PULA: Botswana Journal of African Studies Vol. 28, No. 1, 2014

Communication between caregivers and children perinatally infected with HIV about the disease and medication without disclosure: Qualitative data from Nyangabgwe Hospital, Botswana

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Abstract

Children usually receive antiretroviral treatment for a certain duration before the reasons for the treatment are fully discussed with them. Eventually, adherence to the treatment becomes a challenge. This study explore the communication between caregivers and HIV-infected children about medications and their illness in the absence of disclosure of the HIV status. A qualitative study was conducted with 20 caregivers of children whose HIV status had not been disclosed to. Caregivers were purposely selected from the Infectious Disease Control Centre of Nyangabgwe Hospital, Gaborone, Botswana. The caregivers used the analogy of the immune system as an army and the viral load as bad guys to make the child understand their illness and the importance of good adherence to medication. Communication with children about their medication and illness using "bad guys" and "body soldiers" occurred on a regular basis. Caregivers were aware of the importance of preparing the child for disclosure and all stated that disclosure will happen only when the child is well prepared. Caregivers approached disclosure as a process, and prepared for disclosure by providing children with partial factual information about their illness and medication. The study findings support the view that caregiver readiness to disclose is a key determinant of disclosure. HCWs should provide support to caregivers to facilitate disclosure to HIV-infected children. Further explorative studies should be conducted with children in this and similar settings in Botswana to assess their understanding of their illness and medication.

Key words: Caregivers, HIV infected children, disclosure, Botswana, communication, antiretroviral treatment

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Introduction

Disclosure of perinatal acquired HIV (PAH) is generally delayed until late childhood or adolescence. Children usually receive antiretroviral drugs for a certain duration before the reasons for the treatment are fully discussed with them. Eventually, adherence to the treatment becomes a challenge because they do not see why they should take medications when they feel that they are actually healthy. Caregivers often hesitate to explain to children with PAH what the treatment is for despite the presence of local, national, and World Health Organization (WHO) guidelines (Bikaako-Kajura et al., 2006; Kiwanuka et al., 2014; Kyaddondo et al., 2013). Disclosure to children with PAH is often as a result of the children asking what the medicines were for and when they could stop taking them (Kajubi et al., 2014; Stacey Kallem et al., 2010; Mahloko & Madiba, 2012). However, literature has shown that caregivers who delay disclosure report that children do not ask what the medicines are for (Bikaako-Kajura et al., 2006). This is in contrast to recent data, in a study that was conducted in Uganda on communication patterns of children on ART, the results showed that many children wanted to know more about why they were taking medicines (Kajubi et al., 2014).

Literature also indicates that disclosure to children with PAH occurs to promote adherence to ART medication (Biadgilign et al., 2011; Bikaako-Kajura et al., 2006; Mahloko & Madiba, 2012). The challenge for ART adherence is when disclosure is delayed, and children are told to drink the medication with no information of the importance of the medication or telling them that they are infected with HIV. Failure to communicate the relevance and importance of medication is the underlying reason for poor adherence to ART medications among children with PAH (Motshome & Madiba, 2014).

Of concern is that literature shows that communication to children by caregivers to describe their illness is often inaccurate and false (Kiwanuka et al., 2014). Given that the prevalence of disclosure to children with PAH in developing countries is low (Mumburi et al., 2014; Sahay, 2013; Vreeman et al., 2013), it can be expected that the majority of children on ART do not have factual information about their disease and medication. According to Kiwanuka et al. (2014) caregivers are often presented with opportunities to begin the disclosure process, mostly when children begin questioning the need for taking regular medication and the nature of their illness, but decide to lie. It is for this reason that the WHO guidelines recommend that the child is given some, but not all, the information about their illness in a developmental incremental process. The child may be told that he/she has a disease that is described in a way that is consistent with HIV/AIDS, but the disease not necessarily mentioned by name (Kiwanuka et al., 2014; WHO, 2011).

