

“What If He Tells Others”: Negotiating Disclosure of Children’s HIV-Positive Status Amid Stigma in a South African Rural Community

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Abstract

In this study, we explore how HIV-related social stigma in a South African rural township community informs parents’ and caregivers’ decisions to disclose their children’s HIV-positive status to them. To achieve the aim of the study, we conducted qualitative in-depth interviews with 12 parents and caregivers of HIV-positive children between the ages of seven and 14 years in a rural area based in Mpumalanga in South Africa. We found that, despite the development in HIV education across the country, HIV-related stigma is prevalent at a social level in rural townships and serves as a barrier to disclosing children’s HIV-positive status. We established that the parents and caregivers use “passing” as a stigma management strategy where they conceal their children’s HIV-positive status from them and instead tell them that they are infected with less stigmatised medical conditions such as asthma and tuberculosis. Based on these findings, we argue that, although education on HIV is widespread in South Africa, HIV-related stigma is still prevalent in some rural townships. This stigma compels parents and caregivers to avoid disclosing their children’s HIV-positive status to them and instead employ stigma management strategies that will maintain the concealment of their children’s HIV status.

Keywords: disclosure; HIV; children; stigma; South Africa; parents; caregivers

Introduction

It is estimated that there are approximately 2.1 million children who are living with human immunodeficiency virus (HIV) worldwide, with 90% living in sub-Saharan Africa (UNAIDS, 2023). According to Section 130(2)(a) of the South African Children's Act (Republic of South Africa, 2005) and the United Nations (1989) convention on the rights of the child, children above the age of 12 and those deemed to be "sufficiently mature" can consent to HIV testing, treatment plan and full disclosure. However, it has been established by international and South African literature that most HIV-positive children are not aware of their HIV status, which suggests that parents are still struggling to disclose their children's HIV-positive status, which in turn affects adherence to treatment (Van Elsland et al., 2019). The disclosure process in paediatric HIV is more complicated and poorly understood by many parents and caregivers because it takes into account both their motivation and attitudes towards disclosure as well as children's emotional readiness to learn about their HIV status (Khangale et al., 2022; Van Elsland et al., 2019). HIV disclosure to children is typically handled cautiously out of concern for stigmatisation and discrimination, and is therefore frequently avoided (Kiwanuka et al., 2014).

South African literature on the disclosure of HIV-positive status indicates that parents in various social spaces struggle with disclosing their HIV-positive status to their children owing to fear of stigma and discrimination (Doat et al., 2019; Joyce et al., 2022; Khangale et al., 2022; Madiba & Matlala, 2012). While some studies have explored the disclosure of children's HIV status, they often employ quantitative research designs, focus on adolescent children in mostly urban areas and do not offer critical analysis of how HIV-related stigma informs the disclosure decisions of parents and caregivers (Khangale et al., 2022; Ramsammy et al., 2022). In this regard, little is known about how HIV-related stigma in rural communities facilitates the decisions of parents and caregivers to disclose their children's HIV-positive status to the communities. In this study, we therefore explore how HIV-related social stigma in a South African rural township community informs the decisions of parents and caregivers to disclose their children's HIV-positive status to them. Ultimately, we seek to answer the question: How does HIV-related stigma in rural townships facilitate parents' and caregivers' negotiation of disclosing their children's HIV-positive status? The study is important as it identifies stigma-related challenges that parents and caregivers encounter in disclosing their children's HIV-positive status in rural township areas. It also contributes to the development of HIV-status disclosure policies and programmes that can support parents and caregivers of HIV-positive children in South African rural township communities.

The subsequent section reviews existing literature on HIV disclosure. This is followed by a discussion of Goffman's stigma theory and its relevance to the exploration of parents' and caregivers' experiences of HIV-positive children in rural South Africa. The research methods employed are then outlined, followed by a discussion of the findings. The article concludes with a recommendation and limitations of the study.

Disclosure of HIV-Positive Status and the Related Stigma

Goodwin et al. (2021) define HIV disclosure as sharing an individual's HIV-positive status with other people. Globally, scholars from various disciplines have conducted research on HIV status disclosure and found that the disclosure of children's HIV-positive status is important and regarded as a crucial step in the progression of HIV-positive children's healthcare (Lindberg et al., 2019; Lyimo et al., 2014; Madiba & Diko, 2021). The lifespan of adults and children who test positive for HIV has significantly increased in the last few years owing to the availability of antiretroviral therapy (ART). Nonetheless, there are still issues with parents and caregivers disclosing their children's HIV-positive status to them. Some parents are still reluctant to tell their children about their HIV-positive status, owing to fearing blame, negative judgement, discrimination, resentment and lack of proper disclosure information (Madiba & Diko, 2021; Namukwaya et al., 2017; O'Malley et al., 2015; Sabharwal et al., 2018).

