence, treatment retention and viral suppression are lower among APHIV compared to younger children and adults [4, 5], and evidence for effective interventions to improve these outcomes is sparse [6, 7]. This is likely due

to the complex biological and psychosocial changes associated with adolescence, coupled with challenges of living with HIV. In addition, APHIV experience distinct challenges related to their mode of acquisition of HIV, which further affect their treatment outcomes [5]. Children who acquired HIV perinatally are often not told their HIV-positive status at the time of diagnosis or even ART initiation, with disclosure only later in life often after adolescence. The World Health Organization (WHO) recommends that disclosure occurs at school age (6–12 years), with information provided incrementally from younger ages and full disclosure by age 12 [8]. Adolescents who are aware of their HIV-positive status have been found to report better adherence [9], be more likely to be retained on treatment and more easily access social support compared to those unaware [10–12]. They have also been shown to be more likely to engage in safer sex and have lower rates of mortality [11, 13].

However, a recent systematic review found that the proportion of APHIV who have their HIV diagnosis disclosed to them ranged widely from 9% to 72% [14]. Among APHIV, prevalence of disclosure increased with age [12, 14, 15]. Other factors associated with disclosure include female gender, imminent onset of sexual debut, awareness of caregiver's HIV-positive status and higher levels of caregiver education [12, 16–18]. In contrast, reasons reported by caregivers for non-disclosure include the child's young age, fear of disclosure's negative mental health consequences, risk of stigma if parents' status is unmasked by child and unclear disclosure guidelines [9, 10, 14, 15, 19, 20]. Identifying the predictors of disclosure to APHIV is essential to distinguish sub-groups who may be at increased risk of non-disclosure and require disclosure-focused interventions.

Currently, data are limited on the association between HIV status disclosure and virologic outcomes, with most studies evaluating the relationship between disclosure and ART adherence [9, 21–23]. There is also limited evidence on changes in adherence post-disclosure with most studies assessing cross-sectional relationships between disclosure and adherence. Qualitative studies have reported adolescents experiencing shock and sadness post-disclosure [12, 24]; however, it is unclear if this impacts adherence.

Studies on the effects of disclosure on mental health outcomes among APHIV in SSA have reported conflicting results. Menon et al. found that, among 127 adolescents (11–15 years) on ART in Zambia, those who had not been disclosed to had higher levels of emotional difficulties [25], whereas Vreeman et al. in 2014 found that among 792 children and adolescents (6–14 years) in Western Kenya, rates of depression were higher among those disclosed to [26]. More recently, an intervention to increase rates of disclosure in Kenya which included 285 adolescents (10–14 years) also found higher rates of depression in the intervention (disclosed) arm after 6 months of starting the disclosure intervention [27]. However, there was no difference at 12, 18 and 24 months [27]. Due to paucity of evidence from studies conducted in SSA, current WHO disclosure guidelines were largely informed by studies from high-income countries [8]. These studies, mostly conducted in the United States, found lower levels of depression [28, 29], anxiety [29, 30] and psychological adjustment problems [31, 32] among children or adolescents aware of

their HIV-positive status, compared to those unaware. Though encouraging, these findings may not be generalizable in SSA, where levels of stigma may be higher and access to mental health support lower.

We analysed data from a community-traced cohort study in Eastern Cape, South Africa to (1) identify factors associated with disclosure longitudinally, (2) assess the difference in self-reported ART adherence, viral suppression and mental health symptoms by disclosure status, and (3) explore changes between study rounds in mental health symptoms and ART adherence by disclosure status. These will improve our understanding of this important process for caregivers and health-care providers and determine need for adherence and psychological support through the disclosure process.

## 2 | METHODS

### 2.1 | Study population

The study traced all ALHIV (aged 10–19 at baseline) who had initiated ART from all 52 ART clinics in a large urban, peri-urban and rural district in Eastern Cape, South Africa [33]. Adolescents were identified via paper and computerized records and traced home. At baseline (2014–2015), 1046 ALHIV were recruited, representing 90% of the 1176 patient records identified. These ALHIV were followed-up over a 4-year period for three rounds of data collection (Round 1: 2014–2015, Round 2: 2016–2017 and Round 3: 2017–2018). Quantitative interviews were self-administered using standardized questionnaires on tablet devices. Available viral load data were extracted from participants' clinical records in rounds 1 and 2 and linked to their questionnaire data [33, 34].

