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COMMUNICATION IN THE CONTEXT OF FAMILY CAREGIVING: AN EXPLORATORY STUDY OF UGANDAN CHILDREN ON ANTIRETROVIRAL THERAPY

P. KAJUBI*[1], ANNE R. KATAHOIRE*, DAVID KYADDONDO* AND SUSAN R. WHYTE†

**Child Health and Development Centre, College of Health Sciences, Makerere University, Kampala, Uganda and †Department of Anthropology, University of Copenhagen, Denmark*

Summary. It is important to consider the complexities of family dynamics when deciding when and how to communicate with HIV-infected children about their illness and treatment. Previous research has focused on providers' and caregivers' perspectives on whether, when and how to disclose HIV/AIDS diagnosis and treatment to HIV-infected children. From the perspective of HIV-infected children, communication does not mean just giving information about illness and treatment, but also encompasses emotional and material care. This paper places communication within the broader framework of caregiving in family situations. This exploratory study was conducted in Jinja district, Uganda, between November 2011 and December 2012. Through participant observation and in-depth interviews, communication by, and with, HIV-infected children in the context of family situations was explored from the perspectives of 29 HIV-infected children aged 8–17 years on antiretroviral therapy (ART) using content thematic analysis. Children's communication with caregivers about their illness and treatment varied depending on whom they were living with and the nature of caregiving. Although a mother's care was considered best, children described others who cared 'like a mother'. For some, caregiving was distributed among several relatives and non-relatives, while others felt they had hardly anyone to care for them. Caregiving from the children's perspective involved emotional support, expressed verbally and explicitly in messages of concern, encouragement conveyed in reminders to take medicines, attention when sick and confidential conversations about the challenges of having HIV and taking ART. Caregiving was also communicated implicitly in acts of provision of

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[1] Corresponding author. Email: phoebekajubi@yahoo.com

food/drinks to take with medicines, counting pills to confirm they had taken the medicines and accompanying children to treatment centres. Children's communication about their health and medicines and the care they received was to a large extent shaped by the nature of their relatedness to their caregivers, the extent to which caregiving was dispersed among several people and who else in the household was infected with HIV and on medication.

Introduction

The family plays a crucial role in the chronic treatment of children (Shah, 2007). It is the family that provides daily care and ensures that medicine is taken. Communication about a child's illness and treatment is supposed to occur within the family as a component of caregiving, but for children on antiretroviral therapy (ART) family caregiving can be problematic. Virtually all of these children have been infected by their mothers, making HIV unique among paediatric conditions in that mothers are ill or deceased. Many of the infected children in resource-limited settings like Uganda receive ART in a context that includes very high rates of orphanhood (Bikaako-Kajura *et al.*, 2006; WHO/UNAIDS, 2006; Vreeman *et al.*, 2008; Fetzer *et al.*, 2011). Although HIV-infected children are often viewed as a single group there is diversity in age, circumstances and degrees of vulnerability among them (Garcia *et al.*, 2008; Vreeman *et al.*, 2008).

Previous studies have highlighted the importance of considering the family context of HIV-infected children when making decisions regarding medication management (Williams *et al.*, 2006), and the significance of family relations for children's adherence to treatment has been underlined (Bikaako-Kajura *et al.*, 2006). Family closeness, parental warmth and the positivity and cohesiveness of family interaction patterns have a strong influence on children's compliance with chronic medication (Miller-Johnson *et al.*, 1994; Davis *et al.*, 2001; DiMatteo, 2004). Children who enjoy a trusting relationship with their caregivers are more likely to agree to take their medication without questioning what it is for (Bikaako-Kajura *et al.*, 2006).

Guidelines on disclosure to children also underscore the importance of considering the complexities of family dynamics when deciding when and how to communicate with younger children about their illness and treatment (American Academy of Pediatrics Committee on Pediatrics AIDS, 1999). However, many studies have focused narrowly on disclosure (Wiener *et al.*, 2007; Vaz *et al.*, 2010; Heeren, 2011; Pinzón-Iregui *et al.*, 2012; Vreeman *et al.*, 2013) instead of considering it within larger patterns of communication. By contrast, the present study emphasizes the intertwining of caregiving and communication and places both within the broader framework of the family circumstances that shape them. For HIV-infected children, communication is not just the transmission of factual information, but also the conveying of concern, feelings of affection and implicit messages of support, as well as their opposites. This may be particularly true for HIV-infected children because of the climate of stigma and loss. In the context of AIDS, bereaved children suffer multiple losses, such as the death of their parents or a sibling, separation from surviving siblings, interrupted education and a move to unfamiliar surroundings with a new caregiver (Domek, 2006; Daniel *et al.*, 2007). Children whose parents are very ill and those without parents not only suffer physically from the lack of basic needs, but also experience grief at the loss of their parents, and may also face stigma and discrimination because of their parents' HIV status (Kaggwa & Hindin, 2010; Daniel, 2011; Skovdal & Daniel, 2012). Furthermore, some children face the additional trauma of witnessing their parents' illness and eventual death, resulting in poor physical and emotional health (Fonseca *et al.*, 2008; Kaggwa & Hindin, 2010; Skovdal & Daniel, 2012). Due to the stigma associated with the disease, care that families provide to these children is at times compromised, with foster families sometimes having negative attitudes towards the HIV sero-status of the child, such as the fear of HIV infection spreading to others, resulting in the child being segregated (Garcia *et al.*, 2008).

This study explores the implications of different family constellations for caregiving and communication with children on ART. It examines children's perspectives on relationships with different kinds of caregivers from those who were most, to those who were least, supportive. Using the concept of relatedness, it differentiates caregiving and shows how communication is facilitated or inhibited.

