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Parents' Approaches to HIV Disclosure in Dodoma, Tanzania: A Phenomenological Study

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Abstract
This phenomenological study explores the approaches used by parents to disclose their HIV status to their children. It investigates the lived experiences of 11 parents living with HIV who attend a care and Treatment Clinic (CTC) at the Dodoma General Referral Hospital, Tanzania. Data from semi-structured interviews were analysed using Colaizzi's method. The findings indicate that disclosure is an intentional, staged process that involves managing content, context, and timing. In their disclosures, parents used both direct verbalisation and gradual prompts, such as showing medication, treatment cards, or brochures, and preferred to do so at home during 'happy family moments' to minimise their children's emotional distress. Although parents go through this process on their own because of the lack of formal professional guidance, reliance on trial and error increases the possibility of psychological distress. In response, this study calls for a shift towards longitudinal, family-centred counselling and the standardisation of guidelines. By capitalising on peer-led mentorship and home-based support, disclosure could be made a well-structured transition that reinforces family resilience.

Introduction

The advancement of Antiretroviral Therapy (ART) has made HIV a manageable chronic condition, enabling parents living with HIV to live healthy lives and care for their children. However, studies indicate that a psychosocial dilemma persists regarding parents' disclosure of their HIV status (Yassin et al., 2020). Parents are reported to fear shame or stigma, while others struggle with how to approach the disclosure (Wang et al., 2025). For many parents, the decision to disclose their HIV status to their children is not a single event but a thoughtful and often distressing process (Sun et al., 2020). The literature indicates that parents use different approaches to disclose their HIV status to their children, depending on their social and cultural backgrounds, which shape parent-child interaction and communication (Dlamini & Matlakala, 2020; Mugo et al., 2023). Some parents disclose at home, during a special meal or a favourite family activity, while others need professional support or other trusted adults to initiate conversations about HIV before they can disclose (Lightfoot et al., 2023). In other cases, parents disclose their HIV/AIDS status gradually, whereas others disclose it all at once (Goodrum et al., 2021; Sun et al., 2020).

Despite the growing body of quantitative research on disclosure rates, there remains a significant gap in understanding the subjective, lived experiences of parents approaching the disclosure event. Although it is generally acknowledged that parents' disclosure of their HIV status to their children is

important (Mugo et al., 2023), the manner in which parents disclose their HIV/AIDS status to their children remains unknown in Tanzania. Consequently, as reflected in other studies, this may lead to inappropriate disclosure and negative effects on both parents and children (Goodrum et al., 2021). Therefore, this study aimed to bridge the existing gap by exploring the approaches currently used by parents to disclose their HIV status, examining parents' lived experiences of disclosing their HIV status to their children, identifying contextually grounded support strategies for parents, and generating evidence to guide the design of family-centred disclosure interventions.

Theoretical Underpinnings of the Study

This study is theoretically grounded in Symbolic Interactionism and the Social Construction of Reality. Symbolic Interactionism posits that individuals act toward things based on the meanings they assign to them, which are shaped through social interaction (Schwalbe, 2020). In this study, parents' use of symbols, such as strategically displaying ARV medication and treatment cards or sharing HIV educational brochures, serves as nonverbal language intended to prepare children for the disclosure event. The Social Construction of Reality Theory posits that reality is constructed and maintained by members of a given society through shared meanings (Dreher, 2023). This is reflected in how parents conceptualise the appropriate timing and context for disclosure. The combined theories, the theories provide a framework for understanding how parents manage HIV disclosure.

Methodology

Design

The study employed a phenomenological design as it provides a foundation for understanding individuals' lived experiences (Dodgson, 2023). By focusing on the meanings and interpretations individuals assign to their experiences, the study offers a comprehensive understanding of their subjective realities. Phenomenology recognises that experiences are not objective facts but subjective interpretations shaped by cultural, social, and historical contexts (Dibley et al., 2020). This perspective allows for a deeper examination of the complexities of individuals' experiences, thereby enriching the research findings. Guided by this design, the study seeks to capture parents' lived experiences and the meanings they ascribe to their approaches to disclosing their HIV status to their children.

Sample and Sampling Procedures

In this study, 11 participants were purposively selected based on their experience with the phenomenon under study. In line with qualitative research principles, the sample was determined by data saturation, when interviews no longer provided new information related to parents' approaches to disclosing their HIV status to their children (Squire et al., 2024).