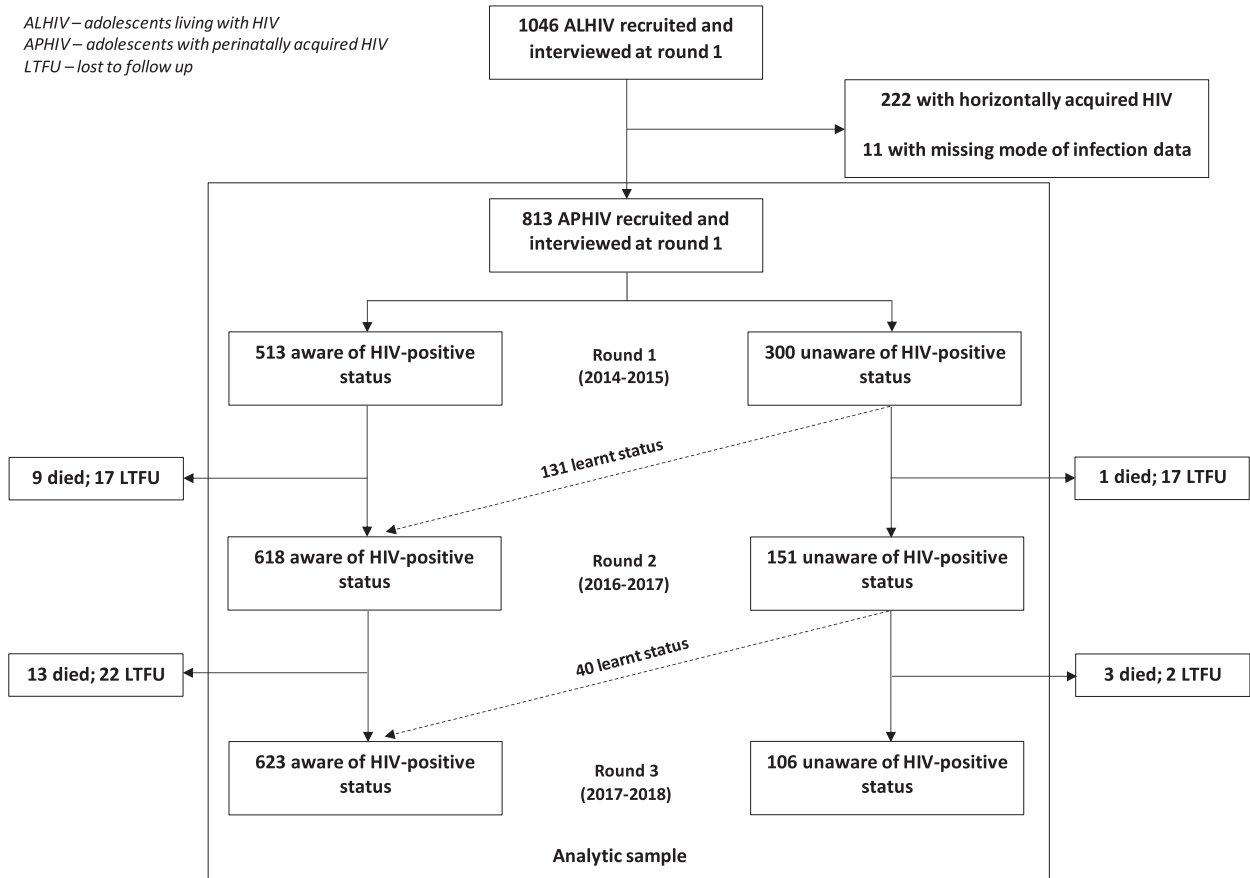
This analysis was restricted to APHIV (Figure 1) determined by ART initiation age  $\leq 10$  years and validated using supporting evidence, such as history of parental death, maternal HIV status and self-reported sexual history [33, 35].

### 2.2 | Study measures

#### 2.2.1 | Outcome variables

The outcome for the first objective was learning one's HIV-positive status (disclosure). Mental health symptomology (anxiety, depression and suicidality) and HIV treatment outcomes (ART adherence and viral suppression) were the outcomes for the second objective, while mental health symptomology and ART adherence were outcomes for the third objective.

At baseline, awareness of HIV status was assessed firstly through clinic records and healthcare worker interviews, and then with primary caregivers during the consent process. In cases of discrepancies, interviewers asked adolescents if they knew what their illness was, if they had ever tested for HIV and if they knew what their medication was [36]. Adolescents were considered fully aware if they reported both knowledge of living with HIV and knowledge of their medication being ART used to treat HIV. For APHIV unaware at baseline, awareness was reassessed at subsequent study rounds from primary caregivers and adolescents during the consent process. Adolescents unaware of their HIV-positive status were asked about "illness" and "medication" as opposed to "HIV"



**Figure 1.** Flow diagram of study and analytic sample.

and “ART” in study questionnaires. Disclosure was defined as being unaware of one’s HIV-positive status at baseline or the second round and being aware at the subsequent study round.

Anxiety symptoms in the past month were assessed using a 14-item abbreviated version of the Children’s Manifest Anxiety Scale-Revised [37]. This scale, which has previously been validated in studies among children living with HIV [38], included “no” and “yes” responses to the experience of each symptom, coded as “0” and “1” with a total score range of 0–14. Depression symptoms in the past 2 weeks were assessed using the Child Depression Inventory (short form) 10-item version [39]. This scale, which has also been used and validated in other SSA populations [40–43], had a 3-point Likert-type scale ranging from 0 to 2 with a total score range of 0–20. Suicidality symptoms in the past months were assessed using the Mini International Psychiatric Interview for Children and Adolescents suicidality and self-harm subscale [44]. This 5-item scale, which has been validated in developed world populations and adapted in SSA settings [45–47], included “no” and “yes” responses to the experience of each symptoms, coded as “0” and “1” with a total score range of 0–5. All symptoms in these measures had equal weight. Due to the small number of participants endorsing the most severe symptoms, we created binary variables for any symptoms versus none on each of three scales.

An adapted version of the standardized Patient Medication Adherence Questionnaire was used to assess self-reported ART adherence in the past week, alongside measures developed in Botswana [48, 49]. Adherence was defined by reporting currently taking ART and not having missed any doses in the past 7 days (including weekdays and weekend) [34]. We included the closest viral load results that were no more than 3 months before or 1 year after the questionnaire interview dates for the respective study rounds. Viral suppression was defined as viral load <1000 copies/ml.

