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The content of disclosure messages to children with perinatal acquired HIV: Implications for disclosure interventions and guidelines for caregivers in resource-limited settings

*Sphiwe Madiba*¹

Abstract

The World Health Organization's guidelines on disclosure of HIV status to children do not specify the content of messages communicated to the infected child. Consequently, there are no data on what caregivers tell children during disclosure. The aim of the study was to assess caregiver's motivation for disclosure and examine the content of disclosure to perinatally infected children. Five focus group discussions were conducted with 49 disclosed and non-disclosed caregivers of children between 5-18 years accessing primary health facilities in Tshwane District, Gauteng Province, South Africa. The recorded interviews were transcribed and analyzed using thematic analysis. Disclosure occurred because of the caregiver's perceptions that it would improve adherence to ART and in response to repeated questioning from the children about their illness or medication. Full disclosure occurred to all the children and disease specific information was based on caregiver's limited HIV-related knowledge. The content of disclosure following the naming of the disease was defined by the reasons for disclosure. Disclosure included a discussion on the value of ART medications and the importance of adherence. Caregivers specified the source of HIV infection for children who wanted to know why and how they were infected and discussed the potential transmission of HIV to others for older children to protect future sexual partners from infection. Relying on the caregiver to disclose without support from healthcare workers has implications on what children are told during disclosure. Disclosure interventions should provide caregivers will biomedical information about HIV to provide factual information during disclosure to children.

Key words: Disclosure messages, perinatal infected children, caregivers, skills, HIV knowledge, reasons for disclosure

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Introduction

More than a decade after the first roll out of antiretroviral treatment (ART) to children with perinatal acquired HIV (PAH), many children and adolescents remain unaware of their HIV status despite receiving ART for long duration of time (Lorenz et al., 2016; Mumburi et al., 2014; Vreeman et al., 2013). Various factors have been associated with barriers to disclosure to children with PAH, but little attention has been paid to what caregivers tell children during disclosure and how children utilize the information to manage their disease. It has been reported that when children know about their HIV diagnosis and treatment, they take responsibility for their health and adhere to ART (Gyamfi et al., 2015; John-Stewart et al., 2013; Kajubi et al., 2014; Vaz et al., 2010). A study conducted in Uganda found that children adhere to their daily ART when they know their HIV status and understand why they need to take their medication continuously (Bikaako-Kajura et al., 2006). With regards to what caregivers tell children, (Kiwanuka et al., 2014) indicate that many caregivers in their study included a discussion on the transmission of HIV to others to allow children to take actions to protect playmates and potential sexual partners from accidental exposure to HIV.

The World Health Organization (WHO) published guidelines on disclosure of HIV status to children and adolescents, however, these guidelines do not specify the content of messages to be communicated to the infected child (WHO, 2011). As a result, children's knowledge of what the medication is for and how to take it correctly is largely reliant on their caregivers. Moreover, caregivers often hesitate to explain to the children what the treatment is for despite the presence of local and WHO guidelines. This is largely due to a lack of consensus concerning the age at which the disclosure process should start (Bikaako-Kajura et al., 2006; Kiwanuka et al., 2014; Madiba, 2012b). Even though disclosure guidelines do not specify the content of disclosure to children, they ascribe the disclosure responsibility to the caregiver and highlight the supportive role of the HCWs in the process (Kajubi et al., 2014). Nonetheless, the literature suggests that relying on the caregiver alone to communicate messages on diagnosis and treatment to children might be insufficient (Kiwanuka et al., 2014).

Available but limited data regarding the timing and content of disclosure to children highlight the challenges of HIV disclosure in resource-limited settings (Mutumba et al., 2015). There is a consensus in support of the WHO's recommendations that disclosure to children is a gradual process in which accurate and developmentally appropriate information is shared with children and should occur over a period, however, there are no data on what caregivers tell children during disclosure. The aim of the study was to assess caregiver's motivation for disclosure and examine the content of disclosure to perinatal infected children receiving ART. There is a need for culturally sensitive and age sensitive guidelines about the nature and content of disclosure to perinatally infected children (Kajubi et al., 2014).

