

'HIV is like a *tsotsi*. ARVs are your guns': associations between HIV-disclosure and adherence to antiretroviral treatment among adolescents in South Africa

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Objectives: WHO guidelines recommend disclosure to HIV-positive children by school age in order to improve antiretroviral therapy (ART) adherence. However, quantitative evidence remains limited for adolescents. This study examines associations between adolescent knowledge of HIV-positive status and ART-adherence in South Africa.

Design: A cross-sectional study of the largest known community-traced sample of HIV-positive adolescents. Six hundred and eighty-four ART-initiated adolescents aged 10–19 years (52% female, 79% perinatally infected) were interviewed.

Methods: In a low-resource health district, all adolescents who had ever initiated ART in a stratified sample of 39 health facilities were identified and traced to 150 communities [$n = 1102$, 351 excluded, 27 deceased, 40 (5.5%) refusals]. Quantitative interviews used standardized questionnaires and clinic records. Quantitative analyses used multivariate logistic regressions, and qualitative analyses used grounded theory for 18 months of interviews, focus groups and participant observations with 64 adolescents, caregivers and healthcare workers.

Results: About 36% of adolescents reported past-week ART nonadherence, and 70% of adolescents knew their status. Adherence was associated with fewer opportunistic infection symptoms [odds ratio (OR) 0.55; 95% CI 0.40–0.76]. Adolescent knowledge of HIV-positive status was associated with higher adherence, independently of all cofactors (OR 2.18; 95% CI 1.47–3.24). Among perinatally infected adolescents who knew their status ($n = 362/540$), disclosure prior to age 12 was associated with higher adherence (OR 2.65; 95% CI 1.34–5.22). Qualitative findings suggested that disclosure was undertaken sensitively in clinical and family settings, but that adults lacked awareness about adolescent understandings of HIV status.

Conclusion: Early and full disclosure is strongly associated with improved adherence amongst ART-initiated adolescents. Disclosure may be an essential tool in improving adolescent adherence and reducing mortality and onwards transmission.

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Introduction

Adolescent adherence to antiretroviral medication remains lower than adult rates in both high [1,2] and lower income settings [3]. Nonadherence leads to morbidity, mortality [4], viral resistance [5] and increased risk of onwards transmission of the virus [6]. The WHO's guidelines for disclosure to HIV-positive adolescents recommend that 'children of school age should be told their HIV positive status' in order to improve health outcomes including adherence [7]. However, these guidelines note that the quantitative evidence-base for linkages between disclosure and adolescent ART adherence remains very limited.

In 2013, a systematic review [8] identified five quantitative studies examining this link, all of which were conducted in single health facilities. In a clinic in India (145 children aged >5 years, mean age 9.1 years), caregivers reported no differences in adherence between disclosed and nondisclosed children [9]. In a clinic in Nigeria (96 children aged 6–14 years, of which 20 were aged over 10 years) [10] and a hospital in Thailand (103 children aged 6–16 years, 41 aged over 10 years) [11], caregivers reported better adherence among disclosed-to children. A study of 96 children in a hospital in Zambia [12] with additional measures of viral load, electronic monitoring and pill-counts found associations between disclosure and improved ART adherence, but only 37 children in the sample were older than 10 years. In a clinic in Ghana (71 children aged 8–14 years, median age 10) [13], there were no associations between disclosure and CD4⁺ cell count. Since this review, a further three studies have been identified, with mixed results. In a hospital in Thailand, 260 children and adolescents aged 6–19 years (228 over 10 years old) showed no associations between HIV disclosure and ART adherence, using measures of pill count, CD4⁺ cell count or viral load [14]. In Nigeria, a study of 213 children (45 over 10 years old) used caregiver or child report and found improved adherence wherein status was known ($P=0.008$) [15]. Lastly, in Kenya, a study of 792 children aged 6–14 years in four 'Academic Model Providing Access to Healthcare' (AMPATH) clinics (339 aged over 10 years) found that disclosure was associated with nonadherence based on child report ($P < 0.03$) [16].