Methods

Study site

The study was conducted in Jinja district, located on the shores of Lake Victoria in eastern Uganda. The overall HIV prevalence in the district was estimated to be 5.8% in 2011 (MOH, 2012). Slightly more than half (56%) of the district total population was below 18 years of age, of which 11% were orphans. At the time of the study, six government and three private not-for-profit health facilities were providing ART for children.

Study sample

Data were drawn from an exploratory study that was conducted by the first author (PK) between November 2011 and December 2012. This was preceded by a cross-sectional survey involving 394 HIV-infected children aged 8–17 years on ART and their caregivers ($n = 393$). Data from the survey have been reported elsewhere (Kajubi *et al.*, 2014). A qualitative research design in the follow-up study enabled an in-depth exploration of the significance of family situations for communication with, and by, children on ART.

A total of 29 HIV-infected children aged 8–17 years on ART were identified during the survey with the help of health care providers and followed up for a year. The children were purposively sampled to include different ages, sexes, family situations (residence, orphan status), education levels and disclosure statuses. The purpose of the research was explained to the caregivers and their children as a study of children's understanding and communication about their health and medicines.

Ethical clearance to conduct this study was obtained from Makerere University College of Health Sciences, Higher Degrees, Research and Ethics Committee, and from the Uganda National Council for Science and Technology. Permission was also obtained from treatment centres where children on ART included in the study were accessed. Informed written consent was obtained from caregivers for their own and their children's participation in the study. Written assent was also obtained from children whose caregivers had provided consent. Only children 8 years and older were enrolled in the study, since according to Ugandan ethical guidelines that is the age of assent. To ensure confidentiality, pseudonyms were used.

Data collection

The main methods of data collection were in-depth interviews with children and participant observation in different social settings, which included the homes of HIV-infected children, post-test clubs and treatment centres. Observations were done simultaneously with the interviews. The first author (PK) lived in the study area during the 12 months of data collection.

In-depth interviews. In-depth interviews were conducted after a period of repeated visits to children's homes and interactions with the children in other social spaces, including treatment centres and clubs, during which time rapport was established with the children and their caregivers. Interviews were conducted with older children who were already aware of their HIV diagnosis (21/29), and these mostly included 13- to 17-year-olds. Children who did not know their HIV status were not interviewed because their caregivers feared inadvertent disclosure. In-depth interviews conducted with HIV-infected children explored their perceptions and experiences, and the significance of family situations and caregiving from their perspectives. The interviews started with 'grand tour' questions about the children's life situations and social worlds (home, school, friends, relatives, daily activities and interesting things about their lives) and tried to achieve the feel of an everyday conversation. Once the children were comfortable with the researcher, questions regarding caregiving and their family situation were delved into. The key issues explored included: who in the family they communicated with about their health and medicines and why, what they communicated about and when and where the communication took place. The conversations were conducted in Luganda or Lusoga (the main local languages spoken in the study area) and English by the first author. They lasted 40–45 minutes and were audio-recorded (with participant permission) in order to capture issues in children's own words. Two graduate research assistants (a male and female) experienced in qualitative research and conversant with the three languages worked with the researcher. The research assistants transcribed and translated the recorded interviews into English. Transcripts were cross-checked and verified by one of the research assistants and the first author for consistency and accuracy.

Participant observation. Participant observation in the homes of the HIV-infected children was a key strategy for collecting data. The first author followed up the 29 children in their homes and other social settings over a period of 12 months, interacted with them, their caregivers and other family members and got to know their family situations. During visits to the children's homes, observations of children's interactions with family members were made. The first author listened to their conversations and observed their communication practices (what children and family members talked about, whom children talked to most of the time, how they interacted). Observations and informal/unstructured interviewing were done simultaneously whereby during conversations with children and caregivers the first author would interject to probe for clarification about issues that arose and which were considered to be pertinent. This helped to build a rapport with children that was conducive to the in-depth interviews, which followed after repeated visits and interactions. The observations conducted after the in-depth interviews shed light on some of the information obtained from the interviews.

The time spent, and visits made, to the homes of each of the children ranged between one and twelve times, depending on the age (younger children/adolescents) and or perceived maturity of the child, whether the child's HIV status had been disclosed to them and the relationship of the child to the caregiver. For four of the younger children (8–12 years) who had not been disclosed to, and in (eight) homes where there was no open communication about the child's illness and medicines, only one or two visits were made; even then, caregivers controlled access to, and conversations with, the children for fear of inadvertent disclosure. Time spent in these homes ranged between three and four hours per visit. Caregivers requested during the first visit that further interactions should be outside of the home setting. Interactions with such children and their caregivers were more at the treatment centres during the monthly clinic appointments. However, even during such interactions, caregivers controlled access to, and conversations with, the children for fear of inadvertent disclosure and the perceived negative impact it would have on the children. Visits to homes of children who stayed with abusive caregivers were usually short-lived (less than one and half hours), and interactions with such children were at treatment centres, where they were not accompanied by caregivers. For the older children (13–14 years) who had been disclosed to, more frequent visits were made to these homes and the time spent was longer, ranging from five to six hours at a time. Caregivers allowed the researcher to spend time alone with children, including having meals with them, and having conversations with them as they did housework and taking walks with them to shops, markets and treatment centres to collect medicines. Older children (15–17 years) preferred meeting at treatment centres on adolescent clinic days, post-test club gatherings on weekends (where they had discussions on topics of their own choice, and shared meals, games, music, dance and drama) and other public settings that included end-of-year parties organized by a few treatment centres. More time was spent with them, ranging from six to eight hours depending on the duration of the activities they were involved in. Field notes written during the course of the day were expanded at the end of each day.

Data analysis

Data comprised transcripts of in-depth interviews and detailed field notes taken during conversations and observations. Preliminary data analysis occurred concurrently with data collection during quarterly meetings the first author had with the co-authors.

