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# ‘Are we allowed to disclose?’: a healthcare team’s experiences of talking with children and adolescents about their HIV status

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## Abstract

**Background** Talking with a child about their HIV status is a complex, emotionally laden and difficult task for caregivers and healthcare providers. Disclosure is an important process which may have psychosocial and health benefits. Despite existing guidelines and materials, disclosure does not always happen for various reasons.

**Objective** This qualitative study explored a healthcare team’s perspectives and experiences about disclosure practices.

**Methods** Three focus groups were conducted with a total of 23 healthcare providers at a paediatric clinic in South Africa. The data were analysed using principles of thematic analysis.

**Results** Results confirm the complexity of the disclosure process and highlight confusion, hesitancy and ethical dilemmas regarding disclosure practices. Tensions were noted within the team which seem linked to professional hierarchies. Counsellors and nurses preferred an indirect approach of encouraging caregivers to disclose to their children and providing psychosocial support, while doctors tended to become more directly involved in disclosing to children out of a sense of duty, legal responsibilities and knowledge of the child’s rights.

**Discussion and Conclusions** This study demonstrates how the complexities of disclosure with children and adolescents bring about additional challenges for healthcare teams. The legal and ethical implications as well as the roles and responsibilities of healthcare providers with disclosure remain unclear. Several recommendations for practice and policy emerge from this study, related particularly to the need for clarification of disclosure guidelines and legal implications. Implications for the healthcare team are also discussed.

## Introduction

Over the past few decades, there has been a strong focus in the field of HIV/AIDS care on encouraging patients to disclose their status with their family and community members.[1] Disclosure involves informing someone about one's HIV status and talking about the disease. In the case of children and adolescents, this discussion should happen in an age-appropriate way and is generally viewed not as a once-off conversation but as a process of helping the child to understand and learn about their illness.[2] Some definitions also distinguish between partial disclosure (revealing some details of the illness without mentioning the term 'HIV') and full disclosure ('HIV' is mentioned and specific information about the disease is provided).[3]

Disclosure can bring about a number of benefits for patients, including health benefits,[4] greater access to support structures,[5] improved adherence[6] and, particularly in the case of children, decreased levels of uncertainty and anxiety.[7] In many cases, children are not informed about their HIV status and talking to children about their HIV status seems a particularly complex, emotionally laden and difficult task for both caregivers and healthcare providers (HCPs).[1,8] Many HIV-positive children enter adolescence not knowing about their illness, which can have significant implications for health, treatment, adherence, emotional well-being and prevention of the spread of HIV.[9,10]

A number of factors can influence how disclosure happens, whether or not a child is informed of their status and by whom.[11,12] Studies have noted barriers to disclosure such as caregiver avoidance of disclosure or emotional unpreparedness for disclosure, fear of stigma, disclosure being treated as a once-off event rather than as a process, and caregivers lacking the skills or knowledge to facilitate disclosure.[12,13] Caregivers often face the added burden of coming to terms with and disclosing their own illness in addition to talking about HIV with their child.[14]

Although many HIV-related topics may be difficult for patients and HCPs to talk about,[15,16] telling a child about their HIV status seems to present a number of additional challenges because related topics such as health, illness, medication, adherence and treatment outcomes will inevitably need to be addressed. Sex and death are difficult issues to talk about,[17] and cultural taboos may prevent caregivers from talking about such topics with children. Conversations about disclosure need to be pitched at an age-appropriate level, appropriately timed in terms of the child's emotional and cognitive maturity, and caregivers need to be able to answer children's questions about these topics. Caregivers may not be equipped, however, with the knowledge or skills necessary to initiate or facilitate such discussions.[18,19]

In the South African context, disclosure is further exacerbated by the fact that in many instances, children are orphaned as a result of HIV/AIDS and their caregiver may not be their parent. Disclosure remains particularly difficult because of on-going stigma towards people living with HIV/AIDS, low literacy and education levels, limited opportunities for access to information in some areas and high levels of stress faced by families as a result of poverty and the epidemic.[18,20]

