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Research Article

Determinants of HIV Status Disclosure to Adolescents in Western Kenya: Developing an Evidence-based Disclosure Guide

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Abstract

HIV status disclosure to adolescents living with Human Immunodeficiency Virus (ALHIV) is essential for adherence to ART treatment and psychosocial well-being yet it remains delayed in high-burden settings. This study examined the rate and timing of HIV status disclosure and identified individual, familial, and socio-cultural determinants influencing HIV status disclosure to adolescents in Western Kenya. A convergent parallel mixed-methods design was used. Quantitative data were collected from 310 caregivers of ALHIV aged 10–19 years attending three health facilities in Bondo Sub-County using structured questionnaires. Qualitative data were obtained through eight focus group discussions (64 caregivers) and 10 key informant interviews with healthcare providers. Quantitative data were analysed using multivariate logistic regression with quadratic age terms, while qualitative data were analysed thematically. Integration was achieved through joint displays and a weaving approach. The HIV status disclosure rate was 74.5%, yet disclosure was delayed in early adolescence: only 1.8% of adolescents aged 10–12 years had been disclosed to, compared with 60.5% of those aged 13–14 years and 96.3% of those aged 15–19 years (mean disclosure age: 11.8 years). Age demonstrated a strong non-linear association with disclosure (quadratic aOR = 0.70, 95% CI: 0.59–0.83; $p < 0.001$). Independent predictors of disclosure included caregiver training the strongest modifiable determinant (aOR = 15.61)—caregiver confidence in discussing HIV (aOR = 2.42), access to adolescent peer support groups (aOR = 3.33), facility of care (aOR = 2.96), and perceived adolescent emotional maturity (aOR = 1.52), while fear of psychological distress emerged as the dominant barrier (aOR = 0.27). Although 34.6% of adolescents experienced initial distress following disclosure, 93.9% demonstrated improved ART adherence and 92.6% improved emotional well-being. Findings showed HIV disclosure decisions depended on caregiver capacity and health system support. In Western Kenya, adolescent disclosure remains delayed beyond guideline recommendations, with age serving as a threshold. Effective disclosure requires alignment between adolescent emotional readiness, caregiver preparedness, and supportive health system structures. An evidence-based disclosure guide was developed comprising three-core components: readiness-based assessment integrated with caregiver capacity building, family-engaged disclosure planning, and health-system enabling with structured post-disclosure support. This framework reconceptualises HIV disclosure from an age-driven expectation to a system-dependent process. There is need to implement structured HIV disclosure approaches that integrate readiness-based assessment, systematic caregiver capacity building, and strengthened adolescent peer support systems. Disclosure should be initiated earlier through individualised, and informed planning. Lastly, trauma-informed post-disclosure follow-up should be embedded within routine care to address initial distress and sustain improvements in adherence and emotional well-being.

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1. Background

The World Health Organisation (WHO) recommends full HIV status disclosure for children living with HIV by early adolescence, viewing it as a developmentally appropriate, staged, and caregiver-supported process, not a single event [1, 2]. Full HIV status disclosure is defined as explicit communication to the adolescent that they are living with HIV, including naming HIV as the illness and explaining the need for lifelong antiretroviral therapy. Partial disclosure, such as referring to medication without naming HIV, was not classified as full disclosure. This approach shifts from age-triggered disclosure to one aligning with a child's cognitive, emotional, and social development. National policies in sub-Saharan Africa, including Kenya's HIV Prevention and Treatment Package for Adolescents and Young People (National AIDS and STI Control Programme-NASCOP) and South Africa's Disclosure Guidelines for Children and Adolescents (NdoH), reinforce the WHO position, emphasising caregiver involvement, gradual information sharing, psychosocial preparation, and post-disclosure support [3, 4]. Operational guidance from the Elizabeth Glaser Pediatric AIDS Foundation (EGPAF) Disclosure Toolkit further translates these principles into programmatic actions: structured readiness assessment, caregiver capacity-building, staged disclosure conversations, and systematic follow-up [5].

These recommendations are grounded in robust evidence that timely, planned, and well-supported HIV disclosure consistently benefits ALHIV. When implemented as a structured process, disclosure improves ART adherence, psychosocial well-being, autonomy, self-efficacy, understanding of lifelong treatment, and transition into adult care [6, 7]. It helps adolescents understand clinic attendance and medication use, reduces confusion, and strengthens engagement with healthcare providers during a critical developmental stage characterised by increasing cognitive and self-management capacity [8]. In contrast, delayed or unsupported disclosure is linked to adverse outcomes. Adolescents who remain unaware of their status, or who experience accidental or poorly managed disclosure, are more likely to report emotional distress, confusion, and reduced trust in caregivers [9]. These patterns are further associated with poor adherence, weakened caregiver–adolescent relationships, and disengagement from care during adolescence, with implications for sustained viral suppression and long-term HIV control in high-burden settings [10].

Closer examination of the evidence highlights several interconnected limitations that constrain the design and scalability of HIV disclosure interventions. A key limitation is the lack of age disaggregation within adolescence, with many studies treating adolescents as a homogeneous group despite clear developmental differences between early, middle, and late adolescence in cognitive capacity, emotional regulation, identity formation, and social context [1, 2]. This obscures important variations in readiness and increases the risk of developmentally inappropriate disclosure, whether premature, delayed, or poorly staged, which may result in psychological distress, misunderstanding, and inadequate coping. Conversely, insufficient preparation in later adolescence leaves older adolescents underprepared for autonomy, relationships, and onward disclosure responsibilities [6, 7]. The absence of developmentally grounded evidence to guide timing and sequencing limits programme effectiveness and scalability [5, 11].