This study involved parents living with HIV, attending a care and treatment clinic (CTC) at the Dodoma General Referral Hospital, Tanzania. Using purposive sampling, the study enrolled participants specifically meeting the inclusion criterion of HIV status disclosure to their children. Additionally, snowball sampling was used, whereby initial participants referred other eligible parents within their social networks (Dragan & Isaic-Maniu, 2022). This approach was particularly useful given the sensitivity of HIV disclosure and facilitated access to participants who might otherwise have been difficult to reach. Children were excluded from this study; it focused solely on parents' lived experiences and the disclosure approaches they used with their children.

Data Collection Method

This study utilised semi-structured interviews as the primary data collection method to capture participants' lived experiences of the phenomenon under study (Henriksen et al., 2022). To ensure data integrity and nuance, interviews were audio-recorded, enabling verbatim transcription and the preservation of emotional tone. Complementing these recordings, reflexive field notes were maintained to document the researcher's observations, non-verbal cues, and personal reflections. This multifaceted approach aligns with qualitative and phenomenological traditions, in which the researcher's self-awareness is considered vital to the interpretive process.

Data Analysis

Data analysis followed Colaizzi's phenomenological framework, involving a seven-step iterative process to extract meaning from the interviews (Praveena & Sasikumar, 2021): (1) Familiarisation by listening to the interview audio, transcribing it, and reading it to grasp the message's meaning; (2) Extracting all significant statements from the transcripts and compiling a comprehensive list relevant to the phenomenon under investigation; (3) Formulating meanings through interpretations derived from all the significant statements provided; (4) Arranging the developed meanings into themes; (5) Integrating the themes to provide a comprehensive picture of parents' experiences of disclosure approaches; (6) Making a clear statement regarding the comprehension of this phenomenon, considering the setting and context. (7) Communicating with the participants to confirm the alignment of their experiences. Since the participants did not provide additional information during this phase, the researcher used direct quotations to contextualise the results while maintaining confidentiality by using pseudonyms.

Rigour

To ensure the quality and trustworthiness of the findings, this study adhered to Lincoln and Guba's (1985) framework, as outlined by Gunbayi (2024). Credibility was established through member checks and peer probing to verify participants' lived experiences, while transferability was facilitated by providing thick descriptions of the setting and participants. To maintain consistency, a detailed audit trail was documented to allow future researchers to follow the inquiry process. Finally, neutrality was achieved by bracketing prior assumptions, ensuring the findings emerged strictly from the data rather than the researcher's bias.

Ethical Issues

Permission to conduct the study was granted by the research and training committee of the Dodoma General Referral Hospital, and permission to access participants at the CTC was obtained from the Medical Officer in Charge, who had previously obtained initial consent for participants to be contacted. A second stage of informed consent was conducted at participants' homes, where they were informed of their right to withdraw from the study at any time. This ensured participants felt comfortable discussing the topic in a private setting, free from the perceived pressure of the hospital environment. To protect anonymity, pseudonyms were assigned. Data security was maintained by encrypting all interview recordings and transcripts, with access restricted solely to the researcher to ensure confidentiality.

Results

This study aimed to explore parents' lived experiences and the specific approaches they used when disclosing their HIV status to their children. During data collection, three major themes emerged: (i) the content of HIV disclosure, (ii) the context of HIV disclosure, and (iii) the timing of HIV disclosure. These themes and their respective responses for each are presented in Table 1.

Table 1: Responses on the Approaches for Parents' HIV Status Disclosure

Approach	Type of Response
Content	-Mentioning HIV -Displaying medication or treatment cards -Questions and answers session with children -No sexually related message to young children -Reading HIV materials -Make disclosure a casual conversation
Context	-Home -Away from home -At a private place
Timing	-One to two weeks after the HIV test -Three to four months after the HIV test -Evening hours -When parents are in good health condition -When children start asking questions about their parents' medication intake -During family happy moments

Source: *Primary data, parents' approaches to HIV disclosure in Dodoma, Tanzania: A phenomenological study, 2025.*

The Content of Parents' HIV Disclosure

The content explained the message regarding parents' HIV status and how it was delivered to children. In this study, parents reported being direct and mentioning that they were HIV positive; although they described details considering the age of the children. Fred, a 31-year-old father of three, stated:

> "When I decided to disclose my HIV status to my children, I planned the message I was going to give them in advance. 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" (2/5/2025).