A study conducted by Armoon et al. (2022) in Canada on the prevalence, socio-demographics and service use determinants associated with disclosure of HIV/AIDS status to HIV-positive children found that 75% of the 340 HIV-positive children had been informed of their HIV status. Although the American Academy of Paediatrics (AAP) emphasised that all children and adolescents should be informed about their HIV-positive status (Armoon et al., 2022; Vaz et al., 2010), the AAP did not provide detailed guidelines on how parents and caregivers can be supported during the HIV disclosure process, including when and how to inform or evaluate the psychological effects of disclosure on their children (Vaz et al., 2010). Similarly, a study conducted by Jantarapakde et al. (2019) in Thailand, which explored an integrated strategy for HIV-status disclosure among affected families, revealed that 50% of the participating parents had refrained from disclosing their HIV status to their children because of a deficiency in assistance and support from healthcare providers regarding the disclosure process. From these findings, Jantarapakde et al. (2019) argue that a notable deficiency exists in both awareness and communication regarding the HIV disclosure process and treatment. They advocate for healthcare professionals to actively support parents in educating their children about the diagnosis, treatment options and the process of HIV disclosure.

In many countries, including those in sub-Saharan Africa, community support is being emphasised as a crucial prerequisite for developing health social structures that assist and support raising the likelihood that people living with HIV will have outstanding health and well-being (Bingaman et al., 2022; Campbell & Cornish, 2010; Placek et al.,

2019). Community sectors have the capacity to reach out and inform individuals about HIV and the importance of providing support to someone who is living with HIV (Placek et al., 2019). However, this is not always the case, as there is still a great deal of stigma associated with HIV positivity for both adults and children, particularly women (Doat et al., 2019). Despite the numerous educational campaigns and outreach programmes designed to increase public awareness of HIV and the stigma associated with it, there is sometimes a subtly negative attitude towards people who are living with the virus (Bingaman et al., 2022; Msoka et al., 2023).

Numerous research studies revealed that one of the causes of non-disclosure is prejudice and stigma from the community towards individuals living with HIV (Bingaman et al., 2022; Msoka et al., 2023; Placek et al., 2019). Most parents and caregivers are willing to tell their children that they are HIV positive, however, some parents choose not to tell their children because they fear negative attitudes and discrimination from the community. A qualitative study conducted by Bingaman et al. (2022) discovered that parents who were honest about their children's HIV-positive status received support from the community. But parents do not always get the support they need as some experience rejection from the community after disclosing their HIV-positive status. Similarly, the study by Kalembo et al. (2018) in Malawi found that it is beneficial for various individuals, including social structures and support groups in the child's family, to be aware of the child's HIV status. Nonetheless, many parents swear their children to silence when they find out that they are HIV positive because they are afraid their children will disclose their status to other people in the community. South African and Zambian literature found that some people choose not to reveal their HIV-positive status to people outside of their immediate families to avoid stigma and discrimination, while others choose to disclose in an attempt to spread awareness and gain support (Hargreaves et al., 2018; Madiba & Diko, 2021).

Studies conducted in South Africa indicate that disclosure of HIV status to children and adolescents is still uncommon, despite children's frequent attendance of health facilities and consistent use of ART (Joyce et al., 2022; Madiba & Diko 2021; Naidoo & McKerrow 2015). According to the guidelines of the South African National Department of Health (2016), parents and caregivers have the primary responsibility to inform their children of their HIV-positive status. However, parents frequently find the disclosure process challenging owing to the widespread HIV-related stigma and discrimination, which delays the disclosure to children (Doat et al., 2019; RoCHAT et al., 2013). Joyce et al. (2022) conducted a study in the Gauteng province of South Africa, which established that the lack of knowledge on how and when to address the issue of disclosure is one of the contributing factors that delay disclosure. In this regard, it is important to pay particular attention to how parents and caregivers negotiate disclosure in rural contexts where HIV-related stigma is prevalent to encourage sensitivity and develop favourable conditions for disclosure. Despite the favourable health benefits of HIV disclosure by parents to their children, little attention has been paid to this particular topic.