The process of typing and reading through the transcripts and detailed field notes helped to draw attention to emerging themes and was an important part of preliminary analysis and identification of thematic categories. A list of themes was generated as part of the process, forming a framework for a codebook. The major themes included children's socio-demographic characteristics, family situations, other significant relations, visits to treatment centres, experiences with medicines, children's communication about medicines and health at home, quality of relationships with caregivers, communication with other people about health and medicines, challenges and concerns of being on ART and having HIV, and the person most talked to about these concerns and suggestions about support to live on life-long medicines (ART). Additional sub-themes that emerged from the data were also included.

The compiled data set was eventually imported into Atlas.Ti.version 7 (Atlas.Ti. Scientific Software Development, Berlin, Germany), which was used to more systematically manage, code and retrieve data. As part of the coding process, segments of data that related to the themes were identified. In addition 'memos' that contained thoughts about the selected segments were written. Together the codes and memos formed the basis for the thematic analysis where patterns and meanings were established. Through this process the large data set was condensed enabling the identification of recurring themes, linkages and similarities. On the basis of this, impressions were developed and eventually explanations and arguments. Comparisons of children's perspectives on relationships with different kinds of caregivers from those who were most, to those who were least supportive, were made. In addition, across the different caregiving/living arrangements, comparisons were made to show how they facilitated or inhibited communication.

The analytical concept of relatedness

The study draws on the concept of 'relatedness' in order to understand the broader meaning of communication in the context of family caregiving. The term 'relatedness' has been used in kinship studies since the 1990s to signal a move away from more formal or restrictive definitions of kinship (Carsten, 2000). This is part of an endeavour to examine the ways in which people in specific social contexts articulate and engage in the relationships that are important to them in everyday life. 'Relatedness' thus includes not only those bonds classically understood by anthropologists in terms of kinship (in other words, between people linked through actual or putative ties of sexual procreation), but also bonds such as those of marriage, adoption, fostering and other forms of what has often been termed by anthropologists as 'fictive kinship'.

Anthropologists working with kinship increasingly use the concept of relatedness to argue that the experience of relatedness does not only come from the biological link one has with different kinds of kin, but from the actual practice of daily interaction (Carsten, 2000). Eating together, sharing a residence, providing resources, talking and generally spending time together enhance the sense of relatedness, beyond any biological 'facts' about linkages. These practices influence the quality of relationships, and in this case of caregiving. Thus one may have a stronger sense of relatedness to one among several siblings, or one among several grandparents. One may even have a stronger sense of relatedness to someone who is not a biological relative. This emphasis on the practice of interaction is helpful for distinguishing different kinds of caregiving relationships.

From a psychological point of view, a sense of relatedness may function as a motivational resource when children are faced with difficulties. Furrer and Skinner noted that in times of stress, children who experience 'trusted others' as 'backing them up' respond with more vigour, flexibility and constructive actions. They found that feeling special to key social persons triggers energized behaviour, such as effort, persistence and participation, and promotes positive emotions such as interest and enthusiasm (Furrer & Skinner, 2003). The interest in adopting this concept is to examine the practices that generate or inhibit that beneficial sense of relatedness between children and certain adults, and to show how it affects communication.

Results

Characteristics of study children and living arrangements

Of the 29 HIV-infected children on ART who were followed, slightly over half were female (16/29). Their median age was 12 and the majority of them were in primary school. Their caregivers were small-scale farmers and traders; a few were professional and non-professional salaried employees. Four of the children were not aware that they were infected with HIV. More than two-thirds (21/29) were orphans: eleven had lost both parents; six had lost only their mothers and four only their fathers; only eight had both parents alive. Table 1 shows the person children were living with when the study began; fewer than half of the children (13/29) lived with a biological parent.

Treatment centres considered and registered a primary caregiver as the adult with whom the child lived, who escorted the child to the treatment centre and was responsible for the child's medicines. In their registers they recorded the name of the child, the parent/guardian (caregiver) and the latter's contact information, which included name of the village where they lived, telephone number of the caregiver and that of the spouse in cases where a child lived with both parents. The majority of registered caregivers were kin of some sort, although this was not invariably the case.

Mothers as ideal caregivers

Children portrayed their relationships with their mothers as the most intimate and supportive. They had bonded with those who gave birth to them and nurtured them in infancy. This sense of relatedness was enhanced by the time spent with their mothers, who fed, talked with and cared for them on a daily basis. Furthermore, they shared the HIV virus as well as the practice of daily medication, even though not all mothers and children discussed this commonality. While some of the children lived with both parents, they talked more about their mothers than fathers. For example, Barnabbas, aged 12 years, who lived with both parents and two siblings, reported that his family

Table 1. HIV-infected children's living arrangements at the beginning of the study, Jinja district Uganda, 2011–12

Who children live with:	*n*
Mother and father	5
Only mother	4
Only father	2
Father and stepmother	2
Maternal grandmother	7
Paternal grandmother	3
Maternal aunt	2
Paternal uncle and wife	1
Paternal aunt	1
Alone	1
Institutional home	1
Total	29

loved him, reminded him to take his medicines and provided him with juice to take with medicines, but felt loved in a special way by his mother because she was also HIV positive. Whenever he felt fed up with the medicines, he confided in her for encouragement and felt that she understood his situation better, as indicated in the excerpt below from the interview with Barnabbas:

> Interviewer: Who do you talk to mostly here about the medicine you take?
>
> Barnabbas: Mummy.
>
> Interviewer: Who helps you to take the medicine?
>
> Barnabbas: Mummy.
>
> Interviewer: What exactly does she do to help you take the medicines?
>
> Barnabbas: She tells me that I should take because the medicine is my life. She reminds me the time and asks me if I have taken the medicine. I tell her no and she tells me that it's time to take. Then I take.
>
> Interviewer: Okay, who do you talk to most about your sickness?
>
> Barnabbas: Mummy.
>
> Interviewer: What about daddy?
>
> Barnabbas: [laughs first] Daddy, hmm, I rarely ask him such questions.
>
> Interviewer: Why?
>
> Barnabbas: [keeps silent]
>
> Interviewer: Why is it your mummy only?
>
> Barnabbas: It's her I want because she knows my condition; she understands me and my concerns more than anybody. Daddy is always busy. I tell Mummy that I am fed up with this medicine and she tells me to take because it's my life. Then I tell her that it's okay, let me take. Because she knows, she understands me. I find it easy telling her anything. Daddy loves me but he is always busy working. It's mummy I talk to.

