



Disclosure of Parents' HIV Status to Children: A Model Derived from the Experiences of Families in Makete District, Tanzania

Naomi H. Isanzu

The University of Dodoma, Tanzania

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Abstract

The HIV/AIDS literature has indicated that parents' disclosure of their HIV status significantly affects children's behaviour. However, in Tanzania, limited research exists regarding how and when parents should disclose their HIV status to children to minimise or avoid negative outcomes. This paper, based on research conducted in Makete District, explores parents' disclosure of their HIV status, to propose a model to guide the process. The study employed a qualitative ethnographic research design, using in-depth interviews, focus group discussions, observation, and documentary analysis as data collection methods. Data were analysed using NVivo 8 qualitative analysis software after saturation was reached. A total of 70 informants—including 33 parents, 20 children, ten family members, and seven healthcare professionals (4 healthcare workers and three community-based HIV service providers)—were included through purposive and snowball sampling. Informants were selected based on their experience with disclosure or their professional roles in providing HIV services. The sample was determined based on the criteria that parents who had disclosed their HIV status to their children, as well as the professionals who offered services to the parents. The findings suggest that a well-planned disclosure process enhances positive outcomes for children. Consequently, this paper proposes a four-stage model tailored to the Tanzanian context: preparation, the disclosure event, consolation, and the disclosure outcome. This model is intended for use by healthcare professionals to guide parents through a recommended approach for disclosing their HIV status to their children.

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Introduction

Parents' disclosure of HIV status to children has several benefits, including relieving parents' stress, clarifying children's misconceptions about HIV, and improving children's mental health (Mugo et al., 2023; Li et al., 2025). Disclosure can also strengthen parent-child relationships and support communication about HIV, which in turn facilitates custody planning and ensures arrangements for childcare in the event of parents' death (Lightfoot, 2023; Li et al., 2025). Despite its documented benefits, parents' disclosure of HIV status remains challenging, as many parents fear its potential negative impact on children (Mugo et al., 2023; Wang et al., 2025). Parents often express concerns



about shame, unintended disclosure by children to others, moral judgement, and the possibility of encouraging children's premarital sexual behaviour (Bezabih et al., 2023). Additionally, some parents avoid disclosure to protect children from stigma and emotional distress, while others are uncertain about the appropriate timing and approach for discussing their HIV status with their children (Davtyan et al., 2023).

Similarly, the fear that disclosure will affect the parent-child relationship and incidences of behavioural changes in children is reported to hinder parents' disclosure of their HIV status to their children (Bezabih et al., 2023; Mugo et al., 2023). Various studies have also indicated that HIV disclosure can result in negative effects in children such as depression, sadness, behaviours problems, stigma, stressful life events and loss of trust with parents (Li et al., 2025; Veeninga, 2025). Therefore, understanding and executing the disclosure process appropriately is important for ensuring positive outcomes for children, as the disclosure event can lead to undesirable emotional experiences.

Existing models of parents' HIV disclosure, such as the Teaching, Raising, and Communicating with Kids (TRACK) (Schulte et al., 2021); the Disclosure Decision-Making Model, (Greene et al., 2009) the Disclosure Process Model (Chaudoir, Fisher, & Simoni, 2011) have not been tested in the Tanzanian context, where cultural factors shape how disclosure is understood and practiced. This study explored the lived experiences of HIV-positive parents in Tanzania and used the findings to develop a context-specific model to guide parents' HIV disclosure.

Methodology

This study was conducted in Makete District, Tanzania, which has the highest HIV prevalence in the region at 9.5% (NACP, 2018). The district was severely affected by HIV in the 1990s and 2000s, with reports indicating that villagers buried at least one HIV-related death daily (Kessy, 2015), prompting more open discussions to reduce stigma. The study focused on four of the most affected wards: Iwawa, Kitulo, Bulongwa, and Tandala (United Republic of Tanzania, 2018).

The study employed a qualitative ethnographic approach, involving direct engagement with families of HIV-positive parents who had disclosed their status to their children. Children who had been informed of their parents' HIV status, immediate family members, healthcare workers, and community-based HIV service providers (CBHSPs) also participated to share experiences of the disclosure process. In total, 70 informants contributed to the study, including 33 HIV-positive parents, 20 children, three healthcare workers, four CBHSPs, and ten immediate family members, with data collection continuing until saturation was reached (DiStefano & Yang, 2024).