A second limitation is the lack of integrated analysis of caregiver and healthcare provider perspectives. Disclosure is shaped by caregiver beliefs, emotional readiness, and perceived responsibility, alongside provider expectations and system constraints [4, 5]. Few studies examine these dynamics jointly, yet misalignment between caregivers and providers often results in inaction, with caregivers delaying due to fear and providers deferring responsibility. As a result, interventions targeting only one group fail to address these interactive processes and are unlikely to reduce delays [12, 13]. A further gap relates to the evolving understanding of disclosure as a staged, rights-based process extending beyond caregiver–child communication to include adolescents' ongoing decisions about disclosure to peers, partners, and others [1]. However, evidence guiding how health systems should prepare adolescents for onward disclosure remains limited. Adolescents lacking structured psychosocial support are more vulnerable to stigma, rejection, and disengagement from care, particularly when disclosure occurs in social contexts without [6, 9, 10]. Interventions focused solely on initial disclosure, therefore fail to address the broader developmental trajectory of disclosure across adolescence. Another major limitation is the scarcity of context-specific evidence from high-burden settings such as Western Kenya, where disclosure is shaped by cultural norms, caregiving structures, and constrained health systems [9, 14]. Caregiver decision-making is influenced by non-biological caregiving arrangements, gender dynamics, and norms around secrecy, while providers face workload pressures and limited psychosocial resources. Consequently, disclosure is often informal and inconsistent, with limited

standardisation across facilities [9].

Global and national guidelines, though conceptually strong, often assume stable caregiving, trained counsellors, and adequate system capacity, which are frequently absent in routine practice. As a result, recommended practices such as staged disclosure, caregiver preparation, and post-disclosure follow-up are inconsistently implemented, particularly in rural, resource-constrained settings where competing clinical priorities dominate [1, 3]. Without locally grounded evidence that reflects these realities, disclosure policies risk remaining aspirational and poorly aligned with practice, thereby limiting their effectiveness and sustainability [9, 14]. The lack of implementation-ready tools for routine disclosure practice compounds these challenges. Although WHO, EGPAF, and national frameworks define what should be done, they offer limited operational guidance on integrating disclosure into overstretched health systems [1, 3, 5]. Without structured protocols, disclosure is often left to individual caregivers' or providers' discretion, leading to wide variation in timing, quality, and completeness within and across facilities [5]. This creates inequities in care, in which adolescents' access to timely and supportive disclosure depends on facility capacity and individual judgment rather than on standardised systems [1]. Overall, the evidence suggests that implementation failure, rather than the absence of policy guidance, is the main barrier to effective disclosure. Weak operational systems, limited caregiver support, unclear provider roles, and inadequate accountability structures drive practice variability, not disagreement about the importance of disclosure [1, 3, 5].

2. Methods

2.1. Study Design and Theoretical Orientation

This study used a convergent parallel mixed-methods design within a pragmatist paradigm to examine HIV status disclosure among adolescents living with HIV in Western Kenya and inform an evidence-based disclosure guide. This approach was appropriate because disclosure is both a measurable outcome (timing, status awareness) and a complex process influenced by caregiver decisions, adolescent development, stigma, and health system dynamics. The study integrated three complementary components: a quantitative cross-sectional survey of caregivers, qualitative focus group discussions (FGDs) with caregivers, and key informant interviews (KIIs) with healthcare providers, alongside a systematic literature review to contextualise findings. Quantitative and qualitative data were collected concurrently, analysed independently, and integrated at interpretation to explain statistical patterns using contextual insights.

The study was guided by the Disclosure Processes Model, which conceptualises disclosure as a goal-directed behaviour influenced by competing motivations, and a socio-ecological framework that situates disclosure within interacting individual, interpersonal, organisational, community, and policy levels. These frameworks informed study design, variable selection, tool development, and interpretation across individual, familial, sociocultural, and health-system domains.

2.2. Study Setting

The study was conducted in Siaya County, Western Kenya, a region with a high HIV burden, with adult HIV prevalence of 15.6% and 24.8% in Bondo Sub-County [15]. Data were collected from three public health facilities providing comprehensive HIV care, namely Bondo County Hospital, Got Agulu Sub-County Hospital, and Usigu Sub-County Hospital. These facilities serve both rural and peri-urban populations and encompass diverse caregiving and service delivery contexts.

2.3. Participants and Sampling

The quantitative component included primary caregivers of adolescents aged 10–19 years who were receiving ART at selected facilities, including biological parents, grandparents, and other primary guardians. Sample size was determined using Yamane’s formula (5% margin of error) for a population of 972 adolescents, yielding a sample of 282 caregivers. With a 10% allowance for non-response, the final target was 310. Proportional allocation ensured representation across facilities, and systematic random sampling was applied within each site using a sampling interval of three, following a random start. The qualitative component employed purposive maximum variation sampling to capture diverse disclosure experiences. Eight focus group discussions were conducted with 64 caregivers, stratified by disclosure status and adolescent age group, alongside ten key informant interviews with healthcare providers, including nurses, clinical officers, psychosocial counsellors, and a clinical mentor. Sampling was iterative and guided by thematic saturation, which was reached and subsequently confirmed through additional data collection.

2.4. Data Collection

Quantitative data were collected using a structured questionnaire administered via KoboCollect on password-protected tablets in private settings, with interviews lasting 40–50 minutes. The tool comprised six sections covering sociodemographic characteristics, disclosure status and patterns, and individual, familial, and socio-cultural determinants. Built-in validation checks enhanced completeness and consistency. Qualitative data were collected through focus group discussions (60–90 minutes) and key informant interviews (45–60 minutes) using semi-structured guides. Sessions were audio-recorded with consent, transcribed verbatim within 48 hours, translated into English where necessary, and independently verified. Field notes captured contextual details, and member checking was conducted to validate key interpretations. All instruments were pre-tested to enhance clarity, relevance, and cultural appropriateness. The questionnaire was

piloted with 10% (n = 31) of caregivers in non-study facilities, leading to refinements to the wording, response options, and sequencing. The focus group and interview guides were also pre-tested to improve flow, facilitation, and data richness.

2.5. Validity, Reliability, and Trustworthiness

Quantitative validity was established through expert review (S-CVI = 0.92) and supported by exploratory factor analysis (KMO = 0.87; Bartlett's test $p < 0.001$), with factor loadings ranging from 0.62 to 0.89. Internal consistency was high across constructs (Cronbach's $\alpha = 0.87$), and test–retest reliability indicated good stability (ICC = 0.76). Multicollinearity was minimal (Variance Inflation Factor-VIFs < 2.5). Qualitative trustworthiness was ensured through triangulation, member checking, peer debriefing, and an audit trail. Reflexivity was maintained through positionality statements and reflective memos, while transferability was supported by a detailed description of the study context, participants, and service settings.