### 2.2.2 | Explanatory and control variables

The main explanatory variable of interest for the mental health and HIV treatment outcomes was awareness of HIV-positive status, as described above. Other control variables were age, age at ART initiation, sex, dwelling type, orphanhood status, relationship with primary caregiver and household poverty. Household poverty was assessed by measuring access to the top eight socially perceived necessities for children as defined by the Centre for South African Social Policy [50]. Adolescents were classified as living in poverty if they reported not having access to all eight necessities. We also included measures of abuse (physical and emotional) and stigma (anticipated and secondary) as control variables. Physical and emotional abuse were measured using items from the

UNICEF Measures for National-level Monitoring of Orphans and Vulnerable Children [51]. Anticipated stigma was measured using two items from the ALHIV-Stigma Scale, which assessed adolescents' views of the community's perception towards HIV and has been used previously among ALHIV in SSA [52]. Secondary stigma due to HIV in families/households was measured using the 6-item Stigma-By-Association scale, which has been validated in South Africa [53]. Adolescents were categorized as having experienced physical or emotional abuse and anticipated or secondary stigma if they self-reported at least one experience of these in the past year.

## 2.3 | Data analyses

Characteristics of study participants overall and by awareness of HIV status in each round were summarized using means, standard deviations, median, interquartile ranges and proportions. Differences between participant characteristics by awareness of HIV status and availability of viral load results at all study rounds were calculated using *t*-tests for continuous variables and chi-square tests for categorical variables.

Second, among APHIV who were unaware of their HIV status at rounds 1 and 2, we used random-intercepts logistic regression to identify factors associated with disclosure between rounds. The outcome was learning one's HIV status at round 2 or 3, and the explanatory variables were demographic, psychological and social factors at the survey prior to disclosure. Individual-level random intercepts were used to account for the repeated observations of the same individuals. Variables identified *a priori* to be associated with disclosure, such as age, age at ART initiation, sex, dwelling location, caregiver relationship and orphanhood status [12, 14, 15, 54, 55], and the study round, were included in a multivariate regression model.

Third, to assess if awareness of HIV-positive status was associated with self-reported ART adherence or poor mental health symptoms, data for all APHIV who were interviewed at any of the three rounds were analysed. Analysis of the association between awareness of HIV-positive status and viral suppression was restricted to APHIV with viral load results. Logistic regression with individual-level random intercepts was used to estimate the odds of ART adherence, viral suppression and reporting any symptom of depression, anxiety and suicidality. We adjusted for potential confounders identified from our conceptual framework and the study round in a multivariate random-intercepts logistic regression model. A sensitivity analysis was conducted using only those interviewed at all three rounds.

Lastly, again among those who were unaware of their HIV status at rounds 1 and 2, we analysed whether there was a differential change in reporting any mental health problems symptom or ART adherence between study rounds for APHIV who were disclosed to versus those who were not. We did not examine the differential change in viral suppression between disclosure groups due to the paucity of viral load results and wide interval between result dates and interviews. We specified the following logistic regression model to estimate if the odds of reporting any anxiety, depression or suicidality symptom, or adherence between study rounds (rounds 1-2 and 2-3), was different between those who learnt their HIV status

and those who did not:

$$\text{logit}(P(Y = 1)) = \beta_0 + \beta_1 \times \text{time} + \beta_2 \times \text{awareness} + \beta_3 \times \text{time} \times \text{awareness} \quad (1)$$

where *Y* represents our mental health outcomes or ART adherence, *time* is a dummy variable indicating round 1 or 2 and *awareness* is a dummy variable indicating awareness of status at round 2.  $\beta_3$  indicates the difference between the log-odds ratio comparing round 1 versus 2 in those who learnt their status at 2 and the log-odds ratio comparing round 1 versus 2 in those who did not. We reported exponentiated  $\beta_3$  estimates (both crude and adjusted for factors hypothesized to be associated with mental health symptoms and adherence from our conceptual framework [Figure S1]). We considered *p*-values  $\leq 0.05$  as statistically significant, and all *p*-values are two-sided. Analyses were conducted in R version 3.6.1 [56].

## 2.4 | Ethical approval

Ethical approval for the study was granted by the Institutional Review Boards at the Universities of Cape Town (CSSR 2013/4) and Oxford (SSD/CUREC2/12-21). Provincial approval was obtained from the Eastern Cape Departments of Education and Health and participating health facilities to conduct the study and access medical records. Written informed consent for the interviews and to access clinical records was obtained from participants and their primary caregivers. Ethical approval for the secondary analyses of study data was obtained from the Imperial College Research Governance and Integrity Team (201C6451).

# 3 | RESULTS

## 3.1 | Summary of participant characteristics

Of 1046 ALHIV recruited and interviewed at baseline, 813 (77.7%) acquired HIV perinatally. Our analyses included the 813 APHIV interviewed at baseline, 769 (94.6%) and 729 (89.7%) interviewed at the second and third rounds, respectively. Seven hundred and twenty-nine were interviewed at all three rounds. The median age of eligible participants was 13, 14 and 15 years at rounds 1, 2 and 3, respectively. The proportion of males and females was nearly equal at all study rounds (Tables 1 and S1). The proportion of APHIV aware of their status increased from 63.1% at baseline to 80.4% at round 2 and 85.5% at round 3. At baseline, 21.9% of adolescents aged  $\geq 12$  years were unaware, compared to 62.2% under 12 years. The proportion of APHIV reporting any symptom of depression, anxiety and suicidality reduced in successive study rounds.