Other parents approached disclosure by strategically displaying their antiretroviral medication (ARVs), or treatment cards, hoping it would prompt questions. Others prepared question-and-answer sessions on HIV to introduce the subject directly. Sarah, a mother of two, explained the following regarding the display of ARVs:

> "When I tested HIV-positive, I considered how to disclose my status to my children, so I decided to leave my antiretroviral medication in places where my children could see it, hoping that would spark their curiosity and prompt them to ask questions, making it easier for me to start the conversation" (28/4/2025).

To make it easier for parents to disclose their HIV status to their children, they also explained that they brought home brochures containing HIV messages for their children to read. In this study, 6 parents reported using this approach. For example, a 39-year-old widow with two daughters described the following during an interview:

> "I used to give my children brochures to read as I came from the CTC. One day, I called them to discuss the contents of the brochures. In the middle of the discussion, I asked them this question: What if one of us is HIV positive? We discussed what that would mean to all of us. The elder daughter answered, "If one of us is HIV positive, it would be difficult, but now that treatment is available, the infected person will be okay ..." Then I told them, well! I am HIV positive" (Amina, 1/5/2025).

This was supported by another participant who said that:

> "You know, with technology these days, children can easily access information about HIV. We also keep brochures and other materials at home that explain HIV transmission, prevention, and related matters. So, no matter how young the children are, as long as they can read and write, they can easily grasp the message." (Albert, 22/04/2025).

The above narrations clearly reflect that the parents employed a range of intentional approaches, from direct verbal disclosure to the use of visual cues and educational tools, to navigate cultural sensitivities and facilitate a manageable disclosure of the parents' HIV to their children.

The Context of Parents' HIV Status Disclosure

The disclosure context examined the environments in which parents disclosed their HIV status to their children. Results indicate that most parents chose to disclose this information at home during suppertime. A 44-year-old man explained the following in the interview:

> "Home is a good place to talk to children, especially after they have eaten. It is difficult to have a productive conversation with a child who is hungry and has just arrived home from school. You need to choose a comfortable environment where you're sure they will listen, understand, and feel free to ask questions. The ideal space should encourage open communication" (Hassan, 30/04/2025).

During the study, only three parents reported disclosing their status away from home. This was described by a 35-year-old mother of five during an interview:

> "I decided to take my children to a quiet restaurant away from home to tell them about my status. I felt that being away from the daily distractions of home would give us the privacy and peace we needed to process the news together without interruption."

Generally, all 11 parents who participated in this study confirmed that they ensured privacy while disclosing their HIV status to their children.

The Timing of Parents' HIV Status Disclosure

This theme indicates the timing of the disclosure. The findings revealed that disclosure timing varied among parents, ranging from days to months. While most parents took some time, those who disclosed immediately argued they wanted the emotional freedom associated with open communication, especially regarding their daily medications. For example, a single mother of two explained the following during a home interview.

> "I didn't wait long. As soon as I found out I was HIV-positive, I told them. I remember it was two days after the test. I told them straight away so they wouldn't be surprised when they saw me taking medication every day" (Nadia 23/04/2025).

Regarding hours in the day, most parents preferred to disclose in the evening, arguing that this allowed children time to process the information overnight and that they might wake up with a clearer mind. Only 2 parents mentioned disclosing in the afternoon, after their children had returned from school. A 36-year-old father of three children argued that:

> "You cannot tell a child that you are HIV-positive in the morning. Children might have questions or things to say, so they shouldn't have to rush to school right away. I believe evening is the best time" (Kennedy, 26/4/2025).

Regarding situations or events, all parents reported considering their own health when choosing an appropriate time for disclosure. Additionally, all parents who participated in this study preferred

disclosing their HIV status to their children during happy family moments. To illustrate this point, a single mother of four children stated that:

> "When you want to talk to a child about your HIV status, timing is important. You shouldn't talk to an upset child after they fail an exam or fight with a friend. The child must be in a good state of mind and ready to receive the news." (Paula, 2/5/2025).

Parents generally reported lacking assistance and specific guidelines for disclosing their HIV status to their children. They received advice from various sources, such as family members, friends, healthcare workers, and community-based HIV service providers, but none offered specific guidance on navigating the disclosure process.