These studies are of great value in the field of adolescent HIV care. However, it is notable that – despite 62% of HIV-positive adolescents living in Southern and Eastern Africa [17] – only two studies with a combined sample size of $N=376$ adolescents come from this region, with only $N=441$ adolescents studied in all African studies combined. In addition, all studies sampled only adolescents attending healthcare facilities, thus excluding adolescents not actively retained in care. This study augments existing evidence by testing associations of adolescent HIV-status disclosure and ART adherence. It uses a large, community-traced adolescent sample in

South Africa that includes those lost-to-follow-up, and intermittent/nonattenders of clinic appointments.

Disclosure is increasingly understood not as a single event, but as a complex and dynamic process [18,19], and can include disclosure of parental HIV-status [20]. This can include 'partial disclosure' wherein a child may know that they have an illness, but not that it is HIV/AIDS. Full disclosure is often described as naming HIV, but research indicates that HIV-positive children or adolescents may not fully understand the meaning of positive serostatus [21]. This study uses a more comprehensive approach: adolescents are defined as being disclosed to if they have been informed that they are HIV-positive ('diagnostic disclosure'), and if they have a basic understanding of HIV and ART [22,23]. Recognizing the complexity of disclosure and in order to identify lessons for programming, this study also qualitatively examines adherence-relevant experiences amongst adolescents whose HIV-positive status has been disclosed to them, as well as healthcare workers and caregivers.

Materials and methods

This study used iterative quantitative and qualitative methods, following recommendations for research approaches of HIV diagnosis among children [7,24]. Qualitative research findings informed the structure and content of quantitative tools, and emerging quantitative trends informed qualitative research topics. Research tools, including questionnaires and interview schedules, were translated, tested and piloted by researchers working on both the quantitative and qualitative components of the study. Analysis and emerging themes were shared on an ongoing basis, informing interdisciplinary findings.

Participants and procedures

The Eastern Cape is South Africa's poorest province, with an antenatal HIV-prevalence of 29.1% [95% confidence interval (95% CI) 27.3–30.9] [25]. In one mixed rural/urban health subdistrict, all public health facilities were visited in 2013, and all clinics that provided ART to more than four adolescents ($n=32$) were identified. Subsequent to this mapping exercise, the national health policy of decentralization of HIV treatment programmes resulted in an increase of the clinic sample ($n=39$ facilities). Within these facilities, all adolescents aged 10–19 years who had ever initiated ART and who had a first or last name and address or village/township recorded were identified. All adolescents were either met at clinics or followed up in their homes, to ensure inclusion regardless of clinic attendance or loss-to-follow-up. Of an initial $n=1102$, 351 were excluded due to mis-recorded age, false names or addresses, or having moved to another province, 40 adolescents or caregivers refused to participate, and 27 adolescents had died. Six hundred and eighty-four ART-initiated adolescents were interviewed.

Voluntary informed consent was obtained from caregivers and adolescents for a 90-min interview (refusal rate 5.5%). Permission to record interviews and focus groups was requested from all qualitative participants. No incentives were provided, but all participants were given a pack containing a snack, toothbrush and toothpaste, and all received a certificate acknowledging participation. To prevent adolescents being identified or stigmatized through participating in HIV-related research, the study was presented as focusing on the needs of adolescents using public health services, and adolescents in neighbouring homes were also interviewed ($n = 259$, not included in these analyses).

Participants for the qualitative study were purposively recruited from the quantitative sample on the basis of consent and availability to participate in in-depth research and reported experience of HIV disclosure and ART initiation. Seventy-two in-depth interviews were conducted with 43 HIV-positive teenagers: twenty-six adolescents were interviewed once (26 interviews), twelve adolescents were interviewed twice (24 interviews), six adolescents were interviewed three times (18 interviews), and one adolescent was interviewed four times (4 interviews). 30 interviews were conducted with 22 caregivers of HIV-positive adolescents: One caregiver was interviewed three times (3 interviews), three caregivers were interviewed twice (six interviews), and 21 caregivers were interviewed once (21 interviews). Four focus groups were conducted with adolescent girls, adolescent boys, adolescent girls and boys combined and caregivers of HIV-positive adolescents. Eighteen months of direct participant observation and healthcare worker interviews were conducted at the family planning, antenatal care, antiretroviral and trauma units of five public health facilities (three hospitals and two health centres).

