



HHS Public Access

Author manuscript

J HIV AIDS Soc Serv. Author manuscript; available in PMC 2017 March 31.

Published in final edited form as:

J HIV AIDS Soc Serv. 2014 October 1; 13(4): 383–401. doi:10.1080/15381501.2012.754392.

A qualitative assessment of barriers to antiretroviral therapy adherence among adolescents in western Kenya

Catherine June Kunapareddy,

Indiana University School of Medicine, Department of Public Health, Indianapolis, IN, USA

Winstone Nyandiko,

Moi University School of Medicine, Department of Child Health and Pediatrics, Eldoret, Kenya, and USAID, Academic Model Providing Access to Healthcare (AMPATH), Eldoret, Kenya

Thomas Inui,

USAID, Academic Model Providing Access to Healthcare (AMPATH), Eldoret, Kenya, Indiana University School of Medicine, Department of Medicine, Indianapolis, IN, USA, and Regenstrief Institute, Inc., Indianapolis, IN, USA

Samwel Ayaya,

USAID, Academic Model Providing Access to Healthcare (AMPATH), Eldoret, Kenya and Moi University School of Medicine, Department of Child Health and Pediatrics, Eldoret, Kenya

David G. Marrero, and

Indiana University School of Medicine, Department of Medicine, Indianapolis, United States, and Indiana University School of Medicine, Diabetes Translational Research Center, Indianapolis, IN, USA

Rachel Vreeman

USAID, Academic Model Providing Access to Healthcare (AMPATH), Eldoret, Kenya, Regenstrief Institute, Inc., Indianapolis, IN, USA, and Indiana University School of Medicine, Children Health Services Research, Indianapolis, IN, USA

Abstract

Antiretroviral therapy (ART) requires nearly perfect adherence to be effective. This study aims to identify key factors identified by HIV-infected adolescents on ART as contributing to medication adherence in western Kenya. Using a qualitative study design, three adolescent focus groups discussions were conducted at an urban and rural clinic site in western Kenya. The study population included HIV-infected adolescents receiving ART through the USAID-AMPATH HIV care system. A trained facilitator conducted groups in Kiswahili using a semi-structured interview guide probing multiple aspects of experience of taking medicines. Transcribed focus group dialogues were analyzed using constant comparison, progressive coding, and triangulation. The adolescents described a context of negative societal beliefs about HIV, necessitating a lifestyle of secrecy and minimizing the information shared about HIV or ART. Assessing and addressing adolescents' fears and behaviors regarding medication secrecy and disclosure may enable more accurate monitoring of adherence and development of intervention strategies.

BACKGROUND

According to the World Health Organization 2008 Global Summary of AIDS, 33.4 million people worldwide are living with AIDS, with 2.1 million of those being children under the age of 15, and 1.8 million of these children live in sub-Saharan Africa (World Health Organization, 2009). Since the majority of the disease burden of HIV is within sub-Saharan Africa, where 280,000 children die each year from HIV, it is important assess what is needed to treat HIV in children in this region.

Combination antiretroviral therapy (ART) has proven to be effective in slowing the rate of progression from HIV to AIDS (J. E. Haberer et al., 2011; Martino et al., 2011). A fundamental challenge is sustaining the high level of ART adherence necessary to achieve long-term suppression of the viral load (Gibb et al., 2003; J. E. Haberer et al., 2011). Non-adherence can lead to a poor virological response and drug resistant strains, increasing HIV morbidity and mortality (Nyandiko et al., 2006). Moreover, access to second-line and third-line therapies for HIV is often limited, making it even more important to adhere to and preserve the first-line regimen (J. Haberer & Mellins, 2009; Nyandiko et al., 2006).

Factors impacting children's adherence to ART in sub-Saharan Africa, particularly the adherence of perinatally infected adolescents, are not yet well understood. A systematic review on pediatric ART adherence in resource-limited settings found children's ART adherence ranged from 49% to 100%, with 76% of articles reporting >75% adherence (AUTHOR, 2008). However, most of these settings have not provided treatment for very long. Studies from other pediatric diseases, such as pediatric cancer, suggest that adherence becomes increasingly challenging over time, especially as children approach adolescence (Davies, Whitsett, Bruce, & McCarthy, 2002). Research examining non-adherence to ART suggests that family dynamics, social factors, and treatment fatigue have all been related to adherence patterns (J. Haberer & Mellins, 2009; AUTHOR, 2008). Disclosure may play a role in adherence as children who do not know why they are taking medications may struggle with why they should comply with treatment or with unanswered questions about their condition (J. Haberer & Mellins, 2009). In a recent qualitative study, caregivers reported that drug characteristics such as the taste, palatability, and volume of drug(s) were a barrier to adherence, but their social situations and persistent fear of disclosure were also consistent barriers to adherence (Gibb et al., 2003). The cultural context of the family, neighborhood, tribe, or church can impact the experience of having a child on ART (AUTHOR., 2009). For example, one study found an association between changes in residence and ART non-adherence (J. E. Haberer et al., 2011). Orphans are also more likely to have ART non-adherence, potentially because of multiple differences in their cultural context (AUTHOR, 2008). For instance, orphaned children in places with limited social services often end up managing their own ART regimens, which may demand more responsibility than they are developmentally ready to handle (J. Haberer & Mellins, 2009). Differences in orphans' adherence to clinic visits compared to adherence to ART may reflect how orphans' caregivers prioritize the social services and support they receive as part of a clinic visit over the actual health of the child (AUTHOR, 2008).

