


Telling Children with Perinatal HIV About Their HIV Serostatus: Healthcare Workers' Practices and Barriers to Disclosing in a South African Rural Health District

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Abstract

In South Africa, caregivers and healthcare workers (HCWs) lack confidence and skills to disclose to children with perinatal HIV (PHIV). Moreover, existing disclosure guidelines do not provide strategies on how to approach disclosure. Although the caregiver has been endorsed as a responsible person to disclose to the child, the involvement of HCWs in the process is critical. Yet research suggests that many HCWs are reluctant to perform disclosure. This study examines the involvement in, practices of, and barriers against HCWs' disclosing to children with PHIV. **Methods:** We conducted 8 focus group discussions with a total of 51 HCWs comprising nurses, lay counsellors, social workers, and dieticians. The HCWs were selected from 23 health facilities in a rural South African health district by purposive sampling. Data were transcribed verbatim, and data analysis followed qualitative thematic analysis. **Results:** A high proportion of HCWs had no formal training in pediatric disclosure and some had never disclosed to children. Those who routinely disclosed approached disclosure as an ongoing process that unfolded over time. They ensured caregiver readiness as a necessary step in the disclosure process. The main barriers for HCWs to participate fully in the disclosure process were the lack of relevant disclosure guidelines, inadequate disclosure skills, and a shortage of skilled staff. Inadequate skills affected the confidence of the HCWs to disclose, while a lack of standardized disclosure guidelines and HCWs' reliance on personal experience during disclosure resulted in confusion and uncertainty among them due to the inconsistencies in their approach to disclosure. **Conclusion:** This study confirms the urgent need to train HCWs to attain skills and confidence in disclosure. Training HCWs in standardized disclosure counselling would lead to an increase in the rate of disclosure to children. It is essential that the district adapt the disclosure guidelines to the local context for use in health facilities.

Keywords

children, disclosing, healthcare workers, HIV serostatus, practices, South Africa

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Introduction

The disclosure of HIV serostatus is part of the comprehensive HIV management of children and adolescent with perinatal HIV (PHIV).¹⁻³ The increased life expectancy of children beyond adolescence to adulthood due to their access to antiretroviral therapy (ART) marks the necessity to disclose their HIV serostatus.^{2,4} Telling children that they are HIV-positive is essential for treatment adherence, acceptance of their HIV status, their wellbeing, and active participation in their own health management.⁵⁻⁷

The World Health Organization (WHO) recommends that children are given developmentally-appropriate information

about their HIV serostatus. This should be progressively from the age of 6 years with full disclosure taking place by the time the child is 12 years of age.⁴ Nonetheless, the rate of disclosure to children and adolescents with PHIV in South Africa is still low, despite their attending clinics regularly and

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taking lifelong ART.^{1,8,9} South Africa has an estimated population of 730 882 of children and adolescents on ART, one of the largest HIV programs in the world.¹⁰ A systematic review of studies in middle-and low-income countries found a median age at disclosure of 13 years, with a range of 10 to 15 years.¹¹

Disclosure to children and adolescents is delayed in spite of the benefits acknowledged by healthcare workers (HCWs) and caregivers in many settings in South Africa and sub-Saharan Africa (SSA).¹¹⁻¹⁵ In South Africa, disclosure to children is affected by the fact that HCWs and caregivers have different views about when to, how to, and who should disclose to children.^{9,15-17} The literature emphasizes that the caregiver is the person with the principal responsibility to disclose to his or her child.^{15,16,18-20} Yet in many settings in South Africa, caregivers find the disclosure process difficult, which results in delaying disclosure to children.^{8,9,17} This explains why caregivers in South Africa^{1,9,17} and other SSA countries^{5,21,22} express the need for HCWs to provide them with expert assistance during the disclosure process.

The need to facilitate disclosure to children puts HCWs under pressure from the caregivers and health service provision. Disclosure to children with PHIV is an important milestone in the continuum of their HIV care.^{1,4} The participation of HCWs in disclosure is rendered more critical as the WHO recommends that health services provide strategies that would allow HCWs to support caregivers to disclose to their children by the age of 12 years.⁴ Thus HCWs are central to the disclosure process, they have a critical role to prepare the caregiver for disclosure. They are further required to ensure that disclosure is a continuous process to enable the child's acceptance of the HIV serostatus and retention in care.^{11,15}