3. Data Analysis

Quantitative and qualitative data were systematically cleaned prior to analysis to ensure accuracy and completeness. Quantitative data were collected using KoboCollect with built-in validation checks, including skip logic, range limits, and consistency rules. Daily reviews were conducted to verify completeness and plausibility, and discrepancies were corrected where possible. Missing data were minimal (<5%) and assessed as missing completely at random using Little's test; multiple imputation was applied under a missing-at-random assumption. The dataset was de-identified, screened for duplicates and inconsistencies, and analysed using Stata version 19.5.

Descriptive statistics summarised key variables, with continuous data assessed for normality and presented using appropriate measures of central tendency and dispersion, while categorical data were summarised using proportions. Bivariate analysis employed Chi-square or Fisher's exact tests for categorical variables, and t-tests or Mann-Whitney U tests for continuous and ordinal variables. Variables significant at the bivariate level, along with theoretically relevant covariates, were included in multivariable logistic regression, with a quadratic age term to account for non-linearity. Model fit was assessed using standard diagnostics, and results are reported as adjusted odds ratios with 95% confidence intervals.

Qualitative data from interviews and focus group discussions were transcribed verbatim, verified against recordings, translated where necessary, and anonymised. Analysis followed Braun and Clarke's thematic approach using a hybrid inductive-deductive framework in NVivo. Codes were iteratively developed into categories and themes through constant comparison, capturing influences at individual, familial, and structural levels. Rigour was ensured through peer debriefing, intercoder checks, and an audit trail, with saturation reached when no new themes emerged.

Integration was conducted at interpretation using a convergent design, aligning quantitative results with qualitative themes through a weaving approach and joint displays to identify convergence, complementarity, and divergence.

4. Results

Findings are based on three sources: a systematic literature review, quantitative data from 310 caregiver–adolescent dyads, and qualitative data from 10 key informant interviews and eight caregiver focus groups. Quantitative results describe the magnitude, timing, and determinants of HIV status disclosure, while qualitative findings explain observed statistical patterns. This integration enabled triangulation and the identification of underlying disclosure mechanisms.

4.1. Findings from the Systematic Literature Review

Systematic searches were conducted in PubMed, Scopus, Web of Science, Google Scholar, and ProQuest, following PRISMA guidelines. Of 1,247 identified records, 412 duplicates were removed, leaving 835 for title and abstract screening. After excluding 523 records, 312 full-text articles were assessed for eligibility, yielding 156 peer-reviewed studies that met the inclusion criteria. An additional 43 literature sources (policy documents, technical reports, and guidelines) were reviewed to contextualise findings. Evidence (Table 1) is concentrated in sub-Saharan Africa, particularly Kenya (Western Kenya), reflecting regional research priorities. Study designs included cross-sectional quantitative (33.3%), qualitative (30.8%), mixed methods (19.9%), cohort/longitudinal (9.6%), and systematic reviews (6.4%). Quality appraisal found 82% high-quality, 15% moderate, and 3% low-quality studies, supporting the evidence base's robustness.

Table 1. *Geographic Distribution of Included Studies.*

Region/Country	Number of Studies	Percentage
Kenya (Total)	58	37.2%
Western Kenya	31	19.9%
Other Kenyan regions	27	17.3%

Region/Country	Number of Studies	Percentage
Uganda	24	15.4%
Tanzania	19	12.2%
South Africa	22	14.1%
Other Sub-Saharan African countries	33	21.1%
Total	156	100%

HIV disclosure rates varied widely (21–78%) across 52 studies. Age-stratified analysis (28 studies) showed significantly higher disclosure among older adolescents (58.7% for 15–19 years vs. 32.4% for 10–14 years; OR = 2.46, 95% CI: 1.98–3.05). Mean disclosure age ranged from 9.8 to 14.2 years, with most disclosures occurring in early to mid-adolescence rather than childhood. Only 18.3% of adolescents learned their status before age 10; 34.2% at 10–12, 29.7% at 13–15, and 17.8% after 15. Gender was not significantly associated with disclosure (female 46.1% vs male 43.2%; OR=1.12, 95% CI: 0.98–1.28). Disclosure rates (Table 2) varied by country and region, reflecting contextual differences in health systems, caregiving environments, and disclosure practices.

Table 2. *Pooled Disclosure Rates by Country/Region.*

Country/Region	Pooled Disclosure Rate	Range	Number of Studies
Kenya (national)	46.3%	28–72%	18
Western Kenya	41.7%	20–60%	12
Uganda	43.2%	25–68%	15
Tanzania	39.8%	21–58%	12
South Africa	52.4%	35–78%	14
Other SSA countries	44.6%	24–71%	21

Disclosure depended on individual, caregiver, sociocultural, and health system factors. Adolescent age was the most consistent individual predictor. Key caregiver factors included biological parent status (aOR=3.42, 95% CI: 2.18–5.36), married or cohabiting status (aOR=2.89, 95% CI: 1.76–4.75), secondary education or higher (aOR=2.14, 95% CI: 1.52–3.01), disclosure training receipt (aOR=8.76, 95% CI: 4.32–17.75), and HIV knowledge (aOR=3.67, 95% CI: 2.21–6.09). Disclosure was also associated with ART adherence (OR=1.88, 95% CI: 1.45–2.44), viral suppression (OR=1.72, 95% CI: 1.31–2.26), and retention in care (OR=1.64, 95% CI: 1.22–2.20).

Evidence gaps include limited context-specific research in Western Kenya; few studies integrating adolescent, caregiver, and provider perspectives; limited longitudinal evidence; insufficient focus on mental health integration; lack of standardised readiness assessment tools; and underexplored areas like adolescent-initiated onward disclosure and its implications for differentiated service delivery.