Questionnaires, interview schedules and consent forms were translated from English into Xhosa, and reviewed subsequent to back-translation. Adolescents participated in the language of their choice. Interviewers were trained in conducting research with HIV-affected adolescents. Confidentiality was maintained, except in cases of significant harm or when participants requested assistance. Where participants reported recent abuse, rape or risk of significant harm, referrals were made to child protection and health services, with follow-up support. Ethical protocols were approved by the Universities of Cape Town and Oxford, the Provincial Departments of Health and Education and ethical review boards of participating hospitals.

Quantitative measures

ART adherence was measured by adolescent self-report [26], using the standardized Patient Medication Adherence Questionnaire [27] and measures developed in Botswana for adolescents for past-week, past-3 days and past-weekend adherence [28]. After piloting in South

Africa, and in order to reduce social desirability bias, vignettes were added that preceded each adherence item, for example 'Andiwe knows he is supposed to take his ARVs every day. Even if he tries his best sometimes unexpected things get in the way and prevent him from taking them . . . This is not his fault'. Nonadherence was measured as any missed dose in the past week, based on a 95% adherence cut-off [29].

Opportunistic infection symptoms associated with non-adherence were measured as sores on the body or face, tuberculosis symptoms (coughing blood and night sweats), shingles and mouth ulcers [30], using a verbal symptom checklist [31], validated in previous studies of adults in South Africa.

Adolescent knowledge of HIV-status was initially assessed from clinic records and healthcare worker report and then checked with primary caregivers in the consent process. However, discrepancies in record-keeping and caregiver report meant that it was essential to check whether adolescents understood their status [32] and to prevent unintentional disclosure through the research process. Adolescents were asked about whether they knew what their illness was, whether they had ever tested for HIV and whether they knew what their medication was for. Those who reported not to know their status were asked about 'illness' and 'medication' instead of 'HIV' and 'ART' throughout.

Potential cofactors included socio-economic and household factors of adolescent age, sex, language, urban/rural location and formal/informal housing, measured using items adapted from the South African census. Household assets were measured using an index of access to the eight highest socially perceived necessities for children, corroborated by more than 80% of the population in the nationally representative SA Social Attitudes Survey [33]. Care-related factors included the relationship of the primary caregiver to the adolescent, and measures of maternal and paternal death using items from a South African national survey of AIDS-affected children [34]. HIV and medication factors included perinatal/horizontal infection, using modelling data from Southern Africa [35]. Adolescents were coded as perinatally infected (during pregnancy, birth or breastfeeding) if they had started ART prior to age 12 or if they had been on treatment for more than 5 years. Daily pill burden was recorded through adolescent-reported pill burden and medication changes in the past year. Healthcare factors included local clinic/hospital care, travel time to the clinic and whether adolescents attended clinic alone or with a caregiver/supporter.

Analyses

Analyses used an iterative approach. Initial qualitative findings identified potentially important themes that were included as cofactors in quantitative analyses. Subsequent

Table 1. Socio-demographic characteristics by HIV-status knowledge.

Factors	Categories	Knows HIV status (n = 480)	Does not know HIV status (n = 201)	Total HIV-positive sample (n = 684)
Sex	Female	259 (73.2)	95 (26.8)	354 (52.0)
	Male	221 (67.6)	106 (32.4)	327 (48.0)
Age	Age in years ^a (mean, SD)	14.12 (2.65)	11.72 (1.83)	13.41 (2.67)
	10–14 years old (mean, SD)	282 (60.6)	183 (39.4)	465 (68.3)
	15–19 years old (mean, SD)	198 (91.7)	18 (8.3)	216 (31.7)
Mode of infection	Perinatal	362 (66.8)	180 (33.2)	542 (79.6)
	Horizontal	118 (84.9)	21 (15.1)	139 (20.4)
Time on treatment	Years on antiretroviral treatment ^a	6.46 (4.56)	5.58 (3.90)	6.20 (4.39)
Residence	Urban	406 (71.6)	161 (28.4)	567 (83.1)
	Rural	74 (64.3)	41 (35.7)	115 (16.8)
Ethnicity	Xhosa	460 (70.2)	195 (19.8)	655 (96.2)
	Other	20 (76.9)	6 (23.1)	26 (3.8)
Housing type	Informal	86 (71.1)	35 (28.9)	121 (17.8)
	Formal	394 (70.4)	166 (29.6)	560 (82.2)
Poverty	Missing any of the basic 8 necessities	327 (72.2)	126 (27.8)	453 (66.2)
Care orphan status	Residing with biological parent	201 (64.8)	108 (34.8)	310 (45.5)
	Maternal orphan	238 (78.0)	66 (21.6)	305 (44.8)
	Paternal orphan	157 (80.1)	38 (19.4)	196 (28.8)
	Double orphan	85 (84.2)	16 (15.8)	101 (14.8)
Healthcare	Hospital care	369 (76.9)	151 (75.1)	520 (76.0)
	Local clinic	111 (23.1)	50 (24.9)	164 (24.0)
Travel time to clinic	Travel time (hours)	.40 (.83)	.29 (.61)	.25 (.43)
	Alone	157 (32.7)	15 (7.5)	173 (25.3)
Clinic attendance	Accompanied	323 (67.3)	186 (92.5)	511 (74.7)
	Two or more	171 (35.6)	72 (35.8)	246 (36.0)
Opportunistic infections	One or less	309 (64.4)	129 (64.2)	438 (64.0)