In South Africa as in other settings, the HCWs' belief that disclosure is the responsibility of the caregiver has been associated with lack of active involvement of HCWs in disclosure to children.^{2,15,16,23} HCWs are of the view that in order for the outcome of the disclosure process to be positive, the caregiver should take the lead in disclosure while being supported by the HCW.¹⁵ The variation in the views of HCWs concerning HIV disclosure to children leads to inconsistent practices in facilities.¹⁶

The limited data from South Africa show that certainly many HCWs are reluctant to do disclosure to children with PHIV due to their own unpreparedness and a lack of the skills required.^{1,15,16} The WHO guidelines on disclosure to children published in 2011 are not specific enough about how certain tasks related to the disclosure process should be achieved.¹⁶ Moreover, these guidelines do not provide HCWs with a strategy on how to approach the issue of disclosure to adolescents.²⁴ The guidelines are limited to children under the age of 12 years even though many children

with PHIV in South Africa^{1,8,9} and in SSA¹¹ are not disclosed to until late adolescence.

However, there are limited studies assessing the involvement of HCWs in disclosing to children with PHIV. The few studies conducted with HCWs in South Africa suggest that the lack of systematic processes for disclosure in pediatric HIV clinics and the lack of adequate training about disclosure affects HCW's confidence and the ability to initiate or facilitate disclosure to children.^{15,16,25} Similarly, in other settings in SSA, HCWs were reported to lack formal training on pediatric HIV, thus making it difficult for them to confidently provide disclosure services to children.^{2,26-28} Besides the WHO guidelines, in 2016, the National Department of Health (NDoH) in South Africa published an adapted version of disclosure guidelines for children with PHIV.²⁹ Thus, disclosure to children and adolescents with PHIV was integrated into the comprehensive management of their HIV disease and forms an important part of HIV prevention.²⁹

The aim of this study was to examine HCWs' practices regarding the disclosure of HIV serostatus to children with PHIV and explore the barriers that they experience against disclosing following the publication of national disclosure guidelines. Previous studies in South Africa were conducted prior to the publication of national disclosure guidelines and assessed the opinions of HCWs about disclosure rather than their practice of disclosure.^{15,25} Therefore, there is dearth of data on the adoption and application of the disclosure guidelines in facilities providing HIV services to children. Identifying factors that impede disclosure may help shape best practices for HIV care of children with PHIV and inform disclosure support interventions.³⁰ Facilitators and barriers associated with disclosure to children need to be factored into new disclosure guidelines that will provide strategies on how to approach disclosure.³¹

Methods

Study Design and Setting

This qualitative explorative descriptive study was conducted in 2 sub-districts of Alfred Nzo District in the Eastern Cape Province of South Africa. Alfred Nzo is a predominantly rural district with an estimated total catchment population of 866 646.³² There are 72 eight-hour clinics, 2 community health centers (CHCs), 6 district hospitals, and 1 TB hospital providing services to the population. About 10% of the adult population in this District is infected with HIV, representing 11% of the total population of the Eastern Cape living with HIV estimated at 25.2%. At the time of the fieldwork, the district had about 6354 children under 15 years enrolled in the HAART program, which is 7.2% of the total population living with HIV in the district.³³ The setting of the study was 23 health facilities. The database of

children receiving ART was used to select the 4 hospitals, 1 CHC, and 18 clinics with the greatest number of children with PHIV.

The study utilized purposive sampling to recruit HCWs to participate in focus group discussions (FGDs) between April and September 2018. Purposeful sampling involves the selection of information-rich cases related to the phenomenon under investigation to answer the research question.^{34,35} Given the small number of nurses who provide HIV services at these facilities, all HCWs who had been involved in offering HIV care services to children and adolescents with PHIV for more than 6 months in each of the selected facilities were invited to participate. HCWs were recruited for FGDs by the lead researcher in collaboration with the facility managers of the selected facilities. Sampling was done to achieve diversity or a heterogeneous sample that included participants representing different categories of health professionals with an extensive understanding of disclosure to children with PHIV.³⁶ In this study, each FGD consisted of 5 to 8 participants comprising nurses, social workers, dieticians, and lay counsellors. PHC facilities do not have resident medical doctors in many settings in South Africa. Facilities offer HIV and AIDS services to children and adolescents through Nurse Initiated Management of Antiretroviral Therapy (NIMART) since 2009.³⁷ This was a strategy to decentralize the provision of ART from hospital-centric services to NIMART to enable scaling up of access to ART for large numbers of HIV-positive adults and children.³⁸ Hence the over sampling of nurses in the study. The study was conducted during a period of high shortage of medical doctors in hospitals, and the 2 doctors who were involved in pediatric HIV care could not participate in the FGDs due to high clinical workload. Social workers and dieticians are only available in the hospitals which explains the small numbers in the sample.