4.2. Primary Study Participants

The quantitative component comprised 310 caregiver-adolescent dyads from three public health facilities. Most participants were from Bondo County Hospital (72.9%), with Got Agulu Sub County Hospital and Usigu Sub County Hospital each contributing just over 13%. This distribution reflects facility patient loads and ensures representation across rural and peri-urban settings. Caregiver age was normally distributed, with most aged 40 to 60 years, primarily middle-aged parents and grandparents. Adolescents ranged from 10 to 19 years, with a higher proportion in the older age groups. Psychometric evaluation confirmed the instrument's suitability. Exploratory factor analysis indicated adequate sampling (KMO = 0.87) and a significant Bartlett's test ($\chi^2 = 1847.63$, df = 190, $p < 0.001$), with factor loadings ranging from 0.62 to 0.89 across determinants. Internal consistency was high (Cronbach's α: 0.87, 0.84, 0.81, respectively). Test-retest reliability among 10% of participants (n = 31) showed good stability (ICC = 0.76, 95%

CI: 0.65 to 0.84), with Cohen's kappa ranging from 0.62 to 0.71.

The qualitative component included 10 KIIs with healthcare providers and eight FGDs with 64 caregivers of ALHIV. The sample captured diverse perspectives on caregiving and the health system. Key informants comprised three psychosocial counsellors, three clinical officers, three nurses, and one clinical mentor, all drawn from the study facilities. Gender distribution was equal. FGD results showed that among caregivers of disclosed adolescents (n=32), biological mothers comprised 62.5% (n=20), followed by grandmothers (18.8%, n=6), biological fathers (12.5%, n=4), and other relatives (6.2%, n=2). A similar pattern was observed among non-disclosed groups (n=32): biological mothers (68.8%, n=22), grandmothers (15.6%, n=5), biological fathers (9.4%, n=3), and other relatives (6.2%, n=2). Caregivers living with HIV were more common in the disclosed group, 78.1% (n=25), compared to 62.5% (n=20) in the non-disclosed group. Inter-coder reliability was assessed by independently coding 20% of transcripts, achieving 86% agreement. Discrepancies were resolved through consensus. Five themes emerged. Disclosure was largely delayed and reactive, often triggered by illness or adolescent questioning. Decisions were guided by perceived emotional readiness rather than age. Caregiver capacity and confidence influenced disclosure, with limited knowledge and training contributing to delays.

4.3. Rate and Timing of HIV Status Disclosure to Adolescents Living with HIV

Of 310 adolescents (10–19 years), 74.5% (n=231) had been informed of their HIV-positive status, while 25.5% (n=79) had not (Table 3).

Table 3. *Overall Disclosure Rate.*

Disclosure status	Frequency	Percent
No	79	25.5
Yes	231	74.5
Total	310	100

Disclosure increased non-linearly with age (Table 4): 1.8% (n=1) for 10–12 years, 60.5% (n=23) for 13–14 years, and 96.3% (n=207) for 15–19 years.

Table 4. *HIV status disclosure by adolescent age group.*

Disclosure Status	10-12yr	13-14yr	15-19yr	Total
No	56 (98.2%)	15 (39.5%)	8 (3.7%)	79 (25.5%)
Yes	1 (1.8%)	23 (60.5%)	207 (96.3%)	231 (74.5%)
Total	57	38	215	310

Of 231 adolescents who received disclosure, 16.9% (n=39) were disclosed to before age 10, 42.0% (n=97) between ages 10–12, 38.1% (n=88) between ages 13–15, and 3.0% (n=7) after age 15. The mean age at disclosure was 11.8 years. Qualitative findings indicated disclosure was delayed, inconsistent, and frequently reactive rather than planned. Healthcare providers reported disclosure in early adolescence was uncommon:

"*It is the exception. Most adolescents do not access HIV testing regularly as recommended in NASCOP guidelines*." — R1, Clinical Mentor.

"*I'd say it's an exception; most adolescents don't know their HIV status, and when they do, it's often late during their early emerging adult years*." — R2, Clinical Officer.

Caregivers reported that disclosure often occurred in response to specific triggers rather than as a structured process:

"*Many of us end up revealing by accident or when they start asking… it is not a planned process*." — FGD1, Caregiver.

Healthcare providers further indicated that delayed disclosure resulted in unintended discovery:

"*When the appropriate time for full disclosure is missed, many adolescents end up discovering their HIV status on their own*." — R6, Clinical Officer.

Caregivers described sustained non-disclosure into late adolescence:

"*She is 17… she keeps asking why she takes medicine every day… I know she suspects*." — FGD7, Caregiver.

Health worker involvement was identified as a facilitator of disclosure:

"*The nurse told me it was time… she sat with me and explained how to do it step by step."* — FGD2, Caregiver.

Only 1 (1.8%) of 57 adolescents aged 10–12 years had been disclosed to, a rate significantly lower than national guideline recommendations. Both quantitative and qualitative findings showed low disclosure in early adolescence and near-universal disclosure in late adolescence, predominantly through delayed and reactive processes.

4.4. Individual, Familial, and Socio-cultural Determinants of HIV Status Disclosure Among Adolescents

As shown in Table 5, caregiver demographic characteristics were associated with HIV status disclosure. Older caregivers (mean age 45 years) disclosed more often ($p < 0.001$). Disclosure rates varied by marital status ($p = 0.002$): married or cohabiting (78%), single (61%), divorced (53%), widowed (86%), and separated (57%). Caregiver gender, education, religion, and occupation were not significantly associated with disclosure ($p > 0.05$).

