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"We can tell them, but not right now!" – HIV status disclosure and related factors among children aged 6–14 years living with HIV in Kilimanjaro region, Tanzania

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ABSTRACT

In Tanzania, disclosing HIV status to children is challenging despite WHO recommendations to inform children between the ages of 6 and 12 based on cognitive and emotional development. This study aimed to determine HIV status disclosure and related factors among children living with HIV in Tanzania. A study employing quantitative and qualitative methods was conducted from September 2021 to March 2022 among children aged 6–14 receiving HIV care. Semi-structured questionnaires were administered to disclosed and undisclosed children (through their parents/caregivers). The analysis included bivariate and multivariate logistic regression analyses and thematic content analysis for qualitative data. A total of 121 children participated in the quantitative analysis, with 51 (42%) aware of their HIV status. Multivariate analysis showed children aged 9–11 (OR=2.7; 95% CI=0.8–9.0) and 12 years (OR=30; 95% CI=7.2–124) were more likely to know their status than those aged 6–8. Having a treatment supporter/relative (OR=2.9; 95% CI=1.0–8.2) was significantly associated with disclosure. Disclosure was not associated with depression. In-depth interviews revealed themes like disclosure challenges, stigma, and reasons for non-disclosure. HIV status disclosure in Kilimanjaro was associated with age and having a treatment supporter. Addressing age-related challenges and emphasizing the role of treatment supporters can improve disclosure outcomes.

KEYWORDS

HIV; children; disclosure; good health and well-being; reduced inequalities

Background

Globally, it is estimated that 1.4 million children under 15 were living with HIV in 2023, and 57% accessed antiretroviral therapy (UNAIDS, 2024). Every day in 2023, approximately 120,000 children under the age of 15 are infected with HIV, with nearly 87 per cent of these children living in sub-Saharan Africa. Additionally, around 250 children die from AIDS daily due to limited access to HIV prevention, care, and treatment services (UNICEF, 2024).

One of the biggest challenges parents and guardians of children living with HIV face is the disclosure of the child's HIV status, even though disclosure has numerous advantages in improving the health and medication adherence of the children. The disclosure procedure, however, generates negative emotions and stigma among healthcare professionals, parents, and caregivers (Gyamfi et al., 2017; Okolo-Francis

et al., 2021). There is a rising concern in Tanzania and other countries within and outside Africa about the limited extent to which disclosure of HIV/AIDS status is being done to children at the necessary age (Cremonese et al., 2021; Fearnley & Boland, 2017). According to WHO guidelines, the disclosure process should be started at the age of six and completed before reaching 12 (WHO, 2011). Thus, a younger child should know their status incrementally at an appropriate time in terms of both cognitive skills and emotional maturity to prepare him or her for full disclosure.

Several studies have been done on disclosure. In Nigeria, a study on prevalence and predictors of paediatric disclosure among HIV-infected children on treatment showed that out of 110 parents/caregivers of children over six years, 34(31%) did not tell their children they were HIV positive (Aderomilehin

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et al., 2016). Also, studies conducted in Western Kenya on disclosure of the HIV status to children showed that among 792 children, 9% of 6 to 7-year-olds knew their status, 33% of 10 to 11-year-olds, and 56% of 13 to 14-year-olds reported knowing their status (Vreeman et al., 2014). In addition, a Tanzanian study on factors influencing HIV status disclosure showed that out of 309 children between 13 and 14 years old, only 102(33%) of HIV-positive children knew their HIV status (Bulali et al., 2018). Furthermore, a Tanzanian longitudinal study on factors associated with HIV status disclosure to orphans and vulnerable children with HIV showed that children aged 8 and 10 years are too young to understand HIV-related processes and 31% of disclosure status occurred between the ages of 11 and 14 (Bajaria et al., 2020).

Several factors are associated with disclosure. A study conducted in Northwest Gondar in Ethiopia on factors related to HIV status disclosure showed that children were informed of their status based on their age and the death of family members (Abegaz et al., 2019; Negese et al., 2012). Also, disclosure decisions are challenging because of stigma, issues with social support, family relations and parenting abilities (Biadgilign et al., 2011).

Not disclosing the child's HIV status to the child may impact the management of living with HIV. A study carried out in Ghana on disclosure and health-related outcomes among children living with HIV found that their disclosure status is related to several other HIV-related factors. The study showed that the more parents do not disclose their children's condition, the less they adhere to their medication (Amankwah-Poku et al., 2021).

Another factor is psychological well-being, in which lack of disclosure creates tension and mistrust, making HIV-positive children curious about their illnesses. This results in fear that the child might not keep the diagnosis confidential, fear of being blamed for infecting the child, and stigma, which breaks the family's harmony and cohesion (Amankwah-Poku et al., 2021).