Data Collection

The discussions used a semi-structured guide containing open-ended questions. The guide was developed after extensive review of the existing studies on the disclosure of their HIV status to children and adolescents, and was further adapted from a previous study conducted by the second author and a colleague.¹⁵ The guide asked open-ended questions pertaining to the HCWs' opinions regarding the contextual barriers against disclosing to children with PHIV, their involvement and participation in disclosure to children, the processes they follow when they disclose, their beliefs about who should tell the child about his/her HIV status, their perceptions, about the ideal age of disclosing their HIV status to children. Follow-up questions and probes encouraged the participants to express in detail their experiences and perspectives of disclosing to children. The FGDs were moderated by the lead researcher (CD) and a research

assistant who was recruited and trained in the conduct of FGDs. Data collection was guided by saturation and ceased after 8 FGDs were held with a total of 51 HCWs. Data saturation was considered to have been achieved once the FGDs were no longer generating new information to contribute to the understanding of disclosure practices.³⁹ The second author (SM) supervised the fieldwork throughout the research project.

The FGDs were conducted at the selected health facilities in a private room allocated by the facilities to ensure privacy. The discussions were conducted in English and IsiXhosa, the local language, to allow the participants to respond in the language that they were comfortable with for maximum participation. Each focus group discussion lasted for about 60 min and was audio-recorded with the consent of the participants. Additional interview and field notes were taken.

Data Analysis

Audio recordings of the FGDs were transcribed verbatim by CD and the research assistant. The IsiXhosa transcripts were then translated to English by the research assistant. CD, who is fluent in the languages, verified the transcription and translation by re-reading the transcribed data while listening to the recorded data. CD was involved in the transcription as a way of familiarizing herself with the data. Both authors were involved in the data analysis and analyzed the English-language transcripts using NVivo™ software, following a thematic approach as described by Braun and Clarke⁴⁰ using both inductive and deductive approaches. The inductive approach was used to identify codes and meanings that emerged from within the data, and in the deductive approach, a priori codes from the focus group guide were used. Analysis began with the authors independently reading a few of the transcripts repeatedly to familiarize themselves with the data and identify initial emerging codes. Next, they searched for statements of meaning, and identified codes and emerging themes across the transcripts as part of the process that formed a framework for a codebook. After consensus about the definitions of themes had been reached by the authors, the codebook was finalized. Once the codebook had been completed, the authors applied coding to the remaining transcripts, and analysis continued until deep and rich themes and subthemes had been arrived at. The final themes and sub-themes were decided upon by agreement between the authors.

Rigor

Rigor in qualitative research ensures that the findings of the study are credible and therefore transferable to other settings in similar contexts.⁴¹ Credibility, dependability, transferability, and conformability are strategies used to attain rigor.⁴²

Table 1. Healthcare Workers' Demographic Information.

Variables	Characteristics	Frequency (%)
Sex	Female	46 (90.2)
	Male	5 (9.8)
Designations of HCWs	Lay counsellor	16 (31.3)
	Enrolled nursing assistant	1 (1)
	Enrolled nurse	2 (3.9)
	Professional nurse	24 (47)
	Social worker	5 (9.8)
	Dietician	3 (5.9)
Age group	20 to 29	5 (9.8)
	30 to 39	15 (29.4)
	40 to 49	16 (31.4)
	50 to 59	14 (27.4)
	60 to 69	1 (2)
Pediatric HIV experience	< 1 year	4 (7.8)
	1 to 4 years	11 (21.6)
	5 to 10 years	19 (37.3)
	> 10 years	17 (33.3)
Ever disclosed HIV to a child?	Yes	36 (70.6)
	No	15 (29.4)
Type of pediatric HIV training received	In-service training	4 (7.8)
	Full training	9 (37.2)
	No training	28 (53)
Pediatric HIV disclosure material available in facility?	Yes	7 (13.7)
	No	44 (86.3)

The triangulation of data sources, keeping an audit trail of the research processes and procedures from the inception of the study, making use of a good audio recorder, transcribing the interviews verbatim, holding peer debriefing sessions, and analyzing the data using NVivo qualitative software are strategies that were used to attain trustworthiness in the study. In addition, both authors conducted the analysis and were immersed in the data to reduce investigator bias, and maintained an audit trail of all the data analysis activities.⁴³

Description of the Participants in the Study

The demographic features of the HCW participants are summarized in Table 1. Data were collected from 8 FGDs involving a total of 51 HCWs, 46 of whom were females, while 5 were males. The study comprised of a large number of professional nurses (24), 16 lay counsellors, 5 social workers, 3 dieticians, and 3 enrolled and assistant nurses. Most of the HCWs (36 out of 51) had more than 5-years experience of working with children with PHIV. Concerning disclosing HIV to children, 36 out of the 51 reported that they had ever disclosed.

