

Factors underlying taking a child to HIV care: implications for reducing loss to follow-up among HIV-infected and -exposed children

Juddy Wachira, Susan E Middlestadt, Rachel Vreeman, Paula Braitstein

Abstract

Objective: With the aim of reducing pediatric loss to follow-up (LTFU) from HIV clinical care programs in sub-Saharan Africa, we sought to understand the personal and socio-cultural factors associated with the behavior of caregivers taking HIV-infected and -exposed children for care in western Kenya.

Methods: Between May and August, 2010, in-depth interviews were conducted with 26 purposively sampled caregivers caring for HIV-infected (7), HIV-exposed (17) and HIV-unknown status (2) children, documented as LTFU from an urban and rural HIV care clinic. All were women with a majority (77%) being biological parents. Interviews were audio-recorded, transcribed and content analyzed.

Results: Thematic content analysis of the women's perceptions revealed that their decision about routinely taking their children to HIV care involved multiple levels of factors including: (1) intrapersonal: transport costs, food availability, time constraints due to work commitment, disclosure of HIV status for both mother and child, perception that child is healthy and religious beliefs; (2) interpersonal: unsupportive male partner, stigma by the family and family conflicts; (3) community: cultural norms, changing community dynamics and perceived stigma; (4) health care system: clinic location, lack of patient-centered care, delays at the clinic and different appointment schedules (mother and child). Furthermore, the factors across these different levels interacted with each other in a complex way, illustrating the challenges women face in taking their children to HIV care.

Conclusion: The complexity and interconnectedness of the factors underlying retention of children in HIV care perceived by these women caregivers suggests that interventions to reduce pediatric LTFU need to be holistic and address multiple socio-ecological levels. Patient-centered care that integrates a family-centered approach to HIV pediatric care is recommended.

Keywords: HIV care, loss to follow-up in children, caregivers.

Résumé

Objectif : Dans l'objectif de réduire les perdus de vue pédiatriques dans les programmes de prise en charge clinique du VIH en Afrique subsaharienne, nous avons cherché à comprendre les facteurs personnels et socioculturels associés au comportement des aidants emmenant les enfants séropositifs et exposés au VIH à leurs sessions de traitement à l'Ouest du Kenya.

Méthodes : De mai à août 2010, des entretiens détaillés ont été menés auprès de 26 aidants sélectionnés à cette fin en charge d'enfants séropositifs (7), exposés au VIH (17) et de statut sérologique inconnu (2), documentés comme perdus de vue à partir d'un centre de traitement du VIH urbain et rural. Tous étaient des femmes, et une majorité d'entre elles (77 %) étaient les parents biologiques de ces enfants. Les entretiens ont été enregistrés sur cassette, retranscrits et leur contenu analysés.

Résultats : L'analyse thématique du contenu des perceptions des femmes a révélé que leurs décisions quant au fait d'emmenner leurs enfants en traitement pour le VIH impliquaient des facteurs à plusieurs niveaux, et notamment aux niveaux suivants : 1) intrapersonnel : les frais de transport, la disponibilité alimentaire, les contraintes de temps associées aux obligations professionnelles, la divulgation de la sérologie pour la mère comme pour l'enfant, la perception que l'enfant est en bonne santé, les croyances religieuses ; 2) interpersonnel : un partenaire masculin s'opposant à une telle décision, la stigmatisation par la famille, les conflits familiaux ; 3) communautaire : les normes culturelles, les dynamiques communautaires changeantes, la stigmatisation perçue ; 4) le système de santé : la localisation géographique du centre de soins, des horaires de rendez-vous différents (pour la mère et l'enfant). De plus, les facteurs de ces différents niveaux interagissaient entre eux de manière complexe, illustrant les défis auxquels les femmes se trouvent confrontées pour emmener leurs enfants recevoir un traitement contre le VIH.

Juddy Wachira has a Masters Degree in Public Health and is currently completing her PhD in Health Behavior at Indiana University, Bloomington, USA. She is also an associate instructor at Indiana University and a research assistant with The International Counseling, Advocacy, Research, and Education Indiana University (I-CARE) project. The I-CARE project aims at addressing mental health concerns associated with HIV-AIDS in sub-Saharan Africa. Prior to attending Indiana University, she worked as the prevention manager for the Academic Model Providing Access to Healthcare (AMPATH), a program that provides comprehensive care to HIV-infected individuals in the western region of Kenya.

Correspondence to: wachirajuddy@gmail.com

Conclusion : La complexité et l'interconnexion des facteurs sous-tendant la rétention des enfants suivant un traitement pour le VIH telles qu'elles sont perçues par ces femmes aidantes suggèrent que les interventions visant à réduire la perte de vue pédiatrique doivent être holistiques et intervenir à différents niveaux socio-écologiques. Une prise en charge centrée sur le patient, intégrant une approche à la prise en charge pédiatrique du VIH centrée sur la famille, est recommandée.

Introduction

In 2009, it was estimated that 370,000 (230,000–510,000) children were infected with HIV and 260,000 died of AIDS (Joint United Nations Programme on HIV/AIDS 2010). Kenya, among the sub-Saharan countries where HIV infection rates remain high, has over 150,000 infected children (Kenya Ministry of Health 2009). Considerable efforts to control the spread of HIV in the region have been made with an increasingly higher number of people receiving free combined antiretroviral therapy (cART) (Joint United Nations Programme on HIV/AIDS & World Health Organization 2009; World Health Organization, United Nations Children's Fund, UNAIDS 2009). As a result, mortality and morbidity rates among HIV-infected children have significantly reduced (Bolton-Moore, Mubiana-Mbewe, Cantrell, Chintu, Stringer, Chi, *et al.* 2007; Ellis & Molyneux 2007; Janssen, Ndirangu, Newell & Bland 2010; Kiboneka, Wangisi, Nabiryo, Tembe, Kusemererwa, Olupot-Olupot, *et al.* 2008; KIDS-ART-LINC Collaboration 2009; Nyandiko, Ayaya, Nabakwe, Tenge, Sidle, Yiannoutsos, *et al.* 2006; Puthanakit, Aurpibul, Oberdorfer, Akarathum, Kanjananit, Wannarit, *et al.* 2007; Wamalwa, Farquhar, Obimbo, Selig, Mbori-Ngacha, Richardson, *et al.* 2007).