Informants were recruited using purposive and snowball sampling techniques (Dragan & Isaic-Maniu, 2022; Isaac, 2023). Data were primarily collected through in-depth interviews to capture first-hand information in natural settings. Additionally, five focus group discussions (FGDs) with eight participants each were conducted to complement interview data and assess consistency. The first FGD included parents attending Care and Treatment Clinics, while the second involved children meeting at their HIV/AIDS club with a healthcare worker.

The study also employed participant observation to gather in-depth and reliable information on people's interactions and communication in their natural environment. Relevant HIV/AIDS documents were reviewed to enrich the data. Data were analysed using thematic analysis, beginning with familiarisation through repeated reading of transcripts and cross-referencing audio recordings with field notes. Key features were coded, and codes were organised into potential themes, which were reviewed against the original data for consistency. Themes were then defined, refined, and named to accurately reflect the findings. NVivo 8 software was used to facilitate the analysis



(Beekhuizen & Bazeley, 2024). Ethical considerations were addressed by informing participants about the study, obtaining voluntary consent, and conducting interviews in secure, neutral settings through healthcare workers and community-based HIV/AIDS service providers to ensure confidentiality and promote open expression.

Results

This study was focused on parents and children, although other informants, such as immediate family members, health care workers, and community-based HIV service providers, were included to share their views because of their relationships or professional assistance they offered to HIV-positive parents. Table 1 indicates the characteristics of all informants. The majority of parents were between the ages of 35 and 44 years. Only three parents were above the age of 45. Children of at least 6 years were included in the study, based on a recommendation by the World Health Organisation (WHO) guideline on HIV disclosure counselling for children that children of school-going age from 6 years should be informed about a parent's or caregiver's HIV-positive status (WHO, 2011). Regarding marital status, the majority of parents were married and staying together, therefore, this facilitated the consistency of information regarding disclosure processes. Most informants were literate, engaging themselves in farming, small business, and livestock keeping. Generally, more women than men participated in the study. Four main themes emerged from the data. These are preparation for disclosure (including the motivation for disclosure), the disclosure event, consolation, and the outcome. The themes are further described below; to assure confidentiality for the informants, pseudonyms have been provided for each quote.

Preparations for Disclosure

Findings from this study revealed that the disclosure process begins with planning about how to communicate a parent's HIV status, including the factors that motivated parents to disclose and the preparation made prior to the disclosure event.

Motivations for Disclosure

Parents were asked to explain what motivated them to disclose their HIV status to their children. Findings from interviews and focus group discussions (Table 1) indicate that the majority of parents were motivated to disclose their HIV status to their children because they had a positive perception of HIV, and they did not regard it as a terminal disease. This was influenced by the fact that HIV had affected nearly every family and that they no longer feared it. Rama, a father of three, was quoted explaining humorously, *"HIV is just like skin oil; everybody applies it. How can you fear and hide it?"* Moreover, during a focus group discussion with the CBHSPs, one participant stated that:

"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 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."

The other thing which motivated parents to disclose their HIV status to children was to encourage their HIV-positive children to take antiretroviral medications. Parents who had HIV-positive children explained that their children had started refusing to take medications every day, claiming that they were tired and that they were not sick. Because of that, parents had to tell their children that they (the children) were HIV-positive and that the parents were also HIV-positive. This was done as a way of protecting children because their health status would eventually deteriorate if they stopped taking the



medication. Parents were of the opinion that the strategy made it easy for them to have a starting point to disclose their own HIV status.

Moreover, the daily medication intake and frequent hospital visits were reported to make children curious and parents stated that they could no longer hide their HIV status because children kept on asking. Patrick explained the disclosure experience to his daughter as follows:

“My eight-year-old daughter used to ask me why I take medication every day. In the beginning, I would tell her I had a headache or some other ailment, but as the days went by, I could no longer hide my HIV status from her. I just decided to tell her the truth so that she would be at peace”.