Themes

This study generated 3 themes and several sub-themes presenting different approaches to disclosure on the part of

HCWs, and 1 theme and 5 subthemes on fundamental issues that affected the implementation of disclosure to children and adolescents with PHIV (Table 2).

HCWs' Involvement in Disclosing to Children

The narratives told during the discussions revealed that not all participants had disclosed to children, but all believed that they had a crucial role to play in disclosing to children with PHIV.

Supporting caregivers to disclose. HCWs implemented different strategies to provide disclosure support to caregivers. They engaged the caregivers to determine their main disclosure challenges, educated, and trained them on how to disclose and deal with the emotional reactions of children after disclosure. They adopted a multidisciplinary approach and involved other professionals such as social workers in the process of supporting the caregivers to disclose.

"I establish the reasons for the reluctance of disclosure from the mother. It helps me to know how I should help the parent before referring her to the social worker because there may be something that makes the parent not to disclose to the child."
(FGD 1: Lay counsellor)

Deciding when to initiate disclose. HCWs believed that disclosure should be initiated by the caregiver when the child

Table 2. Themes and Sub-Themes on Disclosure Practices and Barriers.

Themes	Sample of codes	Sub-themes
HCWs' involvement in disclosing to children	Ongoing counselling for caregiver Referral to experts for support Caregiver request the HCW to disclose Child unaccompanied to the clinic Poor health outcome Poor clinic attendance	Support caregivers to disclose Deciding when to initiate disclose
The process of disclosing to children	Establish child readiness Assess child's understanding of treatment Assess child maturity Provide age related information Create enabling environment for children Provide incremental information Build rapport with child and caregiver Follow-up appointments Refer child to support groups Assist in answering questions from the child Excusing the child during discussion with the caregiver Use of codes to protect child's serostatus Avoid children having access to files Using messengers to carry patients files	Ongoing and gradual process The disclosure event Providing ongoing support Avoiding unplanned disclosure
Messages offered during disclosure	Explaining HIV transmission Tell child about parent's HIV status Use simple language to explain HIV Tell children how to protect others during play Adherence to treatment Treatment is for life Treatment side effects Treatment prolong life Avoiding risky behaviors Prevent the spread of HIV Being positive is not is the end of world Life continues HIV is a chronic disease Disclosing to friends and romantic partners	Explain HIV transmission Educate children about the importance of treatment Promote safe sex practices Encourage children to live a healthy living
Barriers against disclosing to children	Lack of training Outdated HIV training Lack or inadequate in-service training Uncertain about disclosure Lack of confidence about disclosing Use of personal knowledge Use outdated adult guidelines Lack of privacy during disclosure Lack of waiting space for children	Inadequate training Inadequate disclosure skills Lack of disclosure guidelines Shortage of staff skilled in disclosure Poor referral networks

is ready. However, when they identified poor treatment adherence, an unsuppressed viral load and poor health outcomes, the participants initiated disclosure in the presence

of caregivers. They further reported that disclosure was initiated in the absence of the caregivers when delayed disclosure was having negative effects on the child's health.

“Some of the children come to the clinic unaccompanied by parents/ caregivers. When you request the child to bring the parent/caregiver on the next visit, the child tells you that the mother lives in Durban and the grandmother has difficulty in walking due to arthritis; there is no one to bring along. Then I am forced to disclose because the child’s health status is deteriorating. The child has been on treatment for more than 10 years without any knowledge about it.” (FGD 2: Nurse)

“Poor adherence, defaulting treatment and clinic visits, as well as blood results influence the decision to disclose to the child.” (FGD 4: Nurse)

The Process of Disclosing to Children

The participants described the processes and procedures they followed during the disclosure to children and adolescents. They stressed that disclosure needed to be done gradually, as a stepwise and ongoing process. They described disclosure as an ongoing process that included planning and initiation, the disclosure event, and follow-up provided to caregivers and children.