Facilities offering ART services for children in Botswana like the infectious Disease Control Centre (IDCC) report that high proportion of caregivers delay disclosure to their HIV-infected children who are receiving ART. Literature highlights the importance of communicating with children about their HIV diagnosis and treatment (Blasini et al., 2004; Vaz et al., 2010). However, children’s knowledge of what the medication is for is largely dependent on their caregivers and requires open communication with children about their health and medicines. In Botswana, the Botswana-Baylor Children's Clinical Centre of

Excellence developed a comprehensive clinic-based disclosure-support process, to help families support disclosure to their children in developmentally-appropriate ways. The disclosure support has been incorporated into national guidelines for the country as a whole. The goals of the disclosure support program are to allow the child to learn about the illness in an incremental and supported fashion (Lowenthal et al., 2014). This study explored the communication between caregivers and children about medications and their illness in the absence of disclosure of the HIV status. As ART adherence becomes a challenge when disclosure is delayed, the study explored the communication between caregivers and HIV positive children about medications and their illness in the absence of disclosure in a facility where the disclosure support program is implemented.

Methods

This paper reports on communication between caregivers and children who had not been informed of their HIV diagnosis. It is part of a larger qualitative explorative study that was conducted with caregivers who reported that they had disclosed and those who had not disclosed the HIV diagnosis to the children to explore their perceptions about disclosure. The study was conducted at the Infectious Disease Control Centre (IDCC) of Nyangabgwe Hospital, Gaborone, Botswana. The IDCC is an ART clinic which started in 2003 and provides all HIV related services like (CD4 count monitoring, viral load monitoring, ART initiative, and treatment adherence counselling) to adults and children.

Caregivers were selected for the study if they were above 18 years of age, had a child between 7 and 18 years and disclosure of the child's HIV diagnosis had not taken place. In this study, a caregiver was defined as an adult person living in the same household as the child and was responsible for supervising the care of the child at home and accompanies the child to hospital for clinic visits on a regular basis. These included the biological mother, biological father, grandmother, grandfather, foster parent, or other relatives. At the time of data collection, the registration records at the IDCC indicated that approximately 900 children aged between birth and 18 years were receiving ART.

Data collection

Focus group discussion were conducted by the first author assisted by a research assistant trained in qualitative data collection methods. A purposive sampling strategy was used to select the caregivers. Recruitment was done during their routine visit to the clinic to collect medication for their children. The first author and the research assistant approached caregivers individually and explained the purpose of the study and verified the disclosure status of the child. Caregivers who met the inclusion criteria were requested to participate. Those who volunteered to participate were informed that they will be part of a focus group discussion. Detailed information was given to the caregivers prior to the focus group discussion and informed consent was obtained from individual caregivers. Caregivers were also informed that participating in the study was voluntary and that non participation will not affect the treatment and care of their children. All the focus group discussions were conducted in Setswana in a consultation room to ensure privacy and protect the children from unplanned disclosure. Three focus group discussions were conducted with 20 caregivers, and each lasted for about sixty minutes.

Data analysis

Data were analysed using thematic analysis. Focus group discussions were transcribed and translated into English by the first author. For accuracy, the second author, played back the recordings while reading through the transcripts. Both authors read the transcripts repeatedly and created a code book from concepts that emerged from the data. The codebook was finalized after the authors agreed on the definitions of themes. All codes were then applied to the data by the authors using NVivo version 10.

Ethical considerations

The research was approved by the Medunsa Research Ethics Committee (MREC) of the University of Limpopo. The Research Ethics Committee of the Republic of Botswana and Nyangabgwe hospital also granted permission for the study to be conducted. Written informed consent was obtained from individual caregivers.

Findings

The sample consisted of 20 caregivers who reported that they had not disclosed the HIV diagnosis to the child. Their ages ranged from 27-65 years with mean age of 36.5 years. Almost all (18 out of 20) were female, 13 out of 20 were biological mothers, and 16 out of 20 caregivers were HIV positive. This is because biological mothers were the main caregivers and all the children were perinatally infected. Never the less, three children were maternal orphans (Table 1).

Table 1: Description of caregivers who had not disclosed to their children

Variables	Frequency	Percent
Age		
25-35 years	8	40
36-45years	5	25
46-55years	6	30
56-65years	1	5
Gender		
Male	2	10
Female	18	90
Marital status		
Single	10	50
Married	10	50
Relation to the child		
Mother	13	65
Father	1	5
Grandmother	1	5
Grandfather	1	5
Other	4	20

Caregivers HIV status		
Negative	3	15
Positive	16	80
Unknown	1	5
Mother alive		
Yes	17	85
No	3	15
Father alive		
Yes	16	80
No	1	5
Unknown	3	15

The caregivers provided information about the child they were accompanying to the IDCC. The age of the children ranged from 5-15 years. Most (18 out of 20) were diagnosed between 1-5 years and 17 out of 20 had been receiving ART for 6-10 years (Table 2).