Caregiver burden is another factor whereby disclosure may reduce caregiver burden. Children may take their medicines as directed and actively manage their illnesses, including reminding parents to take their medications appropriately (Amankwah-Poku et al., 2021). Furthermore, studies conducted in Tanzania on the factors contributing to the failure to disclose HIV status to children were the specific age category to disclosure and fear of stigma and discrimination (Kiula et al., 2019; Sariah et al., 2016). Strategies are highly needed to smoothen the process of disclosure of the HIV status to the child as recommended by

the WHO (Sariah et al., 2016; WHO, 2011). A Malawian study was done on the acceptability of story-books to help inform children whether they have HIV. The study discovered that caregivers do not educate their children because they lack confidence in disclosing and the necessary communication skills (Kalembo et al., 2019).

Even though studies are conducted in several countries, there is limited information on HIV status disclosure and related factors among children living with HIV in Tanzania. We found that the theme of disclosure played a significant role among children living with HIV in issues related to adherence to treatment. Therefore, we decided to investigate disclosure in more depth. Thus, the current study aimed to determine the level of disclosure and associated factors, including the relationship with the child, duration of ART treatment, psychosocial factors, and the presence of a treatment supporter among children living with HIV in Kilimanjaro, Tanzania. Specifically, we had the following objectives: (1) to identify factors associated with HIV status disclosure among children living with HIV, (2) to investigate the relationship between HIV status disclosure and depression and ART medication adherence and (3) to investigate HIV disclosure challenges and reasons not to disclose the status.

This study's findings will help identify positive approaches to disclosing children living with HIV, which can be adopted by parents/caregivers of children, the community, health professionals, village health facilities, and hospitals.

Methodology

Study design and population

The study employed quantitative and qualitative data collection methods among children aged 6–14 years receiving HIV care in Health facilities of the Kilimanjaro Region. The data collection was part of a formative study to develop a blueprint for a digital adherence tool, the REMIND-KID study. The study had two components: (1) a survey and (2) a pilot study on using digital adherence tools (DATs), in which participants used a DAT for one month, followed by in-depth interviews and focus group discussions. More information about the DAT has been published in the protocol and is available via <https://doi.org/10.1186/s13063-023-07293-1>. Data was collected from September 2021 to March 2022. The study involved children whose HIV status had been disclosed to them. For children whose HIV status had not been disclosed to them, we only involved

their parents or caregivers. The study obtained ethical approval from the College Research and Ethics Review Committee (CRERC) of Kilimanjaro Christian Medical University College (KCMUCo) and the National Health Research Ethics Sub-Committee (NatHREC) of the National Medical Research Institute (NIMR) of Tanzania. For children whose status was disclosed, written informed consent was obtained from their caregivers, followed by oral informed assent from the children. To study the matter of non-disclosure, we will only be able to get viable data if we interview parents or caregivers of children to whom their status has not been disclosed, not the children themselves. Therefore, informed consent was obtained from the parents or caregivers of children whose HIV status had not been disclosed.

Study area

This study was conducted in HIV care clinics, including Care and Treatment Centres (CTC) and antenatal Care Clinics (ANC), in the Kilimanjaro region, Tanzania. The Kilimanjaro region is in the northern part of Tanzania. Participants were recruited in five health facilities: two Referral hospitals (KCMC and Mawenzi), one district-designated hospital (Kibosho), and two health centres (Pasua and Majengo).

Sample size

In this study, we included 121 children living with HIV on treatment with their caregivers. The sample size for the REMIND-KID study was 142 children aged 0–14. This number resulted from the arbitrary percentage of 50% experiencing barriers for using a

DAT with $\alpha = 0.05$ and power of 80% (estimation of single proportion sample calculation). For our sub-study, we selected all children aged 6–14, leading to 121 children. The disclosure decision was made following the World Health Organization's (WHO) recommendation that children should be informed of their HIV status starting from 6 years and above (WHO, 2011) (Figure 1).

Out of the children aged 6–14 years, we purposively selected twenty caregivers/parents with their children to participate in the DAT study with in-depth interviews and focus group discussions. We considered the twenty participants to be enough to reach data saturation.

Inclusion criteria

Inclusion criteria for the children were as follows: (1) children, (2) aged 6–14 years of age, (3) living with HIV, (4) attending care and treatment centres (CTC) in Kilimanjaro region, (5) of whom the caregivers/parents were able to understand and willing to sign the informed consent and (6) if aged 8–14, who were willing to give assent.

