Eastern African Journal of Humanities and Social Sciences
Vol. 4 No. 2 (2025): ISSN (Online): 2958-4558
DOI: https://doi.org/10.58721/eajhss.v4i2.1252

Factors Influencing Parents' Decision to Disclose Their HIV Status to Their Children in Makete District, Tanzania

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Article History
Received: 2025-04-01
Revised: 2025-08-20
Accepted: 2025-08-24
Published: 2025-08-30

Keywords
Children
Disclosure
HIV status
Parents
Tanzania

How to cite:
Isanzu, N. H. (2025). Factors Influencing Parents' Decision to Disclose Their HIV Status to Their Children in Makete District, Tanzania. *Eastern African Journal of Humanities and Social Sciences,* 4(2), 102-112.

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Abstract
HIV remains a major public health challenge in sub-Saharan Africa, and Tanzania is among the most affected countries. Beyond medical treatment, families living with HIV face complex social realities, one of which is whether parents should disclose their HIV status to their children. Disclosure can reduce stigma, improve family communication, and strengthen adherence to treatment, yet little is known about how Tanzanian parents make these decisions. This qualitative ethnographic study was conducted in Makete District, which has the highest HIV prevalence rate in Tanzania. Seventy participants, including HIV-positive parents, children, healthcare workers, family members, and community-based service providers, were engaged through in-depth interviews, focus group discussions, and participant observation. Data were analysed thematically using NVivo8 software. Findings revealed that disclosure decisions were shaped more by children's maturity than age, alongside factors such as the need for treatment supporters (as recommended in national HIV guidelines), children's suspicions, parents' illness experiences, and HIV education programmes. Parents disclosed seeking emotional and practical support and to normalise HIV discussions within families. These findings suggest that HIV policies should strengthen family-centred counselling, expand HIV education, and provide parents with culturally appropriate communication strategies. Tailored disclosure guidelines can empower families, improve treatment adherence, and reduce stigma in Tanzanian communities.

Introduction

The HIV epidemic remains one of the most pressing global health challenges, affecting millions of people across different regions. (Shimiao & Yiming, 2023). At the end of 2024, an estimated 38 million people were living with HIV globally. Of those, 20.8 million were in Eastern and Southern Africa, and 4.8 million were in Western and Central Africa (Payagala & Pozniak, 2024). In Tanzania, a total of 1.7 million people are currently living with HIV, with 32,000 newly reported cases (Adam & Balan, 2025). While significant progress has been made in biomedical prevention, treatment, and potential cures, the social and psychological realities of living with HIV are far more complex (Darmawan et al., 2023; Mendonca et al., 2022). One such complexity involves the decision of HIV-positive parents on whether to disclose their status to their children. Before revealing, parents often weigh multiple factors. In some cases, non-disclosure leads to extreme coping strategies—such as delaying medication or scheduling medical appointments only when children are absent—due to fears of causing worry, embarrassment,

or even losing respect from their children (Appiah et al., 2019; Dlamini & Matlakala, 2020; Lightfoot et al., 2022).

Existing studies highlight the importance of disclosure. It reduces stigma, promotes open dialogue about illness, and strengthens support systems for parents (Armistead et al., 2022; Lightfoot et al., 2022). Disclosure also enhances communication within families, nurtures harmonious relationships (Goodrum et al., 2021; Schulte et al., 2021), and facilitates custody planning in the event of parental death. Several factors have been identified as influencing parents' decisions, including children's age and maturity (Mugo et al., 2023), the need to educate children about HIV risks (Appiah et al., 2019), disease progression, and parents' desire to clarify their HIV status.

However, most of these insights stem from studies conducted in other countries, where social, cultural, and environmental contexts differ from those in Tanzania. As a result, their applicability to the Tanzanian setting is limited. In Tanzania, research on disclosure has mainly focused on parents' decisions to disclose their children's HIV-positive status (Bajaria et al., 2020; Bulali et al., 2018; Joseph et al., 2022; Msoka et al., 2023). Far less is known about the factors that shape parents' willingness to reveal their own HIV status to their children. This gap highlights the need for research that examines these issues from a Tanzanian perspective. Accordingly, this study seeks to investigate and provide deeper insights into this socio-cultural phenomenon.

