**Courage and confidence to stop lying: caregiver perspectives on a video to support paediatric HIV disclosure in Kampala, Uganda.**

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**Abstract**

The World Health Organization recommends that HIV-positive children are told their diagnosis by age 12. However, the majority of perinatally-infected children reach adolescence without having been told their HIV status. Effective strategies are needed to promote disclosure, and optimise children’s health outcomes as they transition to adolescence and adulthood.

This qualitative study explored how caregivers of HIV-positive children age 7-12 perceived and related to a video used as part of a larger behavioural intervention to promote full disclosure to children by age 12. Eight semi-structured interviews and three group reflection sessions with 28 caregivers were analysed thematically.

Five themes were generated: ‘courage and confidence’; ‘reasoning and empathy’; ‘child-caregiver relationship’; ‘foreign but relatable’; and ‘not reaching everyone’.

The video was found to be acceptable and appropriate for fostering readiness to disclose. Through watching it, participants reported they could see people similar to themselves prevail despite challenges, which gave them courage.

**Introduction**

While the focus of much of the HIV disclosure literature has been on adults disclosing their own status to others, there is now a better understanding of the issues around disclosing to a child the child’s own HIV status (Aderomilehin, Hanciles-Amu, & Ozoya, 2016; Kiwanuka, Mulogo, & Haberer, 2014; Pinzon-Iregui, Beck-Sague, & Malow, 2013; Vaz et al., 2011) As access to antiretroviral treatment (ART) has improved, many children who have been perinatally-infected are reaching adolescence and adulthood (UNAIDS, 2013). A global review of 31 studies found that the proportion of children who know their HIV status varied between 1.2% and 75%, and was lower in low- and middle-income countries than high-income countries (Pinzon-Iregui et al., 2013). Studies have indicated that HIV-positive children who know their HIV status have better health outcomes (Bachanas et al., 2001; Mellins et al., 2002; L. Wiener, Theut, Steinberg, Riekert, & Pizzo, 1994), and disclosure is also associated with caregivers’ reduced rates of emotional and psychological distress (Bachanas et al., 2001; Oberdorfer et al., 2006; L. S. Wiener, Battles, & Heilman, 1998). Conversely, lack of disclosure is sometimes associated with children’s poorer treatment adherence (Haberer et al., 2011; Nichols, Steinmetz, & Paintsil, 2016), a lower likelihood of receiving ART (Menon, Glazebrook, Campain, & Ngoma, 2007), and increased mortality (Ferris et al., 2007). The World Health Organization (WHO) recommends full disclosure to children by age twelve (WHO, 2011).

Barriers to disclosure, such as caregivers’ fears of resentment for being the origin of the virus, and concerns about stigma, are commonly recognised (Pinzon-Iregui et al., 2013). In Uganda, where an estimated 96 000 children are living with HIV (UNAIDS, 2015), improving ART adherence is a central motivating factor for paediatric HIV disclosure (Atwiine, Kiwanuka, Musinguzi, Atwine, & Haberer, 2015; Sarah Bernays, Seeley, Rhodes, & Mupambireyi, 2015; S. Bernays, Paparini, Gibb, & Seeley, 2016; Bikaako-Kajura et al., 2006; Kurji, Etima, King, Musoke, & Butler, 2014) while the evidence of the impact disclosure has on adherence is inconclusive (Nichols et al., 2016). An investigation of paediatric HIV disclosure in Kampala found that only 22 of the 69 (32%) children age 7-12 in the study had been told their HIV status (Etima et al., 2014), and similarly, the prevalence of full disclosure among 307 5-17-year-old children in another Ugandan study was 31% (Atwiine et al., 2015). Qualitative research has shed light on the specific barriers to disclosure caregivers may experience. In Kampala, caregivers have reported fears about HIV-related stigma, potentially damaging their relationships with the children or young people, or psychologically harming the child through disclosure as reasons to avoid or postpone disclosure (Namukwaya, Paparini, Seeley, & Bernays, 2017).

