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Title: Dealing with disclosure: perspectives from HIV positive children and their older carers living in rural South-Western Uganda

Authors: Esther Dusabe-Richards[1], Rwamahe Rutakumwa[2], Flavia Zalwango[2], Allen Asiimwe[2], Elvis Kintu[2], Fatuma Ssembajja[2] & Janet Seeley[2,3]

[1]Department of International Public Health, Liverpool School of Tropical Medicine, Pembroke Place, Liverpool, L3 5QA, UK; E-Mail: Esther.Dusabe-Richards@lstmed.ac.uk; Telephone: +44(0)1517052526

[2]Medical Research Council, Uganda Virus Research Institute, P.O. Box 49, Entebbe, Uganda; E-Mails: Rwamahe.Rutakumwa@mrcuganda.org; Allen.Asiimwe@mrcuganda.org; Elvis.Kintu@mrcuganda.org; Fatuma.Ssembajja@mrcuganda.org; Flavia.Zalwango@mrcuganda.org; Janet.Seeley@mrcuganda.org

[3]Department of Global Health and Development, London School of Hygiene and Tropical Medicine, London, WC1E 7HT, UK; E-Mail: Janet.Seeley@lshtm.ac.uk

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Abstract: There are limited data on the challenges faced by carers, in particular older carers, in managing the difficult task of status disclosure for HIV positive children. We report findings from qualitative interviews with 18 care dyads of older people and HIV positive children living in rural southwest Uganda. Our data provide insights into perceptions and norms influencing communication during and following disclosure among both carers and children, including those shaped by gendered expectations of girls' and boys' sexual behaviour. Young participants reported several advantages of knowing their status and showed considerable resilience in the face of HIV disclosure. Better and more support is needed to help health workers and carers (particularly older carers) manage cross-generational communication around HIV disclosure and other related aspects of sexual and reproductive health as critical aspects of children's psychosocial development and wellbeing.

Key words: HIV disclosure, HIV positive children, older carers, psychosocial wellbeing

Dealing with disclosure: perspectives from HIV positive children and their older carers living in rural South-Western Uganda

Introduction

While huge strides have been made in preventing and treating HIV globally there are currently 2.6 million children under 15 living with HIV, the majority of which are living in Sub-Saharan Africa (UNICEF, 2015). Increased coverage of anti-retroviral treatment has played a role in improving the health outcomes of a significant proportion of children living with HIV although barriers to access remain (UNAIDS, 2016). Beyond their physical wellbeing however there are serious concerns for the psychosocial wellbeing of this vulnerable population, given that the period of childhood and adolescence is a critical time of transition and growth (Bernays et al., 2015b, Mutumba et al., 2015a). Carers play a key role in supporting HIV positive children through these stages of development (Klunklin and Harrigan, 2002, Petersen et al., 2010).

HIV disclosure, its management and its potential effects and impact on psychosocial wellbeing, are important aspects of caring for HIV positive children. However, research has shown that carers sometimes delay the moment of disclosure to those in their care (Vreeman, Nyandiko et al. 2010). For example, a review of global data found a lower proportion of children that knew their status in low or middle income countries compared to industrialised countries (Pinzón-Iregui et al., 2013). Research from sub-Saharan African settings suggests that parents and carers sometimes disclose the child's HIV status to him or her when the child directly asks why they are on drugs; when they show no interest in taking their drugs; and when the carer wants the child to avoid 'risky' sexual behavior (Mweemba et al., 2015). Sometimes the process was also facilitated by the child's level of knowledge of HIV and whether the caregiver was knowledgeable about HIV and related services (*ibid.*). However, in many cases carers struggle to disclose HIV status to children due to a range of factors, including fear of negative psychological effects and social stigma, little or no carer disclosure skill and inexperienced counsellors (Vaz et al., 2008, Vreeman et al., 2010, Mutwa et al., 2013,

Mburu et al., 2014). Despite such fears, carers and children have highlighted the advantages of disclosure: to increase adherence to anti-retroviral treatment regimes, for example, and to enable children to access support systems and make psychological gains in terms of confidence and agency (Midtbø et al., 2012, Vaz et al., 2008).