## 3.2 | Predictors of disclosure

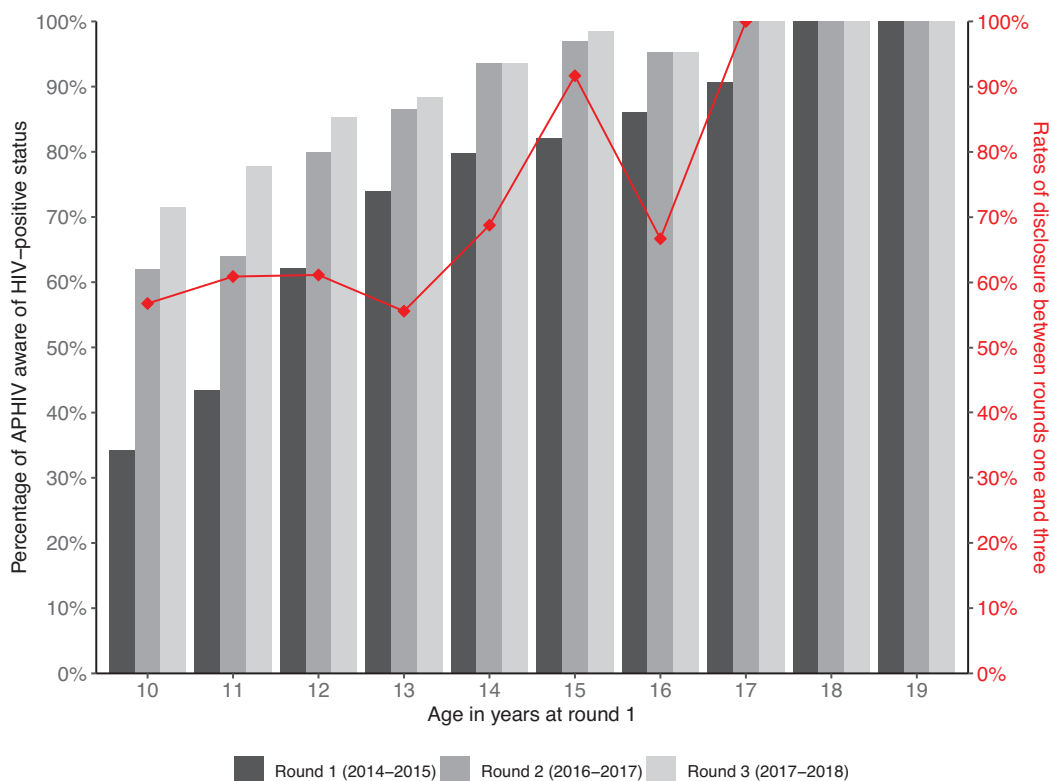
Among the 300 APHIV unaware of their status at baseline, 282 participated in round 2. Among these 282 adolescents, 131 (46.5%) became aware of their status by round 2. Among the 151 adolescents who remained unaware of their status by round 2, 146 participated in round 3, with 40 (27.4%) learning their status. Rates of disclosure were higher among older aged adolescents (Figure 2). In total, 171 APHIV learnt their

**Table 1. Summary of participant characteristics at all three study rounds**

	Study round		
	1 (N = 813)	2 (N = 769)	3 (N = 729)
Age in years, median (IQR)	13 (11–14)	14 (12–16)	15 (13–17)
Age in years at ART initiation, median (IQR)	7 (5–10)	7 (5–10)	7 (5–10)
Female, n (%)	410 (50.4)	390 (50.7)	369 (50.6)
Aware of HIV status, n (%)	513 (63.1)	618 (80.4)	623 (85.5)
<sup>a</sup> Urban dwelling, n (%)	611 (75.2)	581 (75.6)	556 (76.3)
Caregiver biological parent, n (%)	348 (42.8)	296 (38.5)	277 (38.0)
Household poverty, n (%)	531 (65.3)	589 (76.6)	484 (66.4)
Any parental loss, n (%)	502 (61.7)	485 (63.1)	517 (70.9)
Any emotional abuse in last year, n (%)	202 (24.8)	201 (26.1)	138 (18.9)
Any physical abuse in last year, n (%)	261 (32.1)	207 (26.9)	110 (15.1)
Any anticipated stigma reported, n (%)	198 (24.4)	155 (20.2)	115 (15.8)
Any secondary stigma in last year, n (%)	150 (18.5)	63 (8.2)	27 (3.7)
Self-reported past week ART adherence, n (%)	559 (68.8)	517 (67.2)	568 (77.9)
<sup>b</sup> Viral suppression (using results 3 months before, or 1 year after interview), n (%)	331 (81.1)	79.5 (79.5)	97 (82.2)
Any depression symptom in the past 2 weeks, n (%)	352 (43.3)	260 (33.8)	205 (28.1)
Any anxiety symptom in past month, n (%)	505 (62.1)	218 (28.3)	183 (25.1)
Any suicidality risk in past month, n (%)	46 (5.7)	24 (3.1)	24 (3.3)

<sup>a</sup>Type of dwelling data missing for one (0.1%) adolescent at round 2.

<sup>b</sup>Only 408 (50.2%), 331 (43.0%) and 118 (16.2%) adolescents had viral load results within 3 months before or 1 year after their round 1, 2 and 3 interviews, respectively.



**Figure 2. Rates of disclosure:** bars represent the proportion of APHIV aware of their HIV-positive status at each study round by their age at entry into the study (round 1). Red diamonds show the rates of disclosure by age (proportion of adolescents unaware at round 1 who were disclosed to by round 3).