Understanding Disclosure of Children's HIV-Positive Status Through the Stigma Theory

Goffman's (1963) stigma theory helps researchers to comprehend the difficulties encountered by parents and caregivers of HIV-positive children, and certain coping mechanisms they use when disclosing the HIV status to their children. Goffman (1963) argues that society sets standards that may be used to categorise people and assign attributes as natural for people who belong to certain social groups. Social environments mirror the types of people who are most likely to interact with them, making individuals who do not fit into a certain category susceptible to prejudice or rejection (Goffman 1963). Some people in South Africa still believe that HIV originates from sexual deviances and is immoral. In some cases, HIV-positive women are thought to be sex workers, further stigmatising them (Madiba & Diko, 2021). Accordingly, an HIV-positive person may be viewed as sexually irresponsible and exposed to shame and name-calling.

To avoid the unwanted implications of stigma, HIV-positive persons may employ what Goffman (1963) terms "passing", a stigma management strategy where an individual conceals their stigmatised attribute and portrays a socially accepted, non-stigmatised attribute. Being infected with HIV or being associated with someone who is HIV positive may result in rejection from community members since it defies preconceived notions of what members of that society ought to be and may, for some, signify sexual deviance and carelessness. One of the main justifications given by parents for not disclosing to their children that they are HIV positive is to protect them from the stigma associated with the disease (Hayfron-Benjamin et al., 2018). Parents and caregivers of HIV-positive children may employ passing to manage and negotiate disclosure by deliberately concealing their children's HIV-positive status and cite less stigmatised illnesses as the reason for taking chronic medication (Hayfron-Benjamin et al., 2018; Mugo et al., 2023). Although some parents of children who are living with HIV understand the value of disclosure, they may choose to give their children incorrect information or withhold it in an effort to protect them from stigma and to lead "normal" or socially acceptable lives.

Research Methods and Design

In exploring parents' and caregivers' experiences of navigating HIV-related stigma when disclosing their children's HIV-positive status to them, the present study employed a hermeneutical phenomenology. A qualitative research design was adopted to achieve the goals of hermeneutical phenomenology since it allowed for an understanding of the deeper meanings that the participants connect to their daily experiences of raising HIV-positive children and how they navigate HIV-related stigma in their disclosure decisions.

Based on the sensitive nature of the study, identifying and accessing the participants were challenging, therefore the principal researchers worked together with a nurse manager to identify suitable participants. The participants were recruited by the researchers when they came for their monthly clinic visits. Purposive sampling was used to identify parents and caregivers of HIV-positive children who are on ARV treatment. Twelve parents and caregivers, four men and eight women, were selected to participate in the study. An information sheet outlining the objectives of the study was given to the participants before participation. The information sheet and interview guide were written in English; however, some participants opted to use their native languages in instances where they could not express themselves in English. The South African languages that the participants used were isiNdebele and isiZulu, which did not pose challenges with interpretations since the researchers are fluent in both languages. After reading the information sheet, the participants were required to sign a consent form indicating that they are fully informed about the study and wish to participate voluntarily. The participants were based in the Mpumalanga province of South Africa, and their ages ranged from 22 to 63 years.

Qualitative in-depth interviews were conducted with the participants and ranged between 29 to 70 minutes. An interview guide was used to facilitate discussions during the interviews; however, the participants were allowed to answer the questions as they saw fit, without following the order of questions in the guide. All interviews were recorded and transcribed by the researchers. Interview questions were focused on the impact of HIV-related stigma on the disclosure of children's HIV-positive status in rural townships in Mpumalanga. To protect the identities of the participants, each participant's name was replaced with a pseudonym in the transcripts, field notes and analysis. Table 1 presents the descriptions of the participants' respective profiles.