In order to understand how barriers to disclosure can be overcome, an intervention study called DISCO-Kids was conducted in Kampala (ClinicalTrials.gov, 2015). DISCO-Kids was a randomised controlled trial testing the effectiveness of a cognitive-behavioural intervention to support full, developmentally appropriate disclosure to HIV-positive children (7- to 12-years-old) by their primary caregiver, defined as parent or guardian (ClinicalTrials.gov, 2015). Full disclosure was only achieved if HIV was explicitly mentioned by the caregiver, and any information given to the child regarding HIV in the context of disclosure had to be accurate. The intervention consisted of three group workshops for caregivers who had not disclosed, followed by three counselling sessions for child-caregiver dyads. The control group received standard of care counselling and no group workshops. One workshop in the DISCO-Kids intervention arm involved viewing and discussing a video called *“The Power of Knowing – Experiences of youth and caregivers with pediatric HIV disclosure,”* (Inglis & Kromberg, 2014) which consists of interviews with HIV-positive youth and caregivers in KwaZulu-Natal, South Africa, about their different disclosure experiences. The idea to use a video component in the intervention was based on formative research, and the decision to produce the film in South Africa with caregivers who are advocates for disclosure in their communities instead of Uganda was made to protect the privacy of Ugandan caregivers. The film was produced in isiZulu, and made available with Luganda voice-over for audiences in Kampala. The aim of the present study was to explore how caregivers of 7- to 12-year-old children living with HIV perceived, and related to, the video.

**Methods**

The research described here was a sub-study to DISCO-Kids, and was conducted in Kampala with child-caregiver dyads who had access to ART. The research design was qualitative. Data collection consisted of eight semi-structured interviews, and three group discussions with caregivers participating in DISCO-Kids. Interviews were chosen to capture individual views and experiences, and group sessions to capture immediate reactions within the groups attending workshops together. Three pilot interviews and one pilot group session were conducted but not included in the analysis. All group discussions and most interviews were conducted in Luganda, audio-recorded, transcribed verbatim, and translated into English. One interview was in English. All data collection took place at Mulago Hospital in Kampala, in the same facilities where the intervention was delivered. This approach was taken in order to minimise burdening participants with additional travel, as interviews and group reflection sessions were conducted in connection with other visits to the intervention site.

The interviews were conducted with eight caregivers by a researcher and study facilitators from DISCO-Kids. For each interview, both the first author and one of the study facilitators were present, and the interviews took place in private offices or seminar rooms in the hospital. The interview guide covered six open-ended questions related to the experiences and opinions of the caregivers who had seen the video at least one month earlier.

The group reflection sessions were held with three groups of eight to ten caregivers. The groups consisted of caregivers who were attending DISCO-Kids group workshops together (natural groups (Green & Thorogood, 2014)), and were therefore mixed in gender and age. It was decided not to separate men and women into different discussion groups for reflections, as mixed group discussions worked well as part of the intervention. The sessions took place directly after participants had seen the video, and covered similar questions as the interviews but the topic guide for group sessions placed more emphasis on opinions, and immediate reactions to the video, than personal experiences. Discussions were moderated by a study facilitator, while the first author took notes to support the analysis of transcripts.

Participants were recruited from the intervention arm of DISCO-Kids between January and March 2015. During this period, all caregivers who attended group workshops were part of either the reflection sessions or the pilot group discussion. Potential interview participants were approached by study facilitators, and asked if they were willing to share their views about the video. Eligibility criteria for participation were the same as for the intervention study, namely being the parent or guardian of a child age 7-12 living with HIV, and not having yet disclosed to the child their HIV status. In addition, potential interview participants were asked if they remembered the video, and were willing to share their views about it. Half of the caregivers who were invited to participate in individual interviews declined due to not remembering the video well enough. Eleven caregivers agreed to be part of either a pilot interview or a formal interview.