Ongoing and gradual process. The participants indicated that disclosure requires adequate time because it is a process more than a once-off occurrence. They engaged children in several sessions to discuss the disease, taking into considerations their cognitive, emotional, and sexual maturity to ensure that the children were provided with information that they could handle. They further assessed the HIV knowledge which the children already possessed before the actual disclosure event. They stressed that at this stage simple language that suited the age of the child was used to provide incremental information before using the term HIV.

“I assess the maturity of the child to check if the child is capable to understand HIV information. After the maturity assessment, I start to ask questions such as what is HIV, how is HIV contracted to test what the child understands about HIV.” (FGD 1: Lay counsellor)

“I started by giving the general information about HIV before mentioning the word HIV positive.” (FGD 1: Nurse)

“The approach is key during disclosure, you can’t just say you have HIV or you are HIV-positive. You tell the child that you have germs. This is done to accommodate the child’s understanding because at a younger age their understanding is limited.” (FGD 5: Lay counsellor)

The caregivers are involved during the disclosure process to decide where and when the disclosure process would take place and their role in the disclosure event.

“I once disclosed to a 14-year-old child. I first checked if she understood anything about HIV. I did this to check her readiness

so that it could be easy for me to disclose. I made it a point that the counselling session involved both the mother and the child. However, I made it a point that even before the disclosure I requested permission from the parent if I could disclose to the child.” (FGD 3: Lay counsellor)

The disclosure event. Disclosure is carried out in stages using suitable language that can be understood by children and adolescents. HCWs mentioned that the children were provided with general information in stages prior to the full disclosure. They indicated that after they had performed readiness assessment the child was finally informed that he/she was HIV positive.

“The information provided to children is incremental and disclosure counselling to children is not a once off activity but an ongoing process. I do follow up and on every appointment, I continue until I realise that the child understood.” (FGD 1: Lay counsellor)

“We start with the general conversation first, lay a foundation, and then talk about HIV in detail.” (FGD 1: Lay Counsellor)

“We don’t disclose everything at once but it is being done in stages. Disclosure is done step by step. Every time the child comes to the clinic we continue to educate the child to understand and accept.” (FGD 4: Nurse)

Post-disclosure support. HCWs provide continuous support to children and their caregivers to monitor treatment adherence and the emotional well-being of the children. The multidisciplinary team is utilized for further support.

“I give them a follow-up date which is not far from the day of disclosure so that I meet them to establish the emotional status of the child. However, when the child continues to be emotional I then refer him/her to another HCW for further counselling after exhausting every skill I have.” (FGD 7: Nurse)

“I refer the child to a psychologist when after several sessions the child does not improve because I can see that the situation is beyond my counselling scope.” (FGD 2: Social worker)

Avoiding Unplanned Disclosure

HCWs highlighted the risk of accidental and unplanned disclosure for children who attend the clinic alone. They described strategies that they have in place to avoid accidental disclosure.

“I request the child to leave the room and ask the mother if the child knows anything about his HIV status. I then do not ask the mother questions that will trigger the child’s curiosity.” (FGD 4: Lay counsellor)

“In our facility we have messengers to carry files from the OPD to different stations where the children will be attended.

We avoid children or caregivers from carrying their files and children from reading the notes.” (FGD 2: Dietician)

Providing messages to children during disclosure. The interviews revealed that different messages were shared with the children during disclosure.

Explaining HIV transmission. The HCWs provided children with information on the modes of HIV transmission during disclosure. They explained how HIV is transmitted and told the children how they became infected with HIV.

“I explain to him that he got infected from his parents because they were HIV-positive and that the pills he is taking are for life. I explain that he was born infected with the virus hence he is HIV-positive. I do not beat around the bushes but tell the child the truth. However, what is important is to source the information from the caregiver before I disclose to the child.” (FGD 2: Social worker)

“I disclose to the child that she was infected during pregnancy because his/her parents had HIV or they died of HIV and in the olden days there was no treatment.” (FGD4: Nurse)

Educating children about the importance of treatment. The importance of adherence is part of the disclosure conversation between HCWs and children. The participants said that they educate children about the importance of treatment, stress the significance of taking the medication consistently on time all the time, and explain the outcome of defaulting treatment.

“I told him that he is HIV-positive and that he will receive treatment. I assure the child that HIV does not kill because it can be controlled with treatment and stressed that he should take the ARVs daily at a specific time.” (FGD 1: Nurse)

“I also educated the sister to take responsibility for her brother, and ensure that he takes ARVs as prescribed and the reasons why adherence is important.” (FGD 1: Nurse)

The children are also informed that HIV is not curable. Rather, it is a chronic disease, which makes their ART medication a lifelong treatment.