Table 1: Profile of the participants

Participant	Age	Gender	Gender of Child	Age of Child	Relationship	Status Disclosed
Betty	48	Female	Girl	12	Caregiver/aunt	Yes
Rose	63	Female	Boy	7	Caregiver/grandmother	No
Amanda	33	Female	Boy	9	Mother	Yes
Victor	40	Male	Bo	13	Father	No
Nokwanda	22	Female	Girl	9	Caregiver/aunt	Yes
Lizzy	62	Female	Boy	13	Caregiver/grandmother	No
Gideon	38	Male	Girl	8	Father	Yes
Mandla	43	Male	Girl	10	Father	Yes
Mike	40	Male	Boy	11	Father	No
Anastacia	41	Female	Girl	11	Mother	No
Priscilla	37	Female	Girl	13	Caregiver/aunt	Yes
Christinah	53	Female	Girl	7	Caregiver/aunt	Yes

For purposes of analysing the data, we used the thematic data analysis method (Braun & Clarke, 2006, 2019). We used open coding to find themes that appeared in the participants' narratives. We then carefully listened to the recordings and read over the transcripts after conducting all the planned interviews to ensure that all the required information had been collected. Different themes were identified from our critical analysis of and engagement with the data. The implication of stigma on children's HIV-positive status disclosure was one of the major themes that emerged from the thematic analysis process. This theme was informed by the participants' narratives of stigma faced by children and adults who are HIV positive and the unwillingness of societies to accept and treat HIV like other chronic diseases.

To ensure the trustworthiness of this study, we employed strategies recommended by Babbie and Mouton (2011), including reliability, credibility, dependability and confirmability. We ensured reliability by documenting all data gathered during the interviews, debriefing the participants, and revisiting previous research outcomes on HIV disclosure by parents to their children. We used the same notebook to take notes during all the interviews. The participants were selected using purposive sampling in an effort to gather rich data on the impact of HIV disclosure to children by their parents. During the initial recruitment session with the participants, we briefly explained the purpose of the study and provided necessary clarifications. This approach was beneficial in establishing and building rapport. Dependability in this study was achieved by using an audio recorder and writing notes during the interviews. The participants narrated their experiences, and the data were recorded with their consent. We read the transcripts several times to ensure that the data were recorded accurately. An audit trail was meticulously kept by documenting all research decisions, processes and data analysis steps. This ensured transparency and allowed for verification of the study's findings.

Ethical Considerations

Ethical clearance to conduct this study was obtained from the College of Human Sciences Research Ethics Committee of the University of South Africa (No. Rec-240816-052). Owing to the sensitivity of the topic under study, it was imperative to follow ethical practices to ensure that we do not expose the participants to any form of harm. In the interest of maintaining confidentiality and anonymity, the interviews were conducted in a private hospital boardroom which was not near the participants' homes and communities. All transcripts and notes related to the interviews were kept in a password-protected Google Drive folder and were only accessible to the researchers. In addition, all information that can potentially identify the participants, such as their occupations and immediate places of residence, was excluded. All participants were allocated pseudonyms. These measures were necessary to protect the identities of the participants and to comply with the South African Protection of Personal Information Act (Republic of South Africa, 2013). Since there were possibilities that the participants could experience psychological distress while narrating their experiences, arrangements were made with a psychologist in the hospital to accept referrals or intervene in cases

where assistance was necessary. Fortunately, none of the participants reported psychological distress and the psychologist's services were not required.

Findings

This section engages with the findings of the study, and focuses on two themes that reflect the parents' and caregivers' experiences of negotiating their children's HIV-positive status disclosure and managing stigma in rural townships. The themes are first presented in Table 2, and followed by critical presentation and analysis of the participants' narratives.

Table 2: Key statements and themes

Key Statements by Participants	Constructed Meaning	Theme
My child is still young, I cannot tell her. I don't think telling her that she has HIV is important for now. What if she accidentally disclose to her friend and neighbours start talking bad about us?	Parents have difficulty in disclosing their children's HIV status because of fear of stigma and discrimination	Implications of stigma on disclosing children's HIV-positive status
I always emphasised the importance of concealing his HIV-positive statuses and acting "normal" in order to avoid exclusion and discrimination from the community	Parents conceal their children's HIV-positive status and live in a manner that is acceptable by the community	Strategies to manage disclosure amid HIV-related stigma

Implications of Stigma on Disclosing Children's HIV-Positive Status

In this study, we found that the parents and caregivers avoid disclosing their children's HIV-positive status to them owing to the anticipation of stigma which may result in exclusion and discrimination from family members, the community and the children's friends. Parents and caregivers expressed fear that should children know about their HIV-positive status, they would possibly disclose it to other people in their communities, leading to their being stigmatised. Based on the participants' narratives, it was gathered that HIV-related stigma remains prevalent in the rural township context and informs the decisions to disclose children's HIV-positive status to them. The participants cited both anticipated and experienced stigma as a barrier that influenced their decision to disclose:

I don't want them to treat my grandchild a certain way. I am worried that the second I tell him, he might accidentally disclose to others, and they might not want anything to do with us. (Rose, 63-year-old grandmother)

Our neighbours gossip too much, should they know that my son is HIV positive, we will be the talk of the town. Sihle is still young to keep secrets, I am scared he might tell his friends during their soccer practices. (Victor, 40-year-old father)

From both Rose and Victor's narratives it is evident that while disclosing children's HIV-positive status may be beneficial for them, parents are reluctant to disclose owing to fear that the children may not be able to keep the status a secret. Rose and Victor observed the prevalent HIV-related stigma in their communities and realised that it is not a safe space for having their children's HIV-positive status known by community members. Their concerns mainly stem from the fear that their children may not be able to conceal their HIV-positive status, and the information may end up reaching community members. Rose further explained that she is keeping her grandson's HIV-positive status hidden so that he is not treated differently and can lead a life free from stigma:

My grandson is still in the dark about his HIV status. In our community, stigma remains widespread. I want him to live a normal life free from worry about illness and the stigma associated with it. I don't want anything to cause him stress as much as I want him to know about his sickness, but I won't tell him now.

Rose's sentiments were supported by Anastacia and Amanda, who were reluctant to disclose their children's HIV-positive status, despite emphasising the importance of disclosure:

My baby is still young to know, she cannot keep her sickness a secret. I don't trust her. She can disclose to her friends, as a result the entire family will be humiliated and discriminated, therefore, we are forced to act normal like other families (Anastacia, 41-year-old mother)

Despite my awareness of the significance of HIV disclosure, I was hesitant to inform her because I was afraid she wouldn't keep her status a secret. For the sake of our peace, we are forced to act normal so that we can be accepted. HIV is not a sickness you openly talk about, but I am happy finally I got a courage to tell her (Amanda, 33-year-old mother)

Although Amanda struggled with disclosing her child's HIV-positive status, she eventually did, but she had to teach the child to keep their status a secret. She further explained that the child is now used to the reality that they are living with HIV and have managed to keep the illness a secret that only the two of them know about. Similarly, Mandla and Christinah disclosed to their children and argue that disclosure enhanced their children's adherence to treatment and reduced stress and anxiety from hiding the HIV-positive status to children:

It is important for the children to know about their HIV statuses since it is something they are going to live with for the rest of their lives. Children deserve to know about their HIV status at a tender age because the earlier, the earlier the starts taking

responsibility about their health. My daughter is aware that she is HIV positive.
(Mandla, 43-year-old father)

It is crucial for parents to discuss with their children about HIV and their statuses when they are still young, because it will help to reduce the spread of HIV. And it will help them to make informed decisions about their sexual lifestyle when they are older.
(Christinah, 53-year-old aunt)

However, like Amanda, both Mandla and Christina confirmed that their children are aware that their status should remain a secret and should not be disclosed to other people. It is evident that the participants' concerns regarding the disclosure of their children's HIV-positive status is mostly centred on the stigma that their children may encounter in the communities, instead of the illness itself. Among the participants, there is a preoccupation with avoiding stigma, which reduces possibilities of disclosure to the infected children for some parents and caregivers.

By "normal" most of the participants are referring to living a life without HIV, which is indirectly stereotypical as it suggests that living with HIV has some form of abnormality. The participants are not aware that the use of the term "normal" when referring to people who are not HIV positive confirms societal stigmas about HIV, leading to self-stigmatisation since they do not see themselves as living normal lives. Instead, they argue that they try to live normal lives, a misconception that may convince the children that there is something wrong with them should they become aware of their HIV-positive status. Contrary to the other participants, Amanda argued that living with HIV is her child's normal:

Being HIV positive is his normal, all he needs to do is to take his ARVs as prescribed. Telling him that he is HIV positive was the best decision. We watch cartoons and read children's books about HIV, but I have to keep reminding him not to tell anybody about his HIV status.

Although Amanda disclosed to her child and teaches him about HIV through children's books and cartoons, she and Mandla and Christinah make efforts to ensure that the children keep the illness a secret, which is an indication of the fear instilled by widespread stigma in their community. The findings demonstrate that parents and caregivers wish to protect themselves and their children from social shame and psychological distress by not disclosing their children's HIV-positive status.