Data were analysed using thematic analysis (Braun & Clarke, 2006). This enabled inductive, data-driven coding. Initial codes were developed from reading all transcripts. These were used to systematically code relevant features of the dataset, and new codes were generated in the process. Codes were collated into potential themes, and data were organised around these themes. The final themes were arrived at through reviewing themes, and considering alternative interpretations. The analysis process was guided by discussions within the research team.

Ethical approval was obtained through the Institutional Review Boards of the Joint Clinical Research Centre in Uganda, the Uganda National Council for Science and Technology, and Boston Children’s Hospital. Participation was voluntary, and informed written consent for participation and audio-recording was obtained from all individual participants included in the study. Participants were remunerated for their transport costs, but no other incentives were given.

The authors have no conflicts of interest to declare.

**Video synopsis**

The video features youth and caregivers affected by HIV in South Africa. The central characters and events are summarised below.

“The girl”: A teenage girl talks about how she found out about her HIV status accidentally in an argument with her grandmother when she was 10. She describes the experience as painful.

“Boy 1”: A teenage boy talks about how his mother went through full disclosure with him. He accepted this because he felt that he could live like a ‘normal’ person. His relationship with his mother became strong in the process.

“The mother”: The mother of Boy 1 describes how she found out about her son’s illness, and how she disclosed to him. She goes through her approach of telling the boy a story, and at the appropriate point in the story explaining how both she and her son have HIV. The mother and Boy 1 also talk about disclosing to others, and educating people about HIV to decrease HIV stigma.

“Boy 2”: A young man describes how he was on medication without knowing why. Finally, he was told by a doctor that he had HIV, and did not speak to anyone in his family for a month. Years later, he is still resentful and sad.

“The grandmother”: A woman describes how she kept her granddaughter’s HIV status from her for two years after the girl began ART. After realising that young people may become sexually active at an early age, she asked a counsellor to disclose to the girl. She discusses how being close to the child is important for the disclosure process.

 **Results**

In total, 36 participants aged 18 to 74 contributed to the study. Six women and two men were interviewed individually; 26 women and two men contributed to group reflections. The majority (69.4%) of participants were biological mothers. These ratios reflect the mix of different caregiver types and the gender balance in the overall intervention study.

Five themes that describe how caregivers of children living with HIV perceive the video were generated through the thematic analysis: (1) courage and confidence; (2) reasoning and empathy; (3) child-caregiver relationship; (4) foreign but relatable; and (5) not reaching everyone.

 ***Courage and confidence***

*“It gave me the confidence not to keep lying to my child about what he is suffering from, and making up other diseases.”*

– Biological mother, age 26

Participants talked about the complexities of openly discussing HIV with children. The absence of disclosure was not usually silence, but alternative explanations for why the child is ill or takes medication. Disclosure was considered necessary but telling the truth about a child’s HIV-status requires courage. The experience of seeing the video was empowering, as building confidence meant being brave enough to tell the truth, and dispose of lies and fears.

*“There is so much I have always asked myself, so much I have been scared of and could not do. But from what I have watched, I am now confident and strong… It has helped me to stop feeling small about myself.”*

– Biological mother, Group Reflections

Caregivers’ fears were related to their own ability to disclose, but also the potential impact of disclosure on the well-being of the child. Therefore, caregivers were encouraged by seeing children in the video doing well, and not stigmatised or isolated.

*“But when I watched that film, I was encouraged to move on because that child was with his grandmother… The grandmother took care of him and loved him. When he went to school, he spent time with his friends and they didn’t segregate him.”*

– Biological mother, age 30

The video was experienced as something that helped build courage and confidence, which meant accepting the challenges of caring for a child with HIV – including disclosure.