Data collection procedures

Children and their caregivers were recruited from the respective clinics. Children and their caregivers who were eligible were asked to take part in our study. For the survey, we determined eligibility based on inclusion and exclusion criteria. The study was explained thoroughly to the caretaker/parent before informed consent and assent were requested, applying a thorough informed consent and assent procedure. Written informed consent was obtained from the

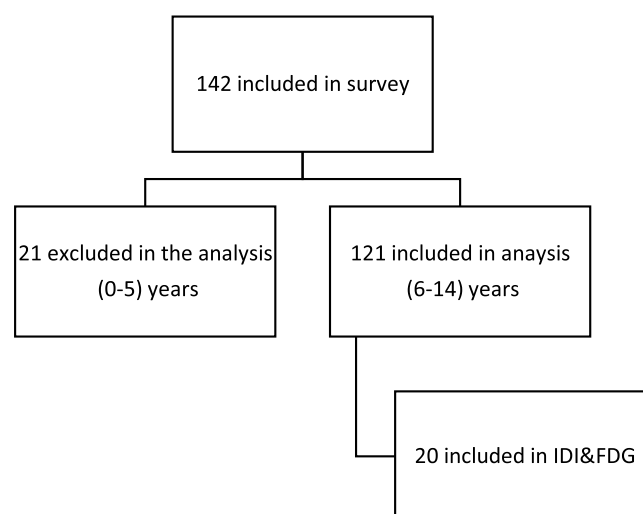


Figure 1. Scheme for selection of participants.

caregiver. During the process, the caregiver was asked whether the HIV status had been told to the child, followed by verification from the health care provider. Children whose status had been disclosed aged eight years or older were then asked for oral informed assent. When assent was given, they were also interviewed. We did not interview children who did not give assent to the study. However, their parents/caregivers were included.

Data collection tools

We conducted a survey using semi-structured questionnaires. After informed consent and assent, a semi-structured questionnaire was administered face-to-face to all caregivers/parents, including those who had not disclosed their HIV status to their children. Also, a questionnaire was administered to the child whose status had been disclosed and who gave assent. Children who had undergone disclosure were provided with a separate questionnaire focusing on social and demographic factors, whereas parents or guardians of children who hadn't been disclosed received the same questionnaires, ensuring a broad understanding of both groups.

For stigma, we used the HIV stigma instrument developed by Holzemer et al. to examine participant's perceived stigma (Holzemer et al., 2007). The stigma instrument was administered directly to children who had undergone disclosure, while for those who had not, it was instead administered to their parents, ensuring a broad understanding of both groups. We selected two domains among six stigma domains because we were interested in looking for social isolation and verbal abuse. This selection was based on the paper from the study applied in our context (Ngocho et al., 2019).

Five items were selected from social isolation items (e.g. People cut down on visiting them), and six items were selected from verbal abuse (e.g. someone insulted them). Questions about stigma could be answered on a Likert scale with four options: (0) never, (1) once or twice, (2) several times and (3) most of the time. Responses were summed for each scale to create stigma scores, with the highest scores indicating higher levels of HIV stigma among children. Moreover, depression was measured using the Patient Health Questionnaire (PHQ9), which contains nine questions assessing depressive symptoms over the past two weeks (Kocalevent et al., 2013). Questions, such as "little interest or pleasure in doing things", were answered on a Likert scale with four options: (0) not at all, (1) several days, (2) more than half the

days, and (3) nearly every day. For children whose status was disclosed, the questionnaire was administered directly to them. In contrast, for children in the undisclosed group, the questionnaire was completed by their parents or guardians as proxies. In these cases, the questions were rephrased to reflect the parent's observations of the child's behaviour, for example, "Has the child had little interest or pleasure in doing things?" Depression was assessed on a Linkert scale, and scores ranged from 0-30, which were summed up and categorised from 0-4 (means no depression symptoms) and 5-14 (means depression symptoms). Adherence to ART medication was measured by using pharmacy refill counts over a period of one month. Participants with medication intake of less than 95% of the pills were categorised with poor adherence, while those with above 95% had good medication adherence.

We conducted in-depth interviews (IDI) and focus group discussions (FGD) separately for children whose status had been disclosed and caregivers/parents of the children to whom the HIV status was disclosed and not disclosed. The IDI and FGD guiding tools focused on challenges of HIV status disclosure among children and the reasons for not disclosing the HIV status. The IDI and FGD topic guides did not align with the quantitative findings because their objectives differ. The IDI aimed to obtain individual views on disclosure status. The FGD aimed to verify the disclosure information by gaining insights into community views. Trained research assistants did the face-to-face interviews in hospital clinics. The topic guides were adapted during the study in an iterative process. Research assistants translated the data collection tools from English to Swahili language, interviews and discussions were transcribed verbatim in Swahili and translated into English by experienced research assistants.