Some would argue that the caregiver is the ideal person to disclose to a child,[21] but HCPs can play a significant role in this process.[22] The precise role of HCPs is not well understood or defined, however, and it is not clear whether HCPs should act as initiators and facilitators of the disclosure process or merely support caregivers. A proliferation of guidelines, tools and materials are available to assist HCPs with disclosure,[11] although it would seem that HCPs are not always aware of these tools nor do they necessarily implement them in their clinical practice.[19,21] There have been calls for greater attention to be paid to the disclosure process[18] and a need to further develop disclosure guidelines and policies.[23]

The HIV care context is something of a minefield because of the numerous legal and ethical issues that exist to protect patients from the stigma and discrimination that surrounds this disease.[24] Within the South African context, HCPs must consider a number of laws and guidelines which may have implications for disclosure – for example, the Children's Act[25] that outlines children's rights to information and participation in healthcare decisions, and guidelines for HIV care supplied by the Department of Health.[26] Some authors have described feelings of uncertainty among HCPs regarding their roles and responsibilities in the disclosure process with children, in the light of these legal and ethical implications.[19,27]

A number of international studies have explored aspects of disclosure practice and particularly HCPs' perceptions of how disclosure should happen. Limited research of this nature has been conducted in sub-Saharan Africa, although Myer *et al.*[21] and Vujovic[19] have examined South African HCPs' views on disclosure practices and they highlight some of the challenges faced by HCPs in this regard. What the literature does not focus on are the perspectives and experiences of healthcare teams on disclosure practices and the particular roles and responsibilities of each team member. Such perspectives are important to explore and understand because it is the healthcare team that works at the 'coalface' of disclosure and grapples with these issues on a daily basis. There needs to be a synergy between the development of guidelines and policies on disclosure and the practical nature of the work of disclosure within a specific context, making the topic of this study an important one.

Thus, this article reports on an exploratory study which focused on the perspectives and experiences of a healthcare team at a paediatric clinic in South Africa with regard to disclosure to children and adolescents. This exploratory study incorporated a descriptive qualitative research design. It constitutes part of a larger study at the chosen research site, which involved exploring HCP, caregiver and adolescent's perceptions and experiences of disclosure, and it builds on previous studies completed by the author at this research site.[28] This paper will focus on the HCP component of the larger study.

## Methods

The study was conducted at a South African HIV/AIDS paediatric clinic in a tertiary urban hospital. The clinic provides care to over 1000 infants, children and adolescents, including routine medical checkups, HIV testing and adherence counselling. Challenges to the provision of care include limited clinic resources, extreme poverty in the surrounding community and large patient numbers. Despite these challenges, the clinic has achieved high levels of adherence and successful patient outcomes.[28] Children treated at this clinic are referred at birth or after diagnosis during childhood. Although this is an HIV clinic, the clinic is not explicitly labelled as such, for reasons related to stigma.

Participants included health professionals and administrative personnel employed at the clinic. The participant group was mostly female, spanned an age range of approximately 20–50 years and reflected a mix of different ethnic backgrounds as is common in South African urban contexts. All staff members were invited to participate via a presentation by the researcher about the study, and all agreed to participate in the study (although the final number of participants was determined by staff availability during the data collection period).

Ethical clearance was obtained from the University Human Research Ethics Committee (Medical). Information about the study was provided in verbal and written format. Participants were informed about the nature of the study, their role in the study and confidentiality and anonymity. It was made clear that participation was voluntary and there would be no negative consequences if staff elected not to participate or withdrew from the study. Written consent was obtained from all participants.

Three focus groups were conducted by the author who was familiar with the context and had previously conducted focus groups at this clinic. Focus groups comprised staff from different professional groups to allow for exploration of team rather than individual perspectives. Focus groups were conducted in

English (as all participants were fluent in this language) and were audio recorded. Krueger and Casey's[29] guidelines were consulted. Each group lasted approximately one hour; limited time was available as staff could not take prolonged time off work.

A question guideline was devised by the author with input from the clinic director and senior clinic staff, research experts in the field of disclosure and a psychologist at the hospital. Questions explored participants' perceptions and experiences of current disclosure practices, perceived barriers and facilitators to disclosure, as well as their suggestions for ideal disclosure practices. Although the clinic director was involved in the planning of the project, this person was not directly involved as a participant or researcher during data collection or analysis, thus eliminating the possibility of bias.