Few studies of pediatric ART adherence in sub-Saharan Africa have included self-reported data from the child's perspective. Rich, self-reported data from older children and adolescents could be especially useful for understanding the experience of adherence for children in a particular cultural context. The perspective of adolescents might be particularly important since there is some evidence that children's age impacts their ART adherence, though studies showing mixed results (Carlucci et al., 2008; J. E. Haberer et al., 2011; Nyandiko et al., 2006; Orikiiriza et al., 2010). Adolescence can be a challenging time developmentally even when a child does not have a chronic disease. For children infected with HIV, even those who were highly adherent to ART at younger ages often report adherence problems during adolescence (Williams et al., 2006). The long-term importance of ART adherence may be lost to other short-term priorities for the adolescent, such as appearance, social/sexual relationships, and overall identity development (J. Haberer & Mellins, 2009). There is much to learn about the course of ART adherence over time for children in Africa as the first cohorts of perinatally infected children begin to enter adolescence.

Qualitative research can offer a beneficial starting point to guide the understanding of a complex health behavior, particularly within a given cultural framework and from the perspective of the participants. The main objective of this qualitative study was to identify the key factors contributing to pediatric ART adherence in western Kenya from the perspective of perinatally infected adolescents.

METHODS

Setting

This study was conducted in western Kenya within the USAID-Academic Model Providing Access to Healthcare partnership (AMPATH). AMPATH grew out of a partnership established in 1989 between Indiana University School of Medicine, Moi University School of Medicine, and Moi Teaching and Referral Hospital (MTRH) (Quigley, 2009). Since 2001, AMPATH has been a model HIV care system for resource-limited settings (Einterz et al., 2007; Quigley, 2009). The AMPATH clinical care system operates in Kenya, a country with a national HIV prevalence of 7.8%, where over 1.4 million persons live with HIV, including 150,000 children (*2007 Kenya AIDS Indicators Survey*, 2008). As of October 1, 2012, AMPATH has enrolled more than 140,000 patients in western Kenya, and currently follows more than 75,000 patients (including more than 24,500 children) at 25 urban and rural clinic locations and 30 satellites. AMPATH provides free ART to all patients qualifying for therapy, as well as comprehensive nutrition services, psychosocial support, and economic development training. The adolescent-focused portion of this study was conducted within two AMPATH clinics. One site was the urban referral center in Eldoret, which has been in operation since November 2001 on the grounds of MTRH. As of October 1, 2012, the MTRH clinic cares for a total of 27,611 patients. Of those patients, 5,672 are children 14 years of age or younger, and 1,037 children at MTRH are currently on ART. The other site was an AMPATH HIV clinic at a rural health center location in western Kenya, which cares for 249 children, of whom 140 are on ART.

Participants

A convenience sample of HIV-infected adolescents on ART was recruited from the two AMPATH pediatric HIV clinics described above. Participants were eligible if they were enrolled in the AMPATH HIV clinic at MTRH or the rural health center, if they were between the ages of 10 and 16 years, if they were HIV-infected with no evidence of horizontal transmission, and if they were currently on ART. The WHO definition of adolescents as children ages 10 and above was used to define the group of eligible children (World Health Organization, 2008). Adolescents as young as 14 years, but particularly those above 16 years of age are treated in the adult AMPATH clinics, and so they were not included in this sample as their care experience is likely different. Eligible subjects were identified by examination of the HIV clinics' registration data, contacted initially by the clinic, and then by study personnel who explained the purpose of the study and obtained informed consent from the parent or guardian and assent from the children or adolescents. Participants were not required to know their HIV status, but clinic personnel only approached eligible children who already knew they were HIV positive. Patients were excluded if there was any physical or mental incapacity leading to an inability to understand the study.

Study Design

Focus groups and individual interviews were used to elicit data from HIV-infected children taking ART in the AMPATH care system. Interviews were initially used in order to establish a more comprehensive understanding of the data and to assess the impact of the questions. Both techniques were used, following the theory that the group discussions allowed for amplification of the shared perspectives and themes, while the individual interviews potentially lessened biasing effects from social norms (Krueger, 1988; Morgan DL, 1998; Sankar, Golin, Simoni, Luborsky, & Pearson, 2006).