Fundamental to promoting the health of both HIV-infected and -exposed children is adherence to treatment and care. Unfortunately, approximately 10% of children in the sub-Saharan region are identified as loss to follow-up (LTFU) within the first year of treatment (George, Noël, Bois, Cassagnol, Estavien, Rouzier Pde, *et al.* 2007; KIDS-ART-LINC Collaboration 2009) and even higher rates (19.2%) are reported during the second year (De Baets, Bulterys, Abrams, Kankassa & Pazvakavambwa 2007). These rates have been noted to be greater in younger children (1–5 years) than older ones (De Baets *et al.* 2007). In western Kenya, LTFU among children has been documented at 18.4 per 100 child-years (cy), with higher (20.1/100 cy) rates among HIV-exposed children compared with HIV-infected children (15.2 cy pre- and 14.1 cy post-cART initiation) (Braitstein, Katshcke, Shen, Sang, Nyandiko, Ochieng, *et al.* 2010). With no appropriate intervention, the adverse outcomes of inconsistent HIV treatment and care (Bangsberg, Perry, Charlebois, Clark, Roberston, Zolopa, *et al.* 2001) are expected.

Within this context, caregivers have the primary responsibility of ensuring that children are adherent to medication and maintain their clinic appointments. A number of studies have explored factors associated with LTFU in children (Bolton-Moore *et al.* 2007; De Baets *et al.* 2007; Ioannidis, Taha, Kumwenda, Broadhead, Mtimavalye, Miotti, *et al.* 1999). However, few studies have examined this from the perspective of the caregivers responsible for taking these highly vulnerable children to care (Vreeman, Nyandiko, Ayaya, Walumbe, Marrero & Inui 2009; Yeap, Hamilton, Charalambous, Dwadwa, Churchyard, Geissler, *et al.* 2010). Given the implications on pediatric LTFU for children's health and well-being, it is critical that we understand the factors

associated with taking HIV-infected and -exposed children to care, as perceived by the caregivers.

Findings from a previous prospective study in western Kenya that randomly sampled HIV-infected and -exposed children who became LTFU, noted varied reasons for these cases. They included HIV disclosure and discrimination, a preference for traditional medicine, faith healing and other poorly described explanations (Braitstein, Songok, Vreeman, Wools-Kaloustian, Koskei, Walusuna, *et al.* 2011). Building on this work, we sought to qualitatively (1) understand the personal and socio-cultural factors associated with caregivers not taking their HIV-infected and -exposed children to care, and (2) recommend effective strategies to improve clinic attendance of these highly vulnerable children. The findings are expected to present critical elements for developing effective strategies to address the problem.

Methodology

Study setting

AMPATH was initiated in 2001 as a joint partnership between Moi University School of Medicine, the Indiana University School of Medicine and the Moi Teaching and Referral Hospital (MTRH). Thereafter, the USAID–AMPATH Partnership began in 2004 when AMPATH received ongoing funding through USAID and the United States Presidential Emergency Plan for AIDS Relief. The initial goal of the program was to establish an HIV care system to serve the needs of both urban and rural patients as well as to assess the outcomes and barriers of ART. Details of the development of this program have been described elsewhere (Einterz, Kimaiyo, Mengech, Khwa-Otsyula, Esamai, Quigley, *et al.* 2007). Since its initiation, the program has enrolled more than 110,000 HIV-infected adults and children in 65 Ministry of Health facilities and numerous satellite clinics in western Kenya (data for satellite clinics are incorporated into their 'parent' clinic). All HIV- and tuberculosis-related care and treatment are provided free at initiation of care.

This study was undertaken at the MTRH–AMPATH and Burnt Forest AMPATH sites, which represent an urban and rural setting, respectively. MTRH–AMPATH is the largest urban AMPATH clinic representing a high ethnic and geographical diversity of HIV patients, located in Eldoret, Rift Valley Province. Burnt Forest AMPATH is a long-standing clinic, located approximately 40 km from Eldoret, in a sub-district hospital.

Study design

This was an exploratory qualitative study conducted between June and August 2010. The study framework was built upon the integration of the social ecological model (McLeroy, Bibeau, Steckler & Glanz 1988) which recognizes that behavior is influenced at multiple levels, including the intrapersonal, interpersonal, organizational, community and policy levels. The complexity of the interactions within these levels is critical in defining the

determinants of caregivers taking children to HIV care. Guided by the social ecological model, the role of the author was to recruit and conduct in-depth interviews with caregivers. Although the author was familiar with the culture of the community and the HIV care system, she was not known to the caregivers. This allowed for open discussions about the issues the caregivers faced in taking their children to HIV care. The author also was engaged in data analysis and report writing. All the co-authors were instrumental in reviewing the reports and manuscript.

Target population

The study targeted caregivers with HIV-infected and -exposed children documented as LTFU between September and October 2009 and whose last known clinic location was MTRH or Burnt Forest AMPATH clinics. LTFU was defined as being absent from clinic for >6 months if the child was HIV infected and on cART and >12 months for HIV-exposed children and those not on cART. HIV-exposed children are monitored for a period of 5 years and if found HIV negative, are discontinued from care. Caregivers of HIV-infected and -exposed children were both included in the study to explore if there were any differences in the socio-cultural factors associated with not taking their children to care.

Sampling

We targeted a sample of 31 caregivers for the interviews. Purposive sampling was used to select these study participants. The sample was obtained from an initial prospective study that aimed at determining the vital status and reasons for children becoming LTFU (Braitstein *et al.* 2011). From this primary study, a random sample of 97 LTFU cases of HIV-infected and HIV-exposed children from the MTRH and Burnt Forest AMPATH clinics was obtained. Follow-up visits were then made by trained community health workers to determine reasons why caregivers of these LTFU children had not returned their children to care. Due to unreliable contact information, relocations and stigma-related barriers, we were only able to locate 76 out of the 97 caregivers. From the 76 cases, we targeted those caregivers whose children were still alive and provided reasons why the children in question had not returned to clinic to included disclosure, fear of discrimination, belief that child was HIV negative, instructions from the doctor, use of traditional medicine, or faith healing. This provided a sample of 31 caregivers and health workers made return visits to these homes to request for their participation in the study. A total of 26 caregivers agreed to be interviewed, 2 had relocated and 3 were not willing to be interviewed.