Research also suggests that lack of disclosure may be linked to broader challenges around communication practices that impact on the psychosocial wellbeing of children living with HIV. Although disclosure of HIV status to children tends to be a process that raises anxiety for carers and parents (Lowenthal et al., 2014, Kawuma et al., 2014, Bernays et al., 2015b, Bernays et al., 2015a) it is sometimes treated as an isolated event and not part of an established communication pattern between children and carers (Vaz et al., 2010). In the Ugandan context socio-cultural norms and beliefs have been found to influence communication related to HIV status, knowledge and care between carers and children (Daniel et al., 2007, Kajubi et al., 2014a, Kajubi et al., 2014b). Daniel et al. (2007) explore the concept of 'cultural silence' and its impact on resilience among Ugandan infected and affected parents and orphans. Their findings illustrate how norms promoting silence and secrecy around sensitive topics such as sex and death have been detrimental to children's coping mechanisms in the face of HIV deaths within their families. Nevertheless a study exploring the psychosocial challenges of adolescents with HIV found that secrecy was used as a coping strategy to deal with potential stigma and discrimination from family members and the wider community (Mutumba et al., 2015b). In another study conducted in Uganda, age was identified as an important factor in HIV disclosure (Atwiine et al., 2015). Full disclosure was commonest among 9-11 year-olds and 12-17 year-olds as compared to younger ages because their carers thought they were emotionally prepared to understand the complexities of their illness and were more likely to infect other children (*ibid.*). The authors demonstrate how openness and disclosure can contribute to the significant coping mechanisms of closeness and competence, which in turn build and develop self-worth and resilience among children.

Socio-cultural norms dictating levels of openness in communication around HIV may also impact on children's adherence to anti-retroviral treatment. Research in Uganda has explored how communication hierarchies within families influence children's HIV treatment behaviour and practices (Kajubi et al., 2014a, Kajubi et al., 2014b). A study from Zimbabwe that focused on adolescent preferences in HIV disclosure practices also reveals the potential dangers of maintaining secrecy around HIV status as leading to accidental discovery by adolescents (Kidia et al., 2014). The study also emphasises the potential for adolescents themselves to provide vital on-going support to peers once disclosure has taken place (*ibid.*).

These findings suggest that there is a need to understand further the process of disclosure from multiple perspectives, across the whole range of caring relationships. An under-researched but important relationship dynamic exists in contexts where a significant proportion of carers are older people who have inherited the care of grandchildren or other younger relatives (Kasedde et al., 2014). Older carers, either with shared or complete responsibility for a child or children may play a vital role in mediating multiple aspects of their care and wellbeing. A study in Western Kenya found that 1 in 5 caretakers of orphans was over 55 years of age and that the older carers faced serious challenges in terms of accessing schooling, medical care and food for children they cared for (Nyambedha et al., 2003). It is important to consider these challenges in the development of interventions to support carers of all ages in the vital role they play in looking after children living with HIV. The MRC/UVRI Uganda Research Unit, in collaboration with the Liverpool School of Tropical Medicine undertook research exploring several aspects of the caring relationship between children (HIV negative and positive) and their older carers in South-Western Uganda. We have reported elsewhere on several aspects of the day-to-day strengths and difficulties of these relationships, and on the complexity of the caring relationship whereby the care is not unidirectional but mutual (see Rutakumwa et al. 2015). This paper focuses specifically on the communication challenges of disclosure and its aftermath within these relationships from the dual perspectives of the older carer and the HIV positive child in their care.

Methods

We purposively selected 18 HIV positive children aged 13 to 17 years and their older carers (50 years or over) from the Rural Clinical Cohort (RCC) of the Medical Research Council/UVRI Uganda Research Unit on AIDS in Kalungu District and a Government Health Centre IV which provides paediatric HIV care. We had originally planned to recruit all the HIV positive children from the RCC but were able to recruit only nine. This was because some of the HIV positive children fell outside of our inclusion criteria, either because they were below 13 or above 17 years, or their carers were below 50 years of age. We accessed the remaining children from another health centre, a Government facility that offered pediatric HIV care within the same district.

We interviewed ten male and eight female HIV positive children, seventeen of whom had lost one or both parents to AIDS. We also interviewed four male and fourteen female older persons who were their primary carers. With the exception of four carers – an uncle, two aunts and a staff member of an organization supporting HIV positive children – all the carers were grandparents of the HIV positive children, 13 of whom were themselves suffering from chronic health problems (such as diabetes, hypertension and persistent fatigue) that impacted their caring duties. Participants were interviewed a maximum of three times over the course of a year, with visits spaced around every 3-4 months. Return visits allowed us to follow up on issues that were unclear from earlier interviews. We found that this sample enabled us achieve saturation, the point at which additional sampling was yielding no new information.