Three focus groups and three individual interviews were conducted using the same script of semi-structured interview questions in Kiswahili. Each of the focus groups consisted of six to eight individuals, with one girls' group and one boys' group at MTRH and one mixed gender group at an AMPATH rural health center HIV clinic. The focus groups at MTRH were stratified by sex because interactions between sexes in adolescents were thought to potentially complicate group dynamics (Krueger, 1988). The group at the rural health center clinic involved a group of adolescents who had consistently been meeting as a support group and who were considered comfortable interacting in a mixed group. The focus groups and interviews were conducted in Kiswahili, one of two national languages in Kenya (AUTHOR, 2010). The groups and interviews were conducted between March 1 and November 30, 2007. The focus groups at MTRH were held in a classroom at the AMPATH referral centre, and the focus group at the rural health clinic was held in a large room that is available for training and which is the usual location of the pediatric support group at that facility. The individual interviews were held in a private research office within each facility. A trained facilitator used identically prepared interview guides, containing open-ended questions to solicit responses during a two-hour session for focus groups and a one-hour session for individual interviews (AUTHOR., 2010). Each focus group was led by a Kenyan research assistant with experience facilitating focus groups in this setting and in conducting

interviews involving sensitive health behavior issues. The facilitator was fluent in English and Kiswahili, the primary languages needed to conduct the focus groups in this population. All data regarding the caregivers and their children were based on the participants' self-reports. All of the participants granted permission to digitally record the sessions to allow for later transcription. All of these digital recordings were transcribed and translated into English by a trained translator. The principal investigator (R.C.V.) was also present at the focus groups and took detailed field notes. Basic demographic information about the HIV-infected child, the family composition, the time and nature of diagnosis, and any associated medical diagnoses were also collected. The translation into English was done by a native Kiswahili speaker with official WHO certification in translation. Both the Kiswahili transcripts and the English translations were independently compared by three individuals: the certified translator, the coinvestigator who had conducted the original focus groups (E.G.W., who is a native Kiswahili speaker and fluent in English), and by an additional coinvestigator (W.M.N.) who is a native Kiswahili speaker and fluent in English. The analysis was carried out using the English versions of the transcripts by one of the members of the investigative team who was bilingual and had reviewed the translations (W.M.N.), by the principal investigator (R.C.V.) who has learned Kiswahili as a second language, but only worked with the English translations of the transcripts, and by an investigator who worked only in English (C.J.Z.).

The questions used in the focus groups and interviews were based upon review of the literature, input of local health care providers, and initial pretesting with a series of five, in-depth key informant interviews with adults that were conducted within subjects' homes (AUTHOR., 2010). Questions were modified for children after three pediatric interviews. Topics covered during the encounter included: cultural context of HIV treatment, medication handling, beliefs about medications, interactions around medicines, and barriers to adherence. The scripted interview guide is available upon request.

This study was approved by the Institutional Review Board of Indiana University in Indianapolis, Indiana and by the Institutional Research Ethics Committee of Moi University School of Medicine and Moi Teaching and Referral Hospital in Eldoret, Kenya.

Analysis

A system of manual, progressive coding of the transcripts was used to identify emerging central concepts. Using open-coding methodology, the transcripts were manually coded in an initial stage of constant comparative analyses, with two separate investigators (R.C.V. and C.J.Z.) working manually, line-by-line to analyze each transcribed page of informant data. Each investigator extracted themes independently and then collaborated to compare results. The two analysts processed the data several times before reaching a consensus on the emerging themes. Following development of the thematic structure, a local Kenyan investigator (W.M.N.) reviewed the coding and analysis for an insider perspective on the data interpretation. Axial coding, the process of relating categories to their subcategories and linking them together at the level of properties and dimensions, was used to organize themes into 'causal' relationships (Glaser B, 1967; Strauss A, 1990; AUTHOR, 2010). Analysts were able to form practical hypothesis and concepts from the data, which lead to the

development of a theoretical framework to describe key aspects in the experience of taking ART from a child's perspective. Selected quotations were used to illustrate themes (AUTHOR, 2010). Triangulation or verification was incorporated on several levels. First, we analyzed and compared transcript data from multiple focus groups. Second, independent reading, coding, comparison, and data visualization were performed by three investigators (R.C.V., C.J.Z., W.M.N.). Finally, we incorporated two sources of peer debriefing and peer checking of transcripts, coding strategies, and themes (T.S.I., D.G.M.). The peer debriefing and peer checking primarily refined the organizational structure and conceptual map created from the data, refining the organization of the causal relationships and confirming the prominent themes.

Results

Twenty-three adolescents participated in the focus groups. They ranged in age from 10 to 16 years (mean 13.2 years.) Eleven were female and 12 were male. All were on ART and knew their HIV status, but their time on ART ranged from one month to four years. Most lived their grandparents (30.4%) or with an aunt or uncle (21.7%), and only 2 had both biological parents alive. Among the 23 adolescents, the most prominent themes related to the experience of taking medication were secrecy and how secrecy and other barriers hindered their adherence to ART (see Table 1). They described common beliefs about HIV disease and its treatment, but their discussions rapidly focused around secrecy and other issues shaping their ability to adhere to ART.