Table 5. *Caregiver Demographics by Disclosure Status.*

Variable	Disclosure status (yes,%)	P value	Chi, (t-test)
Caregiver demographics			
Gender (Female)	184 (74%)	0.794	0.0679
Age in years- [mean, range]	45 [20-76]	<0.001	t = -5.1982
Marital Status			
Single	30 (61%)		
Married/Cohabiting	120 (78%)		
Divorced	8 (53%)	0.002	17.2402
Widowed	61 (86%)		
Separated	12 (57%)		
Level of education			
None	20 (77%)		
Primary	119 (76%)		
Secondary	69 (73%)	0.853	1.0476**
College/Tertiary	22 (73%)		
University	1 (50%)		
Religion			
Christian	229 (74%)	0.555	0.6884**
Muslim	2 (100%)		
Occupation			
None	12 (75%)		
Farming	94 (77%)		
Employed	34 (79%)	7.932	0.094
Business	73 (76%)		
Others	18 (54%)		

** Fishers Exact Test

HIV status disclosure was significantly associated with adolescent characteristics (Table 6). Disclosure increased with age, from 1.8% (n = 1) at 10–12 years, to 60.5% (n = 23) at 13–14 years, and 96.3% (n = 207) at 15–19 years ($p < 0.001$). Education level showed a similar pattern: secondary school adolescents had significantly higher disclosure rates (99%, n = 174) than primary school adolescents (44%, n = 57) ($p < 0.001$). In contrast, sex was not significantly associated with disclosure status ($p = 0.715$).

Table 6. Adolescent Demographics by Disclosure Status.

Variable	Disclosure (yes,%)	P value	Chi
Sex			
Female	137 (75%)	Ref	Ref
Male	94 (73%)	0.715	0.1336
Age in years			
10-12	1 (1.8%)		
13-14	23 (60.5%)	<0.001	216.45
15-19	207 (96.3)		
Level of education			
Primary	57 (44%)		
Secondary	174 (99%)	<0.001	136.2102
None	0 (0%)		
Received formal education			
Yes	200 (97%)		
Not sure	21 (51%)	<0.001	185.9349
No	10 (16%)		

Among adolescents who had been disclosed to (n = 231), as shown in Table 7, caregivers were the primary disclosers (71.4%, n = 165), followed by healthcare providers (24.7%, n = 57), adolescents' self-disclosure (3.5%, n = 8), and others (0.4%, n = 1).

Table 7. Individual Responsible for Disclosure of HIV-Positive Status.

Who disclosed HIV status?	Frequency	Percent
Caregiver	165	71.4
Discovered on their own	8	3.5
Healthcare Provider	57	24.7
Others	1	0.4
Total	231	100

One-on-one disclosure with a caregiver was the most common method, at 69.7% (n = 161), followed by one-on-one disclosure by healthcare providers at 20.8% (n = 48). Group counselling accounted for 8.2% (n = 19), while other methods accounted for 1.3% (n = 3).

Among caregivers of adolescents who had not been disclosed to (n = 79), the most frequently reported reason was that the adolescent was considered too young, at 50.6% (n = 40). Fear of stigma was reported by 22.8% (n = 18), while fear of emotional distress and lack of knowledge were each reported by 12.7% (n = 10). Other reasons accounted for 1.2% (n = 1), as shown in Table 8.

Table 8. Reasons for Non-Disclosure of HIV Status.

Reason	Frequency	Percent
Fear of emotional distress	10	12.7
Fear of stigma	18	22.8
Lack of knowledge	10	12.7
Other	1	1.2
Too young	40	50.6
Total	79	100

Caregivers' intention to disclose varied, with 39.2% (n = 31) unsure of timing. This was followed by 24.1% (n = 19) who intended to disclose within one year, 19.0% (n = 15) after one year, 15.2% (n = 12) within six months, and 2.5% (n = 2) reporting no intention to disclose. Bivariate analysis of Likert-scale determinants revealed significant differences between disclosing and non-disclosing caregivers for six of eight variables ($p<0.05$; Table 9). Non-disclosing caregivers had higher median scores on "Adolescent's age influences my decision to disclose" ($p < 0.001$), "My emotional readiness affects my decision to disclose" ($p = 0.002$), and "Community stigma discourages me from disclosing" ($p = 0.014$). Conversely, disclosing caregivers scored significantly higher on "I feel confident discussing HIV with the adolescent" and "How emotionally mature do you believe the adolescent is?" (both $p < 0.001$). No significant association was found for "Adolescents' perceived maturity influences my decision to disclose," "Family members' opinions influence my decision to disclose," and "Cultural beliefs influence my decision to disclose" ($p > 0.05$).

Table 9. Mann–Whitney U Test Results for Determinants.

Variable	Median (IQR)-Disclosed No (n=79)	Median (IQR)-Disclosed Yes (n=231)	Mean rank (No)	Mean rank (Yes)	Mann-Whitney U	Z	p-value
Adolescent's age influences my decision to disclose	4 (4-5)	4 (2-4)	189.5	143.9	6440	4.186	<0.001

Variable	Median (IQR)-Disclosed No (n=79)	Median (IQR)-Disclosed Yes (n=231)	Mean rank (No)	Mean rank (Yes)	Mann-Whitney U	Z	p-value
Adolescent's perceived maturity influences my decision to disclose	4 (2-4)	4 (2-4)	162.8	153	8552	0.885	0.376
I feel confident discussing HIV with adolescent	2 (2-4)	4 (3-4)	104.6	172.9	5100	-6.225	<0.001
My emotional readiness affects my decision to disclose	4 (3-4)	4 (2-4)	179.9	147.2	7196	3.038	0.002
Family members' opinions influence my decision to disclose	3 (2-4)	3 (2-4)	164.8	152.3	8393	1.115	0.265
Community stigma discourages me from disclosing	4 (3-4)	3 (2-4)	175.6	148.6	7536	2.456	0.014
Cultural beliefs influence my decision to disclose	3 (2-4)	3 (2-4)	153.4	156.2	8960	-0.249	0.803
How emotionally mature do you believe adolescent is?	2 (1-3)	5 (4-5)	97.5	175.3	4546	-6.96	<0.001

Bivariate Analysis of Categorical Determinants

Categorical determinants of HIV disclosure were assessed using Chi-square and Fisher's exact tests, as appropriate. As shown in Table 10, several variables were significantly associated with disclosure status. Caregivers who disclosed were more likely to report adolescents asking about illness or medication (84.0%, n=194, vs. 64.6%, n=51; $p < 0.001$). Disclosure was also associated with the belief that it improves ART adherence (92.2%, n=213, vs. 68.4%, n=54; $p < 0.001$). Other significant associations included perceived risk of transmission ($p = 0.013$), perceived rejection ($p = 0.002$), and perceptions of secrecy ($p = 0.018$).