We tested the topic guides through an initial pilot study with four children, six older carers and two health facility staff members. Topics covered in the interviews included: HIV/AIDS awareness; HIV disclosure; experience with ART; and caring practices, among other topics. In addition, we adopted an inductive approach towards topic guides, developing them iteratively based on our preliminary analysis of the first and second rounds of data collected. Interviews were carried out by trained and experienced research assistants. We matched younger research assistants to young interviewees and matched older research assistants with older interviewees. Where possible and particularly

among the younger participants, we matched the sex of the research assistant with the participant. We did not have a complete set of interviews among our care dyads as one carer of an HIV-positive child died after the first visit. However, we included the child in further rounds of data collection as we did not want to exclude participants once they had been interviewed for the first time.

The interviews were recorded and interviewers prepared transcripts or detailed summaries of transcripts after each round of interviews. Following transcription and translation of the data, a framework analysis was done (Ritchie et al., 2003), which is a transparent and structured analytical approach ideally suited to analysis that involves teams. This involved developing a thematic structure for interpretation, under which individual codes could be grouped. The team read and reread the transcripts, identified emerging themes from the data and, using MS excel, classified the key themes and subthemes, capturing participant narratives accordingly to illustrate each theme. Below we draw on data related particularly to the topic of HIV disclosure, as well as other themes relevant to this such as facilitators and barriers of psychosocial wellbeing and children's ability to cope with their HIV positive status.

Ethics

We took into account a number of ethical considerations in preparation for and during the study. We approached potential participants through local clinics or through established contacts with older people who we knew to be carers of children. We sought informed verbal consent and assent in advance of interviews, ensuring that participants had time to consider their involvement and ask questions about the nature of the research. We reinforced informed consent processes through further detailed introductions to the research background built into the interviews to further ensure that the scope of the study was well understood by participants. We matched interviewers to participants by age and where possible by sex, to reduce power differentials as far as possible. We also used interviewers experienced and trained in qualitative interviewing methods on sensitive topics.

An important and particularly sensitive aspect of the interviews was to ensure that we did not disclose children's HIV status where this was known to the interviewer but not necessarily to the child. We developed topic guides with open-ended and non-leading questions that did not assume any knowledge of the HIV status of the child, either by the interviewer or interviewee. However, where participants disclosed their own status or in the case of carers, the status of the child in their care, interviewers were then able to follow up general questions with more specific ones about their experiences.

We sought and received approval for the study from the Uganda Virus Research Institute Research Ethics Committee and overall approval from the Uganda National Council for Science and Technology.

Results

Disclosure of HIV status

Among our sample of 18 HIV positive children, the majority had been disclosed to prior to the study (13/18). Among those who knew their status, four children reported being disclosed to by a family member (not always their current carer) and nine reported being disclosed to by a health worker rather than a family member. There were sometimes contradictions in reports of disclosure, for example in two cases where children described being disclosed to by a family member, their carers reported that the disclosure had been handled by a health worker. In another case, a carer described disclosing to a child who had reported to us that he had been disclosed to at a local clinic. These discrepancies may be the product of memory lapses, nevertheless they highlight how significant events may be recalled differently by those involved. The fact that the majority of disclosures had occurred via health workers suggests that carers found this a challenging task.

In the following section we explore these fears in more depth, through unpacking further the carer narratives describing why disclosure had not taken place prior to the first round of interviews. The names of research participants have been changed throughout to maintain their anonymity.

Disclosure anxieties and challenges

The carers who had not disclosed the HIV status of the child in their care described feeling fearful for the psychological wellbeing of the child:

> *I fear* [disclosing to the child] *and think about the outcome after disclosing to her. I suspect the child will become unhappy which can even make me cry after disclosing to her the positive results.* (Yvonne, older carer of HIV positive child)

> *What prevented me from disclosing his health status to him was that one time we were in the garden and his colleagues talked about AIDS and we had just lost a relative to it. He replied that that if he realizes that he has AIDS, he poisons himself and die soon or he just moves away with no aim and goes anywhere. I was so touched and decided not to disclose his status to him and still I emphasized my family members not to disclose his status to him.* (Edward, older carer of HIV positive child)

The following short vignettes expand on these fears and anxieties. Each tells a slightly different story of why carers in our study struggled to tell the children in their care about their HIV positive status and outline how disclosure occurred during the course of the study, or the reasons why it did not occur. It is worth reiterating that our interviewers were extremely careful not to disclose information to children about their HIV status and at no point encouraged or discouraged older carers to disclose during the study.