Methods

Study design

This was a qualitative design conducted from October to December 2013 in health facilities in Tshwane District, Gauteng Province, South Africa. Data were collected in two primary healthcare (PHC) facilities providing ART services. Since 2010, PHC facilities in South Africa provide nurse-driven services that provide HIV testing and counseling, initiation and issuing of ART to HIV-infected children and adults.

Interviews

Trained research assistants conducted focus group discussions (FGDs) with a sample of caregivers of perinatal infected children aged between 5 and 18 years who were receiving ART in the health facilities. The interviewers used purposive sampling to select the caregivers during routine visits to the clinics. They were recruited as they waited in line for their children to see their health care providers. All interviews were conducted on the same day after the caregivers had received the relevant services. Interviews were conducted in the local language (Setswana) using a semi-structured interview guide with open-ended questions. The caregivers were asked about their reasons for disclosure and what they told the child during disclosure. All interviews were digitally recorded after obtaining permission from the caregivers. Informed consent was obtained after providing explanations about study objectives. Caregiver socio-demographic data, HIV status, and the relationship of the caregiver to the child were also collected at the end of each FGDs. Children's demographic information and clinical data such as age at first diagnosis, time since diagnosis, and time since ART initiation were provided by the caregivers.

Data analysis

Recorded interviews were transcribed verbatim using the language of the interviews and translated into English. The transcripts were reviewed for accuracy by playing back the recordings while reading through the transcripts to familiarize with the data. Thematic analysis was conducted to identify recurrent emerging codes. A code book was developed, and the key codes were defined. The transcripts were then imported into NVivo version 10, qualitative data analysis software (QSR International Pty Ltd. Version 10, 2016) for application of codes and refining of the themes and sub-themes. The coding of the transcripts was finalized, and the major themes were defined and formed the basis of presentation of the findings.

Credibility, dependability, and transferability of study findings was established by making use of a good digital recorder, transcribing the interviews verbatim, triangulation of data by conducting FGDs, collecting demographic data extensive interview and field notes, using NVivo qualitative software to analyze data, employing the code-recode strategy, peer examination of data analysis processes with colleagues, and keeping an audit trail.

Ethical Considerations

Ethical approval was granted by the Research and Ethics Committee of the University of Limpopo, Medunsa Campus (now known as Sefako Makgatho Health Sciences University). Permission to conduct the study was obtained from Tshwane District Health Research Committee and the managers of the health facilities. Written informed consent was obtained from individual caregivers before the interviews. Caregivers were informed that their participation was voluntary and that they may stop the interview at any time without compromising the care received from the facility. Anonymity and confidentiality were ensured during data collection.

Findings

Description of study sample

The sample consisted of caregivers of perinatal infected children who participated in five focus group discussions, 23 out of 49 caregivers reported that the child had been informed of their HIV status. The age of the caregivers ranged from 30 to 73 years. The caregivers consisted of grandparents, biological mothers, and other relatives including aunts and uncles. Only 10 out of 23 caregivers were the biological mothers of the children; the other 13 children were maternal orphans.

The caregivers provided information of the children they care for, and the ages of the children ranged from 5-17 years. All of the children were on ART, and most had received ART for over five years.

Themes

Reasons for disclosure

Caregivers who had disclosed gave various reasons for having done so, and three main themes emerged from the analysis; to promote treatment adherence, a child asking questions about HIV, and health care worker initiated disclosure.

To promote treatment adherence

Disclosure for most of the caregivers was motivated by poor adherence to treatment. Some reported that the children threatened to stop taking medication while others did not take their medication on time. The caregivers reported that they disclosed to promote treatment adherence as they believed that disclosure would provide children with a reason to take their daily medications.

I have a fifteen-year-old girl, when she was ten years old she used to refuse to take treatment, when I gave her treatment, she threw it under the bed, and she told me that she did not know the reason for taking treatment and she was not going to take treatment for something that she did not know. We decided to tell her why she was taking medication and what she was suffering from (mother of a 15-year-old girl).

The reason for telling the child was because she was not adhering to treatment, we used to find some pills under the bed, and she threw some in the toilet. We were scared that she might end up defaulting (mother of 15-year-old girl).