Material and methods

Research Design

This study adopted a qualitative ethnographic design, which enabled an in-depth exploration of parents' experiences of disclosing their HIV status to their children within their natural cultural and social context (Nixon & Odoyo, 2020). Ethnography allowed the researcher to immerse themselves in participants' everyday settings and capture the lived meanings they attach to disclosure decisions (Paoli & D'Auria, 2021). A combination of in-depth interviews, focus group discussions (FGDs), and participant observation was used to generate rich, triangulated data.

Study Area and Population

The study was conducted in Makete District, Tanzania, a region with one of the highest HIV prevalence rates nationally (NACP, 2018). Participants included HIV-positive parents who had disclosed their status to their children, the children themselves, immediate family members, healthcare workers, and community-based HIV service providers. Parents and children without a disclosure experience were excluded.

Sampling and Saturation

Purposive and snowball sampling techniques were employed (Nyimbili & Nyimbili, 2024; Barasa, 2024). Seventy participants were recruited: 33 parents, 20 children, 10 family members, three healthcare workers, and four community-based service providers. Data collection continued until thematic saturation was achieved, defined as the point where no new themes or insights emerged despite continued data gathering (Hennink & Kaiser, 2022).

Data Collection

In-depth interviews were conducted with parents, children, and family members to capture retrospective accounts of disclosure. FGDs were held separately for parents and children to ensure children could freely express themselves without parental influence. Parent FGDs were conducted at Care and Treatment Centres and in community support groups, while children's FGDs took place within HIV clubs in child-friendly spaces. Participant observation was used in support groups and

during home visits, allowing the researcher to capture spontaneous discussions about disclosure in natural settings.

Ethical Considerations

Ethical clearance was granted by the University of Dodoma Research Ethics Committee, with additional permission from the Makete District Council. Written informed consent was obtained from all adult participants, while parental consent and child assent were secured for participants aged 12–17 (Mayasari, 2022). To ensure confidentiality, pseudonyms were used, and children's sensitive information was kept private from parents. A partial disclosure approach was used with support groups to reduce bias, while healthcare workers and group leaders were fully informed to facilitate access.

Data Analysis

Data were analysed thematically using NVivo8 software (Lochmiller, 2021). Following Clarke and Braun's (2006) framework, analysis began with familiarisation through repeated reading of transcripts, followed by systematic coding of meaningful data extracts. Codes were then collated into preliminary themes, which were iteratively reviewed and refined to ensure internal consistency and distinctiveness. Each theme was clearly defined and named to capture its essence before final synthesis into a narrative that addressed the research objectives. This iterative and reflexive process enhanced the rigour, transparency, and credibility of findings.

Results

This study sought to examine the factors that influence parents' decisions to disclose their HIV status to their children. Following data analysis, six major themes emerged from the data. These themes are presented in the following sub-sections.

Children's Maturity

Parents universally considered a child's maturity, not age, as the essential factor for disclosure. They found that some older children lacked the mental maturity to follow instructions or be trusted with delicate information. Parents sought not just to inform their children but to gain their social and moral support, which required a mature understanding. As a 29-year-old mother of four explained, this need for reliable support guided their decision:

> When you want to talk to a child, you do not just speak to any child. You choose the one who can listen and understand. In my case, I decided to tell my 10-year-old son first. I know this boy can be helpful and attentive when you tell him things, compared to his older brother. I later told his 14-year-old brother, but it was not immediately.

Another parent from Ndulamo village insisted on this point by saying:

> A child who should be informed about a parent's HIV status should be the one who is mature enough to understand the condition of a parent, regardless of their age. So, when I discovered that I was HIV-positive, I decided to tell my younger daughter, who was 8 years old, knowing that she could understand and offer some help in case I had a problem. I have not yet told my other child, who is 10 years old, because I think he can have some stigma.

Although it was clear in the study that young children did not comprehend very well what HIV is, parents said that they were informed purposely to prepare them so that when they later come to understand HIV well, it would not be surprising to them. Parents were sure that children were expected to know more about HIV as they grew up.