Data analysis

We performed descriptive analysis using proportions and frequencies. SPSS version 27 was used to analyse quantitative data. To answer the first objective about factors associated with HIV status disclosure among children living with HIV, we used bivariate and multivariate logistic regression analysis, with the dependent variable being HIV status disclosure and the independent variables being age, sex, duration of ART treatment, and presence of treatment supporter. To answer the second objective about the relationship between HIV status disclosure depression and adherence, we used bivariate and multivariate logistic regression, whereby the dependent variables were

depression or adherence, while the independent variables were HIV status disclosure, including confounding variables such as age, sex, duration of ART treatment and presence of treatment supporter. The variables found to be related with a P-value of <0.1 in bivariate analyses were included in a multiple logistic regression model to obtain independent predictors of HIV status disclosure to children. In the multivariate model, $P < 0.05$ was considered statistically significant.

To address the third objective, concerning the challenges of disclosing HIV status and the reasons not to disclose status, we employed thematic content analysis of the data gathered from individual interviews (IDIs) and focus group discussions (FGDs). We used an inductive open coding approach, which involved repeatedly reviewing the data to enhance familiarity. We also created initial summaries and memos to support the process. The first six transcripts were coded by two researchers (PM and BM) independently, and significant text segments related to challenges of the child's HIV status disclosure were identified, and descriptive codes such as "stigma", "fear of unknown", and "lack of understanding" were assigned. Then, differences were discussed and resolved by refining a shared codebook collaboratively.

After coding, codes with similar ideas or meanings were grouped together into clusters. These clusters represented the main themes found in the data, making it easier to organise and understand the information. For example, "Emotional Impact" and "Disappointment" were grouped under "Sadness and disappointment". These clusters were refined into sub-themes and broader themes such as "HIV Disclosure Challenges and reasons not to disclose status". The coding was done using NVivo software; the codes were systematically organised and linked with specific quotes to validate whether they reflected the raw data. Themes, subthemes and clusters of information were iteratively refined into a clear narrative based on the experiences of participants (See Table 5).

Results

Social demographic characteristics

A total of 121 HIV-infected children on treatment were included in the quantitative analysis, and 51 (42%) children knew about their HIV status. Thirty-one per cent ($n = 38$) of children were between the ages of 6–8; among them, 33(87%) did not know about their status. Thirty-nine per cent ($n = 47$) of children were between the ages of 9–11, and among

them, 32(68%) did not know about their status. Thirty per cent ($n = 36$) were above 12 years, and among them, 5 (14%) did not know about their status. There were 60 girls (49.5% of the total) and 61 boys (50.4%). Most children ($n = 75$; 62%) live with their biological parents. One hundred twelve children had primary education (93%) and 94 (78%) children attended referral hospitals for ART services. Moreover, 86 (71%) children had a treatment supporter (who helps to collect medication). The results showed that among children to whom the status had been disclosed, 48 (94%) have no depression, 2 (4%) have mild depression and 1 (2%) have moderate depression, while in those not disclosed, 58 (83%) have no depression, 10 (14%) have mild depression and 2 (3%) have moderate depression. Moreover, among children to whom status had been disclosed, 8 (44%) had ART adherence of less than 95% and 43 (42%) had adherence of more than 95%, while among children to whom status had not been disclosed, 10 (56%) had ART adherence of less than 95% and 60 (58%) had adherence of more than 95% (See Table 1).

Table 1. Demographic characteristics of HIV status disclosures among the children living with HIV ($N = 121$).

Variable	Total	HIV status disclosure		P-value (bivariate)
		Undisclosed n (%)	Disclosed n (%)	
Total	121	70 (58%)	51 (42%)	
Age of child				
6–8	38 (31%)	33 (87%)	5 (13%)	<0.001
9–11	47 (39%)	32 (68%)	15 (32%)	
>=12 years	36 (30%)	5 (14%)	31 (86%)	
Child's sex				
Boys	61 (50%)	36 (59%)	25 (41%)	0.8
Girls	60 (50%)	34 (57%)	26 (43%)	
Relationship to child				
Biological caregivers (parents)	75 (62%)	48 (64%)	27 (36%)	0.08
Non-biological caregivers	46 (38%)	22 (48%)	24 (52%)	
Child level of education				
Primary	112 (93%)	65 (58%)	47 (42%)	0.8
Others	9 (7%)	5 (56%)	4 (44%)	
Duration of ART treatment				
>5 years	47 (39%)	35 (74%)	12 (26%)	0.007
<=5 years	74 (61%)	35 (47%)	39 (53%)	
Place of ART follow-up				
Referral hospital	94 (78%)	51 (54%)	43 (46%)	0.7
Health centre	27 (22%)	19 (70%)	8 (30%)	
The presence of a Treatment supporter (helps to collect medication)				
Yes	86 (71%)	45 (52%)	41 (48%)	0.002
No	35 (29%)	25 (71%)	10 (29%)	
Verbal abuse	0 (0–0)	0 (0–0)	0 (0–0)	0.78
Stigma Score				
Median (IQR)				
Social Isolation	0 (0–0)	0 (0–0)	0 (0–0)	0.40
Stigma Score				
Median (IQR)				