to this, qualitative analyses investigated themes arising from the quantitative findings. Qualitative interviews were recorded and transcribed in full or (where participants preferred not to be recorded) written notes were taken. Thematic codes were developed from the data, based on the principles of grounded theory [36], and were triangulated through cross-checking with both study participants and researchers on both methodological components of the study.

Quantitative analyses were conducted in three stages in SPSS 22, using the sample of adolescents who had ever initiated ART ($n = 684$). Prior to analyses, socio-demographics were assessed (Table 1). Then, rates of self-reported past-week nonadherence were calculated, and associations with having two or more opportunistic infection symptoms were tested using logistic regressions and controlling for socio-demographics (sex, age, language, location, formal/informal housing and access to necessities) (Table 2).

Second, associations between adolescent knowledge of HIV-positive status and ART-adherence were tested in multivariate hierarchical logistic regressions, following Hosmer and Lemeshow tests [37] (Table 3). In the initial model, all potential predictors and cofactors were included (child age, sex, language, urban/rural location, informal housing, household access to basic necessities, presence of biological caregiver, maternal and paternal orphanhood, perinatal or horizontal infection, pill burden and past-year changes of medication, clinic or

hospital care, travel time to clinic and visiting clinic alone/accompanied). In the second model, all factors associated at p -value less than 0.1 with adherence were included, and in the final model, all factors associated at p -value less than 0.05 were shown.

Third, associations of age of disclosure and ART-adherence were examined for perinatally infected adolescents who knew their status ($n = 362$ of 540 perinatally infected) (Table 4). Horizontally infected adolescents were excluded as the processes of point-of-care testing do not entail family/healthcare worker choice about whether and when to disclose. The WHO guidelines recommend disclosure by the age of 12 for perinatally infected adolescents, and so associations

Table 2. Association of self-reported past-week adherence to concurrent more than two opportunistic symptoms (shingles, mouth ulcers, tuberculosis symptoms).

	Suffering from more than two opportunistic infections Odds ratio (95% CI)
Age	1.02 (0.96–1.09)
Sex	1.08 (0.78–1.50)
Xhosa language	1.08 (0.45–2.56)
Urban location	1.28 (0.84–1.94)
Informal housing	1.00 (0.65–1.55)
Access to basic necessities	0.76 (0.54–1.08)
Past-week full adherence	0.55 (0.40–0.76)***

CI, confidence interval.

*** $P < 0.001$, $P < 0.005$, $P < 0.05$.

Table 3. Associations between HIV status knowledge and self-reported past-week full adherence (full sample).