Parent's Illness

The study findings revealed that parents' illness was also a factor that influenced parents to disclose their HIV status to their children. However, only ten out of 33 parents who were referring to illnesses that they had suffered from in the past, mentioned this factor. It was noted that the parents who fell sick decided to have an HIV test, and after confirming that they were HIV-positive, they waited until the symptoms subsided, then they disclosed it to the children. A 38-year-old mother of four children explained this during an interview in Iwawa village:

> When I became very sick, I decided to go and have an HIV test, and I tested positive. Since it was not possible to hide it, I had to tell my children, but I waited for some weeks until my health condition improved because I did not want them to become very worried.

The above narration shows that parents often delayed disclosure until their health improved to avoid frightening their children with the prospect of death. Focus group participants noted that severe illness is now less common due to high HIV awareness, which encourages regular testing and early treatment. As one participant explained, this proactive health approach has reduced the frequency of critical illness. One participant in a focus group discussion at Makete District Hospital premises stated the following:

> It is indeed shameful for one to become bedridden these days; those days have passed. ARVs are provided for free by the Government. The only thing we need to do is adhere to medication. Those people who wait until they get very sick and then decide to go and have an HIV test are probably coming from other places. In Makete, many people living with HIV are healthy and continue with their daily activities, as you can see.

The above narration suggests that many people living with HIV in Makete are not ill or confined to beds. During the study, it was observed that many people were healthy and engaged in various socio-economic activities. Therefore, the researcher had to inquire about the participants' availability at home before visiting and conducting interviews with them.

Need for a Treatment Supporter

Parents often chose their children as their treatment supporters, which influenced their decision to disclose their HIV status. They found that their children were the most reliable for providing support, primarily by reminding them to take medication and attend appointments, and by collecting medicine when parents were unable to do so due to illness or other commitments. Disclosure also allowed parents to take their medication openly. As one 40-year-old father of four stated, this need for support was a key reason for telling their children:

> You know, when you start using ARVs, you must adhere to the dosage. If you don't do that, you can have side effects or drug resistance, which is very bad. So, if you don't disclose to the children, you won't be free to take the medication in their presence or ask your child to help you collect them from the CTC. As for me, I decided to tell them because, firstly, I needed to pick one of them as my treatment supporter and secondly, I knew I needed them to support me in one way or another, especially to remind me to take the medication as I am a human being sometimes

> may I forget especially at times when I travel or spend a night at the funeral (In-depth interview, Bulongwa village).

HIV Education

HIV education was the primary factor influencing parents to disclose their status. Widespread education from the Government and NGOs increased awareness, reduced stigma, and built confidence to disclose. As one man humorously noted, "HIV is just like skin oil, everybody applies it. How can you fear and hide it?" A community health worker echoed this sentiment in a focus group discussion:

> In the past, it was very difficult to convince parents to disclose their status to family members, particularly to children. This is because they feared stigma and rejection or family disintegration; people were not educated enough on the importance of disclosing their status to family members, since there were no care and treatment services or follow-ups for people living with HIV. The introduction of ARVs and education that came along with it has changed the situation, and people are now confident that they can live a long and healthier life, hence making it easy to disclose their HIV status even to their younger children.

Also, children gave their opinions concerning HIV education and how it influenced their parents' decisions to disclose their HIV status to them. A 17-year-old secondary school boy stated the following during a focus group discussion:

> In our community, HIV education is given in so many places, such as village meetings, churches, schools, and hospitals. I believe this has influenced parents to speak about HIV to children without fear because HIV is almost everywhere.

The above narrations from both parents and children indicate clearly that HIV education is an essential factor that influences parents to disclose their HIV status. Table 1 indicates the kind of education that people living with HIV were given and how it influenced parents' decision to disclose their HIV status to their children. These topics were obtained from the CBHS guidelines and the CTC2 patient record form, and were provided through seminars and training by NGOs and CBHSPs during family visits, as well as by healthcare workers at the care and treatment clinics.