Table 2: Description of children accessing ART at the Infectious Disease Control Centre

	Frequency	**Percent**
Age		
5-10 years	12	60
11-15 years	8	40
Diagnosis age		
0-5 years	18	90
6–10 years	2	10
Age when ART was started		
0-5 years	17	85
6–10 years	3	15
Duration on ART		
0-5 years	1	5
6–10 years	17	85
11 years	2	10
Schooling		
No	0	0
Yes	20	100

Themes

Three main themes related to communication between caregivers and their children about medicines and their illness are discussed below. These include opinions about disclosure, what parents tell children, and intentions to disclose.

Table 3: Themes

Main theme	**Sub-theme**
Opinions about disclosure	Child’s right to disclosure
	Disclosure is the parent’s responsibility
	Disclosing hurts
What caregivers tell children	Making child understand illness

	Explaining hospital visits
	Prevent child from getting sick
	Making child understand medication
Intentions for disclosure	

Opinions about disclosure

Caregivers were asked their opinions about disclosure to HIV infected children and all were of the opinion that disclosing to HIV infected children was a good thing to do. This is what they had to say about it:

Child's right to know

All the caregivers felt that the child should be told his/her HIV status even though they had not informed their children of the HIV diagnosis. They felt that it was the child's right to know about his/her illnesses and all were willing at some point to fully disclose to their children.

> *It's the child's right to know why they are taking this ART medication and how dangerous it is like to live while infected by HIV.*
>
> *When the child knows he will take them (medication) well and will see that this medication helped him to pick up his soldiers (CD4 count).*
>
> *I also think that it's a good thing to disclose to our children in order for them to understand why we are giving them ART*

Disclosure is the caregivers' responsibility

Caregivers perceived themselves as primarily responsible for telling the children about the diagnosis and described disclosure as their responsibility even though some desired to be supported by health care workers to disclose. Some had this to say:

> *It is my responsibility to disclose while she is still young so that she can grow up with knowledge that she is living with HIV.*
>
> *As the mother, I should take that responsibility to disclose but if I see that I am not comfortable then I will have to ask for assistance from the social worker.*

Disclosing hurts

Disclosure is difficult for most caregivers, but caregivers also felt that keeping the HIV diagnosis from the child was difficult and hurting. Some of the caregivers also experienced feelings of guilt about not disclosing. This is what some had to say;

> *Eish…, it is really painful, as a parent you know the child's status while he/she does not know. It is painful, when I am with the child and I know his diagnosis while he is in the dark, I ask myself when I am going to tell him?*
>
> *It is really difficult, sometimes I get worried and it pains me because I do not know what to say and which words to use. I am really afraid to disclose because I do not know how to start.*

> *At first it was very difficult and painful especially when I look at him and remember what really happened to him. Sometimes I ask myself what will he think when he learns how HIV is being transmitted…, this really worries me a lot.*

What caregivers tell children?

Caregivers of perinatally infected children attend adherence classes which introduce ways in which young children can be taught basic concepts related to their treatment. We asked caregivers what they tell their children and established that communication with children was discussed in relation with understanding HIV diagnosis, explaining hospital visits, understanding medication, and preventing the child from getting sick.

Making child understand illness

In an attempt to keep their children healthy, caregivers often make the child to understand the disease. They teach them that they have bad guys (viral load) in their bodies who attack their (soldiers) CD4 count. Caregivers tell children that they are sick without mentioning what they are sick of or mentioning the word HIV.

> *I told her that the reason we come for check-up time and again is because when you do not take your medication well your soldiers (CD4) will drop but if you take them well on time and every day, your soldiers (CD4) will pick up and that will prevent you from becoming sick.*
>
> *I only tell her that she is sick, and that is why she is on medication, but have not disclosed what she is sick of. I only tell her of bad guys.*
>
> *I tell her that she is sick but did not tell what she is sick of. I tell her that if she does not take her medication, bad guy will wake up and destroy her soldiers.*
>
> *The doctor checks if you are taking medication well and on time but if you do not take them well you will get sick because your immunity (soldiers) will be weak.*

Explaining hospital visits

HIV infected children on ART visits the hospital routinely for medical check-up and for their monthly ART medication. Often caregivers disclose because the child start questioning their routine hospital visits. Non-disclosed caregivers used the bad guys and soldiers’ story to explain hospital and clinic visits to their children as reflected below.