	Self-reported adherence		
	Model 1 Odds ratio (95% CI)	Model 2 Odds ratio (95% CI)	Model 3 Odds ratio (95% CI)
HIV status knowledge	2.00 (1.33–2.99) ^{***}	2.20 (1.48–3.27) ^{***}	2.18 (1.47–3.24) ^{***}
Age	0.87 (0.79–0.96) [*]	0.86 (0.80–0.92) ^{***}	0.85 (0.80–0.91) ^{***}
Sex	0.95 (0.68–1.33)		
Xhosa language	0.51 (0.18–1.44)		
Urban location	0.92 (0.59–1.44)		
Informal housing	0.98 (0.62–1.54)		
Access to basic necessities	1.40 (0.97–2.01) ^a	1.41 (0.99–2.01)	
Caregiver biological parent	0.91 (0.58–1.42)		
Maternally orphaned	1.15 (0.73–1.81)		
Paternally orphaned	0.80 (0.54–1.16)		
Perinatally infected	1.44 (0.88–2.37)		
5 or more pills per day	1.11 (0.77–1.58)		
Changed medication past year	1.30 (0.92–1.84)		
Travel time to clinic	0.74 (0.59–0.93) [*]	0.72 (0.58–0.89) ^{**}	0.72 (0.57–0.89) ^{**}
Attends clinic alone	1.41 (0.89–2.25)		
Treatment at hospital	1.24 (0.83–1.84)		

CI, confidence interval.

^{*}*P* < 0.05.

^{**}*P* < 0.005.

^{***}*P* < 0.001.

between disclosure under age 12 and adherence were examined in multivariate logistic regression, using the same process and cofactors as on the full sample above.

Results

Socio-demographic factors are summarized in Table 1. Children were 10–19 years old (mean 13.4, SD 2.67), 52% female and 79% perinatally infected. Ninety-six percent of adolescents spoke Xhosa as a first language, and 18% lived in informal 'shack'

housing while the remainder lived in rural traditional or urban formal structures. Sixty-seven percent lacked basic necessities and 45% lived with a biological parent. Maternal/paternal orphanhood was 45 and 29%, respectively, and 15% were double orphans. Seventy percent of ART-initiated adolescents knew their HIV-status.

Self-reported nonadherence in the past week was 36%. Independent of socio-demographics, past-week full adherence was associated with lower likelihood of adolescents experiencing two or more of concurrent

Table 4. Associations between adherence and disclosure aged under 12 for perinatally HIV-infected adolescents who are aware of their status.

	Adherence		
	Model 1 Odds ratio (95% CI)	Model 2 Odds ratio (95% CI)	Model 3 Odds ratio (95%)
Aged under 12 when disclosed	2.65 (1.34–5.22) ^{**}	2.25 (1.18–4.28) [*]	2.07 (1.10–3.87) [*]
Age	0.86 (0.76–0.99) [*]	0.86 (0.76–0.98) [*]	0.91 (0.82–1.02)
Sex	0.87 (0.52–1.44)		
Xhosa language	0.15 (0.02–1.22) [†]	0.16 (0.02–1.27)	
Urban location	1.72 (0.80–3.71)		
Informal housing	1.05 (0.53–2.08)		
Poverty	1.19 (0.69–2.07)		
Caregiver biological parent	1.28 (0.63–2.60)		
Maternally orphaned	1.66 (0.83–3.33)		
Paternally orphaned	0.90 (0.52–1.56)		
Takes more than 5 pills/day	1.29 (0.76–2.20)		
Treatment changed in past year	1.42 (0.86–2.34)		
Travel time to clinic in hours	0.53 (0.38–0.74) ^{***}	0.54 (0.39–0.75) ^{***}	0.54 (0.39–0.73) ^{***}
Attends clinic alone	1.81 (0.95–3.44) [†]	1.88 (0.99–3.53)	
Treatment at hospital	0.81 (0.42–1.55)		

CI, confidence interval.

^{*}*P* < 0.05.

^{**}*P* < 0.005.

^{***}*P* < 0.001.

[†]*P* < 0.1.

shingles, mouth ulcers or tuberculosis symptoms [odds ratio (OR) 0.55; 95% CI 0.40–0.76, $P < 0.001$] (Table 2).

Associations of adolescent knowledge of status to adherence

In the final adjusted model, adolescent knowledge of their HIV-status doubled the odds of past-week full adherence (OR 2.18; 95% CI 1.47–3.24, $P < 0.001$), independent of all cofactors of age, sex, location, ethnicity, informal housing, poverty, biological caregiver relationship, maternal/paternal orphanhood, perinatal infection, medication burden, changes in medication, clinic type, travel time to clinic and lone/accompanied clinic attendance. Full adherence was negatively associated with being older (OR 0.85; 95% CI 0.80–0.91, $P < 0.001$) and longer travel time to the clinic (OR 0.72; 95% CI 0.57–0.89, $P < 0.005$) (Table 3).