Findings of this study also revealed that children’s level of maturity was another criterion that encouraged parents to disclose their HIV status to children. For them, a mature child is one who is understanding and who can listen to and observe parents' instructions. Age was not considered important, as parents argued that some children had grown older in terms of age and physical appearance but were not sufficiently mature or attentive. A mother of four chose to disclose her HIV status to her 8-year-old daughter over her 10-year-old son. She explained:

“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, but not just a grown-up child in terms of age. In my case, 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 his understanding is very low, and I worry he might stigmatise me. I will tell him one day, though.”
Rahel, interview, 2/2/2024

Table 1: Motivations for Disclosure of Parents' HIV Status (N=33)

Motivation	Frequency (N)
Positive perception of HIV	28
Encouraging HIV-positive children to take ARV	9
Children’s curiosity	16
Children’s age and maturity	22

(Multiple responses were possible)

Preparing for Disclosure

Informants who participated in this study suggested that preparation for disclosure (Table 2) was necessary and important to both parents and children. Findings from this study indicated that the majority of parents stated that preparation for disclosure should start with parents making their own decisions to disclose their HIV status to their children. Parents should not be forced by relatives, friends, healthcare workers, or CBHSPs. Hence, decision-making was identified as a key factor in parents’ preparation for the disclosure event. A 23-year-old mother of two argued that:

“The first important thing for a parent to consider when planning to disclose his or her HIV status to the children is to make their own decision. When someone else tells you to disclose, and you are not willing, you can simply not do it, or when you do it, it will not be effective, and the likelihood is that the disclosure event will affect the children psychologically”. Maria, interview, 12/4/2024

This statement was also supported by other parents during focus group discussions. Who, at different times, mentioned parents’ own decisions as key to preparation for disclosure?

Psychological preparation of children was also considered important. Some parents initiated the disclosure process by deliberately displaying their antiretroviral medication or even asking children to bring them so that the children would ask what the medicines were for. By being asked, parents



were able to initiate the discussion and eventually disclosed their HIV status to their children. Parents further mentioned that they did so when they were in good health, so that children would not worry about them. A 27-year-old woman who employed this technique was quoted saying:

"The easiest way for me was to make sure that my children know that I am on long-term medication; so, what I did was to keep them in an open place and take them every day in their presence. One day, my son asked me why I was constantly taking the medication even when I was not sick; I used that opportunity to disclose to all my children that I was HIV-positive. Tamika, interview, 22/3/2024.

The findings of this study revealed that other parents planned the disclosure process by asking their children about HIV so that they would use that opportunity to disclose their status to their children. The interviewed parents stated that they decided to do that in order to find out what children know about HIV and if there were any misconceptions they needed to clarify before they disclosed to them that they were HIV-positive. A 14-year-old girl explained her experience as follows:

"My parents are both HIV-positive; before they disclosed their HIV status to us, I remember they used to ask us to discuss what we had learned at school. We would tell them about other subjects, and they asked us whether we had learned anything about HIV. We said yes and then they asked us to explain what we had particularly learned and then they added more information. They did that regularly and one day as we were talking, they told us that they had something to share with us then our father told us that they were both HIV-positive and had been on medication for more than one year". Shamila, interview, 14/1/2024.

Preparing children for disclosure was also done by parents, encouraging children to listen to and read various materials concerning HIV. The findings of this study revealed that parents decided to bring home brochures for their children to read in the hope that they might learn a few things before they disclosed their HIV status to them. In this study, 12 parents reported using this approach. For example, a 29-year-old widower of two daughters and one son explained the following during an interview:

"I used to give my children some brochures to read as I came from the CTC. One day, I called them and wanted to discuss the contents of one of the brochures. In the middle of a discussion, I asked them, this question: What, if one of us was HIV-positive? and we discussed what that would mean to all of us. The elder daughter answered, "If one of us were HIV-positive, it would not be difficult because treatment is available, the infected person will be okay ... Then I told them, well, I am HIV-positive. Rhoda, interview 4/4/2024.

Findings also revealed that parents prepared for the disclosure event by seeking professional advice from either healthcare workers or community-based HIV service providers. Parents reported that, in addition to guidance from personal and social interactions with their children, they sought advice to help them communicate with their children; however, health professionals were not involved in the disclosure. A healthcare worker confirmed this during the interview:

"We always advise parents to disclose their HIV status to their children because, at some point, the children would need to know it, and we feel that the information should come to them. If children are told by their parents, it is easy for them to understand their parents' language and soothing words if negative emotions arise during the process" Interview, 30/3/2024

Table 2: Preparing for Disclosure (N=33)

Preparations made	Frequency (N)
Parent's decision-making	33
Preparing children psychologically	33
Seeking professional advice	12

(Multiple responses were possible)



The Disclosure Event

Findings of this study have revealed that the majority of parents embarked on a disclosure event after making preparations, i.e., ensuring they were ready to disclose and had prepared their children for disclosure. Most of the parents explained that they told their children openly that they were HIV-positive and did not other chronic diseases. Rama illustrated this in the following excerpt:

“When I decided to disclose my HIV status to my children, I was very direct and mentioned that I am HIV-positive. My wife and I had agreed that we were not going to hide anything. Being open to children is important because it will help them to protect themselves against HIV infections”. Interview, 11/1/2024.