It was because he was refusing to take his medication, then we called the home-based caregivers, and they explained to him the importance of taking treatment, and from then, he continued with his treatment (aunt of 12-year-old boy).

Child asking questions

Caregivers also disclosed due to persistent questioning by the children about the medicines. They reported that the children asked how long they had to continue taking medication and also questioned why they had to take medication. The caregivers used this as an opportunity to inform adolescents about their HIV status.

I thought that it was important to tell the child because she kept on asking why she was taking pills. She was looking for answers from me; she wanted to know why the other children were not taking medication and she was taking medication, she wanted to know what it was for (grandmother of a 12-year-old girl).

The child was asking too many questions about it, asking what HIV is and I decided to tell him while he was still interested (mother of a 8-year-old boy).

The child wanted to know why I keep on giving her medication on a daily basis. So..., I saw that I am stressing the child because whenever she goes to school, I say don't forget to take medication, so I saw it fit to sit down with this child and explain (Grandmother of a 10-year-old girl).

Health care worker initiated disclosure

While most caregivers were able to disclose to the child at home, other caregivers felt unable to disclose and asked for help from HCWs to assist with the disclosure process. As a result, the disclosure was initiated and conducted by HCWs in the health facility.

My child was disclosed to at the hospital, he started going to the hospital at the age of nine, and started taking ARVs at the same age of nine. They disclosed to the child at the hospital and explained to him what was happening (mother of a 15 year old boy).

The nurses are the ones who disclosed to the child; they asked whether they should tell the child or not. We all sat together, and they told him that he's HIV positive (grandmother of 14-year-old boy).

The disclosure also occurred because the HCWs suggested and encouraged the caregiver to disclose. The caregiver admitted that the encouragement from HCWs played a major role in the decision to disclose.

During counselling, the nurse encouraged us to disclose to children. With me, when I bring the child for check-up here at the clinic, the nurse or doctor always ask whether I had explained to the child why is he taking medication (grandmother of a 7-year-old boy).

Content of disclosure

Five main themes emerged from the data about the content of disclosure to perinatally infected children as outlined:

The importance of taking medication

Most of the caregivers discussed the value of the medication and the importance of taking the medication all the time and on time with the children as part of the initial disclosure event. They also stressed to the child that taking medication was very important to their wellbeing and health. Most of the caregivers reported that their children understood when and how to take the medicines after the discussions.

He kept on asking me why he was taking pills every day. I set him down and explained. I said 'my child, you have a virus, and I give you these pills because I want to control it so that it does not become an illness because if it becomes an illness you are going to die. So you are supposed to these pills on time' (mother of 7-year-old boy).

I said your father was refusing to take treatment, and that's the reason we buried him, and I said to the child since you are taking your treatment, you will live longer (grandmother of a 10-year-old boy).

I told the child so that he can have a good knowledge about this illness, and also to understand the reason for taking treatment (grandmother of 8-year-old boy).

Naming the disease

Disclosure for all the children was truthful, and all the caregivers told their children that they had HIV because they believed that if the child knew the truth, they would not refuse the medications.

I set down with him and explained the situation, he is now nine years old..., I did not hide it from him..., I told him straight that the medication that he is taking is for a disease called AIDS. I also told him that the disease is not curable and that he will take treatment forever (grandmother of a 10-year-old boy).

One day she was talking about other children that they are HIV positive and I told her that she is also HIV positive and that this was the reason she was taking medicine (foster mother of 14-year-old girl).

I told my child that he has HIV and he was born with it [HIV]. The child was asking too many questions about it [HIV] asking what HIV is (mother of 8-year-old boy).

Potential to transmit HIV to others

Some of the caregivers used disclosure to make the child understand how the disease is transmitted and explained to the child that they could transmit HIV to their friends and potential sexual partners. They used disclosure to teach the children what action to take to protect other children or their future sexual partners from being infected with HIV.

I see it [disclosure] as a very important thing because children grow up, there will come a time when she will start dating, you must have started teaching the child about dating and safe sex (aunt of a 14-year-old boy).

When the child plays with other children, she knows that if there's an injury what action to take, she was taught that she must not let other children touch her blood (caregiver of a 10-year-old girl).