Associations of younger-age disclosure to nonadherence

In the final adjusted model, among perinatally infected adolescents who knew their status ($n = 362$), disclosure prior to age 12 was associated with past-week full adherence (OR 2.07; 95% CI 1.34–5.22, $P < .005$), independent of all cofactors of age, sex, location, ethnicity, informal housing, poverty, biological caregiver relationship, maternal/paternal orphanhood, perinatal infection, medication burden, changes in medication, clinic type, travel time to clinic and lone/accompanied clinic attendance. Full adherence was also negatively associated with longer travel time to the clinic (OR 0.54; 95% CI 0.39–0.73, $P < 0.001$) (Table 4).

Qualitative findings identified largely positive experiences of disclosure that may explain associations with higher adherence. In both home and clinic settings, disclosure provided opportunities to ask challenging questions, to express feelings of anxiety, shame and anger, and to improve treatment literacy. Disclosure was often reported as a dialogue, and efforts were made to modify information in accordance with the age, emotional maturity and clinical history of individual children or adolescents. In some healthcare settings, disclosure could also facilitate access to other forms of support such as social grants or support groups.

Many reports of disclosure included locally adapted analogies that healthcare workers used with the aim of explaining the virus and enhancing patient self-efficacy. In the most common of these analogies, healthcare workers described HIV as a *tsotsi* [gangster], the adolescent as a policeman and ART as a weapon: ‘When you drink them [ART], it puts the HIV in jail’, explained a doctor, [direct observation, Hospital X, 2014]. A doctor recounted: ‘At that point I also explain to them that they have a future, and they can live until they are old. They can go to university, and have a car, and have babies, and get married, and do all of the things that they want to

do, as long as they take the ARVs’. In a few cases, strategies to induce fear during disclosure processes were reported to be counter-productive. Where adolescents were threatened with social censure, illness or death should they default from ART, disclosure processes were characterized by anxiety, anger and risks of prompting rebellion through ART defaulting.

Qualitative findings may also help to understand why earlier disclosure was associated with positive outcomes of higher adherence among perinatally infected adolescents. Healthcare workers described earlier disclosure as reducing levels and extent of deception: ‘That’s why I know it’s better if you tell them earlier, at age ten or eleven . . . When we’ve told older children, their reaction is worse . . . Firstly, you’ve lied to them, and they feel very, very hurt by that. And secondly, they are in such a difficult stage of their lives, to add to that, ‘Now you’ve got HIV’, and all the implications of that, it slays them’. [Hospital Y 2014].

However, qualitative findings also indicated that understandings of disclosure may vary between healthcare workers, caregivers and adolescents. For some adolescents, disclosure was only partially understood at first: ‘My grandmother said that I will take these pills until I die, because they are my life. And she said I have HIV. At that time I didn’t understand. I only understood when I was eleven years old . . . I thought she was kidding with me, but I took them anyway because I was sick and I thought the tablets were for my fever’ (14-year old HIV-positive girl, 17 December 2014). Complexities also emerged in the process of undertaking the quantitative research, which identified discrepant perceptions of disclosure. These were primarily cases in which clinics and caregivers reported that adolescents were unaware of their status, but adolescents identified that they were fully aware. For these adolescents, status knowledge had occurred through a range of processes, including ‘googling’ their medication, learning about HIV treatment at school, asking older cousins or siblings and having been told by a previous, now-deceased caregiver.

Discussion

Around 2.1 million adolescents worldwide are currently living with HIV, of which 1.3 million live in Southern and Eastern Africa [17]. Paediatric access to antiretroviral medication in the region is 29%, far behind adult access at 59% [38]. For those adolescents who have access to HIV-treatment, it is essential that they are supported to maintain adherence and thus survive into adulthood [39].