 ***Reasoning and empathy***

*“What I saw is that early disclosure easily becomes part of the child… But then you could tell him at a later stage, it is very dangerous to some… Someone becomes stigmatised, he feels out of society like that one there. So the video is very helpful to some of us.”*

– Uncle, age 44

Caregivers responded to the video through both reasoning and empathy. They talked about how the contrasting stories of the two boys in the video made them see why early disclosure made sense, and how hurtful late disclosure can be. The logical conclusion drawn from the boys’ experiences was that early disclosure by caregivers makes it easier for children to accept their status and not resent the caregiver or react badly in other ways. Reasoning based on the examples shown in the video further involved thinking about how children might initially react badly but would come to terms with disclosure if it is not done when the child is much older.

*“The one who got to know when he was older was really hurt but the one they told when he was young didn’t overly concentrate on it as he grew older.”*

– Biological mother, age 26

From the examples in the video, caregivers also concluded that letting children find out for themselves, as opposed to being the ones to tell them, was a poor alternative.

*“The other thing... from the video was that if you do not disclose to the child and then he or she hears it from somewhere else… He or she perceives it really badly.”*

– Biological mother, age 27

In addition to the reasoning about when and why disclosure makes sense, the story of the boy who was not disclosed to by his family (Boy 2) evoked emotions, and many caregivers were touched by his situation. Seeing his sadness made caregivers feel sad too, as exemplified in the following quote.

*“When the child was crying because the parent had kept it a secret from him... That made me so sad and I felt that it related to me.”*

– Biological father, age 47

There are several parts in the video that could evoke emotions and empathy, but the story of Boy 2 whose family did not disclose to him was particularly striking, even upsetting, for the caregivers. The boy’s story allowed caregivers to empathise with the pain of finding out at an older age.

*“I compared him to my life. I was old when the doctors told me that I was sick… I felt bad. So if it hurt me, then it must have hurt the child too… So that made me realise that it is not right to disclose to the person when he or she is grown.”*

– Biological mother, age 28

Lessons from the video were accessed through using reasoning, and weighing different scenarios against each other, but also through the emotional and empathetic reactions evoked when participants related to the video’s youth and caregivers.

 ***Child-caregiver relationship***

Participants described feeling touched by the love and care displayed by the grandmother in the video, and by the good relationship between Boy 1 and his mother after she had disclosed to him. Caregivers spoke about how this influenced the way they viewed their relationship with their own child. Some were surprised that it is possible to have such a loving relationship with a child that is not one’s own but recognised it as something valuable.

*“The first thing I have learnt is that the relationship between a parent and . . . child is very important. The kind of relationship between you and that child; it doesn’t matter whether the child is your friend’s or your sister’s or if he or she is yours.”*

– Biological mother, Group Reflections

A good relationship was seen as something that makes disclosure easier, whereas not disclosing to a child jeopardises the relationship between a child and a caregiver. The example of the boy (Boy 2), who was filled with resentment after having to find out for himself, was a scenario caregivers wished to avoid.

*“That film showed me that you can become peaceful once you are open to a child and the child too becomes peaceful. But if you aren’t open to a child, you are bound to meet problems.”*

– Biological father, age 47

Caregivers also reflected that developing a good relationship with the child they look after was part of the journey toward disclosure. In sum, the responses of caregivers in the study showed both that a good relationship makes the disclosure process easier, and that disclosure can strengthen child-caregiver relationships.

***Foreign but relatable***

According to study participants, the fact that the video was about South African youth and caregivers did not make the content problematic or irrelevant. A common response to questions about the foreign nature of the video was that it was good to see that the same challenges exist elsewhere. Importantly, caregivers not only found the content relevant, but ‘relatable’, because they could relate to the experiences described in the video. The issues were described as being the same as those that caregivers go through in Uganda.

“*It has showed us exactly what we go through here”*
– Biological mother, Group Reflections

Group participants were asked about similarities and differences between their experiences and the video. Differences were not highlighted by participants, and the video’s origin was not mentioned by them until specifically asked. Unfamiliar issues were attributed to being at a different point on the disclosure journey, rather than being due to differences between Uganda and South Africa.