“I explain to the child that the HIV treatment is for life, so she/he should continue to take it to live healthy for a very long time. Again, the child is told that the pills will control and suppress the virus especially if she/he takes them all the time at the same time without fail. I don’t give the child any hope that one day he/she might have to stop the treatment but I emphasise that the treatment is for the rest of his/her life.” (FGD 7: Nurse)

Educating children about safe sex practices. The participants stated that during their disclosure and adherence counselling engagements with children, they promote good behavioural and safe sexual practices. They teach children about

condom use when they engage in any sexual activity, but also promote delaying sexual debut.

“I educate the child about condom use if the child is at the age of dating.” (FGD 2: Nurse)

“The children are educated about abstinence and protecting other people because the reality is that these children have partners as they grow.” (FGD 6: Lay counsellor)

“Depending on their age, some of these children become sexually active at a very early age, around 11 or 12 years, so we encourage them to use dual protection when engaging in sexual activities.” (FGD 7: Nurse)

Encouraging children to live healthy lives. During disclosure, HCWs encourage and help children to accept their status. They emphasized that HIV is a chronic disease just like other diseases. Different messages about HIV are provided to children to build up their knowledge and understanding about HIV so that they can live healthy and positive lives.

“During disclosure, children are taught about positive living, lifestyle and that being infected is not the end of life, but there are many people who live with the virus.” (FGD 2: Nurse)

“If the child is still attending school, I tell him that there are many other children in his school who are also HIV-positive but he may not notice them because they are not labelled. I further tell him that he is living with HIV but he doesn’t have AIDS.” (FGD 3: Lay counsellor)

Conversations about partner disclosure were initiated when the participants suspected that the adolescents had started dating.

“I talk to them about positive living style and disclosure readiness. I counsel and assist the child to reach a stage of becoming comfortable to disclose her/his own status to other people like a partner, and friends. I encourage them to disclose to their partners or friends when they are ready.” (FGD 2: Social worker)

Barriers Against Disclosing to Children with PHIV

During the discussions with the HCWs, it emerged that they had been experiencing barriers that affected their provision of support to children and their caregivers during disclosure.

Inadequate disclosure training. The HCWs reported that they had not received training on pediatric HIV disclosure and had outdated information which affected the quality of the disclosure process.

“As a social worker, I don’t have any new information about disclosure of HIV to children. I do not even know the age that

should be considered for children disclosure. Yet all children on ARVs are referred to us even though we don't have adequate knowledge. We have outdated information. (FGD 2: Social worker)

"We are not adequately trained on how to disclose, but as professionals, we are just expected to handle disclosure to children and yet some of us are not equipped enough on how to do it. I, personally, was never trained on disclosure." (FGD 8: Nurse)

The lack of skills was a reason for some of the HCWs not carrying out disclosure to children.

"Personally, I feel am not equipped with the technique or skill to conduct disclosure. I have an understanding but I do not know how to approach the situation. I don't have the skill to conduct disclosure to children, so I cannot disclose." (FGD 5: Dietician)

Lack of disclosure guidelines and materials. HCWs work without any specific disclosure materials to guide them on how to carry out disclosure to children and adolescents. The participants reported that they do what they think is appropriate for a specific situation.

"We don't have disclosure guidelines as social workers. We do it the way we know it." (FGD 1: Social worker)

"There are no materials or any guidelines in our facilities, we use our own skills. We are not sure whether what we are doing is right or wrong but it works for us." (FGD 4: Nurse)

"It is a problem that we don't have standard documents that specify the age we should disclose to children. You can see in this very interview that we have been talking about different ages at which we should disclose to children and we are saying all this based on what we personally think and not what we have been trained on." (FGD 8: Nurse)

A few of them mentioned that they used voluntary counselling and testing (VCT) and HIV testing and counselling (HTC) guidelines when they carry out disclosure to children.

"The paediatric book has information about disclosure in children but for all the cases I came across I applied my own general knowledge. Mostly, I was relying on my gut feeling to disclose to the children." (FGD 6: Nurse)

Shortage of staff skilled in disclosure. The high workload due to inadequate staffing in facilities affected the disclosure process to children and adolescents. The situation prevented the HCWs from disclosing to more than one child a day, which constrained the pace of disclosure to the children.