**Table 2. Random-intercepts logistic regression results showing odds of learning HIV-positive status (disclosure) between study rounds 1–2 and 2–3 by demographic and psychosocial factors at the survey prior to disclosure**

Baseline characteristics	Disclosure status mean (SD) or n (%)		Odds ratio (95% CI)	Adjusted odds ratio (95% CI)
	No disclosure n = 111	Disclosure n = 171		
Age	11.2 (1.45)	11.7 (1.84)	1.19 (1.00–1.42)*	1.27 (1.08–1.48)**
Age at ART initiation	6.4 (3.37)	6.6 (3.66)	1.03 (0.96–1.10)	0.97 (0.91–1.04)
Female	54 (48.6)	88 (51.5)	1.23 (0.76–2.01)	1.23 (0.80–1.90)
Urban dwelling	57 (51.4)	130 (76.0)	3.04 (1.72–5.36)***	2.85 (1.72–4.73)***
Caregiver is biological parent	58 (52.3)	80 (46.8)	0.96 (0.60–1.54)	0.85 (0.53–1.35)
Household poverty	77 (69.4)	110 (64.3)	0.72 (0.43–1.18)	0.81 (0.51–1.30)
Any parental loss	53 (47.7)	85 (49.7)	1.50 (0.91–2.47)	1.13 (0.70–1.84)
Any emotional abuse in last year	15 (13.5)	44 (25.7)	1.66 (0.94–2.92)	1.19 (0.69–2.03)
Any physical abuse in last year	35 (31.5)	58 (33.9)	1.10 (0.66–1.81)	0.88 (0.55–1.40)
Any anticipated stigma reported	22 (19.8)	36 (21.1)	1.38 (0.77–2.48)	1.14 (0.68–1.94)
Any secondary stigma in last year	13 (11.7)	29 (17.0)	1.20 (0.60–2.43)	1.00 (0.53–1.88)
Any depression symptom	40 (36.0)	76 (44.4)	1.11 (0.69–1.79)	0.93 (0.59–1.45)
Any anxiety symptom	66 (59.5)	109 (63.7)	1.15 (0.72–1.82)	0.81 (0.50–1.31)
Any suicidality risk	1 (0.9)	10 (5.8)	2.60 (0.62–10.95)	1.80 (0.46–7.11)

Note: All models were adjusted for age, age at ART initiation, sex, dwelling type, caregiver relationship, orphanhood status, anticipated and secondary stigma and study round.

\*\*\* $p \leq 0.001$ .

\*\* $p \leq 0.01$ .

\* $p \leq 0.05$ .

status between study rounds. Factors associated with learning one's HIV-positive status were older age (adjusted odds ratio [aOR]: 1.27, 95% confidence interval [95% CI]: 1.08–1.48) and residing in an urban area (aOR: 2.85, 95% CI: 1.72–4.73) at the previous time point (Table 2).

### 3.3 | Association between awareness of HIV-positive status and ART adherence, viral suppression and mental health symptoms

Among APHIV interviewed at any of the three study rounds, including those who were already aware of their HIV status before the start of the study, there was no association between awareness of HIV-positive status and ART adherence, regardless of the time of disclosure (Table 3).

Among all APHIV interviewed, 50.2% (408 of 813), 43.0% (331 of 769) and 16.2% (118 of 729) had a viral load result within a 3-month period before or 1 year after their first, second and third round interview dates, respectively. The median time from interview dates to viral load results included was 133 days post round 1, 120 days post round 2 and 10 days post round 3. Adolescents without viral load results were older; however, there was no difference in the proportion with viral load results by awareness of status or sex (Table S2). Among those with viral load results, there was no association between awareness of HIV-positive status and viral suppression, regardless of the time of disclosure (Table 3).

There was also no significant association between awareness of HIV-positive status and the odds of reporting a symptom of anxiety, depression or suicidality among APHIV inter-

viewed at any of the three rounds (Table 4). Conclusions were unchanged in the sensitivity analysis restricted to respondents who participated in all three study rounds.

### 3.4 | Differential change in reporting any mental health symptom or ART adherence between study rounds for participants who were disclosed to versus those who were not

Among adolescents not aware of their status at baseline, adherence decreased at the second round among those who were disclosed to ( $N = 131$ ) and increased among those not disclosed to ( $N = 151$ ) (interaction aOR: 0.39, 95% CI: 0.19–0.80). However, there was no significant difference in the odds of reporting any symptom of anxiety, depression and suicidality between rounds 1 and 2 by disclosure groups (Table 5). Among the adolescents ( $N = 40$ ) who learnt their status between rounds 2 and 3, there was no significant difference in the odds of reporting any mental health symptoms or adherence between rounds 2 and 3 by disclosure groups (Table S3).