Like Barnabbas, Shakirah had an intimate relationship with her mother. She reported that her mother always reminded her to take the medicines and even cared enough to check and confirm that she had taken them. Shakirah was very selective in whom she talked to about her health and medicines. Even though she enjoyed a warm relationship with her stepfather and siblings, she only discussed issues about her health and medicines with her mother:

> I love my mother so much…I only talk to mummy about my medicines. I fear to tell other people like my elder siblings but for my mother I know that we are in the same boat.
>
> (Shakirah, 14 years)

Shakirah further reported that her mother stopped working to be with her in hospital when she was admitted:

> My mother was with me in hospital all the time. She stopped working during that time because she was in hospital looking after me. I was so sick, very weak and my mother was just carrying me on her back.

The intimacy between Shakirah and Barnabbas and their mothers and the care they received could possibly also be attributed to the fact that they were the only HIV-positive children in the family and that their mothers were also infected with HIV. These children reported that they felt free sharing their challenges regarding their health and medicines with their mothers because the latter were also infected and on similar medicines:

> I asked my mother how I got infected and she told me that I was born with the illness. I was strong because at least we are two people at home, my mother and I who have AIDS, but it would have hurt me so much to be the only one with this illness at home. She told me not to worry so much about this illness but instead think about the future.
>
> (Shakirah, 14 years)

However, even children with the most intimate relations with mothers found there were issues they could not discuss with them:

> I fear to die and whenever I see someone who has died I become sad…I don't talk to anyone about this, even my mother, but I counsel myself.
>
> (Shakirah, 14 years)

> I wanted to be like my sisters who do not take medicines every day. I find it a challenge to take the medicine…I do not tell anyone my challenges, no one, not even my mother. I just keep them to myself.
>
> (Stella, 14 years)

According to Stella, she did not want to worry her mother or appear ungrateful for the support she was receiving. She seemed to think that revealing her worries would show weakness and a lack of appreciation for the love and support she received from her family.

Although there was a general feeling that mothers were the ideal caregivers, it was clear that biological motherhood did not automatically ensure supportive caregiving. There were mothers who did not care for their children to the extent of abandoning them and leaving them in the care of grandmothers. For example, Matthew, aged 11 years, was abandoned by his mother after the death of his father. Matthew pleaded with his grandmother to find his mother and refused to take his medicines, insisting that he wanted to stay with his mother and young sister. Attempts by the family to find her proved futile.

Derrick, aged 10 years, and his brother Yusuf, aged 9 years, were abandoned by their mother at their grandmother's home. Derrick was left when he was 8 months old and the grandmother reported that one time she came home to find that Derrick's mother had dumped another baby, Yusuf, after he had just been weaned. The whereabouts of their mother was not known and she never checked on the children. Attempts to find their father were equally unsuccessful. Farouk, aged 9 years, was also left with his grandmother, who looked after him and was not in touch with either parent.

Caregivers who cared like mothers

While some biological mothers did not live up to the ideal of motherhood, other carers gave love and affection similar to that of a birth mother. Betty (age 13) and her sister Flavia (age 8) lived with their maternal aunt after the death of their mother. Their aunt had cared for her sister when she fell sick until her death. During that time Betty, who was 7 years old then, and Flavia, 2 years, lived with their maternal aunt, who brought them up as her own children when their mother died. They called her *maama*, the common term for mother and mother's sister in Ugandan languages. At age 10, Betty was told by one of the young children at home that their mother had died of AIDS, that they were also infected with HIV, for which they were on daily medication, and that the *maama* was not their biological mother. Betty later confided in her young sister, who immediately ran to the aunt in disbelief to find out whether it was true. They described their *maama* as very loving and caring, and were shocked to learn that she was not their biological mother:

> I love my mother [maternal aunt] very much and appreciate all she does for me. She treats us as if we are her biological children. She talks to us very well…She really cares. If I am in the village and the medicine is almost finished I tell her and she sends someone to go to the clinic to collect the medicine for me. She reacts quickly and she always asks me when I am going back to the clinic.
>
> (Betty, 13 years)

The children living with maternal grandmothers also described their caregivers as loving and affectionate. Dunstan's mother's mother took him in after both of his parents died. At the time he was very sick and miserable. Dunstan reported that he loved his grandmother very much because she cared for him, did not require him to do many household chores and allowed him to play football with his friends:

> I love my grandmother because much as she doesn't have a job where she earns money, she never tells me to go and get a job or sell anything. Even when there's no food at home, she tries all her best to find something at least for me to eat, even if she doesn't eat, so that I take my medicines. She is the only one I tell when I am sick and I also remind her of my appointments to go and pick medicines.
>
> (Dunstan, 11 years)

Where grandmothers assumed the care of orphaned grandchildren, some acted like mothers with all the positive associations maternal caregiving had. Some grandmothers enacted affection by protecting the children from knowing their sero-status. For example, the grandmother of Derrick (10 years) and Yusuf (9 years) told them that they were suffering from a lung infection for which they had to take daily medicines. Farouk (9 years) was told by his grandmother that he suffered from malaria. They later explained that the children were too young to understand the magnitude of the diagnosis; they also feared the impact it would have on their grandchildren.