"We are experiencing a high staff shortage. There should be younger healthcare workers allocated to provide services all the time to adolescents to give them reassurance, assist, and love them. This provision will make the children to feel free." (FGD 4: Nurse)

"There are no ARV clinic social workers, so as clinical social workers, we are carrying all referrals workload from the ARV clinic; yet, we are not trained on HIV disclosure to children." (FGD 2: Social worker)

Poor referral networks. The scarcity of other role players in health facilities was highlighted as a challenge that affects the efficiency of the referral system during the disclosure process.

"Yes. . . the referral system! I know that we are supposed to work with certain stakeholders in our communities but this just does not happen. For example, you refer a child to social workers but she never finds them at their work place. In our case where we are, near Mount Fletcher, there is only one social worker who is so difficult to access." (FGD 8: Nurse)

Discussion

This study examined HCWs' disclosure practices and barriers against disclosure to children with PHIV in health facilities in a rural district. The HCWs who participated in this study viewed disclosure to children with PHIV as a shared responsibility between themselves and caregivers. Apart from the caregiver, they are the ones who know the HIV diagnosis of the child and share the secret of the child's HIV serostatus. Therefore, for successful disclosure to children, they believed that caregivers and HCWs share the responsibility of disclosure. Similar views were held by HCWs in other studies in South Africa and elsewhere.^{2,5,15,18,28}

Though the HCWs stressed that their role was to support the disclosure process, they pointed out conditions that may require them to initiate and lead disclosure. They indicated situations such as those where the caregiver had failed to disclose, the caregiver requested the HCW to disclose, the child was always unaccompanied at the clinic, or the child has poor drug adherence and clinic attendance. HCWs in studies conducted elsewhere reported that they would lead disclosure to children if the caregivers completely failed to do so.^{2,23}

In the current study, HCWs who had performed disclosure to children reported that in preparation for disclosure, they create a friendly and conducive environment and build rapport with the children and their caregivers. As part of the disclosure process, they encourage and support caregivers to deal with the fears which are preventing them from disclosing to their children in time. Similarly, HCWs in a study conducted in Tanzania educated and counselled caregivers on early disclosure.²

HCWs approached the disclosure event as an ongoing process and the HIV related information they provided to children was incremental in nature. Their accounts of the disclosure process showed that they used analogies of HIV to help the child understand his or her illness. They considered the maturity and HIV-related knowledge of the child before telling him or her about the HIV serostatus. Similar practices were reported in intervention studies conducted with HCWs elsewhere.^{27,44,45} The study found that in their engagement with children, HCWs were conscious of the risk of accidental disclosure to children. Consequently, some of the facilities had put in place measures to prevent accidental disclosure. It is important to prevent accidental disclosure which has been linked to negative outcomes for children by studies conducted with HIV infected children.²⁷

We found that the planning for disclosure further considered the caregiver's disclosure readiness and concerns. HCWs prepare caregivers to facilitate disclosure through consistent counselling to deal with their fears about disclosing to their children. Prior studies in South Africa and elsewhere reported similar practices.^{2,15,44} The current study and others found that caregivers' concerns and fears are the main barriers to timely disclosure to children with PHIV.^{1,12,13,27}

This study found that when HCWs disclose to children, they not only reveal the HIV serostatus but also explain the disease and its outcomes entirely. They encourage children to adhere to medication, promote safe sexual practices, encourage them to accept their HIV status, and empower them to take responsibility for their own health. Other studies documented similar findings.^{15,18,26} Post disclosure, HCWs in the current study monitor the child's treatment adherence and emotional recovery through scheduled follow-ups.

A proportion of the HCWs had never disclosed to children with PHIV despite having provided services to these children for a long time. In spite of having never disclosed, the study found that they had prepared caregivers to carry out disclosure, supported them post-disclosure, and had dealt with the negative responses of the children after disclosure. The lack of pediatric disclosure skills and guidelines to refer to affected their confidence to disclose. This has negative consequences such as delayed disclosure to children, which may result in a poor treatment outcome. A lack of formal training in pediatric disclosure was reported as hindering HCWs from disclosing to children in other studies.^{2,15,18,27,28}