Discussion

This study explored the lived experiences of parents living with HIV regarding the approaches used in disclosing their HIV status to their children. Findings revealed that parents employed various approaches, differing in content, context, and timing. Parents primarily disclosed their HIV status independently, without assistance from relatives or healthcare workers. However, other studies have indicated that children were informed indirectly by other family members or non-family social networks or through accidental means, i.e. unintentional disclosure (Mitchell et al., 2022).

The Content of Parents' HIV Status Disclosure

The study findings revealed that communication patterns between parents and children facilitated better understanding of the message. Parents' mood state during disclosure, along with how they sequenced the message, guided the communication. This finding aligns with Lightfoot et al. (2022) and Sun et al. (2020), who also observed that open communication between parents and children supports effective parents' HIV disclosure. In contrast to other studies (e.g., Dlamini & Matlakala, 2020), where parents used euphemisms such as "blood disease", "blood is not clean" or "parent is sick", participants in this study directly mentioned HIV during disclosure, adopting a gradual approach by revealing information in stages rather than all at once. This involved displaying medication or treatment cards and asking children questions about HIV before the disclosure event: a strategy aimed at preparing their children psychologically and allowing parents to decide what and how much to disclose. This finding aligns with previous research suggesting that disclosing information in stages helps children better absorb news, experience less negative impact, and retain information more effectively. (Guta et al., 2023). Similarly, Mugo et al. (2023) and Lightfoot et al. (2022) found that parents employed a gradual disclosure process, sharing information about their status in ways that aligned with their children's age and maturity.

Furthermore, asking children questions about HIV was reported to be used as an approach to initiate conversations with their children, as also reflected in a study conducted by Bajaria et al. (2020). Consistent with Wang et al. (2025), other parents decided to prepare their children psychologically before disclosing their HIV status to them, by letting them read brochures containing HIV messages, then gradually discussing the information with their children at home. In other cases, parents deliberately left their ARV medications in an open space for their children to notice and ask about the medications, which provided a natural opening for parents to discuss HIV and disclose their status. While parents in this study used medication display as a disclosure approach (Lightfoot et al., 2022), they found a contrasting pattern: some participants reported skipping medication to avoid raising their children's suspicions.

Parents further reported that the information was structured differently depending on the children's ages. For young children, communication about sex was concealed as sex-related matters were

inappropriate for that age group. This is similar to Maina et al., (2020), who emphasised interactive communication about HIV with adolescents but not with young children. This finding suggests that in African culture, parents often find it challenging to discuss sexually related issues with their young children. As a result, many educational programs on HIV and young people have focused on delivering sexual and reproductive health messages through schools rather than directly from parents (Jumini et al., 2023; Triana et al., 2023).

The Context of Parents' HIV Status Disclosure

In this study, the term 'context' referred to both the physical and social environments in which the disclosure event occurred. In sociology, as noted by Dilbarkhon (2021), the social environment encompasses human interactions that shape communication among people within their social and cultural contexts. Parents reported that disclosure occurred either at home or away from home. The home environment was considered ideal for disclosure, as parents reported that children were consistently relaxed when discussing sensitive matters with them. Similar patterns of disclosure within the home environment were observed in Kenya by Mugo et al. (2023). Parents further explained that they preferred to disclose during meals, as children were attentive when there was no other activity to divert their attention. Furthermore, parents reported that disclosure occurred at home or away in a private setting, as Dlamini and Matlakala (2020) and Guta et al. (2023) also reported. In line with this, disclosure occurred naturally within everyday conversations. Parents explained that they avoided scheduling special meetings to ensure children received the news while calm. However, they prepared children psychologically beforehand by talking about HIV regularly. Similarly, studies by Armistead et al. (2022), Goodrum et al. (2021), and Lightfoot et al. (2023) found that parents integrated disclosure into everyday family conversations to facilitate communication and empower children to cope effectively.

The Timing of Parents' HIV Status Disclosure

The study also found that timing was considered an important factor in parents' disclosure of their HIV status to children. Time was described not only in terms of days, hours, and months but also conceptualised and interpreted as moments deemed appropriate for disclosure by parents. This aligns with the social construction of reality theory (Berger & Luckmann, 1967, as cited in Dreher, 2023), which posits that reality is created and maintained by a group through ongoing interaction within their social context. In this respect, the timing in this study is discussed in terms of parents' conceptualisation of time and the shared meanings and experiences that constitute reality.