Table 10. *Chi-square and Fisher's Exact Tests for Categorical Determinants of Disclosure.*

Variable	Disclosed = No (n=79)	Disclosed = Yes (n=231)	Total	P-value
Has adolescent asked about their illness/medication?				
No	26 (32.9%)	37 (16.0%)	63	
Not Sure	2 (2.5%)	0 (0.0%)	2	**<0.001
Yes	51 (64.6%)	194 (84.0%)	245	
Do you believe disclosure would improve adolescent ART adherence?				
No	3 (3.8%)	11 (4.8%)	14	
Not Sure	22 (27.8%)	7 (3.0%)	29	<0.001
Yes	54 (68.4%)	213 (92.2%)	267	
Do you believe adolescent might infect others if not informed?				
No	20 (25.3%)	62 (26.8%)	82	
Not Sure	17 (21.5%)	21 (9.1%)	38	0.013
Yes	42 (53.2%)	148 (64.1%)	190	
Do you believe adolescent would face rejection if disclosed?				
No	23 (29.1%)	117 (50.6%)	140	0.002
Not Sure	14 (17.7%)	21 (9.1%)	35	

Variable	Disclosed = No (n=79)	Disclosed = Yes (n=231)	Total	P-value
Yes	42 (53.2%)	93 (40.3%)	135	
How do you feel about keeping adolescent's HIV status secret?				
Comfortable	52 (65.8%)	110 (47.6%)	162	
Not Sure	11 (13.9%)	56 (24.2%)	67	0.018
Tired	16 (20.3%)	65 (28.1%)	81	

** Fishers exact test

A multivariate logistic regression model, including variables significant at the bivariate level ($p < 0.05$) and a quadratic term for age due to its observed non-linear relationship, was fitted to identify independent predictors of HIV disclosure (Table 11). Age showed a strong non-linear effect (quadratic term OR=0.70, 95% CI: 0.59–0.83, p<0.001). After adjusting for all other variables, caregivers' confidence in discussing HIV with the adolescent remained a significant independent predictor: each one-point increase on the Likert scale more than doubled the odds of disclosure (adjusted OR=2.42, 95% CI: 1.31–4.47, p=0.005). Perceived emotional maturity of the adolescent was also independently associated with disclosure (adjusted OR = 1.52; 95% CI, 1.00–2.29; p = 0.048). None of the other ordinal Likert variables (adolescent's age influences the decision, emotional readiness, community stigma) nor any of the categorical belief variables (adolescent asked about illness, beliefs about ART adherence, infecting others, rejection, secrecy) reached statistical significance in the adjusted model (all p>0.05).

Model Fit: The model was significant ($\chi^2(16) = 259.74$, $p < 0.001$), explaining 75.0% of the variance (Pseudo $R^2 = 0.75$). Calibration was adequate (Hosmer-Lemeshow: $\chi^2(8) = 9.47$, $p = 0.305$), and discrimination was excellent (AUC = 0.942, 95% CI: 0.918–0.966).

Table 11. *Multivariate Logistic Regression for Determinants of Disclosure.*

Predictor	Adjusted odds ratio	95% CI	p-value
Age (centred at mean ≈ 15.4 years)			
Age (centred)	3.63	2.29 - 5.76	<0.001
Age ²(centred)	0.70	0.59 – 0.83	<0.001
Ordinal Likert variables (per 1-point increase)			
Adolescent's age influences my decision to disclose	1.15	0.62 – 2.12	0.662
Confidence discussing HIV with adolescent	2.42	1.31 – 4.47	0.005
My emotional readiness affects my decision	1.02	0.52 – 2.04	0.944
Community stigma discourages me from disclosing	0.69	0.37 – 1.28	0.236
Perceived emotional maturity of adolescent	1.52	1.00 – 2.29	0.048
Categorical variables (reference = "No")			
Adolescent asked about illness (Yes vs No)	0.98	0.19 – 5.11	0.976
Disclosure improves ART adherence (Not Sure vs No)	0.14	0.004 – 4.93	0.276
Disclosure improves ART adherence (Yes vs No)	0.49	0.03 – 7.40	0.603
Adolescent might infect others (Not Sure vs No)	0.56	0.06 – 5.39	0.617
Adolescent might infect others (Yes vs No)	1.82	0.39 – 8.51	0.444
Adolescent would face rejection (Not Sure vs No)	0.2	0.03 – 1.26	0.088
Adolescent would face rejection (Yes vs No)	0.82	0.20 – 3.44	0.788
Feeling about keeping status secret (Not Sure vs Comfortable)	0.64	0.12 – 3.45	0.601

Predictor	Adjusted odds ratio	95% CI	p-value
Feeling about keeping status secret (Tired vs Comfortable)	2.3	0.37 – 14.24	0.37

Qualitative findings indicated that emotional maturity was viewed as the true gatekeeper of disclosure, with readiness not determined purely by age but by the adolescent's emotional maturity, curiosity about their health, and ability to understand illness and treatment.

"Readiness for disclosure is not determined purely by age, but more by the adolescent's level of emotional maturity, curiosity about their health, and ability to understand illness and treatment." — R4, Psychosocial Counsellor.

Caregivers highlighted variation in readiness,

"By 10 or 11 they need to know… my son understood more than I thought." — FGD1, Caregiver, while others expressed concern over sensitivity, "He is still very sensitive… I fear he may not handle it well." — FGD2, Caregiver.

Caregiver experiences reflected guilt, confidence, and responsibility as key influences on disclosure decisions.

"Every time I look at her, I see my mistake… she will hate me forever." — FGD4, Caregiver. Some reported shared coping and improved acceptance, "My husband and I did it together… that unity helped her accept." — FGD3, Caregiver, while others described sole responsibility in disclosure, "Now I must deliver this painful news about her mother." — FGD5, Grandmother Caregiver.

At the socio-cultural level, stigma and cultural beliefs constrained disclosure.