Recordings were transcribed verbatim by the author. Transcripts were analysed using the principles of thematic analysis outlined by Braun and Clarke[30] and Rapley.[31] Themes were identified within each transcript and then compared across the groups. Themes were clustered, subordinate themes were grouped under main category headings and illustrative quotes were selected for each theme. Methods to improve quality and trustworthiness within a naturalistic paradigm were employed, including keeping a reflexive field journal and engaging in peer debrief and member checks.[32,33] In the case of the latter, the themes identified by the author were discussed with a small group of staff who had the opportunity to provide comments. This process informed the interpretation of the data, in particular by contributing to an understanding of why disclosure practices happen in the way that they do at this clinic. The results of the study were presented to the clinic manager, director and some staff in line with an ethical responsibility to provide feedback to the clinic.

## Results

A total of 23 staff members participated in three focus groups, which constituted the majority of staff employed at the clinic at the time of data collection. Groups 1 and 3 consisted of seven participants each, while Group 2 consisted of nine participants. Participants included nine counsellors, six nurses, three doctors, two administrative clerks, one social worker, one dietician and one clinic manager.

A number of themes were identified in the focus groups which related primarily to the team's experiences of disclosure practices in the clinic. These themes have been grouped under three major categories, namely (i) experiences of disclosure, (ii) understanding the concept of disclosure and (iii) perceptions of the HCP's role with disclosure. The findings will be described using illustrative quotes from the transcripts.

### Experiences of disclosure

Participants described various approaches to disclosure in the clinic which confirm the findings of other studies.[19,21] For example, the team highlighted the importance of disclosure as a process rather than a once-off discussion and they distinguished between 'partial' and 'full' disclosure with children. Participants agreed that whenever possible, the caregiver should disclose to a child. They also described the role of support groups at the clinic in providing disclosure support and education to caregivers.

Some participants highlighted the often inconsistent nature of disclosure practices at this clinic. While many of the participants were aware of the availability of various disclosure guidelines, tools and materials, these are not being implemented at the clinic and almost all participants mentioned the need for site-specific guidelines and policies.

Participants indicated that children often know or suspect their HIV status before they are told and the disclosure process may simply act as confirmation. In some cases, children who have been through disclosure appear happier, more confident and better able to communicate with their caregiver. In other cases, disclosure leads to negative reactions such as anger, blame, denial, death wishes or significant behavioural issues such as drug abuse. Caregivers' negative reactions may worsen the child's reaction – for example, if a caregiver is ashamed or angry and if they lie to the child or refuse to discuss the topic further after disclosure.

Participants also mentioned the lack of communication between caregivers and children and the frequent delay in disclosing in these cases – 'I think the problem with disclosure is it becomes this "we [the caregivers] don't talk about anything, about HIV or sex or disease or health or whatever until one day we tell you you've got HIV and then we never talk about it again afterwards"' (FG3). Participants noted that many caregivers do not request help from the healthcare team when it comes to disclosing to their child – 'no one has ever said to me before, what can I say to my child?' (FG3).

Participants described experiences of disclosing directly to a child or indirectly supporting caregivers through the disclosure process. In particular, they spoke about the HCP's burden of responsibility to ensure that disclosure happens and the sense of failure they feel when disclosure does not happen or when the process goes wrong. One participant indicated that 'since I've been [working at this clinic], I've never had an instance of disclosure where things went well' (FG2).

Participants spoke about the secrecy that exists around disclosure because of the threat of stigma, and how this affects their work. For example, HCPs have to be careful not to mention HIV or inadvertently disclose to a child during a consultation; if a child walks in on a caregiver support group, the discussion is halted until the child has left the room; and a coding system is used to label patient files so that HCPs are aware of which children have been disclosed to. The need for secrecy and the protection of patients' rights affects all HCPs at the clinic – 'you've got to be very careful, like I'll never say "HIV" in a consultation' (dietician, FG3).

Other perceived challenges related to evaluating the maturity and mental age of a child to determine readiness for disclosure – 'none of [the guidelines] will say how do you assess the mental age of the child or the developmental age of the child' (doctor, FG3). Some participants indicated that it is not always clear whether a child has understood what has been explained to them during the disclosure process, and other participants expressed uncertainty about how to determine whether a child is in danger of self-harm after disclosure. The need for further training in this regard was highlighted – 'as healthcare workers we're not equipped to pick up serious mental health issues in kids and we don't really know how to deal with them when we do' (doctor, FG3).