Procedure

Before the commencement of the study, ethical approval was obtained from the MTRH Institutional Research and Ethics Committee as well as the Indiana University Institutional Review Board. A set of in-depth interview questions (Appendix 1) that explored caregivers' perspectives on intrapersonal, interpersonal, community and organizational factors associated with taking HIV-infected and -exposed children for their scheduled medical appointments were developed. In addition, basic socio-demographic and economic factors were determined. The questions were pretested on two caregivers attending the MTRH clinic. This ensured that they were well phrased, culturally sensitive

and captured the objectives of the study. Upon making necessary modifications, the interview guides were translated to Swahili.

Trained community health workers who had initiated contact with the targeted households introduced the principal investigator to the homes. Consent was obtained from all participants. The objectives of the study were clearly explained before the interviews commenced. An audio tape recorder was used to record the proceedings, which took approximately 1 h. The investigator also took note of any physical expressions during the interview process. While most of the interviews were held at the homes of the participants, interviews of four participants were conducted outside the home environment such as in a private care, in order to maintain confidentiality. All participants were provided with transport and lunch as an appreciation for their participation in the study.

Data analyses

The analysis was guided by grounded theory (Strauss & Corbin 1990). Recorded interviews were transcribed and translated into English. The data were then coded and themes related to reasons for caregivers not taking children for HIV care were identified. We sought to determine if there were any differences among caregivers of HIV-infected and -exposed children by comparing the themes from these two groups. Themes from different interviews were then pooled together and integrated into common themes. Concepts from these themes were generated and used to organize the presentation of the results. The final write-up consisted of summaries, interpretations and textual excerpts. To ensure the trustworthiness of data, the transcribed data were reviewed against the audio recordings. In addition, independent coding and identification of themes were conducted by two other investigators. Furthermore, the investigators jointly reviewed the coding process and emerging themes. All recordings and data obtained are safely stored in a secure environment. They will remain safely stored for 5 years before being properly disposed off.

Results

At the time of the study, community health workers found and visited 76 LTFU cases; 46 HIV-exposed children, 44 HIV positive and 7 with missing HIV status. Of the 26 interviews conducted, 9 were from Burnt Forest and 17 were from MTRH. Among them, seven had HIV-infected children, two had children with missing HIV status and the rest had HIV-exposed children.

All participants were female; mean age of 33 years. Half (50%) were married, 23% were single, 20% separated and 7% widowed. For all those who were married, their male partners assumed the role of head of household. In terms of education level, 65% had primary, 23% secondary, 7.7% none and 3.8% tertiary. Occupation varied from 38% casual laborers, 27% no occupation, 23% small-scale farming, 7.7% formal employment and 3.8% small-scale business.

Most of the caregivers ($N = 20$, 77%) were the biological parent to the children, three (11.5%) were aunts and three (11.5%) were grandmothers. The average number of children per

caregivers was 5 (range 1–10). Seven of the caregivers had between two and three children requiring HIV care.

Interestingly, there were no thematic differences identified between the caregivers of HIV-infected and -exposed children. Therefore, the most salient factors were categorized into intrapersonal, interpersonal, community and health care system levels. The intrapersonal level encompasses individual characteristics that influence behavior, such as knowledge, attitudes and beliefs. On the other hand, the interpersonal level involves the interrelationships between close individuals including family, friends and peers that provide social identity and support. The community level entails social networks and norms either formal or informal that define perceptions among community members. Finally, the health care system level involves organizational rules, regulation, policies and informal structures, which influences health outcomes and behaviors. These factors were shown to interrelate as presented in the findings below. Also provided is a structure (Figure 1) that suggests a holistic approach to understanding the challenges faced by the caregivers.

Intrapersonal level

All caregivers perceived themselves as having the confidence or self-efficacy to take their children to the clinic as required. Caregivers of HIV-exposed children viewed this as an opportunity for them to ascertain the true HIV status of their children.

Financial constraints

Financial constraints were expressed as a key barrier in all cases. Caregivers in most of the homes reported going for days without food. Meeting the family’s basic needs took precedence over the children’s clinic appointments. Even in homes headed by men, women seemed to bear most of the financial burden. They were forced to look for casual jobs to sustain their families’ needs. Some of them opted to sell the local alcoholic brew ‘changaa’ as a source of income. This also meant that they maintained a busy schedule and lacked the time to take their children to the clinic. In addition, transport costs varied from USD 0.25 to 7.44 depending on the location. Considering meager earnings from their casual jobs, most of them reported this as a major barrier.

A married caregiver reported:

‘I leave for the farm at 7.00 am and I come back home at around 5pm, and yet the clinic is open from 8am to 4pm. Therefore I don’t get time to go to the clinic. I want to go but I don’t have the time to take the children to the clinic ... I have to look for odd jobs, such as ploughing or washing clothes for people so that I can get some money for food and transport.’

Perceived health of child

With HIV care, caregivers generally noted that there was a great improvement in the health of their children. However, when faced



Fig. 1 Structure on the factors underlying taking a child to HIV care

with emotional and financial burdens, taking children to the clinic became secondary because these children were perceived to be healthy:

'When the mother realized the child was fine (healthy), she stopped attending clinic . . . She also stopped taking the child to clinic. She did not see the need.'

HIV disclosure

Disclosure of the HIV status of the child and/or the caregiver to family and community members presented multiple challenges. Most of those caregivers, who had disclosed, did so to the family members closest to them. They believed these persons (mainly spouses, sisters and mothers) would provide them with the necessary emotional and financial support. Themes identified around the reasons for non-disclosure included fear of stigmatization either at work or at home, loss of psychological and financial support after disclosure and HIV infection being a private affair.