Caring fathers

Despite the tendency for primary caregivers to be women, some maternal orphans praised their fathers for being almost like mothers. Samalie (age 15), who lost her mother when she was 1 year old and lived alone with her father, explained that he was caring. He gave her milk tea with sugar and bread or porridge for breakfast, and money to buy lunch or a snack to eat while at school. In addition, he always reminded her to take her medicines and checked in the morning and evening to confirm that she had done so. Samalie, who suffered from a debilitating skin rash, explained that her father encouraged her to take the medicines and assured her that the itching would stop if she took her medicines as prescribed. Daisy (age 17), who reported that her stepmother mistreated her, repeatedly mentioned that her father was a 'father and mother' to her. He was always available for her to confide in, encouraged her to be strong, comforted and reassured her that the cure for HIV would be found, encouraged her to take her medicine, gave her transport money to go collect medicine refills, and always attended to her when she fell sick.

Multiple caregivers

In the absence of a mother, or someone to provide care 'like a mother', children managed with caregiving they considered insufficient. In describing their situations, they told of neglect and abuse, but also of kin and non-kin who communicated some kind of concern. While caregiving was in some cases concentrated in one person, in other cases it was distributed among several people, including non-relatives who offered different kinds of assistance to the children.

Keturah, aged 12 years, who had lost both parents, lived with a paternal uncle, his wife and their five children. She called her uncle 'daddy' (*taata*); in Ugandan languages a father's brother is also referred to as father. Keturah, who looked younger than her age, complained that her uncle's wife denied her food, forced her to do a lot of housework, isolated her from the other children lest she infect them with HIV, made her sero-status public to the neighbours and never reminded her to take her medicines. Her 'daddy' was more caring, but he was often absent:

> I wake up at 5 am, mop the house, take a bath and go to school. The other children take tea. Mummy doesn't give me tea and daddy is never around; he has a second wife. I take the medicine at 7 am without taking tea. The medicine makes me feel uneasy when I take it without eating anything in the morning. I tell Daddy and he gives me money but sometimes he doesn't have money so I just take the medicine. There is nobody I talk to about the medicines except daddy when he is around and my friends at school. Daddy sometimes reminds me if I have forgotten to take the medicine.
>
> (Keturah, 12 years)

Keturah reported that her 'mummy' (paternal uncle's wife) and her children always made negative comments about her and she felt it would have been better if they had not been told that she was infected with HIV:

> It's my daddy who deserves to know about my illness because he is the one who gets my medicine for me and he is the one who cares to find out if I have taken the medicine or not…He buys me something to eat to have before taking the medicine, soap if it's finished, and sometimes he brings me malaria medicines. Sometimes when the children see that mummy is abusing me then they also start to abuse me [saying] that I have AIDS… Mummy tells her children that the disease can be contracted through blood so if they don't avoid me they will be infected too.
>
> (Keturah, 12 years)

In addition to the intermittent care and communication she enjoyed with her paternal uncle, Keturah depended on her three closest friends from school who lived in the neighbourhood. She explained that she told them about being infected and her abusive situation at home and they usually brought her sweet potatoes, mangoes and maize to eat at school and during the holidays. Even the neighbours knew that Keturah was infected with HIV, were aware of her abusive home situation and were supportive by giving her food.

Charity (14 years) also received care from several people in different places. These included the non-relative with whom she shared a house, a teacher in the primary school who provided her with porridge to take with her medicines, a counsellor at the treatment centre whom she described as being like a father and mother to her, a neighbour – her grandmother's friend – who frequently visited her and a maternal aunt who lived in Kampala but occasionally checked on her. Charity never got to know her parents because her mother died when she was still a baby and she never revealed who her father was. Charity was brought up by a maternal grandmother, who unfortunately passed away and left her in the care of a 'non-relative', who took over the grandmother's house and the plot of land. Charity considered this man her 'guardian' because they lived in the same house but she explained that the man and his family did not show her any care. She had to dig for them in order to receive help. Although she shared meals with them, they separated her cups and plates from theirs lest she infect them with AIDS.

Charity reported that she hardly talked to the man and his family about her health. The only communications between her and the 'household members' were reminders to take her evening medicines. She requested them to remind her to take her medicines, which they did. But she mentioned that when she told them that she was unwell or about the side-effects of the medicines, their responses were usually hurtful.

A female teacher at her primary school, on the other hand, cared for Charity, instructed her to bring her medicines to school and provided her with porridge and food to take with the morning medicines. The teacher also provided the emotional support Charity lacked from the people she lived with:

> There is a certain teacher I told my problems and she told me to come with the medicine and give it to her so that I can take it at 10 am – afterwards I take porridge. I tell her of the problems I get from taking medicines and she tells me what to do. When I tell her that such a type of medicine gives me problems so I need to go and see the doctor, she tells me it's the diet that might be the cause that I should change the diet.

Charity reported further that the teacher occasionally gave her transport to the treatment centre, which her aunt refunded whenever she came to visit her. The teacher also cautioned the children at school not to mistreat her. Charity mentioned that one time she missed school when she was sick and when she went the following day, the children told her that the teacher had admonished them to treat her well: to play and study with her, and not to stigmatize her because of her sickness. Charity said that the teacher also informed the deputy headteacher and a male teacher about her status. She explained that this was not ill-intentioned; it was to help her not to be stigmatized by children at school and to make teachers aware of the reason why she sometimes missed school.