Factors associated with HIV status disclosure among children

The results of the bivariate analysis show that older age, shorter duration of ART treatment and presence of a treatment supporter were associated with HIV status disclosure. Multivariate analyses showed that HIV disclosure was more likely among children aged 9–11 years (OR = 2.7; 95% CI = 0.8–9.0) and among children ≥ 12 years (OR = 3.0; 95% CI = 7.2–124) compared to those aged 6–8 years. Children with a treatment supporter were 2.9 times more likely to have their status disclosed compared to those without a treatment supporter (OR = 2.9; 95% CI = 1.0–8.2) (See Table 2).

Relationship between HIV status disclosure, depression and ART medication adherence

The results show that there was no significant relationship between HIV status disclosure, depression and ART medication adherence (See Table 3).

Association between disclosure and ART medication adherence

The results show that there was no significant relationship between HIV status disclosure and ART medication adherence (See Table 4).

Table 2. Crude and adjusted odds ratio for factors associated with HIV status disclosure.

Variable	HIV status disclosure			
	Bivariate OR (95%CI)	P-value	Multivariate OR (95%)	P-value
Age of child				
6–8	Ref	<0.001	Ref	<0.001
9–11	3.0 (1.0–9.5)		2.7 (0.8–9.0)	
≥ 12	4.1 (1.1–15.5)		3.0 (7.2–124)	
Child's sex				
Male	Ref	0.8		
Female	0.9 (0.4–1.8)			
Relationship to child				
Biological caregivers	Ref	0.08	Ref	0.09
Non-biological caregivers	0.9 (0.9–4.0)		2.4 (0.8–6.9)	
Duration of ART treatment				
>5 years	Ref	0.007	Ref	0.3
≤ 5 years	3.0 (1.3–5.8)		0.6 (0.2–1.6)	
Place of ART follow-up				
Referral hospital	Ref	0.7		
Health centre	0.8 (0.4–1.8)			
The presence of a treatment supporter (helps to collect medication)				
Yes	3.3 (1.5–7.0)	0.002	2.9 (1.0–8.2)	0.03
No	Ref		Ref	
>95%	1.1 (0.4–3.1)			

Table 3. Association between HIV status disclosure and depression including other confounding variables.

Variable	Depression level			
	Bivariate OR (95%CI)	P-value	Multivariate OR (95%)	P-value
HIV status disclosure				
Yes	Ref	0.08	Ref	0.07
No	3.3 (0.9–12.4)		0.2 (0.05–1.11)	
Age of child				
6–8	Ref	0.75		
9–11	1.2 (0.3–4.8)			
≥ 12	1.4 (0.3–5.6)			
Child's sex				
Male	Ref	0.43		
Female	1.6 (0.5–4.7)			
Relationship to child				
Biological caregivers	Ref	0.37		
Non-biological caregivers	1.7 (0.5–5.8)			
Duration of ART treatment				
> 5 years	Ref			
≤ 5 years	0.8 (0.3–2.6)			
Place of ART follow-up				
Referral hospital	2.0 (0.4–9.5)	0.38		
Health centre	Ref			
The presence of a treatment supporter (helps to collect medication)				
Yes	2.7 (0.3–21.1)	0.34		
No	Ref			
Verbal abuse	1.1 (0.7–1.7)	0.54		
Stigma Score Median (IQR)				
Social Isolation	1.1 (0.8–1.4)	0.47		
Stigma Score Median (IQR)				
ART medication adherence				
<95%	Ref	0.36		
>95%	0.37 (0.05–3.04)			

HIV disclosure challenges and reasons not to disclose the status

Disclosure of an HIV-positive status should be executed in an ideal environment that supports collaboration between caregivers and healthcare providers, a task hindered by challenges such as lack of understanding, stigma and discrimination, depression, fear of the unknown and misinformation. The themes derived from in-depth interviews and focus group discussions have been summarised below in Table 5.

Description of the themes

Lack of Understanding

Parents said that the reason their children did not know about their HIV status and that they did not disclose it to others was due to a lack of knowledge and skills of the parent in disclosing their HIV status to the infected child about the disease. This was reported;

“And he is not aware of his condition. Even his sister, who is in college right now, does not understand her

Table 4. Association between disclosure and ART medication adherence including other confounding variables.