Not telling for multiple reasons

During the first interviews with Florence and her granddaughter Hope (13 years old at the time of the interviews) it was clear that Hope had not been disclosed to about her HIV status, although it was suspected that she might have found out inadvertently through the process of collecting her ART medication at the clinic:

> *Right now it seems as if she is aware because when we came back here she said that at the clinic they separate them with other patients. Again she said that there is a friend of the*

same status who told her that the children who get their drugs from the children's side (paediatric block) are HIV positive. For me I have never disclosed the status to her according to her former situation I fear to disclose it to her.

She also described how Hope had confounded expectations by surviving and thriving despite having been very ill as a baby:

…that child fell seriously sick and even people were saying that I was just wasting my time to nurse her but as you know that you cannot lose hope to a person who has not yet died, I decided to keep it a secret only to try my best to see that she gets treatment for whatever sickness attacks her… I never expected that she would walk because she walked at the age of four. Secondly I never expected her to talk… We used to get pleased at every stage she reached.

Florence had a further reason to fear disclosure as her granddaughter did not know that her mother was no longer alive having died of HIV and often asked her grandmother if she could visit her. By the second interview Florence had disclosed the information about her mother's death and her own HIV status to Hope, partly because she worried that she might keep asking to visit her mother. Hope disclosed her status to the interviewer at the second visit and explained that although she felt sad at first about learning she was HIV positive she thought it was the right time to have found out. This vignette illustrates how knowledge of HIV status is often intrinsically linked to knowledge of other interconnected family tragedies, making disclosure even harder for those involved.

Deciding who should tell

Bertha described feeling unable to disclose to the child in her care, her grandson Simon (15 years old at the time of the interviews). During the first interview she explained that when Simon had asked her why he was taking medication she had told him to ask his mother who also felt unable to speak about it with him but who had explained to him that he had a 'certain sickness'. As well as feeling uncomfortable about disclosing to Simon herself, she was also fearful about the potential

consequences of others finding out about his status and therefore had developed a 'story' to explain his regular clinic visits:

> *I told the people of our community that he has a problem with his chest so whenever he goes to the clinic those who get chance of seeing him suspect that he has gone to collect drugs for his chest.*

Although neither Bertha nor Simon's mother had not directly disclosed his HIV status Bertha suspected that Simon already knew his HIV status as he would talk openly about his trips to collect treatment at the clinic and about meeting other HIV positive children there.

Simon did not directly disclose his status to the interviewer and appeared uncomfortable discussing HIV in general terms so we were not able to understand more about the circumstances and consequences of his disclosure. In Simon's case it was not clear to the carer where her responsibility ended and his mother's began in terms of disclosing such a difficult secret. This reveals challenges in negotiating disclosure where family members have shared responsibility for a child.

Employing euphemisms to discuss the untellable

During the first two visits Yvonne told us that she felt unable to tell Norah (13 years old at the time of the interviews) that she was HIV positive as she felt she would make her so unhappy and might even cry herself while telling her. To help remind Norah to take her medication, Yvonne would ask her 'have you done my work?' instead of 'have you taken your tablets?' explaining that this was 'their secret'. She also told Norah that she was suffering from liver problems. Yvonne's narrative also highlighted how silence around HIV status had already affected other family members:

> *Interviewer: On the side of her mother, is she not able to disclose status of her daughter to the child?*
>
> *Yvonne: The mother can't because she even failed to tell me her status as her mother. She even fell sick in Kampala and kept silent almost to death point fearing to worry me. When I blamed her she told me that she feared to tell me. I think disclosure will be done when the child becomes thirteen years old.*

However by the third visit Norah told the interviewer that she knew about her HIV positive status. She talked openly about her reaction to the news and was visibly upset during the interview. She found it hard being the only HIV positive member of her household and explained that her grandmother had told her that her young sibling had been protected by her mother attending an expensive medical facility during pregnancy. Although she was unaware of her other siblings' statuses she believed they were not HIV positive either.