> *I explain that we are going to the doctor to check your health status, to see whether you are well or not by checking the level of your soldiers (CD4 count).*
>
> *The doctor will be checking if bad guy (viral load) is still asleep and if he finds that bad guy is awake then you will be hospitalized.*
>
> *I tell her that you are going to the hospital for the doctor to check if you are taking your medication properly and if you do not take them well you will remain at the hospital alone.*

Making child understand medication

The caregivers also make the child to understand the importance of taking their medication on time. They also teach the children that the medication will improve their soldiers (CD4 count) thus bad guy will remain asleep (viral load undetectable) as reflected in the quotations

> *I tell him that if you do not take your medication you will start to get sick, you will become wasted and not well, and we will take you to the hospital to be admitted for 1-3 months until you get better and they will be giving you medications time and again without missing a dose. If you do not take them [medication] well you will not be doing any good to yourself.*
>
> *I explain that he should take his medication on time every day so that his soldiers (CD4) should pick up and if the soldiers (CD4) drop, he will not be in the position to play like he is now and he will be admitted in the hospital.*
>
> *I tell her that if she does not take medication on time bad guy will wake up but if you take them well bud guy will always be asleep as you can see on this pictures.*
>
> *I tell if you do not take medication bad guy in your body will wake up and eat your soldiers/CD4.*

Prevent child from getting sick

We found that part of the conversation the caregivers have with their children is to explain encourage them to adhere to medication to prevent them from getting sick. Although the caregivers used the bad guy and soldiers' story they used coercion and fear to explain the importance of adherence because they could not mention HIV in their conversations.

> *They are being taught that if they don't take medication the CD4 will drop and you will start to be weak. I take it that, that's the only thing she understands because she was always taught and shown pictures when we came for doctor's appointments and doctor told us that if he does not take medication his CD4 will drop and become weak.*
>
> *I tell her that her CD4 will drop and bad guy (viral load) will attack her soldiers (immunity) and eventually you will become weak, thin and you will be sick of any disease and finale you die.*
>
> *I tell him that he is not supposed to miss doses and should take them daily but if not he will get sick.*
>
> *Mostly I tell him about the importance of taking medication on time and that if he misses the time he can get sick.*

Intentions for disclosure

All the caregivers stated that they had intentions to disclose to their children in the future. However, they felt that they would disclose only when the child is well prepared and understand the meaning of the illness. They also discussed the timing of disclosure mainly in terms of the child's age and majority. This is how they expressed their intentions.

> *My wish is that if I see that there is a little bit of light and maturity I can disclose her HIV status.*
>
> *As he reaches 12, 13, or 14 years, I will tell him, so that he can know how to take care of himself as he will be going to junior school.*
>
> *Honestly I delayed disclosure because of my child's low level of understanding, therefore, my wish is to disclose but the problem is understanding, I will wait until she start to ask me questions related to HIV, that will be the time to disclose because I take it that she will be having some insight.*

Caregivers planned to disclose only when they feel that the child is well prepared. These are some of the ways they will use to prepare their children for disclosure.

> *I will try to give some ideas time and again until she has knowledge of what HIV is all about.*
>
> *I think the best age is 7, I will start to give hints about HIV slowly so that by time she reaches 10 or12 years, she is fully disclosed and understand about her status.*
>
> *I will start at 7 years doing partial disclosure, by the time she is 10 years she will be fully disclosed and understanding how to live a positive life while infected with HIV.*

Discussion

The paper explored the communication between caregivers and their HIV infected children who had not been informed of their HIV diagnosis. All the caregivers were of the opinion that children have a right to know their HIV diagnosis, and they had future plans to disclose. This view is supported by findings from studies conducted in other settings in developing countries (Gachanja et al., 2014; Kiwanuka et al., 2014; Motshome & Madiba, 2014; Vaz et al., 2011). Caregivers in a Ugandan study felt that children needed to know their HIV status to make sense of whatever was going on in their lives (Kiwanuka et al., 2014). The most preferred age when HIV disclosure to children should be performed was 12 to 14 years, but all the caregivers planned to disclose when the child is well prepared and understand the meaning of the illness. Recent data from Kenya support the view that children need to be prepared first before full disclosure (Gachanja et al., 2014).