Variable	ART medication adherence			
	Bivariate		Multivariate	
	OR (95%CI)	P-value	OR (95%)	P-value
HIV status disclosure				
Yes	Ref	0.83		
No	1.1 (0.4–3.1)			
Age of child				
6–8	Ref	0.41		
9–11	2.2 (0.7–7.5)			
>=12	1.7 (0.5–5.6)			
Child's sex				
Male	Ref	0.64		
Female	1.3 (0.5–3.5)			
Relationship to child				
Biological	Ref	0.71		
Non-biological caregivers	0.8 (0.3–2.4)			
Duration of ART treatment				
>5 years	Ref	0.49		
<=5 years	1.4 (0.5–3.9)			
Place of ART follow-up				
Referral hospital	1.4 (0.5–4.4)	0.54		
Health centre	Ref			
The presence of a treatment supporter (helps to collect medication)				
Yes	0.2 (0.1–0.7)	0.01	0.5 (0.1–3.1)	0.49
No	Ref			
Verbal abuse	0.7 (0.4–1.0)	0.05	0.7 (0.4–1.2)	0.22
Stigma Score Median (IQR)				
Social Isolation	0.9 (0.7–1.3)	0.73		
Stigma Score Median (IQR)				
Depression				
No depression	106 (88%)	58 (55%)	48 (45%)	0.20
Mild depression	12 (10%)	10 (83%)	2 (16%)	
Moderate depression	3 (2%)	2 (67%)	1 (33%)	

young brother's problem. The moment the younger brother was hospitalised, they knew he had anaemia." (Mother of a 10-year-old boy)

Stigma and discrimination

Parents consistently agreed that stigma and discrimination were the biggest concern when they considered telling their children living with HIV about their status. They voiced strong concerns about what they saw as the community's way of labelling and isolating HIV-positive people and believed that stigmatization in the community was still relatively high. Instead, they chose not to disclose their status. It was stated that;

"Yes, the community can stigmatize her! I think the community will ask many questions or maybe they will isolate themselves from her." (Mother of a 10-year-old girl)

Further, one of the caregivers from the group aired her views and said,

"There is no problem, but you know there is stigma. So, if every person knows that maybe these people are sick and they are giving their child medications.

Because of this problem, not all people that surround you are good." (Mother of 11-year-old boy).

Furthermore, one mother added by saying;

"They may stigmatize the child at school, that he is sick and should not stay with him.

But if there will be counselling with the teachers. I will disclose her status to the teachers and I think the teacher will also teach/provide education on HIV in school." (Grandmother of a 7-year-old girl)

Another one shared her experience by pointing out the frequency of challenges and said,

"The challenge was only once; when fellow children ridiculed her and wanted to stigmatize her; one of the children in the neighbourhood had that behaviour, but we stopped her instantly." (Mother of a 13-year-old girl)

Depression

Parents face difficulties when they have to tell their children about HIV status, it often brings feelings of depression. It's a complicated situation of parenthood, mental health and HIV disclosure. To help parents in navigating this situation, education is provided to provide them with the skills to manage depression and address potential challenges that may arise. This was reported that:

"We normally taught about depression to avoid stress and how to deal with challenges that may occur." (Grandmother of a 7-year-old girl)

Another mother had this to share:

"Depression is there, it's just there." (Mother of a 11-year-old girl)

Fear of the unknown

Some parents worried that their kids would not be able to handle the news and that things would get worse if they told them they are living with HIV. It was clear from several conversations that they were unsure how this news would affect kids who had grown up appearing to be concerned. They voiced concerns that this information would cause their children to experience anxiety and feel unhealthy. This was reported:

"That will bring me a problem. He understands, but my child can't keep a secret. I always tell their father to find a way of letting the kids know." (Mother of a 13-year-old boy)

One mother from the focus group had this to share;

"When I told him that he was supposed to take medication every day because he was infected with HIV/

Table 5. Quotes, memos, codes, subthemes and theme.

Quotes	Memos	Codes	Subthemes	Theme
<i>"And he is not aware of his condition. Even his sister, who is in college right now, does not understand her young brother's problem. The moment the younger brother was hospitalised, they knew he had anaemia"</i>	Parents avoid disclosure due to the belief that other family members lack understanding	Lack of understanding	Lack of understanding	HIV disclosure challenges and reasons not to disclose
<i>"Yes, the community can stigmatize her! I think the community will ask many questions or maybe they will isolate themselves from her"</i>	Fear of stigma from the community impacts disclosure decisions	Stigma	Stigma and Discrimination	
<i>"We normally taught about depression to avoid stress and how to deal with challenges that may occur"</i>	Parents associate non-disclosure with protecting mental health by avoiding stress-inducing situations.	Mental health, Depression prevention	Depression	
<i>"That will bring me a problem. He understands, but my child can't keep a secret. I always tell their father to find a way of letting the kids know"</i>	Parents are uncertain about children's responses and fear breaches of confidentiality.	Fear of unknown, confidentiality	Fear of the unknown	
<i>"There is a way to talk to children, but most people don't know. Most children are misinformed on the actual problem and so they tend to lie to them that the medication is for heart or stomach disease. This is because of poor perception that children do not understand things"</i>	Caregivers often substitute false narratives to avoid addressing the truth, leading to misconceptions.	Misinformation, Communication barriers	Misinformation	
<i>"Aaaaah, Mhh! We can tell the child, but not right now; I think until he reaches 12 years is when I can tell him because his brain is not yet okay"</i>	Parents delay disclosure, believing children will better process the information at an older age.	Timing of disclosure	Appropriate age for disclosure	
<i>"It hurts knowing that you are sick and you will have to take medications for the rest of your life"</i>	Fear of emotional distress from disclosure influences parents' reluctance	Emotional Impact, Disappointment	Sadness and disappointment	