> *She continued that when her grandmother told her what she didn't know and never got a chance to be told why she is taking those drugs, she felt that things were so hard for her being the only one who is HIV positive at home. That, her grandmother told her to separate the things she uses from those of others at home but the other household members keep on putting them together. (Excerpt of detailed summary of interview with Norah)*

This statement poignantly illustrates both the stigma that remains for HIV positive people in relation to the risks they perceive they pose to other household members as well as the dilemma Norah faces having been told to keep her 'things' separate from those of other household members who remain unaware of her status. Despite this Norah still felt it was the right time to be told. This case shows how challenging it can be for carers to choose communication over silence, particularly when telling loved ones a difficult truth: Norah's mother feared the consequences of telling her own mother about her HIV status and in turn, her mother, Yvonne, feared the consequences of telling her granddaughter Norah. Yvonne's narrative also shows how communication around HIV is often mediated through euphemistic language which may or may not be helpful once disclosure eventually occurs.

Fearing the consequences of telling

As far as we know Godfrey (14 years old at the time of the interviews) is still unaware of his HIV positive status. In the first interview his carer Edward reported that he was unaware of his status and explained that the child would probably not understand even if he was told, although we had not previously been told of any specific learning or development problems.

Interviewer: Why haven't you ever disclosed it to him?

Edward: If you were to stay with that child for two days only you would understand the difficulties I face, I have told you that his understanding capacity is very low, it is all the same whether I disclose to him or not.

Interviewer: Hasn't he ever asked the reason why he daily takes the drugs?

Edward: He can't even ask the reason why he is taking them and it is the reason why I chose that elder son to be his drug reminder and I gave two panadols to my son, those tablets play that role, he pretends as if he is swallowing them yet he hasn't and that child (the sick one) assumes that they are all on daily drugs.

During the second interview, the carer explained that the child had been talking to his friends about HIV after a relative had died of the disease and the carer overheard him say that if he discovered he had AIDS he would run away or even kill himself. Edward felt he could not disclose his status having heard that and asked other family members to also maintain silence. To persuade Godfrey to regularly take his medication, Edward told him that he needed to take medication as he had been ill with typhoid fever. According to Edward, Godfrey believed this and had continued with his medication, remembering to take it daily. Similar to the previous case, this illustrates how carers may feel forced to adopt subterfuge to ensure that the children in their care stick to drug regimes. In this case there were also serious fears about the psychological effect that disclosure might have on Godfrey. Despite strides made in treatment for HIV and in addressing stigma related to the disease, the prospect of disclosure remains extremely daunting for carers of children who may fear a diagnosis of HIV above anything.

Deciding what age to tell

As far as we know, Harriet (13 years old at the time of the interviews) is still unaware of her HIV positive status. During the first visit Marion explained that she felt Harriet was too young to know her HIV positive status and that knowing would only worry her. She explained that in order to

persuade Harriet to take her medication regularly she had told her that they were both suffering from diabetes.

> *Interviewer: Doesn't she ask for the purpose of taking those drugs?*
>
> *Marion: She asked me about it and I told her that we were both suffering from diabetes and I reminded her about the time when they went for blood test and that diabetes was the reason why they went for testing.*
>
> *Interviewer: Don't the other children she stays with ask for the reason why she is taking the drugs?*
>
> *Marion: Since I am also taking drugs daily, I told them that she is also taking drugs for diabetes.*

While the other children in the household were told the same, Marion had told two other adult family members about Harriet's positive status so that if she died, she would not leave her with carers who were unaware of her status. Marion also revealed her apprehension about caring for Harriet given her HIV status:

> *Marion: If she wasn't my daughter's child, I wouldn't have cared for her because I fear her at times I think that she can infect us not through sex but she can use a razor blade to cut her nails when I am away and another child uses it.*

Once again, this demonstrates how carers find ways to avoid disclosure by using other illnesses as cover. However the case also highlights how, paradoxically, fears about disclosure may foster further anxiety around inadvertent HIV exposure.

Coping in the aftermath of disclosure

We also discussed with carers and children how they felt after disclosure and what they felt were advantages, or disadvantages of disclosure. Understandably, the initial shock of the disclosure was challenging and children often described 'feeling bad' when they were first told.