The healthcare workers and community-based HIV service providers also stated that they had advised parents to tell children the truth by clearly mentioning that it was HIV. On their part, children whose parents disclosed their status to them confirmed that their parents mentioned to them that they were HIV-positive. A conducive environment was also mentioned to be an important factor to consider during the disclosure event. The majority of parents who participated in focus group discussions explained that the disclosure event took place at home when children were relaxed, and they approached it as a casual conversation. The aim was to ensure that children were comfortable while receiving the information about their parents’ HIV status in order to minimise negative outcomes thereafter. A mother of four explained this during an interview:

“You know, disclosing an HIV status could be an emotional experience for children; so, home is a very good place to talk to them, especially when they have already had dinner. You cannot talk to a child who has just come home from school and is hungry. You must choose the environment which is conducive, and you are sure that they will listen and understand or ask some questions for you to clarify. Generally, the place must provide a space for a fruitful conversation”. Stella, interview, 25/4/2024.

Moreover, parents and family members emphasised the importance of considering social and cultural values during this stage, particularly the choice of words where sexual-related terms were discouraged. This was explained by Sam during a focus group discussion:

“You know, these days there are a lot of radio programmes that broadcast issues about HIV, and we know our children do listen. It is just that it is not in our culture to talk about sexual-related issues with young children because of the misconception that HIV is transmitted through sexual intercourse. So, when we want to disclose, we give them the information that we can easily discuss with them and we increase the dose as they grow up”. Interview, 15/2/2024.

Parents emphasised that choosing the right time for disclosure, preferably when they were in good health and during positive family moments, helped ensure children were not distressed and minimised potential negative effects, as illustrated by a father who had been on antiretroviral therapy for two years.

“In my case, I was very careful and observed the right time to talk to my children. I remember it was on a Saturday evening, when everybody had finished their activities, and we were in the sitting room, that I opened up to them. It was actually in the middle of a normal conversation. I didn’t want to make it very formal as I knew they would be worried. Peter, interview, 15/2/2024.



Consolation

The study found that after each disclosure, parents reassured their children that they were not at risk because they were taking antiretroviral medication and allowed the children to express their feelings. Parents further explained that the disclosure aimed to help children understand and cope rather than cause negative effects. A parent was quoted saying this:

“After I disclosed my status to them, I had to take some time again to comfort them and tell them to relax, as nothing bad would happen to me. You know, you cannot break such news to the children and expect them to go outside and play happily as if you have not said anything”. Sarah, interview, 4/4/2024

The majority of parents who participated in this study explained that they needed to make sure that they gave children some kind of emotional support and ensure that they coped well. The Study findings also indicate that other parents continued to monitor their children's behaviour and social interactions for some time to see whether they were living a normal life after the disclosure event.

Outcomes of Disclosure

Parents reported that preparation for the disclosure was helpful and contributed to positive outcomes for children. This is because disclosure was a process and did not occur in a single day. Moreover, parents were careful to choose the appropriate time and a conducive environment for disclosure. Judy explained:

“Before I told my daughter that I was HIV-positive, I was a bit worried about how she would receive the news, but I was surprised by how she received the news; she thanked me for telling her the truth about my status. Interview, 13/3/2024

Children who participated in this study reported that disclosure was beneficial, as it helped them understand their parents' condition and take care of them when necessary. This was confirmed by Rebecca, a 17-year-old secondary school girl who commented the following:

“My mother and I are like good friends, but I feel the friendship has become stronger after she disclosed to me her HIV status. Her act of confiding in me gave me a reason to be closer to her”. Interview, 16/4/2024

During the interviews and focus group discussions, informants also confirmed that a well-planned disclosure process enhances positive outcomes for children. The five stages of the disclosure are summarised in Table 3.