Some cases seem to hold particular significance in terms of the team's response. For example, all of the focus groups spoke about a case in which an adolescent who had not yet been disclosed to found out about her status at the clinic (either during the support group or by reading her clinic file) and she subsequently committed suicide. This case seemed to have had a significant impact on the team, both emotionally and in terms of their approach to disclosure practices. In particular, it seemed to have led to greater caution regarding their involvement with disclosure. With reference to this case and others, participants mentioned feelings of guilt – 'we didn't do enough for her, we were not there for her, maybe we didn't pick up enough [of her distress] and maybe we didn't support her enough' (FG1), helplessness – 'sometimes you go home and you feel totally helpless. Trained, but helpless. You ask yourself wasn't there something [I could have done]' (FG1), trauma – 'we were traumatized…that was my worst day' and regret – 'I look back and I'm just like kind of horrified at some of the stuff that I did. Well that was just out of ignorance…I had the best intentions.' (FG3). Although the participants did attempt to engage in peer debrief at the time and 'let off steam' after this particular incident, the need for formalized support and team debrief structures was highlighted.

### Understanding the concept of disclosure

Although the literature and various policy documents do provide definitions of the concept of disclosure, it became evident during the focus groups that some participants did not completely understand the concept or had only developed an understanding of the concept recently. For example, one of the doctors (FG3) revealed 'I also thought that disclosure meant telling the child they've got HIV, not this idea of talking to your child about health…that they've got a chronic disease that needs medication and there's a germ that's being controlled, the whole partial disclosure thing'. This doctor went on to describe how it was only through her own research and exploration of available guidelines and materials that she was able to understand the concept of disclosure more completely.

Towards the end of one of the focus groups and after a lengthy discussion of disclosure practices at the clinic, one of the counsellors (FG3) posed a question to the rest of the group: 'What I would like to know, are we [HCPs] allowed to disclose or maybe help the caregiver to disclose? Are we allowed to disclose?'. What is interesting to note is that this counsellor is experienced and well trained, yet her question encapsulates the uncertainty and confusion regarding the roles and responsibilities of the individual HCP and the team in facilitating disclosure.

An intense discussion ensued regarding HCPs' involvement in disclosure to children, with reference to ethical implications, children's rights and the Children's Act. There appeared to be significant discrepancies in team members' interpretation of the Children's Act and the age at which children can be disclosed to, as illustrated in this excerpt from FG3:

| | |
|---|---|
| Doctor | What you're saying is there should be rules. |
| Counsellor | There are. |
| Doctor | … there are no rules. |
| Counsellor | Uh-uh. There are. The Children's Act stipulates that. |
| Doctor | I just read the Children's Act. A child from the age of twelve is allowed [to be disclosed to]. |
| Counsellor | Yes. |
| Doctor | It says if they're sufficiently mature, but it doesn't state how you evaluate it. |
| Counsellor | Ja, the maturity, ja. |
| Dietician | Ja that maturity thing is- it's your interpretation. |
| Doctor | It's very broad. |

All participants indicated the need for training on the topic of disclosure, and in particular, clarification of the process and the legal implications – 'we need to have a guideline as to what to do because each one of us just does what we think is right' (FG1). There was agreement that although a 'one-size-fits-all approach' to disclosure practices at the clinic was not appropriate, site-specific guidelines and team training could prevent further inconsistencies and tensions around disclosure practices.

### Perceptions of the HCP's role in disclosure

When asked about who should be involved in disclosure, one group suggested that it should be 'the most comfortable person' (FG1) for the child and caregiver. There was general consensus that disclosure needs to be a team responsibility – 'I still believe that each and every healthcare professional must take responsibility for disclosure, as long as they actually have some insight of how to do it' (clinic manager, FG3).