Beliefs about HIV disease and its treatment

The children described being surrounded by many negative societal beliefs about HIV, its transmission and its treatment, most of which were not scientifically accurate.

Participants in this study reported hearing that HIV is a curse or that it is a disease that hides in the bones, and that the antiretroviral medicines are manufactured from the parts of dead people. Even among those who had heard statements supporting the efficacy of ART, this was not necessarily viewed positively. One child said that he heard HIV medicines are corrupt because they impede the ability to differentiate between sick and healthy people, stating, "You may see a girl and think she is okay. You don't know whether she is sick or she is okay so you may end up having sex with her and you get infected". The adolescents also reported hearing inaccurate, fearful claims about how HIV was transmitted. For instance, some participants had been told that you can acquire HIV by sitting beside someone with the virus:

"Some say that if you have the virus and then I come and sit beside you, you will be transmitting the virus to the other person's body. Then they get the disease so they would not want to sit next to you."

They also reported that traditional, complementary, or alternative medicines were often seen as a first-line of treatment for HIV or HIV-related symptoms. Both younger and older children described using herbs, fruits, and teas, both orally and topically, as well as more unusual recommendations such as drinking urine:

“I used those herbs and I have even drunk urine because there is someone who came and lied to us that drinking urine can heal HIV. So I just used to drink urine for 3 months.”

Using these alternative therapies was typically reported as practices that were tried before beginning ART, although some adolescents reported the continued use of alternative therapies while on ART.

Secrecy

Secrecy related to HIV status and HIV treatment was repeated throughout the data as a central theme, and was described as way of life for these adolescents. Nearly all of the participants in the focus groups described the importance of keeping their disease secret, which had implications for their ART adherence. HIV-infected children strive to maintain secrecy within their families, peer groups, neighborhoods, and school. They reported how their lives were shaped to ensure that as few people as possible know about their disease; to cautiously control information-sharing; and to take, store, and dispose of medications in secrecy.

Minimize the number of people who know

One aspect of keeping their HIV status a secret was only telling others about anything related to HIV care when it was absolutely necessary. Many of the participants reported that only a small number of immediate family members who were directly involved in their care, such as a parent, grandparent, or sibling, were aware of the child’s positive HIV status and use of medications. They often stated that no one at school or in their community knew about their disease, and not even all members of the immediate family might know about the HIV diagnosis. Sometimes the child’s school teacher will be included in this intimate group of people who know about their disease because they needed permission to attend doctor appointments when school is in session.

Beware of the risks of sharing information

Generally, positive HIV status is information guarded very closely by the adolescent and the caregiver. Some information-sharing may be done to gain more support in caring for the child or when necessary to maintain HIV treatment; however, participants reported an ongoing emphasis on minimizing information-sharing. Taking medication in front of other people was seen as a behavior that might convey information that would generate questions and accusations about HIV:

“If you use the ARVs where a visitor is, they will start asking you so many questions, and they want to know why you are using [the drugs]. Sometimes, if someone just sees the medicine, they will not want to ask, they will just know that there is a person in that family that uses those drugs. So it will spread and people will know even without being told.”

Not taking medication in front of other people was prioritized over the need to take medications on time or to take them every day; adolescents believed withholding information was more important than adherence.

Negative consequences to information-sharing were the primary reason participants felt that secrecy needed to be a major aspect of their lives and their behaviors related to HIV care. As demonstrated by the following excerpts, children were fearful that disclosing HIV status to others would lead to rejection, discrimination, and blame:

“It is not good for people to know because when some know, they go and spread it out and don’t want to stay with you.”

“You are not supposed to tell people that you are using those drugs because they will broadcast that you have HIV and are using those drugs and everyone will know. People will start looking down upon you [and] avoid you. You can’t even take water in someone’s house; they will not give [it to] you, and say that you are sick and will infect them.”

Covert storage of medications

Hiding medication from public view was another key component of keeping HIV status secret, which also had implications for medication adherence. In conjunction with viewing HIV as a stigmatized disease, the adolescents reported that they and their families feared that neighbors, extended family members, or other people in the community might recognize their medicines as a sign of their HIV status unless they were concealed carefully. If the child’s medicine was found or seen, they felt that their HIV status could be exposed to their peers or to the entire community, which was anticipated to result in the negative consequences.

To avoid having the medications seen, respondents reported taking care to keep their medicine in a safe place in the house. While many of the participants lived in very simple, shared, one-room homes, medications were kept in whatever the most secure and hidden place in the home might be. Some common hiding locations included the “cupboard”, “bedroom”, “wardrobe”, and a “secure box.” One child expressed the importance of keeping his medication hidden for fear of recognition:

“Because most of our family people are doctors, for example my aunt. Sometimes she can come [over] and maybe she knows the medicines so I don’t want her to know. That’s why I lock and put the key where no one can reach.”