Table 3: Stages for Disclosure of Parents' HIV Status to Children

Stages	Informants' Suggestions
Preparations for disclosure	<p>Parents should consider what motivates them to disclose:</p> <ul style="list-style-type: none"> - Parents' positive perception toward HIV - Encouraging children to adhere to ARVs - Children's age, and maturity - Pre-disclosure preparation - Parents' autonomous decision-making - Preparing children psychologically - Seeking professional guidance for planning
Disclosure event	<p>Things to consider during the disclosure event:</p> <ul style="list-style-type: none"> - Be clear: explicitly state it is HIV - Choose a private, supportive environment (e.g., home) - Use age-appropriate language - Consider children's age and maturity - Approach disclosure as a calm, normal conversation - Disclose at the right time: when parents are healthy and during positive family moments
Consolation	<p>Support and Reassure Children</p> <ul style="list-style-type: none"> - Reassure children that HIV is manageable and not a death sentence - Allow children to express their thoughts and feelings about the disclosure

The Proposed Model

The proposed model (Figure 1) contains four interrelated stages for effective disclosure of parents' HIV status to children: The preparation stage, disclosure event, consolation, and disclosure outcomes. It is proposed that those stages are taken into account for disclosure to be effective. These stages are explained in detail in the following sections.

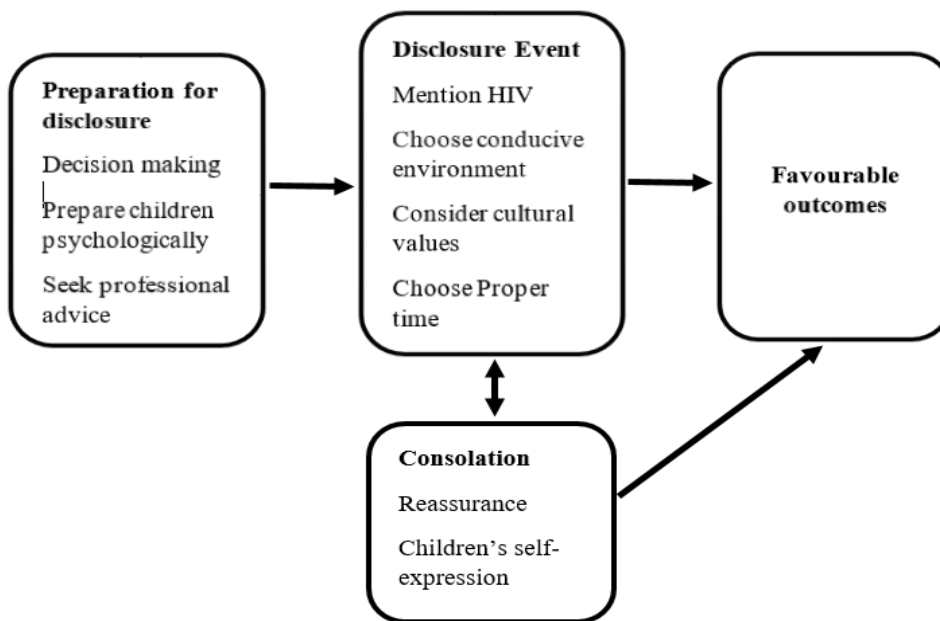


Figure 1: A proposed model for Disclosure of Parents' HIV Status to Children



Explanations for Stages of the Model

Preparation

Successful disclosure largely depends on careful planning from start to end. Parents must prepare themselves and their children, assess their motivations, and make their own decisions to disclose. The study also highlighted the importance of seeking guidance from health professionals, as disclosure may trigger negative emotions such as sadness or anxiety, and professional advice can help parents manage potential psychological effects before disclosing to their children.

Disclosure Event

This stage involves parents informing their children that they are HIV-positive, ensuring the message is clear and accurate. The findings highlight that effective disclosure requires consideration of the social and cultural context of parent-child communication, as well as careful selection of information appropriate to the child's age and maturity.

Consolation

Parents play a key role in addressing children's reactions during disclosure by reassuring them that HIV is manageable and that one may live a longer, healthier life. Disclosure should be accompanied by ongoing communication that allows children to express their thoughts and concerns.

Outcomes of Disclosure

The outcome refers to results emanating from the whole process of disclosure, including how disclosure is planned and executed. The findings of this study have established that when disclosure is well-planned by observing the stages in the proposed model, the likelihood is that favourable outcomes will be manifested. It is therefore hoped that this model will be useful for that purpose.