Strategies to Manage Disclosure Amid HIV-Related Stigma

Parents' and caregivers' perspectives and experiences regarding HIV-related stigma in their surroundings and the prevalent attitudes of those around them have influenced the development of ways to manage stigma and their approaches to telling or not telling their children about their status. This study found that the participants employed Goffman's (1963) passing to manage the implications of HIV-related stigma on disclosure.

Since the participants know that their actions are under surveillance in the community, they all indicated that they hide their children's HIV status and live in a manner that is acceptable by the community. Amanda stated that even though she understands the importance of HIV disclosure, she was hesitant to tell her child. Her fear of being discriminated against pushed her to prolong the disclosure process and continue to conceal her and her child's HIV-positive status. Similarly, Anastacia and Mike emphasised the importance of concealing their HIV-positive status and acting "normal" to avoid exclusion and discrimination from the community.

I'm not good at keeping secrets, but I have to wait a little while on this one. For now, she knows nothing. Last year I wanted to tell her but due to the stigma related to HIV in the community I decided to wait. Is not easy to tell your child that you infected her. (Anastacia, 41-year-old mother)

For now we are still keeping his status a secret. As long as he is taking his treatment, I'm happy. However, sometimes is a challenge especially when we have visitors as we have to wait for them to leave the house before we can give him his medication. (Mike, 40-year-old father)

Anastacia and Mike changed their minds after initially wanting to fully disclose their children's HIV-positive status. Their fear was that the children will tell others about their HIV status particularly when they are not around to supervise them. As a result of their concealment, we noticed a disruption to ARV treatment adherence since Mike has to change his child's daily dose of ART to avoid people noticing that the child takes chronic medication. When we asked the participants how they felt about not telling their children that they were HIV positive, the participants responded:

I informed him that for the time being, the medication is protecting him from developing cancer because the disease runs in the family. I regret having to lie to him because of the harsh society we live in makes it unsafe for me to tell him the truth right now. This is difficult for me because I have to constantly recall what I say. (Lizzy, 62-year-old grandmother)

When my son asks why he takes medicine every day, I always answer him that he has asthma, but I also suggest that he read books about chronic diseases such as HIV, diabetes and cancer. (Victor, 40-year-old father)

I wonder what my niece's life may have been like if her HIV test had not come up positive. She's a sweet girl but living with HIV would be challenging for her. It's difficult to live with HIV especially as a woman because she will be expected to explain herself to her future sexual partner. (Priscilla, 37-year-old aunt)

The participants adopted passing to fit in the community because of the perceived lack of familial and societal support and fear of rejection.

The participants were aware that the social context was not safe for their children's HIV-positive status to be known, and this forced them to employ strategies that would protect their children from possible rejection by and exclusion from community members. This study's findings indicate that passing allows parents to avoid answering many questions about taking medication daily from their children and rejection from the society. However, this also requires the participants to unwillingly lie, which results in living dishonestly, and which can have a detrimental emotional impact on the parents and the caregivers.

Discussion

In this study, we explored the HIV-status disclosure management strategies and experiences of parents and caregivers of HIV-positive children in a rural township community amid HIV-related stigmas. The findings of this study indicate that parents and caregivers do not have challenges in accepting their children's HIV-positive status, however, since the community members use HIV-positive status to oppress and sideline various groups, parents and caregivers have no choice but to conceal the information from their infected children or disclose and constantly emphasise concealment to the children. Previous studies have indicated that fear of discrimination significantly influences the decision-making process of parents and caregivers regarding the disclosure of their children's HIV-positive status (Hayfron-Benjamin et al., 2018; Vreeman et al., 2017). However, we found that the lack of familial and community support, combined with the fear of rejection owing to stigma in rural township communities, further prevents parents and caregivers from disclosing their children's HIV status. Parents and caregivers in this study feared disclosing their children's HIV status to them owing to concerns that the children might inadvertently reveal this information to others, resulting in stigma-related repercussions.