AIDS, he told me that he cannot take medication every day because he thinks he is not infected." (Mother of a 10-year-old boy)

Misinformation

In our conversations, parents said there is a way of communicating with children to make them understand their status. However, they familiarize themselves with the wrong information regarding the disease and the drugs they take. One mother commented:

"There is a way to talk to children, but most people don't know. Most children are misinformed on the actual problem and so they tend to lie to them that the medication is for heart or stomach disease. This is because of poor perception that children do not understand things." (Mother of a 9-year-old boy)

Another mother had this to share:

"Since when he was young, he knew he had chest problems. I haven't told him the actual disease he is suffering from." (Mother of a 10-year-old boy)

Appropriate age for disclosure

During conversations, it became clear that children with an age below 12 years were considered to not be having an age for the "appropriate moment" to start disclosing. Most caretakers believed the children would have developed the capacity to interpret

such information above 12 years. This was illustrated by:

"Aaaaah, Mhh! We can tell the child, but not right now; I think until he reaches 12 years is when I can tell him because his brain is not yet okay." (Mother of 10-year boy)

A mother from a group discussion commented;

"I want to inform the doctor to tell the child. It is high time that I tell the boy what he is suffering from and what medication he is taking." (Mother of 13-year-old boy)

Sadness and disappointment

Most of the disclosed children had a hard time accepting that they were living with HIV. They experienced feelings of sadness and disappointment. This was reported by a child who said that:

"It hurts knowing that you are sick and you will have to take medications for the rest of your life. The elder child was furious. He was very emotional; he was near the examination dates and was so confused that he could not do the examination." (Mother of a 13-year-old boy)

Discussion

Our study found that 58% of children below age 12 do not know their HIV status. It was shown that being

older than 12 years is a significant predictor of knowing their status, which aligns with the WHO guidelines. Also, we found a relationship between the presence of treatment supporters and HIV disclosure to children. Most caregivers seemed to agree that telling children their HIV status was important, but most thought it should wait until the child is over twelve years old enough to understand.

Nearly half of the children (42%) in this study who were living with HIV had formal notification of their status given to them by their caregivers. A previous study conducted in Tanzania's Southern Highlands Zone discovered a lower disclosure proportion of thirty-three per cent, associated with the child's age (those ten years and above were more likely to know their status; Bulali et al., 2018). Additionally, a Tanzanian longitudinal study on the factors linked to HIV status disclosure to orphans and vulnerable children with HIV revealed that thirty-one per cent of disclosure status occurred between the ages of 11 and 14 years (Bajaria et al., 2020). Even though our study's prevalence of disclosure is higher than studies by Bulali et al. and Bajaria et al. from Tanzania, our disclosure rate is lower than that of research from Zimbabwe, where the percentage of disclosure was sixty-seven percent and from Ethiopia, where it was fifty percent (Finnegan et al., 2019; Mengesha et al., 2018).

Children who participated in this study expressed concerns about taking medication for the rest of their lives, which they often found overwhelmed by the idea of managing a chronic condition. A study from Southern Ethiopia showed that disclosure of children's HIV status is essential to chronic care and long-term disease management. This is observed through good ART adherence levels, improved awareness of living with HIV, and decreased worries and confusion (Guta et al., 2020; Walle et al., 2022). Similarly, a study from South Africa showed that children knowing their status helped them to take their medications consistently (Madiba & Diko, 2020).