Unfortunately, lack of disclosure resulted in various hurdles. Caregivers who had formal employment were unable to request regular time off to take their children to the clinic and school-going children missed their appointments during the exam period. Furthermore, those caregivers, who were not the biological parents of the children, were not always aware that the children left under their protection needed HIV care. Some of them discovered this during the visits made by the community health workers.

A caregiver taking care of an orphaned child infected with HIV reported:

'I realize that my sister used to go to the clinic but I did not know about it. I only came to know about it when the community health worker informed me that she used to go to Burnt Forest clinic for HIV treatment with her child . . . I also did not know since we didn't live in the same household.'

Interpersonal level

Family dynamics

Family dynamics that define the relationships between family members was also noted as critical. For families headed by men, their role was deemed as important in facilitating their children's clinic attendance. Unfortunately, most caregivers complained of their unsupportive male partners, most of whom had not sought HIV care. Some caregivers reported that they had not disclosed their HIV status to their partners due to fear of physical and emotional abuse. They therefore lacked the support needed to ensure consistency in maintaining their children's clinic appointments.

One caregiver narrated the following about her husband:

'At times he leaves me here with the children. He goes for 4 months or 3 months and comes once in a while. I have to struggle to get a packet of flour, and when I don't get anything we just stay without food. I look for work like washing clothes or cultivating land, so that I can get some food for the children to eat . . . He says that he is not infected, that every time he

gets tested he is HIV negative. He says I will infect him and wonders where I got the disease. Because of this he says I should fend for myself, survive on my own . . .'

In addition, conflicts involving partners and other immediate family members (parents and siblings) presented more barriers. These conflicts were either related or unrelated to the children or caregivers being HIV infected, forcing some to relocate in search of safety or a better life. The emotional, physical and financial strain caused by these events influenced their ability to take children to care. Lack of family support was also attributed to geographical distance from other family members.

One caregiver narrated:

'Sometimes we argue and fight to a point that I get stressed and lose appetite . . . They talk ill of me . . . I almost feel like giving up, or even poisoning both my sick children and I so that we die and leave behind the healthy children with my family . . . It would even be better if I stopped living at home.'

Another caregiver reported:

'I was discriminated by my parents! I was a burden! My mother, brothers and sisters did not want me at home. They felt I was a burden since I was HIV, did not even have a job and had children . . . So I was forced to leave home.'

Community level

Cultural norms

Norms define the way caregivers are perceived and assigned responsibilities. Culturally, women are given the task of taking care of all the children's needs including health. As mentioned earlier, the caregivers interviewed were all women, thus the responsibility of taking children to the clinic was entirely left to them. In only a few cases did they receive assistance from a sister or mother. In the event that these caregivers had more than one child under their care, the caregivers lacked any form of support during scheduled clinic days. Most of them could not bear taking the HIV-infected or -exposed child to care while the other children remained home unattended. This resulted in missed appointments.

Community dynamics

Systems and structures within communities were reported to have an insignificant role in supporting caregivers. Community dynamics were said to have changed with economic times, forcing each member to bear their own burden. HIV was therefore seen as a personal burden:

'Nowadays everyone is on their own because there is no money. It is not like back then when people assisted one another. People nowadays mind their own business and so do I. I guess I am on my own and do not seek help from my community.'

Furthermore, fear of being stigmatized by community members resulted in caregivers keeping their HIV status and those of their children a secret:

'When you tell people about your status, they will announce everywhere. I am from the village and not like in town where everyone minds their own business. In the village when people sit, all they do is talk about you.'

Health care system level

The availability of free HIV treatment by medical experts who continuously monitored the health of their children was reported as a positive factor to care. This also meant alleviated medical costs for a wide range of diseases managed at the HIV clinics. Caregivers of HIV-infected children also mentioned receiving professional medical advice as well as psychosocial support.

However, various components within the health care system were highlighted as contributing to the factors that deter caregivers from taking their children to care.

Distance to the clinic

A clinic appointment was reported as a whole day's affair and valuable time wasted. Most (77%) of the caregivers lived in rural areas, requiring them to walk between 30 min and 2 h to the main road before boarding a vehicle to the clinic. Some of them lived in areas outside the AMPATH clinic catchment area, which required them to travel for more than 300 km to the nearest clinic. Caregivers who had more than one HIV-infected or -exposed child faced greater challenges following the difficulty of carrying two to three children to the clinic without any help. In the event of a minor illness, most of them preferred taking their children to the nearest health facility while others opted to buy medicine off the counter.

A caregiver stated:

'It takes eheh! 5 hours ... I go on foot because there are no vehicles ... When I have to go to clinic I leave the house at 5am, with the child on my back; we arrive there at around 10am. In essence the problem is lack of food and transportation. I was relieved when the doctor told me to stop taking the child to clinic.'

Patient-centered care services

A considerable number of caregivers both of HIV-infected and -exposed children claimed that they stopped taking their children to the clinic following instructions from their doctors. We attempted to verify these claims with available medical records. All HIV-exposed children had documentation in their medical files that showed proof of their negative status. However, for HIV-infected children there was no documentation indicating that they were HIV-negative or should be discontinued from care. Their medical files still showed that they were HIV-positive and needed follow-up care. For these HIV-positive cases, we were left to assume that the caregivers may have misinterpreted the medical instructions given to them by their doctors. Generally, medical instructions were held highly and questions on the child's progress were rarely asked. It was not clear to them at what point HIV-exposed children are discontinued from the program. Hence, follow-up clinical visits were interpreted as check-up sessions where the child's growth was monitored.

A caregiver reported:

'I stopped taking my child for care when they told me that the child does not have it (HIV) ... I don't think I was told why. I was just told that the child doesn't have the disease, and was advised to stop breastfeeding ... You know, the doctor is the one who decides because he is the one who knows best.'

Another caregiver stated:

'When we came back the results were out and he didn't have the virus and the doctor told me there was no need of bringing the child back because he was tested three times and the child didn't have the virus ...'

Despite efforts to encourage caregivers to consistently bring their children to the clinic, health personnel were viewed as being unprofessional and lacking empathy. Fear of being reprimanded and unfairly treated resulted in further postponement of the scheduled clinic appointments. Some caregivers reported they had lost their children's clinic cards and feared notifying the health personnel, hence additional delay.