## 4 | DISCUSSION

Despite WHO recommendations of full disclosure by 12 years of age [8], over one-third (37%) of APHIV in this study were unaware of their HIV-positive status at baseline (22% of those  $\geq 12$  years). But 61% of those unaware learnt their status during the 4-year follow-up period. Older adolescents and



**Table 3. Mixed effects logistic regression results showing crude and adjusted odds ratio and 95% confidence intervals (CIs) for factors associated with self-reporting past week ART adherence and having a suppressed viral load within a 3-month period before or 1 year after interview**

Explanatory variable	Self-reported past week ART adherence (N = 813, 769 and 729 at rounds 1, 2 and 3)		Viral suppression (N = 408, 331 and 118 at rounds 1, 2 and 3) <sup>a</sup>	
	Odds ratio (95% CI)	Adjusted odds ratio (95% CI)	Odds ratio (95% CI)	Adjusted odds ratio (95% CI)
Aware of HIV status	1.05 (0.83–1.32)	1.04 (0.80–1.36)	0.85 (0.22–3.23)	0.90 (0.19–4.27)
<b>Control variables</b>				
Age	1.00 (0.97–1.04)	0.99 (0.93–1.04)	0.90 (0.71–1.15)	0.99 (0.68–1.47)
Age at ART initiation	0.98 (0.95–1.00)	0.97 (0.94–1.00)	0.89 (0.74–1.06)	0.90 (0.71–1.14)
Female	1.05 (0.86–1.29)	1.08 (0.87–1.34)	0.83 (0.22–3.22)	0.95 (0.22–4.04)
Urban dwelling	1.00 (0.79–1.27)	1.09 (0.85–1.40)	1.22 (2.73–5.41)	1.14 (0.23–5.56)
Caregiver is biological parent	0.82 (0.67–1.00)	0.82 (0.65–1.03)	1.86 (0.62–5.56)	2.47 (0.65–9.44)
Household poverty	0.96 (0.78–1.18)	0.94 (0.76–1.17)	0.83 (0.31–2.22)	1.33 (0.45–3.98)
Any parental loss	1.14 (0.92–1.40)	1.07 (0.83–1.37)	1.06 (0.31–3.58)	1.84 (0.41–8.22)
Any emotional abuse in last year	0.51 (0.41–0.63)***	0.62 (0.49–0.80)***	1.77 (0.53–5.94)	1.50 (0.39–5.78)
Any physical abuse in last year	0.55 (0.44–0.68)***	0.69 (0.54–0.88)**	2.24 (0.66–7.54)	2.24 (0.59–8.58)
Any anticipated stigma reported	0.71 (0.56–0.89)**	0.84 (0.66–1.07)	1.41 (0.37–5.42)	1.51 (0.35–6.53)
Any secondary stigma in last year	0.58 (0.43–0.78)***	0.77 (0.56–1.07)	0.40 (0.10–1.53)	0.28 (0.06–1.29)
Round 2	0.93 (0.74–1.15)	0.90 (0.70–1.14)	0.63 (0.25–1.54)	0.65 (0.22–1.96)
Round 3	1.65 (1.30–2.10)***	1.45 (1.09–1.93)**	1.23 (0.34–4.46)***	1.26 (0.24–6.60)***

Note: Viral load results were abstracted from clinic records in 2014–2015 (round 1) and 2016–2017 (round 2) only.

<sup>a</sup>Time from questionnaire interview dates to viral load result, median (IQR): R1: +133 days (+33 to +235 days); R2: +120 days (+16 to +242 days) and R3: +10 days (–32 to +78 days).

\*\*\* $p \leq 0.001$ .

\*\* $p \leq 0.01$ .

those residing in an urban location were more likely to learn their HIV-positive status. Reporting of any poor mental health symptom declined over the cohort rounds, and there was no significant difference in the change in mental health symptoms between adolescents who became aware of their status and those who remained unaware. Adolescents who learnt their status between baseline and the second round were less likely to report adherence post-disclosure compared to those who remained unaware. However, there was no association between awareness of HIV-positive status and ART adherence, viral suppression or symptoms of anxiety, depression or suicidality among all APHIV during the study.

The association between age and disclosure in this study is consistent with results from other studies [12, 14, 15]. Also, our finding of higher odds of disclosure among urban dwelling adolescents is similar to results from a recent study among ALHIV in Tanzania [54]. This may be due to greater awareness of HIV in urban communities and better access to disclosure information in urban health facilities, which may facilitate disclosure.

The lack of evidence of a difference in mental health symptoms disclosure groups is consistent with results from Vreeman et al., who found no difference in rates of depression at 12, 18 and 24 months between disclosure groups in a disclosure intervention in Kenya [27]. These findings may suggest that the emotional and psychological challenges experienced post-disclosure, often a concern

to caregivers, may be short-lived [12, 28]. However, disclosure between surveys in this study was associated with non-adherence in the subsequent survey, but only between rounds 1 and 2. This is similar to results from a recent study among APHIV in Botswana, which found significant declines in ART adherence post-disclosure compared to pre-disclosure, although, the study lacked a non-disclosure comparison group [21]. Non-adherence post-disclosure may be due to the experience of fear, shock, and withdrawal post-disclosure [12, 24] or disclosure may have been precipitated by developing adherence concerns [20]. These findings contrast with positive associations between disclosure and ART adherence previously reported by cross-sectional studies [9, 57] and highlight the potential need for adherence support post-disclosure.

However, it is unclear if non-adherence post-disclosure persists. We found no association between awareness of HIV status and non-adherence among all APHIV in the study. There was also no association between awareness of status and viral suppression. Most studies have been unable to assess the association between HIV status awareness and virologic outcomes, instead relying on self-reported ART adherence, which may be prone to recall or social desirability bias [9, 57]. Our results suggest that disclosure may not be associated with long-term non-adherence [27, 58], and age-appropriate disclosure should be encouraged to support long-term adherence and positive health trajectories.