Behaviors for keeping their medicines secret even extended to covertly destroying the empty medicine bottles:

“Like the empty medicine bottles, we pile them in a big polythene bag. Then my mother goes to burn them later on when there are no people around. During the holidays, she burns them in the compost pit.”

In summary, the need for secrecy plays an important role in the life of an HIV-infected adolescent on ART in western Kenya. Because of their fear of disclosure and subsequent stigmatization, children on ART and their families limit who is told about their HIV infection and how much information they share with others, while taking precautions not to take medicines in front of others or to have their medicines discovered by other.

Adherence to Medication

This qualitative study revealed several factors shaping the context in which adolescents maintain ART in western Kenya. In addition to the dominant concerns about secrecy, which shaped many of their experiences related to their ART, participants described how adherence could be impacted by their responsibility for taking medicines, their experience with and perceptions of barriers to adherence, and their hesitancy in communicating about non-adherence with caregivers and healthcare providers.

Responsibility for medications

Many of the adolescents indicated that they have no one who helps them to remember or to take their medicines. Those receiving help commonly specified that it was from a parent, grandparent or sibling. In many cases, the caregiver may be “reminding” the child to take the medicine, especially “when [the child] comes home late from school” or around the time a dose would be expected. However, the adolescents acknowledge personal responsibility for actually taking the medicine: “Maybe [have help with] reminding, but taking, I do on my own.”

They use various methods to remember to take their medication, often employing a clock, phone alarm, or a watch. Others discussed that knowledge of their disease status has “programmed [their mind] to remember,” even suggesting that there is an internal “clock that is always set” that reminds them.

The adolescents frequently suggested that disclosure had a strong impact on adherence. Learning of one’s own HIV status was often described as an important factor in assuming responsibility for their medicines and in subsequently improving their own adherence to ART. As two adolescents described:

“You remember the day you were shocked when they told you that you have this dangerous disease, and you know that you have to take the medicine.”

“I remember when I became shocked when they tell me that I have this dangerous disease. Then something comes to your mind, you have to take your drugs or you will die.”

Barriers to adherence

The children in this study acknowledged numerous barriers to adherence. Some commonly reported issues included “forgetting,” “not feeling sick,” “delaying taking [medicine] in front of others,” and “oversleeping.” Delays or missed doses related to not having the medicines with them or not planning for absences were also frequently reported, as depicted by the following excerpts:

“You have gone on a journey, and you are sure you are coming home that day, so there is no need of carrying the drugs. So when you reach there, something happens to the vehicle and you can’t travel that day or you come back very late. Such things can make you miss the drugs for 2 days or more.”

“I may delay at school due to rain or meeting, and I reach home late. I can’t carry the medicine to school to take at six because I will be known”.

“If I go on a journey and it gets late, then I delay taking the meds.”

These quotes also reinforce how the adolescents consistently strive to maintain secrecy by not taking their medicines along on trips or to school. Their efforts to maintain secrecy could also impair adherence because of their reluctance to take medicines in front of other people:

“We are many in the house and it is only the parents who know [that I have HIV], so if they are not there and the others see me removing those drugs, they will be anxious to know what they are for and why I am taking them. So it forces me to delay taking the drugs if they are around. At times, I even forget and the time for taking the drugs passes. I swallow [the drugs] late.”

The participants also described being overwhelmed by the requirements of their treatment regimen. Fatigue with taking medications became a barrier to adherence as they grew tired with the duration of their treatment and the number of medicines required:

“Maybe if you have taken for a long time, and you are not getting well, you give up and get tired of taking the drugs.”

“Others see the medicine as being many, so they may throw it away.”

They described several additional issues associated with the pill burden, noting that the pills can be “too big in size so they get stuck in the throat” or “syrups may be bitter and one may vomit.” One child stated that there are simply “too many” pills that “you opt not to take them all” and only “take the ones for the disease you are suffering from at the time and leave the normal ones.” Even measuring out the medication was noted as a problem at times, particularly for the liquid formulations where the spoon may “tilt a bit and [it] spills.”

Interpersonal conflicts were presented as another barrier to the adolescents’ adherence to ART. Participants described how their behavior regarding their medications reflected their feelings about their interpersonal relationships. Taking or not taking their medications could be used as a form of rebellion with their caregivers:

“You forget to take the drugs in the morning and in the evening you delay a bit. Then the guardian quarrels you, abuses you, and forces you to take them. So you get angry and say I am not even taking them. Let them stay and the day ends like so.”