An HIV-infected caregiver who had been inconsistent with taking her child to the clinic reported:

'Some health personnel would tell me, "You don't see the importance of coming to hospital and that is why you are doing this (delaying)?" ... Others would say, "Or did you feel your child got healed so you decided to stay back? Did someone tell you that you are healed?" ... So such things offended me.'

Reports of other services such as food and money for transport being unfairly restricted to them were also mentioned. Food was seen as a major incentive to attend the clinic; therefore, cessation of such benefits meant that they no longer saw the reason to take the children to the clinic. Delays at the clinic with long queues during certain days of the month were also stated as a barrier. For patients transferring to other clinics within the program, a clear referral system was said to be lacking:

'We were transferred to Khunyangu clinic but we did not go ... When I called my initial clinic-MTRH they told me that I had to go to Khunyangu clinic and bring back my medical files to MTRH clinic ... they sent me away every time and insisted that I go to Khunyangu clinic for treatment and ask them to transfer the files back [to MTRH], in order to continue with treatment. ... so I stayed back for a while, since I had never been to Khunyangu and I didn't even know where it was.'

As previously highlighted, most of the caregivers were the biological parent (mother) to the children. Therefore, apart from taking their children to the clinic as scheduled, they also had their own clinic appointments to keep. Some caregivers had two to three HIV-infected or -exposed children who all had different clinic appointment dates. With the cost and time implications, these caregivers opted to take all the children including themselves on the day most convenient for them.

A caregiver taking care of two HIV-infected children reported:

'... the problem is when I have to take one child to the clinic today and take the other one the next day. I will then be given different appointment dates which make it challenging because of transport costs.'

Apart from the AMPATH program, there were other non-governmental organizations offering health care services in the communities. These organizations offered incentives such as food, clothing, school fees and de-worming medications alongside treatment. Caregivers choose to enroll their children in such programs regardless of the care provided in order to receive these benefits.

External factors

Religious beliefs, relocation and unexpected events were identified as other external factors. Families were sometimes forced to relocate and with the limited coverage of AMPATH services, caregivers were unable to continue taking their children to the clinics due to distance. In addition, illnesses of caregivers or deaths in the family were some of the unexpected events reported as presenting obstacles to care. In one household, faith leaders were called upon for prayers whenever the infected child or any other family member fell ill. Household members refrained from any form of treatment to obtain absolute healing. It was also noted that most caregivers referred to God as the reason why their children were not ill despite the fact that they had not taken them to the clinic for follow-up care.

A religious caregiver narrated:

'We stopped taking the child to the clinic when we started going to church... You know when a person is prayed for they get healed... they told us to stop taking the medicines. One cannot take medication and still go to church. The pastor told us to stop going for treatment and I just stopped taking the child to the clinic; all of us just stopped going.'

Discussions

Our findings revealed the presence of salient factors at the intrapersonal, interpersonal, community and health facility level that are critical for the retention of HIV-exposed and -infected children in care, consistent with previous studies (Vreeman *et al.* 2009; Yeap *et al.* 2010). The complexity of the interrelationship between the components embedded within various social levels makes it difficult to isolate the individual from their social network. Hence, the social ecological model (McLeroy *et al.* 1988) was found to be an ideal model that could be adopted to identify factors associated with caregivers taking their children to care in our environment. These factors were found to be similar across both HIV-exposed and -infected children; however, further research is needed to understand critical elements between the two groups following the different care and treatment regimens which might influence caregivers' perceptions and behaviors.

We noted that all the caregivers were women who unfortunately received minimal support from their male partners and family members. This was not surprising considering that African

communities place much of the child-rearing burden on women. Evidently, studies have shown that male involvement is essential in promoting HIV care for children at risk (Tonwe-Gold, Ekouevi, Viho, Amani-Bosse, Toure, Coffie, *et al.* 2009; Wachira, Otieno-Nyunya, Ballidawa, & Braitstein 2010). Therefore, the lack of male support as we noted presented financial and emotional obstacles to care for these children.

A study in Malawi noted that parents of infants LTFU were less educated and more likely to be in farming occupation (Ioannidis *et al.* 1999). We also noted that most of the caregivers had a primary level of education and were involved in casual labors. These factors seem to have an influence on the level of understanding and resources needed to maintain children's clinic appointments.

Interestingly, caregivers showed a clear understanding of the benefits of treatment for their HIV-exposed and -infected children. This concept was better articulated following the availability of free treatment that extends to a wide range of diseases. Sadly, caregivers interpreted improved health as an excuse for not taking children to the clinic. Treatment was mainly sought during grave illness, partly due to financial constraints. Unfortunately, this increases the susceptibility of these already highly vulnerable children to exacerbated morbidity and even death.

Poverty, lack of food, distance to the clinic and transport costs have been expressed as barriers to pediatric HIV care, consistent with the findings of others (Bikaako-Kajura, Luyirika, Purcell, Downing, Kaharuza, Mermin, *et al.* 2006; Vreeman *et al.* 2009; Yeap *et al.* 2010). Given that most caregiver had low-paying jobs and received minimal support, the financial burden outweighed their desire to take their children to the clinic. As would be expected, sacrificing health care for other basic necessities (Ramadhani, Thielman, Landman, Ndosi, Gao, Kirchherr, *et al.* 2007) was apparent. This also translated to a busy work schedule and lack of time. The provision of incentives such as food, clothing and school fees by other organizations within the community was therefore valued and preferred regardless of the quality of health care services provided.

Stigma and discrimination continue to pose a major threat to HIV prevention, care and treatment efforts (Bikaako-Kajura *et al.* 2006; Byakika-Tusiime, Crane, Oyugi, Ragland, Kawuma, Musoke, *et al.* 2009; Vreeman *et al.* 2009). Disclosure of HIV status presented challenges, as in the case of other studies (Bikaako-Kajura *et al.* 2006; Ramadhani *et al.* 2007). Worse still was when orphaned children were left under the care of caregivers who are unaware of their status and/or medical requirements. It has been shown that being an HIV-exposed or -infected orphan in itself presents greater risks of LTFU, morbidity and mortality (Braitstein *et al.* 2010; Nyandiko *et al.* 2006; Vreeman *et al.* 2009). Non-disclosure was mainly associated with the perceived lack of emotional, physical and financial support either at home, work or in the community. It was therefore not surprising that disclosure was limited to persons thought to provide any form of support.