However, in cases where disclosure had occurred, children reported several advantages of being aware of one's own HIV positive status. Some of their observations, and those of their carers,

indicated that disclosure could allow them to take control of their healthcare by proactively seeking care when necessary, visiting a health facility unaccompanied, and ensuring that their medication was taken regularly and on time. This had positive implications for ART adherence. Another important advantage was the increased ability for children to communicate effectively about their physical health and to be able to ask and access help from their carers. These benefits were also linked to children's developing maturity, as the below quote illustrates:

> *By the time we disclosed his health status to him, he was still young, let me say that he didn't understand it well, but now he has become more aware as he has grown up. The good thing is that by the time he understood it, he was no longer falling sick as he used to. Now, when he falls sick he knows what to do and he tells me quickly that he is not feeling well and he goes to the clinic. Sincerely his knowing has helped both me and him so much.* (Natalia, older carer of HIV positive child)

Children also perceived that when they knew their status they were better able to help themselves, to have their needs addressed and, more broadly, to minimise the risk of infection to others, as articulated by a young participant:

> *I asked her the other advantages of disclosure and she responded that disclosure helps a person to be taken care of and helps in sensitization of those who are concerned about that disease (HIV) so that when one gets a problem, they can help her/him. It also saves the society members from contracting HIV as a parent who is aware that so and so is HIV positive and will not share that child's razorblade with another child who is not positive thus disclosure helps in prevention of the spread of HIV.* (Excerpt from detailed summary of interview with Jane, HIV positive child)

Children and their carers were also understandably concerned about disclosing a child's HIV status to others, as they felt they might encounter (and in some cases had experienced) stigmatising attitudes from peers and community members. Jane, whose words above describe her views on advantages of disclosure, nevertheless felt that disclosure to others could be potentially stigmatising:

> *…there are those people who can't keep it to themselves when one has disclosed her status to them, they go on telling each and every one making a victim a topic throughout the entire society which she said is dangerous to that person they are talking about…* (Excerpt from detailed summary of interview with Jane, HIV positive child)

Maintaining confidentiality throughout the disclosure process was therefore a significant concern for both older carers and the children in their care.

Psychosocial wellbeing in the long-term

Among those who had been disclosed to prior to the study the majority appeared to have come to terms with their status and although a number of them described experiencing a difficult time when they were initially disclosed to, many expressed positive views about their current state of psychosocial and emotional wellbeing. A common factor among the majority of young women and men was a sense of connection between awareness of their status and their ability to adhere to and benefit from treatment. They appeared to have developed a stronger sense of agency through being able to come to terms with the knowledge of their status:

> *He said that having gone through all that, it means that he is living a happy life because he no longer gets worried because of that. He said he cannot get worried because he is now used to taking his treatment unlike others who just sit down and think a lot about taking their treatment hence being worried.* (Kennedy, HIV positive child)

> [When asked what helps her to cope with her HIV positive status] *She responded that nothing has enabled her but disclosing her sero-status makes her feel well and enables her gain strength to religiously swallow her drugs.* (Grace, HIV positive child)

Children also identified coping mechanisms through identifying with their peers' experiences of HIV. For example a young participant described her journey from a sense of initial trauma after discovering her status, to being comforted and better able to accept the news through learning that other young HIV positive people had survived into adulthood:

She continued that at first she felt bad and thought of many things because her mother had all her hope in her and that after counseling got from counselors and her aunts, she became strong and gained hope because many HIV positive living children have grown up, studied and become responsible people in the world which she didn't know but with the comfort got, she said that she became strong and that she is feeling at peace now because she knows that she is not going to die tomorrow. (Joyce, HIV positive child)

In one case there was a significant discrepancy between the reports of a carer and the child in her care about his experiences of living with HIV. When asked if he was worried about his status Catherine responded that she thought he was coping well and had opportunities to discuss his status with others:

He does not show that he minds about it, and when we go to the health center for the medicine he finds other children of the same status. So he is not worried about it. He talks with those children and they talk about themselves in their group. (Catherine, older carer)

However interviews with Laurence revealed that he might wish to talk more about his HIV status:

Ever since he established that he was HIV positive he has never talked about it again and he has no hope of talking about it again. It is only his grandfather and grandmother who know about his HIV status but his other colleagues do not know about it. (Excerpt from a detailed summary of interview with Laurence, HIV positive child).

Although Laurence did not appear generally unhappy, this excerpt provides insight into his perception of the communication constraints around his ability to discuss his status in comparison with the perception of his carer.