Social stigmas associated with HIV put pressure on parents and caregivers to adopt passing as a stigma-management strategy. In accordance with Goffman's stigma theory (1963), the act of concealing their children's HIV-positive status and portraying socially acceptable attributes (such as appearing HIV negative) constitutes passing, as the parents and caregivers make conscious efforts to avoid social HIV-related stigma in the community. Some researchers argue that people living with HIV frequently assume a false negative status to escape the potential consequences of disclosing their actual HIV status (Bingaman et al., 2022; Mugo et al., 2023). However, while passing is crucial to acceptance in the community, it comes at the expense of the parents' and children's well-being. The participants are under constant pressure to manage their own and their children's behaviour to avoid accidental disclosure. This aligns with Bingaman et al. (2022), who argue that passing entails psychological and emotional strain owing to the need for meticulous attention to detail in maintaining acceptable behaviour.

In addition, to maintain the HIV-negative image, parents have to conceal their children's status from them, which may compromise the children's adherence to ARV treatment. This required deliberately deceiving the children, making them believe that they are taking medication for other less stigmatised chronic illnesses apart from HIV. Parents who had disclosed to their children, had to teach them to carry the burden of keeping their HIV-positive status concealed. This finding aligns with that of Bingaman et al. (2022), who discovered that while some parents normalise an HIV-positive status by openly discussing it with their children, they still prefer to keep their children's HIV status secret from extended family members and society to avoid stigma. The lack of acceptance, intolerance and stigma associated with HIV in the rural township create a pervasive culture of dread among parents and caregivers. This context pressures the parents and caregivers to conceal their children's HIV-positive status from both the community and the children themselves. Consistent with previous studies (Bingaman et al., 2022; Hayfron-Benjamin et al., 2018), this lack of disclosure owing to stigma is concerning because it may have an impact on children's adherence to treatment and care, especially when they need help from others because of injuries or other issues.

In accordance with the study by Bingaman et al. (2022) conducted in the USA, this study found that stigma was the most challenging aspect of having an HIV-positive child in rural areas and townships in South Africa. Based on the findings of this study, we argue that HIV-related stigma in the rural township community compromises children's right to know about their HIV-positive status since parents and caregivers may not disclose the children's status to them, threatening the management of HIV. Although passing may help the parents to avoid their children being stigmatised, it maintains the status quo where HIV-related stigma remains unchallenged. We therefore argue that the lack of visibility of HIV-positive children in rural townships creates a false impression that the communities are not affected by HIV, which leaves room for the limited transformation of HIV-related stigmas and ideologies that threaten the well-being of HIV-positive children. Although some efforts have been made by government and NGOs to spread education about HIV in South African communities, the findings of this study indicate that there is a need to disrupt HIV-related stigmas in rural townships to create environments that are conducive to supporting HIV-positive children. It is particularly important to address HIV-related stigmas in the rural township space for children to enjoy their right to know about their HIV-positive status and learn to care for themselves from an early age.

Conclusion

In conclusion, parents of HIV-positive children are already dealing with many issues including the psychological well-being of their children and treatment adherence and should not have to devise strategies to manage disclosure because of societal stigmas. In this regard, we call for further research to explore ways in which HIV-related stigma and its implications on children's HIV-positive status disclosure can be reduced in rural township contexts to allow children to thrive and not carry the burden of taking chronic

medication without knowing the reasons or carrying a secret that they have to maintain throughout their childhood. HIV disclosure can only be beneficial when there is a non-stigmatised supportive social structure (Van Elsland et al., 2019). To successfully address HIV-related stigma, the complex social context needs to be taken into account.

The key limitations of this study were that it exclusively relied on the narratives of parents and caregivers living in a rural township and did not contain the perspectives of the children themselves and parents and caregivers from urban areas. In this regard, future research can broaden the scope of the study by conducting comparative studies of experiences of disclosing children's HIV status in rural and urban areas, and considering how aspects such as race, class and level of education inform parents' and caregiver's disclosure decisions. In addition, it would be beneficial to interview children who are affected to gather the implications of status disclosure from their own perspectives.

The lack of disclosure to children is an indication that the Children's Act (Republic of South Africa, 2005) and the guidelines of the South African National Department of Health (2016) have not been successful in promoting disclosure to children who are HIV-positive. While the Act and the guidelines hold that children have the right to know about their HIV-positive status, social implications of HIV-related stigma on disclosure are not considered, leaving the parents with the burden of negotiating disclosure in social spaces where stigma prevails. Parents and caregivers need to be given an opportunity to express their concerns, anxiety and frustrations about disclosing to their children that they are HIV positive. Policymakers and health providers should take these HIV-related stigma obstacles into consideration when putting requirements for disclosing children's HIV status into practice.

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