Adherence and behaviors around the medications were also used as a mechanism for these older children to express their emotions, particularly related to their family situations and their illness status. Participants reported deciding not to take their medication because they felt like they were not getting support from their family or as a way to externalize their internal emotional state:

“My aunt tells me to ‘go away -- your mother died of it and now you are bringing it to me; you are just disturbing me, you better go to another place.’ I felt like she is now being harsh to me because of that disease. Okay, let me die and the medicine

go to hell because I felt it was like nothing. It was now worthless for me to take the medicine.”

While some participants described not taking medications as a response to harsh treatment, others reported receiving severe punishments because they had not been adherent to their ART. Some children admitted to being “beaten very badly” and “treated harshly” as punishment for delaying or forgetting to take medication.

Hesitancy in reporting non-adherence

Although the adolescents freely described challenges with ART adherence in the setting of the focus groups, they also expressed not feeling comfortable communicating these issues to their healthcare providers in the course of their routine clinical care. Adolescents will often minimize the extent of their non-adherence when communicating with clinic personnel:

“I may have missed for one week so I will just tell them I’ve missed for 3 days.” They attributed this hesitancy in reporting non-adherence to discomfort or unfamiliarity with the medical staff, as well as to a fear of abuse by the caregiver if their non-adherence was discovered:

“I fear. When [clinicians] are new and I don’t know them, I fear to tell them.”

“When I come with my guardian and we see the doctor together, you fear telling the doctor because the guardian may abuse you or do a terrible thing.”

Despite their reluctance to communicate adherence problems, the participants in this study were under the impression that the doctors “can just tell” when a child is lying and would be able to recognize signs of illness and non-adherence, such as “rashes or CD4 count,” when they are not adhering. One adolescent suggested that the doctors need to be more alert to the child’s mannerisms:

“When you are asking them, you will see their reactions, either worried, fidgeting, thinking of what to say. They are asking themselves can I say the truth or not.”

DISCUSSION

HIV-infected adolescents on ART in western Kenya describe many layers of secrecy related to their disease and how this secrecy and other challenges impact their adherence to ART. Secrecy, stealth, and covert behaviors have become a way of life for them, as they believe that they must keep their disease status hidden. Adolescents fear that they will be discriminated against or abandoned by family and peers if their HIV status is found out. In efforts to avoid the stigmatization associated with HIV, adolescents only communicate their status to a minimal number of people, largely on a need-to-know basis.

This emphasis on secrecy pervades the adolescents’ behaviors related to the HIV therapy. Medications are stored in very guarded locations, preventing household members and visitors from easily finding them. These older children are very conscientious about only taking their medications when others are not around to observe them. They take deliberate actions to reduce the possibility of information-sharing -- not carrying medicines with them, not taking the medicines in front of other people, and handling medication procurement,

storage, dosing, and disposal with great care. Consequently, as reported by the adolescents, the actions to reduce information-sharing, often cause delayed or missed doses. Other barriers to adherence include the pill burden (quantity, size, taste, side effects), forgetting, medication fatigue, and lack of planning to bring medication on journeys away from home. Behavior around the medicines was also embedded within their interpersonal relationships. The adolescents reported refusing to take medicines in an attempt to punish their caregivers or using their adherence as leverage in conflicts or as a reflection of their emotional state. Abandoning the medicines was recognized as an action reflecting their own feelings of abandonment. Despite the many challenges to medication adherence freely described in the focus groups, these adolescents were hesitant to provide accurate reports of missed doses in clinical settings, citing the redundancy of lectures on adherence, unfamiliarity with their medical providers, and fear of harsh repercussions from caregivers.

As cited by other studies, keeping HIV status secret can generate substantial barriers to adherence, including stress and inadequate support (Marhefka, Tepper, Brown, & Farley, 2006; Mellins, Brackis-Cott, Dolezal, & Abrams, 2004; Polisset, Ametonou, Arrive, Aho, & Perez, 2009). Adolescents carry a great burden of stress through their worry and their considerable measures to ensure their secret is safe. Their support network may be reduced by only relying on themselves and their caregiver. In contrast, disclosure of the child's HIV status to family and the community might help reduce stress and mobilize support for adherence (J. Haberer & Mellins, 2009; AUTHOR, 2010). For example, some studies suggest that disclosure to school nurses could be beneficial in maintaining adherence, especially when dosing must occur during school hours (J. Haberer & Mellins, 2009). Although disclosure to others has been associated with good adherence in settings like Uganda there is always the possibility of stigma and discrimination, which leads to reluctance in seeking support from others (Brouwer, Lok, Wolffers, & Sebagalls, 2000; J. Haberer & Mellins, 2009). Informing children of their own HIV status has been shown to improve adherence in several studies (J. Haberer & Mellins, 2009; AUTHOR, 2010; AUTHOR, 2008; Wiener, Mellins, Marhefka, & Battles, 2007). However, disclosure of HIV status to a child can be a complex process for families, as they fear not only the stigma associated with the diagnosis, as well as the potential for emotional distress for the child or for parental guilt about mother-to-child transmission (Wiener et al., 2007). These findings from western Kenya suggest that guiding families through the process of disclosure to children and then engaging thoughtfully in disclosure to even one or two other people may enhance their psychosocial support, possibly sustaining and improving adherence.