*“The things that seemed different are... For some people I have seen in the film… Some of the things directly affect them and they haven’t occurred to me yet.”*

– Brother, age 27, Group Reflections

Participants accepted the experiences of South African youth and caregivers as relatable and relevant to their own situations, and as such did not mind that the video was from a different setting.

***Not reaching everyone***

While the general response to the video was positive even when participants were asked to specifically reflect on shortcomings, there were some concerns raised about the lessons in the video not reaching all viewers, and about people not being responsive.

*“[The video] would have been good but then people are overly absent-minded and they understand little, so it is really hard.”*
- Grandmother, age 74, Group Reflections

Two main explanations for the video’s messages not reaching everyone were given. One was people’s inability to pay attention, understand, or change their behaviour. The other reason was people’s different ways of learning.

Biological mother 1: *“That film is the same as a child in class… It doesn’t mean that every child in the class will be the first…”*

Biological mother 2: “*Exactly, there are those who will learn and those who won’t learn.”*

- Group Reflections

By comparing caregivers who view the video to children in the same class at school, the point was strongly made that the video’s messages will not be received in the same way by all who see it.

 **Discussion**

Caregivers identified both benefits and shortcomings in the video “*The Power of Knowing”.* Participants named a possible shortcoming as being the extent to which all viewers would be able to assimilate and learn from the video. Nevertheless, caregivers portrayed the video as encouraging and educational. The video evoked both reasoning and empathy, and fostered confidence by demonstrating that youth and caregivers in a different setting had overcome the same challenges that Ugandan caregivers were concerned about in relation to disclosure.

Examining the video as a source of courage and confidence in one’s own ability to go through disclosure is highly relevant for considering how paediatric HIV disclosure can be supported. Courage and confidence are comparable to self-efficacy in social cognitive theory (Bandura, 1998, 2001, 2004), as the concept highlights that knowledge and skills are not sufficient for behaviour change. Believing in one’s own ability to perform a specific behaviour also plays into the process. A caregiver who does not believe in their own ability to go through the disclosure process with a child is unlikely to feel motivated to disclose. The role that a video may play in fostering a sense of self-efficacy is a form of learning through ‘vicarious experiences’ whereby “seeing people similar to oneself succeed by sustained effort raises observers’ beliefs that they too possess the capabilities” (Bandura, 1998) p.626). The findings of the present study therefore correspond with theoretical notions of behaviour change, and shed light on how disclosure-related fears can be alleviated through use of a video.

The relationship between self-efficacy to disclose, and disclosure itself, has not been fully investigated, and cannot be established through these qualitative findings, but a South African study building on the Theory of Planned Behaviour found that self-efficacy was a significant predictor of caregivers’ intention to disclose, however, only in univariate analysis (Jemmott et al., 2014). The authors nevertheless recommended trying to increase caregiver’s self-efficacy to disclose in order to prepare them for disclosure.

Another recommendation from the South African study was to promote communication between children and caregivers because it seems to predict intentions to disclose (Jemmott et al., 2014). It is therefore encouraging to note that caregivers in the DISCO-Kids study reflected about the importance of a good dyadic relationship based on what they had seen in the video.

A systematic review of video-based health education in high income countries found videos to be effective in modifying various health-related behaviours (Tuong, Larsen, & Armstrong, 2012). Video interventions have also been found effective in modifying attitudes towards potentially stigmatising behaviours, such as seeking mental health treatment (Buckley & Malouff, 2005). No examples of supporting paediatric HIV disclosure through videos could be found. Nevertheless, the manner in which caregivers in the intervention arm of the DISCO-Kids trial reflected on the video suggests that video-based interventions can be appropriate for supporting paediatric HIV disclosure by caregivers in this setting. The full DISCO-Kids disclosure intervention, of which the video is only one component, is currently being offered to the control arm of the original trial, and findings regarding the intervention’s effectiveness will be reported in forthcoming publications.