**Table 4. Random-intercepts logistic regression results showing crude and adjusted odds ratios (OR) and 95% confidence intervals for factors associated with self-reporting a symptom of anxiety within the past month, depression within the past 2 weeks and suicidal ideation within the past month of study interview**

	Anxiety		Depression		Suicidality	
	Odds ratio (95% CI)	Adjusted odds ratio (95% CI)	Odds ratio (95% CI)	Adjusted odds ratio (95% CI)	Odds ratio (95% CI)	Adjusted odds ratio (95% CI)
<b>N = 813, 769 and 729 at rounds 1, 2 and 3</b>						
<b>Explanatory variable</b>						
Aware of HIV status	0.81 (0.66–0.98)*	1.05 (0.81–1.36)	0.93 (0.76–1.15)	0.88 (0.69–1.11)	1.16 (0.44–3.06)	1.62 (0.49–5.37)
<b>Control variables</b>						
Age	0.93 (0.89–0.96)***	1.02 (0.97–1.06)	1.02 (0.98–1.05)	1.07 (1.02–1.11)**	0.98 (0.82–1.17)	1.25 (1.00–1.56)*
Female	1.14 (0.96–1.34)	1.19 (0.98–1.46)	1.00 (0.83–1.19)	0.99 (0.83–1.19)	1.62 (0.58–4.54)	1.63 (0.56–4.74)
Urban dwelling	1.04 (0.86–1.27)	0.94 (0.74–1.19)	1.05 (0.85–1.30)	1.00 (0.81–1.24)	1.34 (0.43–4.15)	0.82 (0.26–2.57)
Caregiver is biological parent	1.04 (0.88–1.23)	0.95 (0.76–1.19)	0.93 (0.78–1.12)	0.93 (0.75–1.14)	0.75 (0.31–1.84)	0.68 (0.24–1.93)
Household poverty	0.83 (0.69–0.99)*	0.94 (0.76–1.16)	1.00 (0.83–1.21)	1.03 (0.85–1.25)	1.47 (0.69–3.16)	1.39 (0.62–3.12)
Any parental loss	0.94 (0.79–1.12)	0.95 (0.75–1.21)	1.03 (0.85–1.24)	0.95 (0.76–1.18)	0.88 (0.34–2.26)	0.75 (0.24–2.32)
Any emotional abuse in last year	2.90 (2.38–3.53)***	2.29 (1.79–2.92)***	2.29 (1.87–2.82)***	1.83 (1.46–2.30)***	5.54 (2.74–11.22)***	2.54 (1.10–5.89)*
Any physical abuse in last year	2.65 (2.18–3.24)***	1.80 (1.42–2.29)***	1.61 (1.32–1.97)***	1.13 (0.90–1.41)	4.66 (2.27–9.57)***	2.49 (1.06–5.85)*
Any anticipated stigma reported	1.92 (1.57–2.36)***	1.43 (1.12–1.82)**	1.79 (1.44–2.21)***	1.37 (1.10–1.71)**	5.05 (2.39–10.70)***	2.73 (1.24–6.04)*
Any secondary stigma in last year	5.56 (4.09–7.55)***	3.22 (2.29–4.55)***	3.53 (2.66–4.67)***	2.46 (1.82–3.31)***	12.73 (5.56–2.92)***	6.58 (2.74–15.84)***
Round 2	0.22 (0.18–0.28)***	0.22 (0.17–0.28)***	0.66 (0.54–0.81)***	0.67 (0.53–0.84)***	0.30 (0.14–0.63)***	0.28 (0.12–0.65)**
Round 3	0.19 (0.15–0.24)***	0.22 (0.17–0.29)***	0.50 (0.40–0.62)***	0.54 (0.42–0.69)***	0.35 (0.17–0.73)**	0.39 (0.15–1.06)

\*\*\* $p \leq 0.001$ .

\*\* $p \leq 0.01$ .

\* $p \leq 0.05$ .



**Table 5. Differential change in the odds of reporting any symptom of anxiety, depression and suicidality or ART adherence between rounds 1 (R1) and 2 (R2), between those who became aware of their HIV status between surveys, versus those remaining unaware of their status**

	n (%)				<sup>a</sup> Differential change estimate (95% CI)	
	No disclosure R1-R2 (n = 151)		Disclosure R1-R2 (n = 131)		Crude	<sup>b</sup> Adjusted
	Round 1	Round 2	Round 1	Round 2		
Anxiety	95 (62.9)	30 (19.9)	80 (61.1)	41 (31.3)	1.99 (0.96–4.13)	2.10 (0.99–4.48)
Depression	58 (38.4)	43 (28.5)	58 (44.3)	44 (33.6)	1.00 (0.50–2.00)	0.99 (0.48–2.02)
<sup>c</sup> Suicidality	4 (2.6)	0 (0.0)	7 (5.3)	5 (3.8)	–	–
ART adherence	94 (62.2)	107 (70.9)	92 (70.2)	77 (58.8)	0.41 (0.20–0.83) <sup>*</sup>	0.39 (0.19–0.80) <sup>*</sup>

<sup>a</sup>The differential change estimate represents the ratio of the odds ratios of reporting any symptom of anxiety, depression and suicidality or ART adherence between rounds 1 and 2 between those who became aware versus those remaining unaware.

<sup>b</sup>Adjusted for age, sex, dwelling location, household poverty, caregiver relationship, orphanhood status, physical and emotional abuse and anticipated and secondary stigma.

<sup>c</sup>Model for suicidality failed to converge due to zero value in cell.

<sup>\*</sup> $p \leq 0.05$ .