Comparable to our findings, studies among HIV-infected adults revealed that domestic violence and relocation were also reasons

for drop-out rates (De Baets, Ramet, Msellati & Lepage 2008). Efforts to promote family-centered HIV care have been suggested in order to uphold pediatric adherence to care (Tonwe-Gold *et al.* 2009). It is important that family involvement and counseling are enhanced to counter the outcomes of these factors in promoting children's clinic attendance.

Although community systems have been shown to play a critical role in adherence to HIV care (De Baets *et al.* 2008; Vreeman *et al.* 2009), caregivers in our study did not appreciate this role. Community dynamics seem to have changed with the economic times and caregivers did not anticipate any community support. This raises the question of whether communities should still be considered as a support system in the current society. Even if stigma and discrimination are addressed, community systems may have been weakened by poverty. We also noted the influence of religious beliefs in sustaining the health of the children as perceived by the caregivers. Although we acknowledge the influence of spirituality in promoting health, it might have adverse effects on pediatric HIV care if not integrated with HIV treatment and care. An integrated approach to culture and spirituality in pediatric care (McEvoy 2003) is needed to provide insights on how to address these obstacles.

LTFU rates have been reported to vary among health facilities with the degree to which ART programs are decentralized (De Baets *et al.* 2008). Patient-centered health facilities are slowly being appreciated as key to promoting patient-doctor relationship as well as adherence to HIV care (Beach, Keruly & Moore 2006; Schneider, Kaplan, Greenfield, Wenjun & Wilson 2004). Our finding suggests that this approach should be incorporated into the pediatric HIV care system. The lack of a patient-centered approach resulted in clinic delays and may have contributed to the misinterpretation of the children's HIV status. The belief that providers are experts and rarely questioned made it difficult for caregivers to interact freely with their providers. For caregivers who were themselves patients and/or had more than one child needing care, the challenges of different appointment dates were tremendous. In such cases, a clear system of ensuring that members from one family have the same appointment date will reduce the financial burden incurred in form of transport costs. As was reported in LTFU cases among adults (De Baets *et al.* 2008), we also realized that having clear guidelines for the referral of patients is critical in ensuring that patients who relocate continue receiving the care they deserve.

Study limitations

One of the major limitations of this study is the generalizability of the findings to a wider population. The sampling procedure was purely non-probabilistic, hence the findings do not represent the diverse social-cultural differences present in Kenya. This limits the study findings to western Kenya because they cannot be generalized to the entire Kenyan population or other geographic locations in sub-Saharan Africa. Furthermore, the study population was homogenous with only women caregivers. The views presented therefore do not include those of male caregivers. However, given the cultural context of the study, women caregivers reflect the population that provides majority of child care within western Kenya.

In conclusion, our findings revealed that factors associated with caregivers taking their children for HIV care in the context of LTFU are nested within the intrapersonal, interpersonal, community and health care systems. The complex interrelationship between these components suggests a holistic approach to address the challenges faced by caregivers in taking their children for their HIV clinical appointments. Following our findings, we also recommend a patient-centered approach to HIV pediatric care. This will aid in identifying the various obstacles faced by caregivers at the intrapersonal and health care levels. This should be integrated with a family-centered approach to promote male involvement including other family members who are a strong support system. Although community support was not appreciated, continuous HIV campaigns are needed to address stigma and discrimination that present major barriers to care. The health care systems should aim at embracing the different cultural and religious beliefs in identifying effective strategies to support caregivers sustain adherence to care for their children. These efforts will go a long way in providing support systems required by caregivers to ensure that HIV-exposed and -infected children continue to receive the care they deserve.

Acknowledgements

The authors would like to thank all the clinicians in all the AMPATH clinics, especially the Clinical Officers, Medical Officers, pediatricians, nutritionists, outreach workers, and social workers, for their dedication in caring for patients. We would also like to thank the administrative and clerical staff for enabling the collection, management, interpretation, and publication of these data. We wish to acknowledge and extend our humble appreciation to the AMPATH Orphans and Vulnerable program and the CHWs working with them. They did an outstanding job in tracing and reconnecting the LTFU children with care. Their work is invaluable to the program as a whole. The authors are particularly grateful to the International epidemiological Databases to Evaluate AIDS (IeDEA)-East Africa Consortium for funding this study.

References

- Bangsberg, D.R., Perry, S., Charlebois, E.D., Clark, R.A., Roberston, M., Zolopa, A.R., *et al.* (2001). Non-adherence to highly active antiretroviral therapy predicts progression to AIDS. *AIDS*, 15(9), 1181–1183.
- Beach, M.C., Keruly, J. & Moore, M.D. (2006). Is the quality of the patient-provider relationship associated with better adherence and health outcomes for patients with HIV JGIM: *Journal of General Internal Medicine*, 21(6), 661–665.
- Bikaako-Kajura, W., Luyirika, E., Purcell, D.W., Downing, J., Kaharuza, F., Mermin, J., Malamba, S., *et al.* (2006). Disclosure of HIV status and adherence to daily drug regimens among HIV-infected children in Uganda. *AIDS and Behavior*, 10(0), 85–93.
- Bolton-Moore, C., Mubiana-Mbewe, M., Cantrell, R.A., Chintu, M., Stringer, E.M., Chi, B.H., *et al.* (2007). Clinical outcomes and cd4 cell response in children receiving antiretroviral therapy at primary health care facilities in Zambia. *JAMA*, 298(16), 1888–1899.
- Braitstein, P., Katshcke, A., Shen, C., Sang, E., Nyandiko, W., Ochieng, V.O., *et al.* (2010). Retention of HIV-infected and HIV-exposed children in a comprehensive HIV clinical care programme in western Kenya. *Tropical Medicine and International Health*, 15(7), 833–841.
- Braitstein, P., Songok, J., Vreeman, R., Wools-Kaloustian, K., Koskei, P., Walusuna, L., *et al.* (2011). 'Wamepotea' (They have become lost): Outcomes of HIV-positive and HIV-exposed children lost to follow-up from a large HIV treatment program in western Kenya. *Journal of Acquired Immune Deficiency Syndromes*, 57(3), e40–e46.
- Byakika-Tusiime, J., Crane, J., Oyugi, J.H., Ragland, K., Kawuma, A., Musoke, P., *et al.* (2009). Longitudinal antiretroviral adherence in HIV+ Ugandan parents and their children initiating HAART in the mtct-plus family treatment model: Role of depression in declining adherence over time. *AIDS and Behavior*, 13(0), 82–91.