Charity also received care from a lady in the neighbourhood whom she referred to as 'grandmother' (*jaaja*). She said that the lady gave her telephone number to the counsellors at the treatment centre and checked on her frequently and would inform her whenever she was needed at the treatment centre. She explained that the counsellors at the treatment centre called the lady for updates on Charity's well-being:

> She stays in this village and she is like a grandmother to me because she used to visit my grandmother when she was still alive and they could chat; that's how they became friends. Then she decided to help me because I am the granddaughter of her late friend. She tells me when the doctors are coming and at what time they are to come. She tells me if I am needed at the treatment centre.
>
> (Charity, 14 years)

However, the person Charity considered most like a relative was a male counsellor at the treatment centre. Charity spoke very passionately about how he cared for her like a biological parent. He travelled the long distance on a motorcycle to the remote village where she lived and took phone contacts of people from the village, who could be contacted for updates about her situation.

Charity's story gives an insight into the dynamics of caregiving involving non-relatives and shows that in the absence of mothers and other relatives, non-kin can assume caregiving responsibilities for children infected with HIV.

Minimal caregiving and communication

Children who had lost mothers or both parents were in some cases driven by unfavourable home situations to live on the streets. Ronald, aged 14 years, had lost both of his parents and had no known relatives. When his parents died he went to live with his paternal grandmother, who passed away. He then moved on to stay with another grandmother, who also passed away. He went and lived with a grandfather who also died, after which he became homeless and started roaming the village looking for food and a place to sleep. The caregiver with whom he was living during the study was a non-relative who provided him with a mat and a corridor in which to sleep. The 'caregiver' recounted that nobody was willing to take care of the boy because of the belief going round the village that the child had an omen trailing him ever since the death of his real parents: whoever takes up the boy dies shortly.

Zerinah (aged 15 years) had no fixed caregiver; she moved from one home to another and at one point was driven to live on the streets. She had no contact with her father; her mother had left him when he took another wife:

> I don't know where my father lives. I have never stayed with him. I last saw him at my mother's funeral when he was quarreling with my aunties about my guardianship. He said that I will be taken back to him when I am dead. Imagine, he is my real father but he doesn't even know about my illness!

Maternal orphans who felt deprived of care explained that they had no one to remind them to take the medicine or give them food to have with it or provide transport money to go to treatment centres. They missed having someone to attend to them when ill and to talk to about life challenges. These were mostly older children who had lived with their parents when they were still young and had memories of having been parented and cared for. Zerinah, who kept on moving from one home to another, many times wished her mother were alive to provide her with a stable home and care, and other times wanted to die to join her mother:

> I wish my mother were alive. If my mother were still alive she would have cared for me. When I got off the streets I was admitted in the hospital and I was there alone, I had no

> relative to attend to me. Whenever I get annoyed I start thinking about my late mother. I don't talk to anybody about my challenges, I only cry and sleep.

Zerinah came back to her mother's mother whenever the circumstances proved difficult in the other homes. However, she reported that she disliked her grandmother because she kept on telling people in the community that she was infected with HIV and as a result people gossiped about her status. Her grandmother was also very quarrelsome. Zerinah felt that her grandmother, aunts and sister did not care about her and she never discussed with them anything concerning her medicines and illness. She reported that the only people she confided in, and talked to about her medicine and illness, were the counsellors at the treatment centre.

Like Zerinah, Carol (aged 15 years) – a double orphan living in an institutional home – missed her mother. She complained of being abused by the home caretaker, who called her a 'walking dead body' in front of other people. Carol commented:

> A mother acts like a mother – she always keeps secrets. If my parents were still alive they wouldn't have mistreated me and I would have been able to confide in them.

Carol and Zerinah's reports of their experiences and expectations indicated that they were deprived of both emotional care (affection, comfort, attention when sick, guidance and a relative to confide in) and material care (food to take with medicines, transport money to the treatment centre and a stable home).

Discussion

Given the importance of family relations for communicating with children about their diagnosis and ARV medicine, this study addressed how these topics are embedded in other communication between children and their caregivers. The study found that communication by, and with, HIV-infected children means much more than transmitting information about HIV status and medication; it is part of the larger relationship of care.

Caregiving is multi-dimensional

While treatment centres assumed that the person with whom the child lived was the caregiver, the study found that this was not always the case. Caregivers, as defined by children, did not necessarily match their living arrangements, but despite this, from the point of view of health care providers there was some reinforcement of a 'caregiver' being a person one lives with, rather than to whom one is related.

Many previous studies have focused narrowly on caregiving as responsibility for a child's medication. Whereas two studies defined a primary caregiver as a person who lives with the child, participates in the child's daily care and is the most knowledgeable about the child's health and adherence (Bikaako-Kajura *et al.*, 2006; Haberer *et al.*, 2011), Fetzer *et al.* (2011) consider the primary caregiver as the adult who primarily serves to assist the child with taking ART. Biadgilign *et al.* (2011) define a primary caregiver as a person who persistently assumes responsibility for the housing, health or safety of the child, administers the child's medication daily and brings the child for clinic appointments. This contrasts with a broader description of a primary caregiver as the person the child would turn to if he/she needed food, clothes, personal items, affection, comfort or guidance (Howard *et al.*, 2006).

Children in this study shared this broad understanding of caregiving as including both emotional and material support. For them, caregiving was expressed verbally and explicitly in messages of concern, encouragement and support conveyed in reminders to take medicines, and confidential conversations about the challenges of being infected with HIV and taking daily medicines for life. Conversely, lack of sympathy was communicated in rough words and loose negative gossip about their HIV infection. They indicated that caregiving was implicit in acts of providing food and drinks to take with medicines, counting pills to confirm they had taken the medicines, attending to them when sick, especially when admitted in hospital, and escorting them to treatment centres or giving them transport money for clinic appointments. Their descriptions of caregiving fit with the notion of relatedness as the actual practices of interaction that generated a sense of closeness. A study on the experiences of grandparents fostering children orphaned by AIDS in South Africa found similar results, though there were variations in care provided by foster caregivers in urban and rural areas (Nyasani *et al.*, 2009). Whereas grandparents in rural areas were more concerned with meeting basic material needs (housing, food and education), those in urban areas were more inclined to providing emotional and psychological support.