The views of caregivers in the present study also demonstrate that a foreign context may be relatable enough to strengthen viewers’ sense of self-efficacy through vicarious experiences. Since the targeted behaviour in DISCO-Kids is disclosure to a child by the caregiver, empathy towards the young persons in the video may be seen as another example of vicarious learning. Caregivers were not only identifying with the caregivers in the video, but also making connections between the experiences of the video’s youth, their own experiences, and the experiences of the children they look after.

Empathy has not been specifically examined in disclosure-related studies, but the authors of a study of clinic-based paediatric HIV disclosure in Botswana reflected that learning about the traumatic experiences of children who found out about their status accidentally was a powerful motivator for caregivers and healthcare workers to addressing paediatric HIV disclosure (Lowenthal et al., 2014). A qualitative study on ART adherence among HIV-positive children in Uganda also suggests that empathy is important for constructively addressing children’s non-adherence, because it can support open communication between the child and the caregiver (Kawuma, Bernays, Siu, Rhodes, & Seeley, 2014). Thus, evoking empathy can be a useful way to approach various issues that caregivers of HIV-positive children go through. Caregivers’ views of “*The Power of Knowing*” suggest that using a video that shows what others are going through is a helpful tool in this regard.

Another aspect of the video that provided motivation for disclosure was seeing the benefits and risks related to disclosure. These scenarios can be conceptualised as gain-framing, which shows benefits of disclosure, and loss-framing, showing the risks of non-disclosure (O’Keefe & Jensen, 2007). Both aim to appeal to the disclosure decision-making process faced by caregivers. Video interventions using gain-framing have been found somewhat more effective than loss-framing for motivating behaviour change in high income settings (O’Keefe & Jensen, 2007).(36,40) Nevertheless, the caregivers’ responses indicate that both the positive (gain-framing) and the loss-framing scenarios were helpful, as they could see that the experiences of caregivers and young persons were similar to their own. Being able to relate to *real* people, and to weigh disclosure against continuing secrecy (or dishonesty) were important aspects of the video according to caregivers. Implementation research highlights acceptability as one of the prerequisites for successful implementation of health interventions (Proctor et al., 2011). It is thus important that the relatable experiences of youth and caregivers in the video made it acceptable to participants despite the video’s foreign origin.

 ***Limitations***

The data collection team also worked on delivering the intervention, and therefore knew the participants. This could have affected the selection process as well as the responses of participants, making it more likely for interviews and group reflection sessions to capture positive views about the video. Participants were encouraged to openly share any suggestions for improvements, or aspects of the video that they did not like. Apart from suggestions to share the video more widely, rather than just to caregivers of children living with HIV, participants did not recommend changes or improvements. However, they did express some critical or negative views, such as the video not reaching everyone.

Due to the study design, it is not possible to draw conclusions regarding how different caregiver types may have responded to the video differently. This could be relevant to address in future research, as there was an understanding within the research team that particularly biological mothers of perinatally-infected children face different challenges from other caregivers due to feelings of guilt or fears regarding how children will react if they find out the mother is the source of the virus.

Another limitation is the combined analysis of interview and group reflection data. It is important to acknowledge that different data collection methods may affect the responses participants give. Nevertheless, the decision to analyse both types of data together was made because the use of ‘natural groups’ in the reflection sessions resulted in participants sharing their personal experiences and opinions very openly during the group discussions, and the anticipated difference between more general observations from group participants, and in-depth individual accounts in interviews was not present in practice.

 **Conclusion**

Combining new and existing lessons of behaviour change can help develop new interventions, as well as adapt interventions into new contexts. Motivations for changing behaviour, and self-perceived ability to do so, are both important to consider in supporting paediatric HIV disclosure. Therefore, paediatric HIV disclosure interventions should foster readiness to disclose as well as showing the importance of disclosure. A video-based intervention component was considered acceptable and appropriate for this purpose by the participants of DISCO-Kids.

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