- De Baets, A.J., Bulterys, M., Abrams, E.J., Kankassa, C. & Pazvakavambwa, I.E. (2007). Care and treatment of HIV-infected children in Africa: Issues and challenges at the district hospital level. *The Pediatric Infectious Disease Journal*, 26(2), 163–173.
- De Baets, A.J., Ramet, J., Msellati, P., & Lepage, P. (2008). The unique features of pediatric HIV-1 in sub-Saharan Africa. *Current HIV Research*, 6(4), 351–362.
- Einterz, R.M., Kimaiyo, S.K., Mengech, H.N., Khwa-Otsyula, B.O., Esamai, F., Quigley, F., et al. (2007). Responding to the HIV pandemic: The power of an academic medical partnership. *Academic Medicine*, 82(8), 812–818.
- Ellis, J. & Molyneux, E.M. (2007). Experience of anti-retroviral treatment for HIV-infected children in Malawi: The 1st 12 months. *Annals of Tropical Paediatrics: International Child Health*, 27, 261–267.
- George, E., Noël, F., Bois, G., Cassagnol, R., Estavien, L., Rouzier Pde, M., et al. (2007). Antiretroviral therapy for HIV-1-infected children in Haiti. *Journal of Infectious Diseases*, 195(10), 1411–1418.
- Ioannidis, J., Taha, T., Kumwenda, N., Broadhead, R., Mtimavalye, L., Miotti, P., et al. (1999). Predictors and impact of losses to follow-up in an HIV-1 perinatal transmission cohort in Malawi. *International Journal of Epidemiology*, 28(4), 769–775.
- Janssen, N., Ndirangu, J., Newell, M.L., & Bland, R.M. (2010). Successful paediatric HIV treatment in rural primary care in Africa. *Archives of Disease in Childhood*, 95(6), 414–421.
- Joint United Nations Programme on HIV/AIDS (UNAIDS) (2010). Global Report. UNAIDS Report on the Global AIDS Epidemic. http://www.unaids.org/documents/20101123_GlobalReport_em.pdf
- Joint United Nations Programme on HIV/AIDS (UNAIDS) & World Health Organization (WHO) (2009). AIDS Epidemic Update. http://data.unaids.org/pub/Report/2009/JC1700_Epi_Update_2009_en.pdf
- Kenya Ministry of Health (2009). Kenya AIDS Indicator Survey 2007 Nairobi, Kenya Ministry of Health.
- Kiboneka, A., Wangisi, J., Nabiryo, C., Tembe, J., Kusemererwa, S., Olupot-Olupot, P., et al. (2008). Clinical and immunological outcomes of a national paediatric cohort receiving combination antiretroviral therapy in Uganda. *AIDS*, 22(18), 2493–2499.
- KIDS-ART-LINC Collaboration (2009). Low risk of death, but substantial program attrition, in pediatric HIV treatment cohorts in sub-Saharan Africa. *Journal of Acquired Immune Deficiency Syndrome*, 49(5), 523–531.
- McEvoy, M. (2003). Culture and spirituality as an integrated concept in pediatric care. *The American Journal of Maternal/Child Nursing*, 28(1), 39–43.
- McLeroy, K.R., Bibeau, D., Steckler, A. & Glanz, K. (1988). An ecological perspective on health promotion programs. *Health Education Quarterly*, 15, 351–377.
- Nyandiko, W.M., Ayaya, S., Nabakwe, E., Tenge, C., Sidle, J.E., Yiannoutsos, C.T., et al. (2006). Outcomes of HIV infected orphaned and non-orphaned children on antiretroviral therapy in western Kenya. *Journal of Acquired Immune Deficiency Syndromes*, 43(4), 418–425.
- Putnanakit, T., Aupibul, L., Oberdorfer, P., Akarathum, N., Kanjananit, S., Wannarit, P., et al. (2007). Hospitalization and mortality among HIV-Infected children after receiving highly active antiretroviral therapy. *Clinical Infectious Diseases*, 44(4), 599–604.
- Ramadhani, H.O., Thielman, N.M., Landman, K.Z., Ndosi, E.M., Gao, F., Kirchherr, J.L., et al. (2007). Predictors of incomplete adherence, virologic failure, and antiviral drug resistance among HIV-infected adults receiving antiretroviral therapy in Tanzania. *Clinical Infectious Diseases*, 45(11), 1492–1498.
- Schneider, J., Kaplan, S.H., Greenfield, S., Wenjun, L. & Wilson, I.B. (2004). Better physician–patient relationships are associated with higher reported adherence to antiretroviral therapy in patients with HIV infection. *JGIM: Journal of General Internal Medicine*, 19(11), 1096–1107.
- Strauss, A., & Corbin, J. (1990). *Basics of qualitative research*. Newbury Park, CA, Sage.
- Tonwe-Gold, B., Ekouevi, D.K., Viho, I., Amani-Bosse, C., Toure, S., Coffie, P.A., et al. (2009). Implementing family-focused HIV care and treatment: The first 2 years' experience of the mother-to-child transmission -plus program in Abidjan, Côte d'Ivoire. *Tropical Medicine and International Health*, 14(2), 204–212.
- Vreeman, R.C., Nyandiko, W.M., Ayaya, S., Walumbe, E., Marrero, D. & Inui, T. (2009). Factors sustaining pediatric adherence to antiretroviral therapy in western Kenya. *Qualitative Health Research*, 19(12), 1716–1729.
- Wachira, J., Otieno-Nyunya, B., Ballidawa, J. & Braitstein, P. (2010). Assessment of knowledge, attitudes and practices of infant feeding in the context of HIV: A case study from western Kenya. *Journal of Social Aspects of HIV/AIDS*, 6(3), 120–131.
- Wamalwa, D.C., Farquhar, C., Obimbo, E.M., Selig, S., Mbori-Ngacha, D.A., Richardson, B.A., et al. (2007). Early response to highly active antiretroviral therapy in HIV-1-infected Kenyan children. *Journal of Acquired Immune Deficiency Syndrome*, 45(3), 311–317.
- World Health Organization, United Nations Children's Fund, UNAIDS (2009). *Towards Universal Access: Scaling up Priority HIV/AIDS Interventions in the Health Sector*. Progress Report 2009, Geneva, World Health Organization.
- Yeap, A.D., Hamilton, R., Charalambous, S., Dwadwa, T., Churchyard, G.J., Geissler, P.W., et al. (2010). Factors influencing uptake of HIV care and treatment among children in South Africa – a qualitative study of caregivers and clinic staff. *AIDS Care: Psychological and Socio-medical Aspects of HIV/AIDS*, 22(9), 1101–1107.