As demonstrated in this study, one major aspect of protecting information-sharing involves delaying doses when other people might be around. Consistent with previous findings in Kenya, pediatric adherence is very much shaped by the people around the child and the family, by the information shared with these people, and by their responses to that information (AUTHOR., 2009). While these findings may be particularly relevant to resource-limited settings, a study involving caregivers of HIV-infected children throughout Europe reported similar reasons for why the child missed doses, including "visiting relatives over the weekend," "visitors in the house," and "because he is visiting or out with friends" (Gibb et al., 2003). While disclosure to others carries serious risks of stigma or discrimination for HIV-infected families, delaying or missing doses could result in

detrimental consequences to their health, leading to viral resistance and treatment failure. In these instances, examining the deep emphasis on secrecy and considering selective disclosure to others may improve adherence by enabling children and adolescents to find ways to take their medicines even when other people might be around. Efforts to combat the strong HIV stigma in this culture may be another important intervention to enhance and support pediatric ART adherence. Providing communities with accurate information on how the disease is acquired and transmitted may decrease stigma and debunk currently held misperceptions about HIV.

Many of the participants in this study reported taking sole responsibility over their medication regimen. Families may not understand all the challenges associated with long-term adherence and inaccurately assess the child's capacity for this responsibility (Gibb et al., 2003). Varying levels of maturity or developmental delays could inhibit the child's ability to bear the responsibility alone and adherence could suffer (Gibb et al., 2003). Increased support from the family, and shared responsibility can have a positive effect on adherence (Mellins et al., 2004; Naar-King et al., 2009). Assessing the extent to which families offer adherence support to older children, even as the adolescents make developmentally appropriate gains in their autonomy for their medical treatment, may be important to understanding their adherence challenges.

There are several limitations present in this study. Convenience sampling from two clinics in western Kenya and a small sample size may limit the generalizability of the data to other populations and geographical regions. Nonetheless, this method was chosen to collect rich contextual data to better direct further research. Moreover, the sample size is not atypical for a qualitative study, and good thematic saturation was found. In addition, the findings of these focus groups were very consistent when compared with a much larger number of interviews and focus groups done with parents and caregivers from the same setting, offering further validation for how these factors impact pediatric ART adherence within western Kenya. Another limitation is that, while the focus group methodology invites an open group discussion, it is difficult to induce a response from every participant on each topic. This could bias the results if only certain participants engaged in the conversation. Nonetheless, the study team attempted to create an open atmosphere within the groups, where adolescents were all invited to share. In both the groups and the individual interviews, the participants did not hesitate to describe sensitive topics such as non-adherence and interpersonal conflicts. In fact, the group discussions contained even more of this information. Although there are limitations to this study, the data provide a broad prospective of lived experiences from adolescents in a resource-limited setting, which may be more representative of the experience in similar settings in sub-Saharan Africa than studies done in resource-rich areas.

This qualitative study provides insight into understanding HIV-infected adolescents' experience of taking medicine in western Kenya. The study participants emphasized the importance of secrecy to managing life with HIV and commonly experienced barriers to adherence. The data presented in this study can educate and alert practitioners about problematic issues that HIV-infected children and adolescents are facing, but may not be comfortable admitting, and to foster open discussion of such issues during clinic visits. Combating stigma and lessening the need for secrecy may be important interventions to

maintain pediatric ART over the long-term. Future studies could use these data as a foundation to explore interventions that may reduce the barriers to pediatric ART adherence in resource-limited settings and promote sustained adherence.