What became particularly evident, however, was a dichotomy of views towards disclosure practices, roles and responsibilities, especially between nurses and counsellors, and doctors. At times, the group discussions became intense and this topic seemed to spark disagreement among what has been described elsewhere as a generally efficient and collaborative team.[28]

Nurses and counsellors tended to describe their role in a more indirect, tentative way, as one that involved encouraging caregivers to disclose to their children – 'at this clinic we encourage the caregivers to disclose to their kids' (FG1), 'we don't really like to just go ahead and tell the patient on our own', 'parents must decide when to disclose' and '[we] wait until the caregiver allows it' (FG1). The nurses talked about 'unwritten rules' (FG1) when it comes to disclosure practices and knowing when to step in and assist a caregiver and child through the disclosure process, perhaps reflecting what some authors have described as 'intuitive expertise'.[30] Nurses and counsellors seemed hesitant to initiate disclosure with a child or interfere with the disclosure process between caregiver and child, unless specifically asked to by a caregiver. Some participants felt reluctant to overrule a caregiver's decisions: for example, participants in FG1 referred to the case of a seventeen-year-old girl who had not been disclosed to. While sitting in the counsellor's room, the mother had lied to the girl about her status but the counsellor did not feel able to tell the girl the truth – 'if you say something then [the caregiver] becomes very difficult'.

Reasons for this indirect stance towards disclosure seemed grounded in a desire to avoid negative repercussions ('some parents get very upset if you tell the children' – FG3) and litigation ('aren't we opening ourselves as healthcare workers to where we have a situation like those who say 'I'm going to report you'?' – FG3). Nurses and counsellors also referred to prior experiences in which HCP disclosure had led to detrimental outcomes for the child, caregiver and/or HCP. Their hesitancy also appeared to reflect hierarchical team structures with regard to role allocation and their deference to the doctors as authority figures – 'we always say to them [caregivers] you can discuss it [disclosure] with doctor' (FG1) and 'usually what happens is they disclose with the doctors and then they can call us to support' (FG2).

In contrast, the doctors appeared to take a more direct stance regarding disclosure to children. A sense of ethical duty and their belief that a child has a right to know their status seemed to motivate them to disclose directly to a child in some cases or to prompt caregivers to disclose to their child in the medical consultation – 'I'll usually bring it up and we [doctor and caregiver] disclose together'; 'I've talked about disclosure to loads and loads of parents' (FG3). This sense of duty and responsibility seemed particularly strong in cases where an adolescent had not yet been disclosed to, if a child was orphaned, if a caregiver was not available or if it was clear that a caregiver did not intend to disclose to their child – 'if I don't do it, they [the caregiver] will never ever do it' (FG3). Although the doctors favoured a more direct approach, their responses sometimes indicated hesitancy regarding their role in disclosure – 'I don't know if I'm doing the right thing [by talking about disclosure with caregivers]' and 'it felt like the right thing to do at the time' (FG3).

As a result of this dichotomy of opinion and practice, there seemed to be a degree of underlying tension among the team and a tendency to apportion blame to members of other professional groups. For example, one of the counsellors indicated that 'most of [the doctors] disclose to the child when the parent is not around… they don't follow up to see how this child is coping' (FG2) and one of the doctors expressed that 'the counsellors I don't think are actively initiating [disclosure] really and there have been some inconsistencies' (FG3). Two focus groups described a case in which a doctor had disclosed to a child without the caregiver present, the caregiver became angry with the clinic HCPs, and the nurses and counsellors had to 'take over' and placate the caregiver. These diverse approaches and resulting inconsistencies in disclosure practices also seemed to result in internal conflict for HCPs – 'there's a conflict between ethics, like you have a duty to the child' (FG3) – and this conflict was highlighted by some of the participants.

## Discussion

Of all the areas of HIV management, disclosure to children and adolescents seems to present one of the biggest challenges to healthcare teams.

This study reveals that even experienced, trained HCPs may be unclear about the implementation of disclosure practices, and this uncertainty may have significant implications for team function. The complexities of disclosure, particularly with children and adolescents, coupled with the burdens and urgencies associated with working in an HIV care setting[15] bring about additional challenges for healthcare teams. As Penn shows,[34] the task of disclosure is an intricate and nuanced one which is considerably influenced by individual backgrounds and circumstances as well as contextual variables.

Although guidelines and policies do exist, the practical enactment of disclosure may be complex and uncertain, in part because of the significant gaps between policy and practice and the 'inconsistent guidance' available.[3,23] As the participants in this study have confirmed, existing guidelines are often not specific enough about how certain tasks related to the disclosure process should be achieved – for example, how maturity or mental age should be determined. The sensitivities around disclosure and the unique aspects of each case require some degree of intuitive expertise, which is not considered in existing guidelines. On the other hand, this study seems to suggest that HCPs do not seem comfortable to rely entirely on intuitive expertise but need explicit frameworks and consensus with colleagues to guide disclosure practices.