The kinship obligation and ideal

Although there are differences between countries with regards to who within the family assumes the primary responsibility for the care of children (Gillespie *et al.*, 2005), there is general agreement that kinship obligation is the most important factor (Nyambedha *et al.*, 2003a; Madhavan, 2004; Whyte & Whyte, 2004; Howard *et al.*, 2006). Kinship and family networks become even more important during sickness (Xu *et al.*, 2010; Kyaddondo *et al.*, 2013). This study concurred in that most of the children lived with relatives. Children not living with their biological parents had been taken up during times of crisis when the children or their caregivers were very sick or after the death of the latter. The four children who eventually lived with non-relatives did so after the death of the relatives with whom they had been living.

Some researchers suggest that biological kinship in itself guarantees better care. Beegle *et al.* (2010) explain that the quality of caregiving may be dictated by the extent of biological connectedness such that more closely related caregivers provide higher quality care to children than more distantly or non-related caregivers. Madhavan (2004) notes that living with a caregiver who is not a parent may lead to worse outcomes for the children. A quantitative study on survival of HIV-infected children of HIV-infected mothers in Rakai District Uganda found that the effects of biological relatedness on child survival tended to be stronger for both HIV-negative and HIV-infected children of HIV-infected mothers. Lower biological relatedness of a child was associated with a statistically significant reduction in child survival (Bishai *et al.*, 2003).

The concept of relatedness requires us to go beyond biology and ask what qualities of caregiving might generate closeness. This study's findings show that biological motherhood is not invariably associated with attachment. Some mothers abandoned their children. Where the relationship was close, as the ideal claims it should be, it was because of what the mothers did in caring for their children. The children in this study gave specific examples of how their mothers ensured their welfare, or what they would have done had they still been living. Biology played a particular role in mother–child relations because they shared the virus. Some studies suggest that where a biological parent is HIV-infected, parental HIV illness may disrupt healthy parenting and adherence behaviours, placing children at increased risk of adverse outcomes (Mellins *et al.*, 2004; Williams *et al.*, 2006; Shah, 2007). Yet the present study's findings showed that where mothers shared the experience of HIV and ART with their children, the intimacy of the relationship was enhanced. For several children, their mothers' HIV infection was experienced as a basis for closeness. It facilitated communication and gave the children a feeling of not being alone with their illness and treatment.

Gender and practices of relatedness

There was a feminine predominance in everyday care. Consistent with other findings (Nyambedha *et al.*, 2003a; Bikaako-Kajura *et al.*, 2006; Karimli *et al.*, 2012), this study found that most of the caregivers of HIV-infected children were female. When both parents were living, it was the mother who was perceived as the most important caregiver. Even maternal orphans with a living father were often in the hands of a father's wife or father's mother, who fed them and were more often at home than their fathers. Because women had responsibility for feeding and caring for children, they were more associated with these aspects of care. They spent more time with children and tended to have more interaction with them. In many cases this generated a sense of relatedness, such that the attachments to female caregivers were stronger, even when responsible men were also present. Calasanti (2010) argues that gender relations generally go unchallenged because they are embedded in taken-for-granted routines of such social institutions as paid work and family life, and women also uphold gender divisions of labour, which designate them primarily responsible for such domestic labour as care work. For example, although Barnabbas' father and mother were both involved in paid work, he was closer to his mother and found her more caring and always available to provide both emotional and material support, whereas his father's inability to provide such care was attributed to his being busy. The literature suggests that caretaking is not work for which men hold themselves primarily responsible, in that they do not identify themselves as natural caregivers or nurturers (Ribeiro *et al.*, 2007; Calasanti, 2010).

However, it is important to look at the actual substance of caregiving. As the case of Keturah shows, a 'father' may be seen as more caring than a 'mother' figure if he communicates sympathetically and provides money. Furthermore, given that women are more expected to provide certain types of care work in these settings, when they do not meet these expectations (even if they are providing other help, e.g. sending money) their 'relatedness' is lowered, whereas if men provide only money, which is the expected gendered care work activity, they are viewed as 'more caring' and therefore related. In this study, where women were sending money, as in the case of Charity's maternal aunt (the only known living relative/kin), her relatedness was unrecognized, whereas the counsellor who travelled long distances to the remote village where Charity lived and endeavoured to provide both emotional and material support was described as the most caring and as a 'father and mother' to her.

The lens of relatedness requires us to consider which of the possible (female) relatives are closest to the children and why. Grandparents have a special position in the lives of children in many communities in Uganda, and there is often more informal intimacy with grandparents than with parents (Baarøy, 1999; Whyte & Whyte, 2004). Many of the children in this study indicated that they had a loving relationship with grandparents, especially with grandmothers, and they listed the actions that showed how their grandmothers cared. The preference for grandmothers may have a structural base as well, in that they do not have young children of their own whom they might favour over orphans (Karimli *et al.*, 2012). A study in Botswana found that when the new caregiver was the maternal grandmother, there was greater stability for the children who had lost their parents, while when an aunt or uncle took responsibility the children were more likely to suffer physical and psychological abuse (Daniel, 2011). Keturah's experiences of discrimination, verbal abuse and deprivation of affection and care concurs with existing evidence that maternal and double orphans may also be discriminated against by the uncle's wives, who may show preference for their own children (Madhavan, 2004). Consistent with other studies, although grandparents were reportedly affectionate and enacted love similar to biological mothers, they experienced challenges in providing quality care, especially sufficient feeding due to poverty (Rutakumwa *et al.*, 2015). In addition, there were instances where the relationship between the old carers and adolescent grandchildren was characterized by tension due to unmet mutual expectations, as was the case with Zerinah.