Strengths of this study include its large community-traced sample, ability to follow participants over three rounds and the high rates of retention, which enabled analysis of changes in HIV treatment and mental health outcomes. However, our findings should be interpreted considering the following limitations. First, inability to recruit 10% of potentially eligible ALHIV due to misrecorded information, refusal to participate and deaths may have introduced selection bias [36, 59]. Second, awareness of status was taken as a dichotomous variable, failing to account for the evolving nature of disclosure or potential differences in the understanding of full disclosure between adolescents, caregivers and healthcare workers [60]. Some adolescents may have had partial knowledge of their status. Third, most of the study variables were assessed by self-report, including ART adherence, which can be unreliable among adolescents [61]. Even though standardized tools were utilized, there remains potential for social desirability or misclassification bias. Fourth, the viral suppression results should be interpreted in light of the wide interval between interview dates and results, which limits our ability to confirm temporal precedence between disclosure and viral load testing. Also, the paucity of results and significant age differences between the APHIV with results and those without may have biased our results. Lastly, the low prevalence of mental health symptoms meant that we were unable to examine the clinical levels of mental health problems.

## 5 | CONCLUSIONS

Older age and residing in an urban location were factors associated with disclosure among APHIV in Eastern Cape, South Africa. There was no increase in mental health symptoms associated with adolescents learning their HIV-positive status. Adolescents who were aware of their HIV-positive status were also not more likely to have higher rates of mental health symptoms, or lower rates of ART adherence or viral suppression. These findings suggest that disclosure is unlikely to have negative HIV treatment and mental health

outcomes among APHIV and should be encouraged alongside post-disclosure adherence support to enable APHIV take charge of their treatment.

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### COMPETING INTERESTS

The authors declare that they have no competing interests.

### AUTHORS' CONTRIBUTIONS

OE performed the analysis and wrote the first draft of the paper. YS, JWE and LO provided overall supervision and guidance of statistical analysis and contributed to revisions of the manuscript. LC and ET conceptualized the study on which this manuscript is based, were the lead investigators and contributed to revisions of the manuscript. SZ contributed to creating the final study dataset, reconstruction of study variables and revisions of the manuscript. All authors have read and approved the final manuscript.

### ACKNOWLEDGEMENTS

We thank all the young people and their caregiving families who agreed to participate in this study, and the fieldwork team who have shown great dedication and resilience over the years.

### FUNDING

This study was funded by the UK Research and Innovation Global Challenges Research Fund (UKRI GCRF) Accelerate Hub [ES/S008101/1]; UNICEF Eastern and Southern Africa Office, Nuffield Foundation [CPF/41513]; Evidence for HIV Prevention in Southern Africa, a UKAID programme managed by Mott MacDonald; Janssen Pharmaceutica NV part of the Janssen Pharmaceutical Companies of Johnson & Johnson; and the International AIDS Society through the CIPHER grant (155-Hod; 2018/625-TOS); Claude Leon Foundation (08 559/C);

Oak Foundation (R46194/AA001, OFIL-20-057); the John Fell Fund (103/757 and 161/033); the University of Oxford's Economic and Social Research Council Impact Acceleration Account (IAA-MT13-003; 1602-KEA-189; K1311-KEA-004); the Leverhulme Trust (PLP-2014-095); Research England; the European Research Council (ERC) under the European Union's (EU) Seventh Framework Programme (FP7/2007-2013)/ERC grant agreement 313421, the EU's Horizon 2020 research and innovation programme/ERC grant agreement (737476, 771468); the UK Medical Research Council (MRC) and the UK Department for International Development (DFID) under the MRC/DFID Concordat agreement, and by the Department of Health Social Care through its National Institutes of Health Research (MR/R022372/1), Oxford University Clarendon-Green Templeton College Scholarship, the Regional Inter-Agency Task Team for Children Affected by AIDS - Eastern and Southern Africa (RIATT-ESA), the Fogarty International Center, National Institute on Mental Health, National Institutes of Health under Award Number K43TW011434.

OE was funded by Wellcome Trust (reference 222376/Z/21/Z) and the MRC Centre for Global Infectious Disease Analysis (reference MR/R015600/1), jointly funded by the UK Medical Research Council (MRC) and the UK Foreign, Commonwealth & Development Office (FCDO), under the MRC/FCDO Concordat agreement and is also part of the EDCTP2 programme supported by the European Union. YS was supported by DECIPHer and the Wolfson Centre for Young People's Mental Health. DECIPHer is funded by Welsh Government through Health and Care Research Wales. The Wolfson Centre for Young People's Mental Health has been established with support from the Wolfson Foundation. JWE was supported by the National Institute of Allergy and Infectious Disease of the National Institutes of Health under award number R01AI152721. Funders had no role in the study design, data collection and analysis, decision to publish or preparation of the manuscript.

## DISCLAIMER

The content is solely the responsibility of the authors and does not represent the official views of the funders.

## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available for non-profit use upon reasonable request following the data sharing protocols available here: <http://www.mzantsiwakho.org.za/publications>.

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## SUPPORTING INFORMATION

Additional information may be found under the Supporting Information tab for this article:

**Figure S1.** Conceptual framework

**Table S1.** Characteristics of study participants stratified by awareness of their HIV-positive status at the three study rounds

**Table S2.** Differences in demographic variables between individuals with and without viral load results at all study time-points.

**Table S3.** Differential change in the odds of reporting any symptom of anxiety, depression and suicidality or ART adherence between rounds 2 (R2) and 3 (R3), between those who became aware of their HIV status between surveys, versus those remaining unaware of their status.