It would seem, paradoxically, that the availability of so many guidelines, materials and tools is perhaps adding to the confusion and further complicating disclosure practices for healthcare teams. These materials and tools are not necessarily being implemented nor are they practically useful.[19] HCPs continue to highlight the need for disclosure guidelines (as confirmed in this study), there is 'no definitive stand-alone resource for disclosure'[23] [p. 2], 'a wide gap between legislation and implementation' exists[35] [p. 25], and the roles and responsibilities of HCPs with regard to disclosure practices remain unclear. The challenge lies in finding ways to integrate and interpret existing guidelines into clinical practice while considering established clinical roles and team and professional hierarchies.

The legal and ethical complexities of disclosure and the resulting uncertainty among team members regarding roles and responsibilities may also contribute to inconsistent disclosure practices, adverse patient outcomes and tensions within the team, as described by the participants. Because roles and responsibilities regarding disclosure are not clear, HCPs may revert to the safety of existing professional groups and power hierarchies.[36,37] There is a sense of 'I' versus 'we' in the data presented, with doctors on one side and nurses and counsellors on the other. Ultimately, this dichotomy fosters a move away from a sense of team responsibility for disclosure and instead seems to promote a power struggle over the establishment of the 'disclosure philosophy' of the clinic.

Ultimately this dichotomy may result in conflict within the team and intrapersonal conflict for individual HCPs as they attempt to embed their own convictions regarding how disclosure should happen within larger ethical and legal frameworks. Importantly, these results emerged from an HIV care team that has been shown to be effective and collaborative through their focus on patient-centred care, successful HCP–patient communication and organizational routines,[28] suggesting that disclosure poses particular challenges to teams working in HIV care. These results also suggest that the greater issues of team function and clinic philosophy regarding disclosure need to be addressed in conjunction with clarification of guidelines, to promote the success of interventions to improve disclosure practices.

## Conclusion

There are a number of research imperatives that emerge from this study. Clinicians and researchers need to work together to find ways of enhancing disclosure practices, clarifying existing confusion and uncertainty around roles and responsibilities with disclosure, supporting staff and caregivers, and most of all, ensuring that disclosure happens in an appropriate, sensitive and timely manner with children. Such research also needs to consider the challenges that arise as a result of the influence of disease, cultural and social contexts.

The results of this study hold important policy and practice implications for supporting clinic teams and enabling them to improve disclosure practices with children and adolescents. In the words of one of the participants, HCPs need to ‘sing the same songs’ when it comes to disclosure practices. While a ‘one-size-fits-all’ approach to disclosure is probably not going to be appropriate or effective, some clarification of the legal implications of disclosure for HCPs together with carefully worked out site- and team-specific guidelines may encourage more consistent disclosure practices (the on-going work of groups such as the South African HIV Clinicians Society in this regard is applauded). In addition, HCPs need support when it comes to understanding children’s developmentally related language and cognitive needs, and guidelines and materials need to take these aspects into consideration. The establishment of disclosure routines may also provide a protective psychological mechanism to decrease anxiety and uncertainty for all parties involved.[38]

Perhaps one of the most significant findings of this study is the role of the team in facilitating (and unfortunately in some cases perhaps inhibiting) disclosure. Traditional attitudes in medicine and nursing in particular have fostered a sense of hierarchy, bureaucracy, independence and allegiance within these fields,[39,40] and these observations certainly seem to be reflected in this study. Davies[39] suggests that what is required for an effective team is a sense of ‘working together’ as opposed to ‘working alongside’. When it comes to disclosure, teams need to clarify their objectives and approaches, decide on individual roles and responsibilities, work through conflicts around disclosure practices in a constructive manner, put mechanisms in place to ensure regular communication about disclosure, and foster opportunities for reflection, debrief and peer support.[40] The task of disclosure may also require some degree of fluidity in team members’ roles, as Penn’s study illustrates.[34] In addition, promoting a sense of ‘expert intuition’[41] within the team will go a long way to ensuring sensitive, appropriate and successful disclosure practices.