Discussion

This study described the entire HIV disclosure process from the preparation to the disclosure of a parent's HIV status. The proposed model incorporates four stages that span the HIV disclosure process: preparation, disclosure event, consolation, and outcome. Previous proposed models in literature such as the four-phase model (Blasini et al., 2004), and the TRACK HIV Disclosure Intervention model (Armistead et al., 2022) are specific for preparing children for disclosure of their own HIV statuses while other models guide the disclosure of parents' HIV status to children and/or disclosing HIV status to infected children (Gachanja & Burkholder, 2016). The models that specifically guide the disclosure of parents' HIV status to children (Armistead et al., 2022; Dlamini & Matlakala, 2020; Kitetele et al., 2023; Mugo et al., 2023) are structured differently and do not reflect the socio-cultural context of Tanzania. The proposed model is appropriate for parental HIV disclosure in Tanzania, as it emphasises direct disclosure by parents to their children, prioritising the parent-child relationship rather than involving third parties such as healthcare professionals or relatives.

This model emphasises the importance of careful preparation for parents' HIV disclosure, as unplanned or inappropriate disclosure has been linked to negative consequences (Veeninga, 2025). Findings from this study, consistent with Li et al. (2025), Wang et al. (2023), and Kirabira et al. (2025), indicate that well-planned, parent-driven, and culturally appropriate disclosure leads to more positive outcomes for children. These results further align with Symbolic Interactionism Theory (Blumer, 1986), which emphasises the role of shared meanings, communication, and cultural context in shaping parent-child interactions and disclosure processes.

Effective disclosure requires parents to provide clear and accurate information that children can easily understand. In this study, parents explained that they openly stated that they were HIV-positive



without disguising the condition as another illness. This finding is consistent with Mugo et al. (2023), who noted that parents used explicit terms such as “HIV” or “virus” during disclosure. The study also found that disclosure was most effective when conducted in a supportive environment, preferably at home during positive family moments. Similarly, other studies have shown that parents preferred to disclose their HIV status at home, often in the presence of family members (Lightfoot et al., 2023; Mugo et al., 2023), while still wanting to disclose personally rather than through another person (Bojo et al., 2025; Fikadu et al., 2024; Kairania et al., 2023).

Moreover, the study found that parents’ health status was a key consideration in HIV disclosure, as illness was perceived to negative reaction among children who might fear parents’ death. Consistent with Li et al. (2025) and Lightfoot et al. (2023), parents preferred to disclose when their health had improved. In contrast, other studies report that disclosure during illness led to emotional distress in children (Msoka et al., 2025; Ramsammy & Galvin, 2023). Accordingly, parents in this study delayed disclosure until they were in good health. The study also found that parents deliberately set aside time to console their children after disclosure, with the aim of reassuring them, encouraging emotional expression, and minimising negative outcomes. This practice aligns with the Disclosure Process Model (2011), which emphasises reducing negative effects and maximising positive outcomes for both parents and children following disclosure.

The study found that parents’ disclosure of HIV status generally resulted in favourable outcomes for children due to careful planning and effective execution of the disclosure process. Participants also reported reduced fear of HIV and diminished community stigma, indicating that social perceptions of HIV contributed to positive outcomes for children. This aligns with the Social Construction of Reality Theory, which posits that meaning is shaped by shared social experiences (Berger & Luckmann, 1967). Accordingly, well-planned disclosure that respects cultural context is more likely to produce positive outcomes for children. To assess its practicality, the model was validated by training healthcare workers to implement it with a new group of parents attending the care and treatment clinic.

Limitations

The study encountered logistical challenges in recruiting children in the study as many were often away for school or recreational activities. This was addressed by building rapport with parents and community-based HIV/AIDS service providers to schedule interviews at convenient times. FGDs were coordinated with healthcare workers managing clubs for children living with HIV/AIDS to ensure a representative sample. These efforts created a safe and organised environment for data collection, allowing the study to achieve its objectives despite initial accessibility challenges.

Conclusions

The study highlights the importance of parents’ active role in disclosing their HIV status, indicating that careful planning, cultural sensitivity, and supportive environments lead to positive outcomes for children. It is recommended that this model be integrated into Community-Based HIV/AIDS Services (CBHS) guidelines and the CTC2 patient record form to provide healthcare workers and counsellors with structured guidance, enhance follow-up protocols, and better support parents through the disclosure process.



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