Table 1: Education and How it Influenced Parents' Decision to Disclose their HIV Status to their Children

S/N	Topic	Influence on Disclosure
1.	Disclosure and identifying treatment supporter	Healthcare workers encourage parents to disclose their status to a family member who becomes a treatment supporter. Through this process, parents disclose their status to their children
2.	Treatment adherence and monitor therapy: Importance of adherence, how to remind, plan what to do when travelling, sick etc.	Regular clinic visits and daily medication intake necessitated disclosure to children
3.	Home-based counselling and testing	When CBHSPs advise family members of people living with HIV to have HIV tests, a need for parents to disclose their HIV-positive status arose
4.	HIV Prevention	It necessitated protecting children from HIV infection, hence making disclosure inevitable
5.	Programmes for socio-economic strengthening and support	Within support groups, people living with HIV were taught the importance of disclosure, or they encouraged each other to disclose to children
6.	Coping and planning for the future	People living with HIV were encouraged to plan for the future well-being of their children, especially when they become ill; therefore, disclosed in the course of this process
7.	Stigma management	Encouraged parents to disclose because they knew they would not face stigma and discrimination

Source: *CBHS guidelines (2015) and CTC2 patient records form*

Children's suspicion

The study findings revealed that most parents (25 out of 33) decided to disclose their HIV status when children started suspecting that parents had health problems, particularly by observing regular medication intake. It was reported that children often asked their parents about the reasons why they were taking medication daily and went to the hospital even when they did not complain of any sickness. Parents believed that their children's curiosity would lead them to seek information from other family members or friends. Therefore, they disclosed because they wanted to be free to use their medication and wanted to avoid unintentional or forced disclosure. One participant in a focus group discussion at Mafanikio group further explained that:

> You know when children start suspecting things; it is the right time to tell them. They might have overheard you talking to another person or even the home-based care providers who often visit us. I remember how difficult it was to hide and take my medication. One day, my daughter told me that she had been observing me taking medication regularly, and she wanted to know if I had a problem that I was hiding. That was a big question for me. I told her I was not ill, and the following day I decided to tell her the truth. I am now very free; I can even ask her to bring me the medicine.

This finding was also supported by all ten immediate family members who were interviewed to verify the consistency of the information. These family members confirmed having been asked on several occasions by children about their parents' health conditions. The family members explained that they did not openly express what was wrong with their

parents, but instead reported their suspicions to them, who then disclosed the issues. A woman who was living with her elder brother explained the following during an interview:

> My brother tested HIV-positive two years ago, and he did not tell his children. I also kept quiet because I believed he was the right person to do so. Last year, one of his children started asking me if his father was HIV-positive. I asked her why she was saying HIV and not any other disease, and she said that she has been observing him take medication every day and that they were taught at school that people living with HIV are supposed to take medication every day. I told her that I didn't know about that, but later I told my brother that the children were suspecting, and he said he would find time and tell them the truth.

On their part, children (particularly older ones aged between 14 and 17) also said that they had been suspecting that their parents were HIV-positive because of their parents' regular medication intake. A 15-year-old boy explained this during an in-depth interview at his home in Dombwela Street:

> I thought my mother was HIV-positive because I used to see her take medication every day at 8 pm. I had learned that people living with HIV are supposed to be on lifelong medication, so when I started seeing her take the medication, I suspected she was also HIV-positive, although she never told me before. When she later decided to tell me the truth, it was just a confirmation, and I was not surprised.

Another 14-year-old secondary school girl had the following to say concerning his parents' HIV status.

> Three years ago, I saw two cards, written 'CTC1' with my parents' names on top of each other, when I was cleaning their bedroom. At that time, I didn't know what CTC cards were, although I connected them with HIV, but I was not very sure. This is because I noticed other details, such as dates for clinic visits, and I also used to see them go to the hospital every month. One day, I decided to ask my mother about it, and she confirmed to me that they were both HIV-positive.

This study found consistency in the information provided by parents and children, especially when both were interviewed and provided the same information. For example, in one family at Kitulo, a 12-year-old girl had this to say:

> I remember my father used to tell me to bring his medicine every evening. I did that although I never knew the kind of medication he was taking. But as the days went by, I started suspecting he was HIV-positive because my friend had told me that her mother also used to take medication every day, and when my friend asked her, her mother told her that she was HIV-positive. I also thought that my father could have the same problem. One day, I asked him, and he told me he was HIV-positive and that he was supposed to take that medication for the rest of his life.