Before HCPs can truly support and empower caregivers to disclose to children, these issues need to be worked out. Significant changes to disclosure practice may thus come about through improving the structure and function of the healthcare team. This finding is important not only in the field of HIV care, but in other fields where teamwork and the function of the healthcare team are essential to providing quality patient care – for example, teams involved with paediatric cancer.[42]

Disclosure remains a difficult task for healthcare professionals and caregivers, particularly with children and adolescents. This exploratory study was conducted with one team working at a particular clinic in a specific disease context, which might be considered a limitation. That said, the results confirm the findings of other studies and highlight a number of team challenges to disclosure with children that are likely to be present in other clinical settings in South Africa and globally.

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## Conflict of interest

None to declare.

## Reference

1 Wiener L, Mellins C, Marhefka S, Battles H. Disclosure of an HIV diagnosis to children: history, current research, and future directions. *Journal of Developmental and Behavioral Pediatrics*, 2007; **28**: 155–166.

2 Vuyovic M. HIV disclosure in children. Presentation at the Paediatric Aids Treatment for Africa Forum. 2011. Available at: http://www.teampata.org/downloads/Marnie%20Vujovic%20Disclosure%20in%20Children.pdf, accessed 27 May 2013.

3 Medecins Sans Frontiers. *Therapeutic Education: Recommendations Regarding Disclosure of HIV Status to Children under ARV in MSF Projects*. Paris: MSF, 2005.

4 World Health Organisation. *Guideline on HIV Disclosure Counselling for Children up to 12 Years of Age*. Geneva: World Health Organisation, 2011.

5 Norman A, Chopra M, Kadiyala S. Factors related to HIV disclosure in 2 South African communities. *American Journal of Public Health*, 2007; **97**: 1775–1781.

6 Vreeman R, Nyandiko W, Ayaya S, Walumbe E, Marrero D, Inui T. The perceived impact of disclosure of pediatric HIV status on pediatric antiretroviral therapy adherence, child well-being, and social relationships in a resource-limited setting. *AIDS Patient Care and STDs*, 2010; **24**: 639–649.

7 Santamaria K, Dolezal C, Marhefka S *et al*. Psychosocial implications of HIV serostatus disclosure to youth with perinatally acquired HIV. *AIDS Patient Care and STDs*, 2011; **25**: 257–264.

8 Moodley K, Myer L, Michaels D, Cotton M. Paediatric HIV disclosure in South Africa – caregivers' perspectives on discussing HIV with infected children. *South African Medical Journal*, 2006; **96**: 201–204.

9 Instone S. Perceptions of children with HIV infection when not told for so long: implications for diagnosis disclosure. *Journal of Pediatric Health Care*, 2000; **14**: 235–243.

10 Lester P, Chesney M, Cooke M *et al*. When the time comes to talk about HIV: factors associated with diagnostic disclosure and emotional distress in HIV-infected children. *Journal of Acquired Immune Deficiency Syndromes*, 2002; **1**: 257–275.

11 Naeem-Sheik A, Gray G. HIV disclosure in children. *South African Journal of HIV Medicine*, 2005; **6**: 46–48.

12 Vaz L, Eng E, Maman S, Tshikandu T, Behets F. Telling children they have HIV: lessons learned from findings of a qualitative study in sub-Saharan Africa. *AIDS Patient Care and STDs*, 2010; **24**: 247–256.

13 Kouyoumdjian F, Meyers T, Mtshizana S. Barriers to disclosure to children with HIV. *Journal of Tropical Pediatrics*, 2005; **51**: 285–287.

14 Hackl K, Somlai A, Kelly J, Kalichman S. Women living with HIV/AIDS: the dual challenge of being a patient and caregiver. *Health and Social Work*, 1997; **22**: 53–62.

15 Watermeyer J. "Now here come the pills that are going to save your life": Pharmacists' discussions of antiretroviral drugs in a context of life and death. *Aids Care*, 2011; **23**: 807–813.

16 Watermeyer J, Penn C. "Only two months destroys everything": a case study of communication about non-adherence to antiretroviral therapy in a South African HIV pharmacy context. *Health Communication*, 2012; **27**: 602–611.

17 Cameron E. *Witness to Aids*. Cape Town: Tafelberg, 2005.

18 Lesch A, Swartz L, Kagee A *et al*. Paediatric HIV/AIDS disclosure: towards a developmental and process-oriented approach. *AIDS Care*, 2007; **19**: 811–816.