Gendered expectations about living with HIV

During discussions about challenges faced in their care of children, three carers of girls described experiencing anxiety related to the sexual activity of those in their care, as illustrated below:

She is growing so fast, and I am so worried in case she involves herself in sexual affairs and passes on the sickness to others. (Marion, older carer to HIV positive child)

I don't have enough money to fulfil all my plans and if this child involves herself in sexual issues and becomes pregnant, that will also prevent me from achieving my goals. (Yvonne, older carer to HIV positive child)

I try my best to tell this child about sex because she moves away from the home during evening hours which I suspect to be bad habit, secondly I tell her to be careful and avoid sex as she is still young and I fear because of her HIV positive status to get pregnancy. (Mary, older carer to HIV positive child)

These comments were mirrored in two cases by young female participants themselves. For example, the story of Naomi (see below) reveals how girls and young women may internalise and reproduce this kind of 'moral' expectation. Naomi's awareness and understanding of her HIV status were clearly connected to her perceptions about expectations of her sexual behavior:

I asked her how our conversations have made her think about anything differently over the past few months or have triggered new ideas about her experiences and she replied that, our conversations have enabled her share with us and understand how she is treated at home and her experiences as an HIV positive child and that, she feels good and is happy deep inside her heart that we visited her and she has thought of continuing abstaining from sexual intercourse with boys. (Excerpt from a detailed summary of interview with Naomi, HIV positive child)

Interviews with young male participants revealed that they hoped to marry in the future, and in one case, a young male participant mentioned that he knew he would need to reveal his status to his future wife. Nevertheless there were no explicit references to any moral expectations related to their sexual activity or decision-making, either by carers or the children themselves. The fact that we did not find similar data in interviews with male children or their carers suggests that there may be a greater 'policing' of young women's sexuality, presumably related to socio-cultural gendered norms

and beliefs. While it is a common aspect of many cultures and societies to view women as 'guardians' of sexual morality, it becomes a particularly dangerous trope in the context of children and young people growing up living with HIV, especially where such attitudes ignore boys and men's roles and responsibilities in sexual decision-making.

Discussion

While the majority (13 out of 18) of the HIV positive children included in the study had been disclosed to before the study commenced, we found that most (9 out of 13) were disclosed to by a health worker, not their guardian or carer. Significantly, five children had not been disclosed to by either health workers or carers and by the end of the study (after 1 year), two out of 18 still appeared to be unaware of their status. Although the number of participants is relatively small, this study provides us with important insights into the challenges, anxieties and struggles entailed in the disclosure process, experiences of children following disclosure and communication challenges and opportunities that persist beyond the point of disclosure.

The finding that disclosure had often been handled by health workers supports evidence suggesting that carers struggle to discuss disclosure of HIV status with the children in their care (Pinzón-Iregui et al., 2013). Similar to other studies, carers fear the psychological effects and social stigma they perceived might follow from disclosure (Vaz et al., 2008, Vreeman et al., 2010, Mburu et al., 2014). Our study adds to the literature by focusing on the specific dynamic of children cared for by older carers, mainly family members, but importantly not parents.

Although only a small number, the cases where disclosure had not occurred prior to the study provide important insights into the complex reasons for older carers not to tell children about their status and illustrate broader communication challenges that arise from this reticence. As we found, older carers may wish to protect children from associated knowledge or they may not feel it is their place to tell where there are closer family members still alive. Older carers may also perceive that health workers are better equipped to disclose and/or may struggle to judge the age at which disclosure should occur.

Research suggests that lack of disclosure can lead to negative outcomes for children, who may discover inadvertently about their HIV status, from others in the community or at school or through their own gradual realisation related to their need to take drugs, or their experience of symptoms (Kidia et al., 2014). Other studies have also pointed to the potential psychological and physical dangers for children of 'cultural silence' on sensitive subjects that relate to sex and death (Daniel et al., 2007, Kajubi et al., 2014a, Kajubi et al., 2014b, Kawuma et al., 2014). For example children may adopt feelings of shame and stigma that are fostered by the secrecy surrounding HIV (Kawuma et al., 2014) or may find themselves unable to discuss important questions about their medication with carers or health workers where communication lacks openness and is not child-centred (Kajubi et al., 2014a).

In contrast to the fears of their carers children disclosed to either preceding or during the study, appeared to cope well in the face of their diagnosis. As in other settings, many of the young participants in our study described their experience of disclosure in positive terms (Midtbø et al., 2012, Vaz et al., 2008). While it was clear that they found the process a difficult one and expressed how they had felt sad and upset at discovering their HIV positive status, participants went on to describe how they had learned to cope with the information and how disclosure had helped them in practical ways, for example, to maintain a regular pattern of medication taking. However, there were few examples of carers and children reporting regular discussions about other aspects of their psychosocial wellbeing and in fact there were a number of discrepancies between older and younger narratives which suggested that participants either remembered disclosure events differently or had different perceptions of their ability or willingness to communicate on this difficult and sensitive topic.