Caregivers were also of the opinion that they have a responsibility to disclose and believed that they were the best person to inform the child of their HIV diagnosis. Consistent with other studies, caregivers perceived disclosure as emotional and hurting. Biological parents, expressed feelings of guilt about having transmitted the HIV infection to their children (Gachanja et al., 2014; Kiwanuka et al., 2014; Madiba & Mokwena, 2012; Motshome & Madiba, 2014). Though caregivers desired to disclose, most did not trust their ability to handle the disclosure process and expressed the need to be supported by HCWs to be able to disclose. The need for caregivers to be assisted to disclose has been confirmed in prior research (Gachanja et al., 2014; Heeren et al., 2012; Kiwanuka et al., 2014; Madiba & Mokwena, 2012).Moreover, studies in developing countries have recommended that HCWs prepare caregivers for disclosure to HIV-infected children (Beima-Sofie et al., 2014; Kallem, 2012; Madiba & Mokgatle, 2015; Mumburi et al., 2014).

Previous studies have shown that in the absence of disclosure caregivers give children inaccurate information that deflect attention from HIV. They often tell children that they have illness such as TB, pneumonia, and common cold (Gachanja et al., 2014; Kiwanuka et al., 2014; Motshome & Madiba, 2014; Vaz et al., 2010; Vreeman et al., 2014). This is in contrast to the current study findings, we found that care givers used the analogy of the immune system as an army and the viral load as bad guys to make the child understand the diagnosis and the importance of good adherence to medication. A Namibian study that developed a disclosure model also reported that the simplified concept of regularly taking medicine to keep "body soldiers" strong and "bad guys asleep" helped caregivers to motivate adherence to care and treatment (O'Malley et al., 2015). Our findings support what was found in Namibia, suggesting that the keeping the "bad guys" asleep and "body soldiers" awake teachings reduces caregiver fear of disclosure and increases confidence to begin the process of disclosure because of the delayed mention of HIV in the communications they have with their children (Lowenthal et al., 2014; O'Malley et al., 2015).

The findings further revealed that teaching the children about their medication and illness using the bad guys and body soldiers occurred on a regular basis, caregivers would use the teachings to explain visits to the hospital or to promote adherence. We found that the frequent communication between caregivers and their HIV infected children suggest a way of preparing the children for disclosure in an incremental and age-appropriate manner. This is in line with the disclosure training and support received by caregivers in health facilities in Botswana which stresses communicating disclosure-related messages to children over time (Lowenthal et al., 2014). Similarly, care givers in Kenya prefer to provide limited information over time corresponding to what children were being taught in school about the disease. These however, are the views of caregivers and not those of HIV infected children. It is imperative that their views be obtained on how they would prefer disclosure to be packaged

Caregivers who had fully disclosed to their children, also explained that HIV-positive children need to be reminded of their illnesses and to take ART (Gachanja et al., 2014). A review of studies conducted in developing countries also found that some caregivers begin partial disclosure by telling children that they are taking medication to stop them from getting sick (Vreeman et al., 2013). In partial disclosure, the child may be told that he/she has an illness but he/she is not told specifically that he/she has HIV infection (Vaz et al., 2010). Our findings are in contrast to recent data from Uganda, the researchers found that most caregivers perceived disclosure as a single event of truth-telling that is usually preceded by a period of sustained avoidance and deliberate deception (Kiwanuka et al., 2014).

Conclusion

Caregivers in this study approached disclosure as a process. They contemplated disclosure and prepared for disclosure by providing their HIV infected children with partial factual information about their illness and medication. The training that caregivers received on how to communicate truthfully to young children about their illness using the "bad guys" and "soldiers" analogy assisted them to develop the skills to communicate in a manner that improved the children's understanding of their illness and their medication. Caregivers were also aware of the importance of preparing children for disclosure, but all stated that disclosure will happen only when their children are well prepared.

The study findings support the view that caregiver readiness to disclose is a key determinant of disclosure. HCWs should provide support to caregivers of HIV infected children to facilitate disclosure to children. Further explorative studies should be conducted with children in this and similar settings in Botswana to assess their understanding of their illness and medication.

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