"Families fear being judged, discriminated against, or socially isolated if the adolescent's status becomes known." — R4, Psychosocial Counsellor. Social exclusion was also reported: "Some neighbours do not allow their children to play with her child because of the child's HIV status." — R6, Clinical Officer, alongside beliefs linking HIV to supernatural causes: "There are beliefs that HIV infection is a result of curses and that there's a cure through faith and prayers." — R1, Clinical Mentor.

Caregiver confidence (aOR = 2.42, p = 0.005) and perceived adolescent emotional maturity (aOR = 1.52, p = 0.048) were significantly associated with disclosure, leading to the rejection of the null hypothesis. Both quantitative and qualitative findings consistently linked these factors to disclosure, while sociocultural factors influenced disclosure indirectly through caregivers' perceptions and fear.

5. Discussion

5.1. Rate and Timing of HIV Status Disclosure

The rate and timing of HIV status disclosure among adolescents aged 10–19 years showed a high overall disclosure rate of 74.5%, exceeding pooled estimates for Western Kenya and national estimates of 41.7% and 46.3%, respectively [16-18]. However, age-disaggregated analysis revealed substantial delays in early adolescence, with only 1.8% of adolescents aged 10–12 years disclosed to, compared with 60.5% among those aged 13–14 years and 96.3% among those aged 15–19 years. Among those disclosed, the mean age at disclosure was 11.8 years, yet only 16.9% had been disclosed before age 10, indicating misalignment with guidelines recommending disclosure by age 12 and supporting rejection of the null hypothesis [1, 3, 19, 20]. These findings are consistent with regional evidence showing delayed disclosure across East and Southern Africa. Similar patterns have been reported in Uganda, where disclosure among younger adolescents remains low and is associated with psychosocial challenges, and in South Africa, where disclosure increases with age but often remains delayed beyond recommended timelines [10, 21, 22]. The present study extends this evidence by demonstrating that strict classification of full disclosure accentuates delays in early adolescence, suggesting that failure to distinguish between partial and full disclosure may overestimate coverage [23].

The findings align with the Disclosure Processes Model, which conceptualises disclosure as a decision shaped by competing motivations [24]. In this study, avoidance motivations, including fear of psychological harm, stigma, and blame, were particularly evident among caregivers of younger adolescents. Despite these concerns, reported post-disclosure outcomes indicated improved adherence and emotional well-being, consistent with evidence linking disclosure to better treatment engagement and psychosocial adjustment [6, 7]. This contrast reflects a recognised perception gap, where anticipated harms exceed observed outcomes, and aligns with longitudinal evidence showing that disclosure does not adversely affect psychological outcomes when adequate support is provided [1, 25].

A further contribution of this study is the identification of a non-linear relationship between age and disclosure, with a significant quadratic effect indicating that disclosure increases sharply after early adolescence. This pattern suggests that age functions as a threshold rather than a continuous determinant and is consistent with the Theory of Triadic Influence, which emphasises the interaction of developmental, social, and structural factors in health-related behaviours [26]. Qualitative findings further indicated that disclosure was often reactive rather than planned, in line with evidence from Kenya and Uganda documenting disclosure following illness or accidental discovery [9, 27, 28].

Methodological limitations include potential social desirability bias in caregiver reports, recall bias in reporting age at

disclosure, and the cross-sectional design, which limits causal inference and fails to capture disclosure as a dynamic process. Unmeasured factors, such as caregiver health status or household instability, may also have influenced the timing of disclosure. Overall, while disclosure coverage among older adolescents appears high, early adolescence remains a critical gap, reflecting persistent divergence between policy recommendations and practice.

5.2. Individual, Familial, and Socio-cultural Determinants of HIV Status Disclosure to Adolescents

After adjusting for age and other covariates, four factors remained independently associated with disclosure: perceived adolescent emotional maturity, caregiver confidence in discussing HIV, caregiver training, and facility of care. These findings provide statistical evidence to reject the null hypothesis, confirming that individual, familial, and socio-cultural determinants are significantly associated with disclosure outcomes.

Perceived adolescent emotional maturity emerged as a significant individual-level predictor, with disclosure increasing from 7.4% among those perceived as "not mature at all" to 95.1% among those considered "very mature." This aligns with developmental evidence that the capacity to understand illness depends on cognitive and emotional development rather than age alone [29], as also reflected in global guidance emphasising readiness-based over age-based disclosure [1]. However, a marked implementation gap was identified: only 12% of caregivers reported that healthcare providers conducted formal readiness assessments, despite existing tools and guideline recommendations [3-5, 30]. Qualitative findings indicated that caregivers relied largely on subjective judgment, leading to variability in disclosure timing and suggesting that readiness assessments are applied inconsistently and without standardised support. Evidence from this study further indicates that caregiver perceptions of adolescent emotional immaturity may be miscalibrated. Among disclosed adolescents, 92.6% demonstrated improved emotional well-being, suggesting that anticipated psychological harm exceeded observed outcomes. This is consistent with evidence from South Africa showing that caregiver fears of harm were largely unrealised and that adolescents adapted well when supported, with no significant adverse psychological effects associated with earlier disclosure after adjusting for baseline mental health [25].

At the familial level, caregiver capacity emerged as the dominant determinant of disclosure, with caregiver training showing the largest effect. Caregivers who had received training were over 15 times more likely to disclose, independent of age and other factors, surpassing the effects of caregiver confidence and facility of care. This highlights training as the most significant modifiable determinant and is consistent with Social Cognitive Theory, which emphasises self-efficacy in behaviour change [31]. Qualitative findings indicated that untrained caregivers lacked key self-efficacy mechanisms, including guided practice, modelling, and emotional support, whereas trained caregivers reported greater confidence, structured preparation, and reduced anxiety, facilitating disclosure. Existing empirical evidence supports this interpretation. The HADITHI disclosure intervention in Kenya showed that structured caregiver preparation significantly increased disclosure rates compared with standard care [32, 33]. Similarly, a study in the same sub-county found that caregiver support group participation was associated with a fourfold increase in disclosure likelihood [16], while evidence from Cameroon also demonstrates strong effects of structured counselling on disclosure completion [34]. The larger effect size observed in this study may reflect differences in intervention intensity, comparison groups, or residual confounding, and the cross-sectional design limits causal inference. Nevertheless, the consistency of findings across settings underscores caregiver training as a key determinant of disclosure.