A body of research on youth sexual and reproductive health needs in Uganda argues powerfully for the need to address the issue of cross-generational communication more effectively (Kinsman et al., 2000, Bell and Aggleton, 2012, Bell and Aggleton, 2013). Our findings strengthen this perspective and demonstrate that services and interventions need to find more effective ways of increasing

positive communication between adult carers and children, both with significant adults such as health workers and teachers, but also within the intimate household relationships that mediate psychosocial development. However, there is a need to carefully consider how to address the power dynamics and social norms that might undermine safe and positive communication. It is not enough to ask older carers to talk more to the children in their care if conversations generated are underpinned by norms and beliefs that place unhelpful moral expectations on young HIV positive women. Such conversations would be unlikely to address underlying issues such as consent, sexual and gender based violence and reproductive self-determination. Bell and Aggleton (2012) argue persuasively for adopting a 'counterpublic' approach when dealing with young people's sexual and reproductive health. Such an approach would include facilitating young people themselves to be able to better challenge harmful social and gender norms by 'strengthening their ability to participate in dialogue and negotiation with adults' (p. 395). In our case, there is also an argument for facilitating older carers to reflect on their views and beliefs in a 'safe space' for their psychosocial wellbeing. Research on the structural drivers of HIV among older people in Uganda has highlighted the need to develop policies and programmes that reach beyond the conceptualisation of older people (especially women) merely as 'carers', to recognise their own health and wellbeing needs as individuals (Richards et al., 2013).

In conclusion our study sheds light on communication challenges within caring relationships between older carers and HIV positive children, related to disclosure of HIV status and its impact on psychosocial wellbeing. These insights chime with research on caring relationships in other contexts and on other aspects of cross-generational communication in the Ugandan context. Further research is needed to explore opportunities for working with children, their carers (especially older carers) and health workers to address cultural norms that promote silence around the difficult topics of HIV status, sexual health and relationships.

Implications for Practice

Based on their findings on disclosure processes in Kenya, Vreeman at al. (2014) have argued that carers' views on disclosure are vital for enabling better understanding and monitoring of paediatric anti-retroviral treatment. Our findings highlighted the vital role of health workers in the process of disclosure and as such, clinic-based interventions in paediatric ART need to continue to develop and integrate training and support for disclosure processes. Ideally health workers need to work with carers, older or otherwise, to facilitate disclosure that involves safe and open communication within the caring environment of the home as well as within the medicalised space of the clinic. Peer support can play an important role here, especially for young people, but potentially also for older carers who face social isolation due to their age and physical frailty and who have vital care needs of their own (Richards et al., 2013). The Addendum to the National ART Guidelines recommends disclosure by the age of 10 years (Uganda Ministry of Health, 2013), while the HIV Counselling and Testing Policy recommends disclosure to begin at age 7 and be completed by 12 years (Uganda Ministry of Health, 2010). However, given how challenging it can be for carers, especially those who are older, to communicate effectively with children about their HIV status we would argue that they should not be put under pressure to disclose HIV status to the children in their care, rather they should be supported to do so in ways that promote the psychosocial wellbeing of themselves and their children.

Following disclosure, there are further cross-generational challenges to be addressed, which require very particular kinds of support (Bell and Aggleton, 2012). The need to deal with the stigma of HIV in communities and in schools is already well established. However, stigma and discrimination related to adolescent sexual behaviour and practices is one which remains extremely difficult to tackle, especially where gendered social norms are prescriptive in the area of girls' and young women's sexual agency. An important aspect of disclosure to children and young people living with HIV is the provision of non-discriminatory and open information on intimate relationships, sexuality and how to engage safely in sex. Health workers require training on supporting this communication through

clinical encounters and on encouraging carers, where possible, to engage in appropriate communication beyond the clinical setting. Children's agency and participation needs to be nurtured to allow them to communicate more effectively not only in their peer groups but across generational divides. In particular, those planning and administering interventions to address the psychosocial wellbeing of children, whether related to disclosure processes or sex and gender education, must also pay attention to the support needs of the older women and men delivering such vital care.

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