Sharing information on parental HIV status

As a way of making the child understand the nature of the disease, caregivers who were not the biological parent of the child, discussed the source of infection with the child. They told the child that his or her parent was also HIV positive and also explained the absence of the mother during the initial disclosure event.

We had a long talk about it [HIV], and I said to her that it is okay and it is not her fault because she wanted to know how she got it. I told her that it must have come from her mother and that is how she might have contracted it, and then she wanted to know about the mother..., I felt it was important for her to know (foster mother of 14-year-old girl).

I said HIV is a disease that you can't see, it can only be detected through blood, and that is why with you when your mother was pregnant with you, she did not take pills to prevent you from being infected. She discovered while she was pregnant with you that she has this disease (grandmother of 12-year-old girl).

The doctor then told him that HIV killed his mother and that she transferred the disease to him (grandmother of 13-year-old boy).

Discussion

The study found that most of the disclosure to perinatally infected children occurred at home and was conducted by the caregivers. Disclosure occurred mainly because of the benefits caregivers perceived would be derived from disclosure; they were of the view that disclosure would improve adherence to medication. This is similar to findings reported in other studies conducted in resource-limited settings (Abebe & Teferra, 2012; Atwiine et al., 2015; Gyamfi et al., 2015; John-Stewart et al., 2013; Kiwanuka et al., 2014; Mahloko & Madiba, 2012; Motshome &

Madiba, 2014). The current findings suggest that disclosure to children was not planned but occurred because of caregiver's concerns with the child's non-adherence to ART medication. This is in contrast to recommendations that disclosure should be viewed as a process, rather than an event, and should follow a gradual developmentally appropriate manner to provide the child with age-appropriate information (Lesch et al., 2007). Similar concerns that disclosure may be conducted over a relatively short period, rather than a gradual process of gradual delivery of information were raised in another study (Atwiine et al., 2015).

Disclosure also occurred in response to repeated questioning from children about their illness or the medication they were taking every day even when they did not feel sick (Gyamfi et al., 2015; John-Stewart et al., 2013; Madiba, 2012a; Mahloko & Madiba, 2012; Motshome & Madiba, 2014; Mweemba et al., 2015). The study findings are similar to other studies which found that caregivers believe that when children start asking questions about their disease and medication, they are ready for disclosure (Kallem et al., 2010; Madiba, 2012a; Vaz et al., 2010). (Atwiine et al., 2015) who suggest that inquiring about their medication and illness may be related to increased age because as children grow older, they tend to want to know what they are suffering from and why they take medication. Therefore, it is essential that disclosure guidelines should suggest how information could be packaged for the different age groups (Kajubi et al., 2014).

The study further found that the encouragement caregivers received from HCWs to disclose to children played a major role in the decision to disclose. Caregivers reported that disclosure occurred because HCWs encouraged them to disclose. In most cases, the HCWs were of the view that the child was old enough to be informed of their HIV diagnosis or the child was receiving ART for a long period and they were aware that disclosure had not occurred. (Kidia et al., 2014) reported that HCWs encouraged caregivers to disclose at home and prioritized this method over disclosure in the health facility. The disclosure was also initiated by the HCWs who disclosed to children for various reasons. Considering that caregivers in several studies expressed the desire for HCWs support for disclosure, disclosure by HCW should be expected (Kiwana et al., 2014; Madiba & Mokwena, 2012; Mahloko & Madiba, 2012; Mweemba et al., 2015; Sirikum et al., 2014).

Full disclosure occurred to all the children, and they were told the name of the illness and disease specific information as defined by (Wiener et al., 2007). The study found that even though children received full disclosure, disease specific information was limited to naming the disease and explaining that there is no cure and that they will take medication all their life. (Atwiine et al., 2015) suggest that a single disclosure conversation without adequate preparation may have adverse outcomes in the child. A study conducted with young people aged 10-24 years found that while all knew that they were living with HIV, not many knew what that meant (Bernays et al., 2016). Relying on the caregiver alone to communicate messages on diagnosis and treatment to children has implications on what children are told, particularly given

caregiver's admission of lack of knowledge and skills on how to conduct disclosure to children (Madiba & Mokwena, 2012; Mweemba et al., 2015). In a study conducted in Ghana, caregivers indicated that they lacked skills necessary for handling the disclosure process particularly around naming the disease (Kiwanuka et al., 2014). It is, therefore, important that HCWs provide factual information to the children about medication and their illness in support of caregivers (Kajubi et al., 2014). In a study conducted with HCWs on HIV disclosure to children, they indicated that one of their roles was to provide caregivers with factual information about HIV to prepare them for disclosure (Madiba & Mokgatle, 2015).