The literature on East Africa indicates that traditional mechanisms of caring for children, including orphans, were based on patrilineal kinship ties in most societies (Nyambedha *et al.*, 2003a; Karimli *et al.*, 2012). In Uganda, women moved to their husband's family at marriage and the children belonged to the paternal clan (Oleke *et al.*, 2005). Orphans were taken care of either by their remaining biological parent or some of the patrilineal kin (Nyambedha *et al.*, 2003a). However, evidence suggests that the AIDS epidemic has distorted the traditional mechanisms of caring for children; customary patrilineal care has been replaced by matrilateral and grandparental care, with little or no support from the paternal clan (Madhavan, 2004; Whyte & Whyte, 2004; Oleke *et al.*, 2005; Roby *et al.*, 2009; Beegle *et al.*, 2010), as was the case in this study. The reasons cited to explain this emphasize that the practice of care is more decisive than the ideology of biological descent from the father. Several studies report that terminally ill mothers are often cared for by their families and children remain in the same household after their mothers' death (Madhavan, 2004; Whyte & Whyte, 2004; Adato *et al.*, 2005). In their study of South African children in the shadow of AIDS, Adato *et al.* (2005) noted that many children – like Zerinah – do not maintain links with their fathers or fathers' relatives despite formal obligations, because 'fathers have often long ago disappeared'. They also observed that fathers' relatives and brothers' wives are not always welcoming of the orphaned children.

Caregiving is dynamic and dispersed

A cross-sectional survey identifies the child's situation at the moment of study, while a qualitative approach like that adopted here can show changes over time. There were children whose living and care arrangements were dynamic as they moved from one home to another. In the course of the study year, three children shifted residence when the grandmother with whom the child was living died. Most of the older children reported that they had lived with several different people. This was especially true for some of the maternal and double orphans who first lived with extended family members but later were forced to move from home to home. The extended family that often takes in such children has been described as a 'safety net with holes in it' leading to a high risk of multiple placements for orphans, as was the case with some of the maternal- and double-orphaned children in this study (Garcia *et al.*, 2008). Furthermore, studies on the living and caregiving arrangements of children affected by HIV/AIDS in sub-Saharan Africa have noted that the traditional extended family system that cared for orphans is so overwhelmed by the increased number of orphans that it is no longer adequately prepared to meet the orphans' needs, especially in terms of education, health, clothing and nutrition (Nyambedha *et al.*, 2003a, 2003b; Madhavan, 2004; Oleke *et al.*, 2005; Roby *et al.*, 2009; Beegle *et al.*, 2010; Daniel, 2011; Karimli *et al.*, 2012). Thus, some of those children, as indicated in this study, were taken in by orphanages or other institutions (Madhavan, 2004; Garcia *et al.*, 2008; Daniel, 2011) and others were forced to live on the streets (Garcia *et al.*, 2008). Such children, like Ronald whose known relatives were deceased, depended on minimal and intermittent caregiving from non-kin.

Following from the above, even though one person might be named as the caregiver by treatment centres, caregiving for some children was distributed among several people, including relatives and non-relatives, who offered different kinds of assistance to the children. Maternal orphans, in particular, might seek different kinds of care from different sources. While a father might provide some financial support, a child might have a counsellor or a teacher with whom he or she could talk about concerns and find reassurance, as did Charity, who spoke of her counsellor as 'a father and mother'. Madhavan points out that anecdotal evidence suggests non-kin play a role in the care of children orphaned by AIDS by providing financial and material support and suggests that it would be useful to identify non-kin caregivers for children orphaned by AIDS and why they take on this responsibility (Madhavan, 2004).

Relatedness and communication

An approach that looks at practices of relatedness is able to place the communication of information in the context of other interactions. It is not just a question of whether a message has been given, but of its significance in view of relationships. For example, two girls in this study told how their grandmothers had revealed their HIV status to others. Charity's grandmother told a teacher, who told others at the school. Charity remarked that passing on this information was not ill-intentioned; her grandmother also told a friend who continued to visit and help Charity after her grandmother died. In contrast, Zerinah reported that her maternal grandmother was not able to give her material help and that she did not care about her. She disliked her grandmother for telling others about her HIV infection, which became a topic of gossip. Both girls had the same biological relationship to their mother's mother. But the qualities of relatedness were so different that the communication of information was seen as positive in one case and negative in the other.

In explaining whom they talked to concerning their illness and medicines, children drew on the overall pattern of interaction they had with different individuals. Keturah's father's brother, whom she called 'daddy', was often absent, but he demonstrated care by collecting her medicine from the clinic, checking that she had taken it and buying her snacks when he had money. She only talked to him (and some friends at school) about her medicines because he showed care, while his wife and their children, with whom she spent more time, were abusive.

The examples of dispersed caregiving show that different kinds of relatedness are associated with different patterns of communication. Those children with a living mother, or someone who cared like a mother, tended to communicate with them about medicines and to some extent illness. But even those 'fortunate' ones did not always discuss their deepest fears with their 'mothers'. The children with multiple caregivers often reported that the people with whom they lived did not enact care in its different dimensions and therefore they found communication about medicines and illness problematic. If words were said about these topics, they were sometimes uttered in harsh or disparaging ways. Some children found others who gave aspects of care and with whom they could communicate more positively.

In conclusion, children's communication about their health and medicines was found to be embedded in more comprehensive practices of caregiving. Children's reports revealed the different ways caregivers communicated care to them, which were explicit or implicit, verbal or non-verbal; in these ways adults showed that they cared or not. The study findings revealed that children's communication about their health and medicines and the care they received was to a large extent shaped by the nature of their relatedness to their caregivers, the extent to which caregiving was dispersed among several people and who else in the household was infected with HIV and on medication. There is clear evidence that household and family constellations affect communication and caregiving for HIV-infected children positively and negatively. This study argues that issues such as disclosure and information about medicine should not be seen in isolation. Rather, they exist within broader relations of caregiving and communication.

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