Findings indicated that parents took varying lengths of time to disclose their HIV status to children. Some disclosed immediately upon diagnosis, while others took longer, from one week to four months. Compared with other studies, the disclosure time in this study appeared shorter. For example, Goodrum (2021) and Armistead (2022) reported that mothers living with HIV disclosed their status after 15 months. Mugo et al. (2023) found that parents generally disclosed after a median of two years post-diagnosis. Lightfoot et al. (2022) did not specify an exact timeframe, focusing instead on waiting until children were old enough to understand, while Kumar (2023) reported that parents often delay disclosure due to fear of stigma.

In this study, parents who did not disclose immediately explained that they valued having sufficient time to prepare. According to them, the preparations included educating themselves more about HIV, joining support groups, observing instructions provided during adherence counselling and preparing the children for the disclosure event. The findings from this study have shown that the best time for parents to disclose their HIV status to their children was during family happy moments. Parents reported that disclosure was easier when both children and parents were happy, compared with

stressful moments such as deaths or fights. While a study by Da et al. (2024) also revealed that parents often disclose their HIV status to children during special family moments, aiming for a stress-free environment, Kring et al. (2024) offer a contrasting perspective, suggesting that disclosure should occur after important life events, rather than being tied specifically to happy moments.

Moreover, parents reported that the best time for disclosure was when they were in good health. They considered this appropriate because they believed it was easier for children to hear the news when their parents were well, so children would not be shocked, as also reported by Mugo et al. (2023), who noted that parents waited until they were in good health, believing it would be less frightening for the children. During the interview, parents who disclosed while ill reported that their children experienced moments of sadness, but these resolved over time. This was also indicated by Lightfoot et al. (2022) and Ramsammy et al. (2022), who found that when parents reveal their HIV status to their children during times of illness, the children often experience emotional distress. However, participants in this study reported that ARVs have improved their health, thereby simplifying disclosure.

The findings of this study indicate that the best time for parents to disclose their HIV status is when children start asking questions about their parents' health conditions and daily medication intake. When such questions arise, parents reported that disclosure became easier, as Mugo et al. (2023) also noted. The concept of time also indicated suitable hours of the day for parents to disclose. In this study, most parents reported that evening hours were appropriate because children had returned from school or had completed other household activities, allowing them to talk while relaxing.

Limitations

Several limitations were identified in this study. From a methodological point of view, although the phenomenological design provided deep insights into various aspects of the participants' lived experiences, the study was limited because participants were recruited from a single care and treatment clinic, which may not be representative of all parents living with HIV in Tanzania. Moreover, because the quality and richness of data derived from the phenomenological design are strongly influenced by participants' ability to express their feelings, the study may reflect the experiences of more articulate participants, potentially overlooking the perspectives of those who found the disclosure process too distressing to describe in detail. Secondly, the study relied on retrospective self-reporting, which may be subject to recall bias, whereby participants could have rationalised their conduct more than it was performed. Moreover, because the study was conducted in the home environment, participants may have exhibited social desirability bias, overreporting "happy family moments" rather than more difficult experiences. In addition, as the study focused exclusively on parents' perspectives, the children's lived experiences and emotional reactions remain unexplored. Other studies may focus on the children's perspectives.

Conclusion

This study demonstrates that parents' HIV disclosure is a phased process that considers message type and delivery (content), context, and appropriate timing. However, there is a gap between clinical care and home reality; the absence of structured professional guidance leaves parents to rely on trial and error, which increases the risk of inappropriate disclosure and psychological strain. Strengthening family-centred care and peer-led support is essential to transform the disclosure event into a structured, supportive process that builds family resilience.

Recommendations

To bridge the gap between clinical care and the home environment, healthcare providers should move from an episodic counselling model to a longitudinal, family-centred support strategy. Such frameworks empower parents to identify and implement the most socially, culturally and developmentally appropriate approaches to disclosure over time. Furthermore, the Ministry of Health and Social Welfare should standardise national disclosure guidelines that incorporate parents' lived experiences, specifically focusing on how and when parents can effectively disclose their HIV status, and on leveraging support groups where disclosed parents can mentor others. Finally, future interventions should include home-based support from trained community health workers to provide a safety net within the preferred home context, ensuring that disclosure becomes a constructive process that strengthens family resilience rather than a source of distress.

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