Not having guidelines to refer to resulted in the HCWs approaching disclosure with uncertainty. We also found variation in the opinions about the ideal age of disclosure. Sariah et al.² argue that HCWs reliance on their personal judgment and experience result in confusion among children and caregivers due to inconsistencies in the

information provided to them. The study findings confirm the heightened need to provide appropriate training for HCWs to attain skills and confidence in disclosing to children. Training for HCWs on standardized pediatric disclosure counselling is likely to lead to an increase in the rate of disclosure to children.^{2,15,18,27} Research suggest that when HCWs have the necessary skills and training, children are informed of their HIV status in an appropriate sensitive manner.¹⁵ An evaluation of a disclosure intervention in Namibia revealed that a structured intervention improved HCWs' confidence to engage in disclosure to children.²⁶

In spite of the challenges to disclosure and the lack of formal training on disclosure counselling reported by HCWs, we established that most HCWs disclosed to children routinely. They used their professional experience and existing disclosure guidelines for adults, like the VCT and HCT guidelines. These findings are not different from those reported in previous South African studies.^{2,15,16,18} However, their inadequate training created uncertainty regarding their roles and responsibilities in the process of disclosing to children.¹⁶

HCWs stressed that the staff shortage, the high workload, and time constraints affected the provision of disclosure to children in their facilities. Time constraints were reported as a barrier to providing children with disclosure support in a previous study in South Africa.¹⁶ Additionally, the environment and settings of facilities were barriers to effective disclosure to children. The lack of place for confidential conversations about disclosure was a major barrier affecting both the quality and the quantity of disclosures to children. We established that poor referral system in the health district affected the provision of disclosure counselling services for children. HCWs recommended the creation of child-friendly areas in health facilities to improve the provision of disclosure counselling.

Limitations

The limitations of this study include the fact that the results cannot be generalized because it was an explorative study and the findings are based on focus group data from a small number of HCWs. Their views and experiences of disclosure are not necessarily representative of all the healthcare service providers of the district. Mixed methods design studies with representation samples will feel this gap. The participation of different professional categories and types of HCWs from across 23 different health facilities is a strength in this study. In addition, unlike previous studies, the data presented here represent their practice of disclosure rather than their opinions. The non-participation of doctors is another limitation of the study, their views and experiences of disclosing to children might differ from that of other categories of health professionals.

Conclusion

The study found that despite the reported lack of disclosure guidelines for children, most HCWs disclosed routinely to children with PHIV. Poor child health outcomes, refusal by caregivers to disclose, and requests that HCWs lead disclosure influenced the decision of HCWs to tell the child about his or her HIV serostatus. Although most HCWs lacked formal training on disclosure counselling, they approached disclosure as an ongoing process that unfolded over time. This was consistent with the WHO's recommendations that HCWs adopt a process-oriented approach. This approach increased the likelihood that children were given developmentally-appropriate information to facilitate acceptance of their HIV serostatus.

The main barriers preventing HCWs from participating fully in the process of disclosing to children are the lack of relevant disclosure guidelines, inadequate disclosure skills, and a shortage of human resources. Yet the WHO and the NDoH have published guidelines and recommendations for disclosure to children with PHIV. We established that the district had not adopted the WHO guidelines and the HCWs were not aware of the NDoH guidelines. This explains the HCWs' claim that there was a lack of guidelines to guide disclosure practice in health facilities. This led to delaying disclosure to beyond the WHO recommended age of full disclosure. Delaying telling the child about his or her HIV serostatus has negative outcomes for children. It denies them the opportunity to make informed decisions about their health and increases the risk of defaulting or refusing to take medication.

It is essential that HCWs are trained on the existing WHO guidelines so that they may participate fully in the disclosure to children with PHIV. For this to happen, it is crucial that the district adopt and adapt the disclosure guidelines to the local context for use in health facilities. Furthermore, health facilities should develop disclosure programs that are aligned with the NDoH disclosure guidelines to allow HCWs to support caregivers to disclose. The HCWs in the current study expressed the need for pediatric disclosure training, the lack of skilled HCWs affects not only the quality of the disclosure counselling but also the number of children that is counseled.

The provision of assistance to caregivers by HCWs to ascertain that caregivers are ready to disclose is a necessary strategy for safe and timely disclosure to children. Training will equip HCWs with appropriate skills to assist caregivers in respect of the process of disclosure. This is important, given the common held view that disclosure to children should be a joint responsibility of the HCWs and caregivers.

Adaptation of the WHO disclosure guidelines to the local cultural and community contexts will enable the provision of a safe environment to disclose to children. This could be achieved through the maintenance of the

functionality of the adolescent and youth-friendly services in all facilities.

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Ethics Approval and Informed Consent

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Availability of Data and Resources

All data used in the study are available from the lead author on request.

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