19 Vujovic M. *An Exploration of Disclosure with Children living with HIV*. Durban: Children's Rights Centre, 2010.

20 Demmer C. Experiences of families caring for an HIV-infected child in KwaZulu-Natal, South Africa: an exploratory study. *AIDS Care*, 2011; **23**: 873–879.

21 Myer L, Moodley K, Hendricks F, Cotton M. Healthcare providers' perspectives on discussing HIV status with infected children. *Journal of Tropical Pediatrics*, 2006; **2**: 293–295.

22 Vaz L, Mamam S, Eng E, Barbarin O, Tshikandu T, Behets F. Patterns of disclosure of HIV status to infected children in a sub-Saharan African setting. *Journal of Developmental and Behavioral Pediatrics*, 2011; **32**: 307–315.

23 Vujovic M. National HIV disclosure guidelines for children, 2012. Available at: http://www.sahivsoc.org/upload/documents/Vujovic_National_HIV_Disclosure_Guidelines_for_Children.pdf, accessed 18 September 2013.

24 Spencer D. Doing HIV medicine in southern Africa – what does the epidemic teach us? *South African Medical Journal*, 2007; **97**: 1203–1205.

25 Children's Act 38. Government Gazette Vol. 492, 19 June 2006, No. 28944. Cape Town.

26 Department of Health. *Guidelines for the Management of HIV in Children*, 2nd edn. Pretoria: National Department of Health South Africa, 2010.

27 Klitzman R, Marhefka S, Mellins C, Wiener L. Ethical issues concerning disclosures of HIV diagnoses to perinatally infected children and adolescents. *Journal of Clinical Ethics*, 2008; **19**: 31–42.

28 Watermeyer J. "This clinic is number one": a qualitative study of factors that contribute towards 'successful' care at a paediatric HIV/AIDS clinic. *Evaluation and the Health Professions*, 2012; **35**: 360–379.

29 Krueger R, Casey M. *Focus Groups: A Practical Guide for Applied Research*, 3rd edn. Thousand Oaks: Sage, 2000.

30 Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology*, 2006; **3**: 77–101.

31 Rapley T. Some pragmatics of data analysis. In: Silverman D (ed) *Qualitative Research: Issues of Theory, Method and Practice*, 3rd edn. Los Angeles: Sage, 2011: 273–290.

32 Erlandson D, Harris E, Skipper B, Allen S. *Doing Naturalistic Inquiry: A Guide to Methods*. London: Sage, 1993.

33 Patton M. *Qualitative Research and Evaluation Methods*, 3rd edn. Thousand Oaks: Sage, 2002.

34 Penn C. "Too much for one day": a case study of disclosure in the pediatric HIV/Aids clinic. *Health Expectations*, 2013; doi:10.1111/hex.12140 [Epub ahead of print].

35 Van Rooyen H. Children's guidelines and assessment tool: overview of content, process and next steps, 2012. Available at: http://www.sahivsoc.org/upload/documents/Van_Rooyen_Childrens_Guidelines_and_Assessment_Tool_Overview_of_Content_Process_and_Next_Steps.pdf, accessed 18 September 2013.

36 Jormsri P. Moral conflict and collaborative mode as moral conflict resolution in health care. *Nursing and Health Sciences*, 2004; **6**: 217–221.

37 Anstrand C. Narratives revealed: uncovering hidden conflict in professional relationships. Unpublished Masters thesis, Texas A&M University.

38 Lewin S, Green J. Ritual and the organisation of care in primary care clinics in Cape Town, South Africa. *Social Science & Medicine*, 2009; **68**: 1464–1471.

39 Davies C. Getting health professionals to work together: there's more to collaboration than simply working side by side. *British Medical Journal*, 2000; **320**: 1021–1022.

40 Firth-Cozens J. Multidisciplinary teamwork: the good, bad, and everything in between. *Qualitative Health Care*, 2001; **10**: 65–69.

41 Gobet F, Chassy P. Towards an alternative to Benner's theory of expert intuition in nursing: a discussion paper. *International Journal of Nursing Studies*, 2008; **45**: 129–139.

42 Heeren A. Changing methods of disclosure. Literature review of disclosure to children with terminal illnesses, including HIV. *Innovation – The European Journal of Social Science Research*, 2011; **24**: 199–208.