When the father of the girl was asked to explain why he used to send his little girl to bring him medication every day, he said that he wanted to prepare her psychologically to receive the news about his HIV status.

Children's HIV Status

Parents disclosed their own HIV status as a strategy to reveal their children's positive status. As children on medication grew older and began questioning their constant need for treatment, some started rejecting their medicine. This forced parents to disclose that both they and their children were HIV-positive and required lifelong medication. A mother of an HIV-positive daughter explained this difficult situation:

> My daughter was born HIV-positive, and since then, I have been giving her ARVs. But two years ago, when she turned eight, she started questioning me why I was always giving her medicines even when she was not sick. I then had to tell her the truth that we were both HIV-positive and it is essential that we take the medication every day.

Furthermore, parents explained that they had to use that opportunity of disclosing their children's HIV status also to disclose their own HIV status to encourage them to keep on taking the medication and to train them to go and collect their medication at the CTC. The other reason was that parents wanted to comfort and reassure the children that they were not the only ones suffering from the disease. On their part, all CBHSPs and HCWs also confirmed that they had advised parents to disclose their children's HIV status after realising they were growing up and they needed to know that they were HIV-positive.

Discussion

This study found that parents in Makete disclosed their HIV status to children based on maturity rather than age. Parents believed that mature children could better understand the situation and provide support, even when younger than their siblings. This contrasts with studies suggesting parents should wait until children reach adolescence, reflecting how cultural context shapes disclosure. Children's socialisation, responsibilities, and family roles also influenced how maturity was defined (Seah & Beencke, 2019; Anand & Bharti, 2018; Giddens & Duneier, 2018).

Parents' illness also prompted disclosure, but unlike other studies where disclosure occurred during advanced disease stages (Lightfoot et al., 2022), parents in Makete often disclosed after recovery from opportunistic infections to avoid distressing children. This highlights the role of disclosure as a means of seeking emotional and social support (Lightfoot et al., 2022).

The requirement for treatment supporters, as per national guidelines (URT, 2019), was another major influence. Parents selected children as treatment supporters, so they could understand medication schedules, clinic visits, and prevention strategies. This reflects symbolic interactionist principles emphasising communication and relationships (Wang, 2023) and is consistent with findings from Uganda and Zimbabwe (Nalugya et al., 2018; Lightfoot et al., 2022). However, other studies note that many parents prefer adult supporters due to cultural taboos around disclosing to children (Ashburni et al., 2021; Fortwengel, 2018; Muza & Naidoo, 2023).

HIV education also empowered parents to disclose. Government and NGO programmes increased knowledge, reduced stigma, and promoted acceptance, thereby encouraging openness (Armistead et al., 2022; Lightfoot et al., 2022; Schulte et al., 2021). Conversely, lack of education has been linked to delayed disclosure (Appiah et al., 2019).

Children's suspicions, triggered by observing medication use and frequent clinic visits, were another key factor. Parents disclosed to avoid misinformation or unintended disclosure, echoing findings from Ghana, Kenya, Uganda, and Zimbabwe (Appiah et al., 2019; Lightfoot et al., 2022; Mugo et al., 2023). While some studies caution that suspicion complicates disclosure (Yetti et al., 2020), in Makete it often accelerated the process.

Finally, disclosure of children's HIV status sometimes led parents to reveal their own, creating a supportive family environment and strengthening treatment adherence. This finding aligns with evidence that disclosure is linked to improved medical outcomes and family support systems (Armistead et al., 2022; Sornillo et al., 2023; Wang et al., 2023).

Conclusion

This study highlights that parents' decisions to disclose their HIV status to children are shaped less by age and more by maturity, alongside factors such as treatment support requirements, HIV education, illness experiences, and children's suspicions. These findings emphasise the importance of embedding disclosure support within culturally sensitive, family-centred care models.

Actionable recommendations include integrating structured disclosure guidelines into national HIV care policies that are sensitive to local cultural contexts, training healthcare workers to provide family-centred counselling tailored to children's maturity rather than age and strengthening HIV education through community and school-based programmes to prepare children better and reduce stigma within families.

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