This study provides strong empirical support that full disclosure to adolescents of their HIV-positive status is associated with higher ART adherence. Amongst perinatally infected adolescents, early disclosure prior to age 12 is

associated with further improved adherence. Adherence was associated with reduced opportunistic infection symptoms. It is clear that paediatric disclosure is important, ideally undertaken early, and may be insufficiently utilized as a means to improve treatment outcomes.

Findings also suggest that paediatric disclosure can be done well in a low-resource context and in a range of government health facilities. Qualitative findings report that healthcare workers and caregivers are responsive to the incremental nature of disclosure, and that adolescents may require multiple opportunities to comprehend the meaning of their status. This aligns with HIV literature suggesting that disclosure is a multistage process rather than an event [40] and must adapt for paediatric developmental processes, perhaps especially when accompanied by HIV-related cognitive delays [41]. Disclosure may also need to be sensitive to the caregivers' stages of disclosure of their own HIV-status [23].

These findings add to a mixed but small literature. Of the seven known studies worldwide, only two include samples of over 100 adolescents and find either no associations between disclosure and adherence in Thailand [14] or negative associations in Kenya [16]. However, both studies combined adolescent data with that of children as young as 6, and so adolescent-disaggregated analyses would allow more opportunity for comparison. In three smaller African studies [10,12,15], disclosure was associated with higher adherence. Other studies examine outcomes linked to adherence, such as a recent study in Cote D'Ivoire that found disclosure positively associated with adolescent retention in care [42]. A recent meta-analysis of disclosure to children under age 12 found a 20%, but statistically nonsignificant association with adherence [40].

However, findings, and those of other studies in the region [18], also show inaccurate assumptions about whether and the extent to which disclosure has taken place. Clinic documentation may be unreliable, and caregivers may inaccurately assume that adolescents know or understand their HIV-status. Such confusion may be exacerbated by changes in continuities of care, for instance when adolescents change clinics, transition from paediatric to adult care or change caregivers due to illness or bereavement. Findings additionally suggest that adolescents are not passive recipients of disclosure, but are actively engaging in searches to understand their illness and medication. Very few studies assess the effectiveness of programmes to support the process of paediatric disclosure, although recent encouraging evidence from a South African study of a family-based disclosure intervention for younger children shows increased disclosure, reduced parental and child psychological distress and improved child behavioural outcomes [43,44]. Emerging data from Zimbabwe and South Africa suggest positive adherence and communication impacts of family-based programmes for HIV-positive adolescents [45,46].

This study has a number of limitations. Firstly, although all disclosure had taken place prior to reporting of past-week adherence, the cross-sectional nature of the data limits corroboration of causal pathways. Secondly, only self-reported measures of adherence were available, due to infrequent testing of viral load and CD4⁺ cell count in low-resource health services. Thirdly, some of the qualitative findings, such as potential negative effects of ultimatum-based disclosure, were unable to be substantiated by testing in the quantitative data. And fourthly, of the 1075 living adolescents originally recorded in clinic records, 351 were unable to be traced due to false names or addresses given, or migration. This reflects the challenges facing both HIV-research and HIV-services serving a highly stigmatized and mobile young population. Despite these limitations, this study has notable strengths. It is the largest known study of ART adherence and disclosure among adolescents, and it is the only known study to use community-tracing in order to include adolescents not actively engaged in clinical care. Of 724 adolescent-caregiver dyads approached, refusal rates were very low at 5%. Self-reported adherence was strongly associated with lower rates of multiple opportunistic infection symptoms. Disclosure definitions followed guidelines requiring both naming and basic understanding of HIV [40], and disclosure was assessed sensitively and using multiple sources.

Adolescent adherence to ART remains a major challenge. But adherence is also a gateway to reducing HIV-mortality, preventing onwards transmission and limiting viral resistance. Disclosure of HIV status to children and adolescents may be daunting, particularly for families negotiating stigma, illness and bereavement [47]. But this study shows substantive adherence benefits of HIV-status disclosure to paediatric and adolescent patients. It also shows that disclosure can and does take place well within resource-constrained state health services and family settings. It provides the first empirical testing and strong evidential support of the WHO's recommendations to disclose under the age of twelve. Full, enabling and developmentally appropriate disclosure of their HIV-status to paediatric populations may be a vital tool in promoting adolescent adherence.

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Conflicts of interest

Authors declare no conflict of interest in conducting and publishing this research.

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