The preferred age for commencement of disclosure by the caregivers was above twelve years, which is not in line with WHO guidelines, which state that partial disclosure should begin at the age of six years and should be completed at 12 years of age (WHO, 2011). The age for disclosure was consistent throughout our study's quantitative and qualitative components, demonstrating that parents preferred to tell their children they are living with HIV when they are above 12 years old. In a similar pattern, Yami et al. reported that thirty-five per cent of caregivers mentioned that the reason to disclose the HIV status to their children is when a child

is mature enough age greater than 12 years (Yami et al., 2022). In addition, a higher percentage of disclosure was also found in a study by Vreeman et al., which states that older children were more likely to be aware of their status than younger children, possibly because of increased maturity, independence, and self-care responsibilities (Vreeman et al., 2014). The disclosure was mostly described as mutually beneficial for caregivers and children in our study, where it showed that disclosing the status to children improves drug adherence. A study from Ghana with similar findings showed that the main benefits of disclosure included enhanced medication adherence and helping prevent re-infection with different virus strains (Gyamfi et al., 2017). Another study from Ghana on caregiver disclosure status experiences showed an improvement in children's adherence and well-being, which reduced their caregiver's anxiety (Klutsey et al., 2021).

In the study, parents and caregivers of children were afraid of disclosing HIV status to their children in such a way that they may unintentionally disclose their status to others, leading to discrimination and social exclusion. A study conducted by Doat et al. stated that parents are worried that their children might disclose their status to others, which can result in stigma and discrimination (Doat et al., 2019).

The study also found that stigma was not significantly associated with the child's HIV status disclosure for children living with HIV. Caregivers' perceptions of stigma were used as a proxy for the stigma experienced by children, but this approach presented challenges. This was also shown in other studies. For instance, a study conducted in Kenya on factors associated with caregiver compliance to an HIV disclosure intervention among children living with HIV found that caregiver reports might not fully align with children's own feelings about stigma (Magill et al., 2023). Integrating direct assessments of children's experiences with stigma is important for a clear understanding of its impact on disclosure outcomes.

Additionally, in our study, the depressive symptoms among children whose HIV status had not been disclosed were based on assessments provided by their parents and caregivers. We did not find a significant association between disclosure and depression among children living with HIV. This contrasts with findings from a study conducted in Ghana that examined the influence of HIV status disclosure on health outcomes in children living with HIV and their caregivers. Caregivers assessed that non-disclosure may be associated with high reports of depressive

symptoms in children living with HIV (Amankwah-Poku et al., 2021). Again, the fact we did not find the relationship could be caused by the different approaches in measurement between undisclosed and disclosed children.

The study also examined the experiences of parents and caregivers of children whose HIV status has not been disclosed, with participants providing informed consent. This approach aligns with ethical guidelines in HIV research, which emphasise the importance of safeguarding participants' autonomy and privacy while studying groups which have not disclosed their HIV status (WHO, 2011). Previous studies have focused on caregivers' perceptions of disclosure status among children living with HIV, recognising that parents are the primary decision-makers and possess valuable insights into the factors influencing disclosure and the barriers they face (Amankwah-Poku et al., 2021; Bulali et al., 2018).

Our study has several limitations. It involves comparing parents' perceptions in the undisclosed group with children's perceptions in the disclosed group. This approach presents a limitation, as a study in Kenya showed that these perceptions are often different (Magill et al., 2023). However, we believe this method was the most feasible for this study. For future studies, we recommend using questionnaires that have been validated for such an approach and measure the same perceptions in both groups. Second, since the research was confined to a single region, the results may only be applied to a narrow context. Thirdly, our sample size might be too small to find a relationship with other factors that were not significant. Lastly, we did not interview healthcare workers who could also give great insights on the topic of disclosure.

The strength of our study was that it combined quantitative and qualitative methodologies to learn about HIV status disclosure and related factors among children when they visited an HIV clinic in the Kilimanjaro region.

Conclusion

Despite the existence of WHO guidelines for the disclosure to be done gradually over time, the proportion of HIV status disclosure among children aged less than 12 years was low in our study. The disclosure status of most children living with HIV in Kilimanjaro was significantly related to age above 12 years and having a treatment supporter. It is important to focus on the challenges related to different ages and highlight the key role of treatment supporters in making disclosure easier.

Recommendations

The study suggests that future research should consider combining data from both parents and children into a single measure to understand better the psychological and emotional effects of HIV status disclosure on children living with HIV.

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Data availability statement

All data generated or analysed during this study can be communicated with the first author upon signing of a data transfer agreement from according to the nation's policy.

Authors' contributions

NE, IS, and RM contributed to the design, research implementation, and manuscript review. LM and BM analysed the results and wrote the manuscript. MS supervised the project and reviewed the manuscript. PM and BM contributed to the manuscript writing. KN contributed to the data collection and data analysis.

Ethical approval

Ethical approvals were obtained from the National Institute for Medical Research with reference No. NIMR/HQ/R.8a/Vol.IX/3825 and the Kilimanjaro Christian Medical University College Research Ethical Committee No. 2519. All methods and study procedures were carried out in accordance with the Declaration of Helsinki. Participants provided

informed consent prior to study entry after a detailed explanation of the study provided by study nurses.

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