Appendix 1

Field data collection tool

FIELD DATA COLLECTION TOOL

In-depth interview guide for care givers

Introduction:

Thank you for agree to meet with me today. My name is.....and I work for AMPATH. AMPATH, as you probably know, is one of the leading HIV programs in this country, providing treatment and care to HIV/AIDS infected and HIV-exposed children and adults.

We are interested in understanding why so many of our patients become lost to follow-up (don't come back to the clinic for a long time). You have already been kind enough to talk to a community health worker and help us know how your child, or the child you are the caregiver of, is doing.

Your initial participation has indicated to us that many caregivers are facing problems that seems to be resulting in them not bringing their children for follow-up care.

It is with this in mind that we hope to understand the reasons behind this phenomenon by interviewing key individuals. We are requesting whether you would be willing to give an in-depth interview about this issue. Your experience and understanding will greatly help us to understand what the issues are, and how we can modify our programs to help you overcome them. Your opinions from this discussion will assist us to developing effective strategies to address this problem.

So that I can be certain to remember all that you tell me, I will be taking notes and recording our conversation. If you have no objection, I kindly require your verbal consent to begin this interview. Your names or any identifying information will not be recorded on any of these documents. Anything you tell us will not be traced back to you individually. Everything you tell us will be kept completely confidential. The only exception to this is if you tell us something that makes us worry that you or the child in your care are in immediate danger. In this case, we will discuss with you how to proceed, but may have to involve a social worker.

Do you understand that:

- This is a research study
- You are free to participate or not, as you choose
- Your participation will not cost you anything
- Everything you tell us will be kept completely confidential, and your names will not be recorded anywhere that could be associated with what you tell us today.

Are you willing to participate in this interview?

Serial No.....

Background Information

Clinic:.....

Name/ID:.....

Age:.....

Sex: Male Female

Marital status: Single
 Married
 Divorced
 Widowed

Level of Education: Primary level
 Secondary level
 Tertiary level
 None

Occupation: Formal employment
 Business
 Farmer
 No

Number of children.....

Age(s) of child/children.....

Number of children HIV infected.....

Age(s) of child/children HIV infected.....

Child/children on cART?.....

For how long have they been on treatment?.....

Relationship to the HIV child/children:
 Parent
 Guardian
 Sibling
 Relative
 Neighbor
 Other.....

For caregivers who are not the biological parents, how did you become responsible for the child?

HIV status of caregiver

- Positive.....on medication?.....
 Negative

Distance to the clinic

Interpersonal Level:

Who is the main decision maker in your household?

If someone in your household gets sick where would they first seek treatment?

Who gets to decide when and where medical treatment is sought?

Are you the only one responsible for taking the child/children to the clinic? If no who else is responsible for taking the child/children to the clinic?

In what ways does your family support you in taking the child/children to care?

In what ways does your family make it difficult for you?

For children above 6 years.....Is the child aware of his/her HIV status? If no why?

Have you disclosed the HIV status of the child/children to anyone else? If yes who? If no why?

At what age do you think the child/children will be responsible enough to seek medical attention on their own?

Intrapersonal Level:

How many times in a month do you take the child/children to the clinic?

What are the advantages of taking the child to the clinic for HIV care?

What are the disadvantages of taking the child to the clinic for HIV care?

Is there any need to take an HIV infected child who feels well to the clinic? Why?

If a child is not on medication is there need for them to visit the clinic? Why?

What is the longest time you have gone without taking the child to the clinic? What were the reasons behind this?

What makes it easy for caregivers to take their child for HIV care?

What makes it difficult for caregiver to take their child for HIV care?

Who in your supports you in taking the child for HIV care? Probe: at the family and community level

Who disapproves of you taking the child for HIV care? Probe: at the family and community level

Whose opinion do you value the most? Why?

Do you perceive yourself as having the confidence to take the child for HIV care? Probe:

- If no why?
- If yes.....Are there times when you have not felt confident taking the child/children to care? (If yes, under what circumstances?)

Community Level:

What does the community think about a child who is HIV infected?

Have you or the child been stigmatized by the community because of your HIV status? If yes, in what ways?

In what ways are caregivers stigmatized for taking their children to the clinic?

What mechanisms exist in the community to support caregivers with children who are infected with HIV? Probe:

- In what ways does the community make it easy for you?
- In what ways does the community make it difficult for you?

Organizational Level:

When was the last time you took your child/children to the clinic? Talk to me about your experience during that visit?

Tell me about an experience that made you uncomfortable?

Tell me about an experience that made you feel supported?

In what ways do the program assist caregivers keep their children's medical appointment?

In what way does the program present difficulties for caregiver in keeping their children's medical appointment?

Recommendation:

What would make it easier for caregivers to consistently take their children for HIV care?

Who would be critical in supporting caregivers to consistently take their children for HIV care? how?

What are some of the ways family members could support caregivers take children for HIV care consistently?

What are some of the ways community members could support caregivers take children for HIV care consistently?

What are some of the ways the AMPATH program could support caregivers take children for HIV care consistently?