The content of the disclosure was further defined by the circumstances or reasons for disclosure. Where disclosure was a response to children questioning why they needed to take regular medication and or non-adherence to medication, the naming of the illness was followed by a discussion on the value of ART medications, the importance of adherence, and the long-term consequences of HIV to the child. Other studies also mentioned that caregivers had similar discussions with children during disclosure (Kiwanuka et al., 2014; Mutumba et al., 2015). In this study and others, caregivers focused on the incurable nature of untreated HIV/AIDS and in most cases mentioned death as a consequence of not adhering to medication (Kiwanuka et al., 2014; Mutumba et al., 2015). These discussions have implication on children and adherence to ART, while evidence from several studies show that disclosure improves adherence (Abebe & Teferra, 2012; John-Stewart et al., 2013; Mahloko & Madiba, 2012; Motshome & Madiba, 2014). There are limited data on how the information children receive during disclosure impact on their life.

Disclosure included sharing the source of HIV infection and specifying how the child was infected with HIV. This was an attempt by the caregivers to make the child understand the nature of the disease (Kiwanuka et al., 2014; Madiba, 2012a; Mutumba et al., 2015). The findings also indicated that non-biological caregivers discussed the source of infection with the child than biological parents. In contrast, (Kiwanuka et al., 2014) reported that despite recognizing that specifying the source of HIV infection would mean inevitable disclosure of their status, caregivers in their study went ahead and specified the source of infection during disclosure. In addition to specifying the source of infection, caregivers also explained that the transmission of HIV from the mother was unintentional. Caregivers further explained mother to child transmission of HIV to dispel confusion in the child's mind since the child may only know HIV to be sexually transmitted (Kiwanuka et al., 2014). Disclosure to children also included a discussion on the potential transmission of HIV to others. Consistent with other disclosure studies (Atwiine et al., 2015; Kiwanuka et al., 2014), for younger children, caregivers explained that they could transmit HIV to others through some forms of contact when they play while for older children HIV could be transmitted to others through sexual activity. Thus, caregivers disclose to teach children how to protect others from HIV infection (Gyamfi et al., 2015; Mweemba et al., 2015; Vaz et al., 2010)

Conclusion

Our study revealed that disclosure to children occurred mainly because of the benefits caregivers perceived would be gained from disclosure. Key among these benefits was the perception that disclosure would improve adherence to ART. The findings of the study further suggest that generally, perinatally infected children who are not informed of their HIV diagnosis do not adhere to ART medication. Hence the purpose and the content of disclosure was centered on medication adherence.

The study further found that the content of the disclosure following the naming of the illness depend on the reasons for disclosure. Disclosure included a discussion on the value of ART medications and the importance of adherence. Caregivers specified the source of HIV infection for children who wanted to know why and how they were infected and discussed the potential transmission of HIV to others for older children to protect future sexual partners from infection. Relying on the caregiver to disclose without support from healthcare workers has implications on what children are told during disclosure. Disclosure interventions should provide caregivers will biomedical information about HIV to provide factual information during disclosure to children.

Although full disclosure occurred to all the children during disclosure, disease specific information was based on the caregivers' limited HIV-related knowledge. Disclosure interventions and guidelines should focus on providing caregivers will biomedical information about HIV as well as communication skills to disclosure to children. Considering that caregivers and HCWs believe that caregivers have the primary responsibility to disclose, relying on the caregiver to communicate messages on diagnosis and treatment to children without support from HCWs impacts negatively on what children are told during disclosure. Caregivers should be empowered to use the opportunity presented by children when they ask questions about regular medication and their illness to begin disclosure.

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