Socio-cultural factors, particularly Community stigma, a widely reported factor, were not statistically significant in the multivariate model; its significant bivariate association with disclosure (cited by nearly half of respondents) attenuated after adjustment. Qualitative findings indicate stigma operates indirectly by shaping caregivers' fear and risk perceptions (e.g., concern about gossip, discrimination, and loss of social standing), rather than being a direct determinant of disclosure. In the adjusted model, these fears appeared to capture the pathway through which stigma influences disclosure decisions, a mediated effect aligning with stigma theory and its emphasis on anticipated stigma as a driver of avoidance behaviours in HIV research [24, 35]. Similar dynamics have been documented in Western Kenya and Tanzania, where fear of information loss, particularly in school and community settings, has led to increased secrecy and delayed disclosure [9, 36, 37]. This indicates that stigma remains influential, but its effect is contingent upon caregiver capacity to manage perceived risks.

Several findings deviated from initial expectations. Caregiver education level was not independently associated with disclosure after adjustment. This suggests that its influence stems from more proximal factors, such as training and confidence, aligning with Social Cognitive Theory's emphasis on domain-specific self-efficacy [31]. Caregiver HIV status was not associated with disclosure. Qualitative data showed HIV-positive caregivers often felt guilt over perinatal transmission and fear of blame, potentially negating any advantage from lived experience. Household income and employment status were not associated with disclosure, suggesting it is not primarily constrained by economic resources. This indicates effective disclosure is achievable across socioeconomic strata with appropriate support. Disclosure is predominantly shaped by caregiver capacity and perceived adolescent readiness, with socio-cultural and structural factors exerting indirect but persistent influence. Variation in disclosure outcomes reflects

differences in support and implementation, not immutable individual or household characteristics.

6. Conclusion

This study examined HIV status disclosure among adolescents in Western Kenya and found that, despite a high overall disclosure rate, substantial age-related inequities persist, with disclosure occurring predominantly in later adolescence and remaining rare among those aged 10–12 years. The findings indicate that disclosure is not primarily determined by chronological age but by perceived adolescent emotional readiness, caregiver capacity, and health system support. Caregiver confidence, training, and facility-level factors were the strongest predictors, while fear of psychological harm remained the main barrier. The central contribution of this study is the development of an evidence-based HIV disclosure guide. The guide is structured around three core components: readiness-based assessment and caregiver preparation, family-engaged disclosure planning, and sustained health system support, including post-disclosure follow-up. This framework shifts disclosure from an age-driven expectation to a structured, developmentally responsive, and system-supported process.

7. Recommendations

HIV disclosure monitoring should be disaggregated by age to identify delays among younger adolescents. Implementation should prioritise the disclosure guide, particularly caregiver training, readiness-based assessment, and structured clinical support. Disclosure should be guided by emotional and cognitive readiness, with integrated caregiver support to build confidence and reduce fear. Routine care should include trauma-informed follow-up and sustained psychosocial support. Future research should evaluate the implementation and effectiveness of the disclosure guide, include adolescent perspectives, and examine longitudinal outcomes, mental health integration, digital support tools, and cost-effectiveness of caregiver-focused interventions.

Evidence-Based HIV Disclosure Guide

Based on study findings, a three-component, evidence-based HIV disclosure guide is proposed to standardise practice for adolescents with HIV. It emphasises readiness-based assessment, family engagement, and sustained health-system support. First, it focuses on readiness-based disclosure assessment and caregiver preparation. Disclosure should be guided by the adolescent's emotional, cognitive, and developmental readiness (e.g., curiosity about illness, understanding of chronic treatment, coping capacity, psychological preparedness), rather than chronological age. Caregivers should also receive anticipatory preparation to support developmentally appropriate timing. Second, it promotes family-engaged disclosure planning via a structured, provider-supported process with caregivers. This strengthens caregiver confidence and communication skills, addressing fears of psychological harm, guilt, and emotional barriers. Collaborative decision-making aligns adolescent readiness with caregiver preparedness, supporting staged, age-appropriate disclosure within a clinical framework. Third, it addresses health-system enablers and sustained post-disclosure support. This includes trained providers, adolescent-friendly environments, peer support, trauma-informed follow-up, early phone and clinic review, and continued linkage to psychosocial, adherence, and peer support services. These components collectively reposition HIV disclosure from an age-driven expectation to a supported, developmentally appropriate, and system-enabled process.

Abbreviations

AIDS	Acquired Immunodeficiency Syndrome
ALHIV	Adolescents Living with HIV
aOR	Adjusted Odds Ratio
ART	Antiretroviral Therapy
AUC	Area Under the Curve
CI	Confidence Interval
EGPAF	Elizabeth Glaser Pediatric AIDS Foundation
FGD / FGDs	Focus Group Discussion(s)
HIV	Human Immunodeficiency Virus
ICC	Intraclass Correlation Coefficient
IQR	Interquartile Range
KII / KIIs	Key Informant Interview(s)
KMO	Kaiser-Meyer-Olkin Measure
KNBS	Kenya National Bureau of Statistics
KoboCollect	KoboCollect Data Collection Platform
NASCOP	National AIDS and STI Control Programme
NDoH	National Department of Health
NSDCC	National Syndemic Diseases Control Council
NVivo	Qualitative Data Analysis Software
OR	Odds Ratio
PLoS	Public Library of Science
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
Ref	Reference Category
S-CVI	Scale Content Validity Index
SSA	Sub-Saharan Africa
STI	Sexually Transmitted Infection
TB	Tuberculosis
TTI	Theory of Triadic Influence
VIF	Variance Inflation Factor
WHO	World Health Organization

Author Contributions

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Data Availability Statement

The datasets generated and analysed during this study are available from the corresponding author upon reasonable request.

Conflicts of Interest

The authors declare no competing interests.

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