References

- 2007 Kenya AIDS Indicator Survey. Nairobi, Kenya: Kenya Ministry of Health; 2008.
- Brouwer CN, Lok CL, Wolffers I, Sebagalls S. Psychosocial and economic aspects of HIV/AIDS and counselling of caretakers of HIV-infected children in Uganda. *AIDS Care*. 2000; 12(5):535–540. [PubMed: 11218540]
- Carlucci JG, Kamanga A, Sheneberger R, Shepherd BE, Jenkins CA, Spurrier J, et al. Predictors of adherence to antiretroviral therapy in rural Zambia. *J Acquir Immune Defic Syndr*. 2008; 47(5): 615–622. [PubMed: 18209678]
- Davies B, Whitsett SF, Bruce A, McCarthy P. A typology of fatigue in children with cancer. *J Pediatr Oncol Nurs*. 2002; 19(1):12–21. [PubMed: 11813137]
- Einterz RM, Kimaiyo S, Mengech HNK, Khwa-Otsyula BO, Esamai F, Quigley F, et al. Responding to the HIV pandemic: The power of an academic medical partnership. *Academic Medicine*. 2007; 82(8):812–818. [PubMed: 17762264]
- Gibb DM, Goodall RL, Giacomet V, McGee L, Compagnucci A, Lyall H, et al. Adherence to prescribed antiretroviral therapy in human immunodeficiency virus-infected children in the PENTA 5 trial. *Pediatric Infectious Disease Journal*. 2003; 22(1):56–62. [PubMed: 12544410]
- Glaser, BSA. *Grounded Theory Procedures and Techniques*. New York: Aldine Publishing Company; 1967.
- Haberer J, Mellins C. Pediatric adherence to HIV antiretroviral therapy. *Curr HIV/AIDS Rep*. 2009; 6(4):194–200. [PubMed: 19849962]
- Haberer JE, Cook A, Walker AS, Ngambi M, Ferrier A, Mulenga V, et al. Excellent Adherence to Antiretrovirals in HIV plus Zambian Children Is Compromised by Disrupted Routine, HIV Nondisclosure, and Paradoxical Income Effects. *PLoS One*. 2011; 6(4)
- Krueger, R. *Focus Groups: A Practical guide for Applied Research*. Newbury Park, CA: Sage Publications; 1988.
- Marhefka SL, Tepper VJ, Brown JL, Farley JJ. Caregiver psychosocial characteristics and children's adherence to antiretroviral therapy. *AIDS Patient Care and STDs*. 2006; 20(6):429–437. [PubMed: 16789856]
- Martino R, Kerguelen A, Valcarcel D, Sureda A, Fachini L, Pinana JL, et al. Reduction of infection-related mortality after allogeneic PBSCT from HLA-identical siblings: longitudinal analysis from 1994 to 2008 at a single institution. *Bone Marrow Transplantation*. 2011; 46(5):690–701. [PubMed: 20818448]
- Mellins CA, Brackis-Cott E, Dolezal C, Abrams EJ. The role of psychosocial and family factors in adherence to antiretroviral treatment in human immunodeficiency virus-infected children. *Pediatric Infectious Disease Journal*. 2004; 23(11):1035–1041. [PubMed: 15545859]
- Morgan, DL., KR. *The Focus Group Kit*. Thousand Oaks, CA: Sage Publications; 1998.
- Naar-King S, Montepiedra G, Nichols S, Farley J, Garvie PA, Kammerer B, et al. Allocation of family responsibility for illness management in pediatric HIV. *Journal of Pediatric Psychology*. 2009; 34(2):187–194. [PubMed: 18586756]
- Nyandiko WM, Ayaya S, Nabakwe E, Tenge C, Sidle JE, Yiannoutsos CT, et al. Outcomes of HIV-infected orphaned and non-orphaned children on antiretroviral therapy in western Kenya. *J Acquir Immune Defic Syndr*. 2006; 43(4):418–425. [PubMed: 17099313]
- Orikiiriza J, Bakeera-Kitaka S, Musiime V, Mworozzi EA, Mugenyi P, Boulware DR. The clinical pattern, prevalence, and factors associated with immune reconstitution inflammatory syndrome in Ugandan children. *Aids*. 2010; 24(13):2009–2017. [PubMed: 20616700]
- Polisset J, Ametonou F, Arrive E, Aho A, Perez F. Correlates of adherence to antiretroviral therapy in HIV-infected children in Lome, Togo, West Africa. *AIDS Behav*. 2009; 13(1):23–32. [PubMed: 18654845]

- Quigley, F. *Walking Together, Walking Far: How a US and African Medical School Partnership is Winning the Fight Against HIV/AIDS*. Bloomington, Indiana: Indiana University Press; 2009.
- Sankar A, Golin C, Simoni JM, Luborsky M, Pearson C. How qualitative methods contribute to understanding combination antiretroviral therapy adherence. *J AIDS-Journal of Acquired Immune Deficiency Syndromes*. 2006; 43:S54–S68.
- Strauss, ACJ. *Basics of qualitative Research: Grounded Theory Procedures and Techniques*. Newbury Park, CA: SAGE Publications; 1990.
- AUTHOR. Factors sustaining pediatric adherence to antiretroviral therapy in western Kenya. *Qualitative Health Research*. 2009; 19(12):1716–1729. [PubMed: 19949221]
- AUTHOR. Factors Sustaining Pediatric Adherence to Antiretroviral Therapy in Western Kenya. *Qualitative Health Research*. 2009; 19(12):1716–1729. [PubMed: 19949221]
- AUTHOR. The Perceived Impact of Disclosure of Pediatric HIV Status on Pediatric Antiretroviral Therapy Adherence, Child Well-Being, and Social Relationships in a Resource-Limited Setting. *AIDS Patient Care and STDs*. 2010; 24(10):639–649. [PubMed: 20836704]
- AUTHOR. Association of Antiretroviral and Clinic Adherence With Orphan Status Among HIV-Infected Children in Western Kenya. *J Acquir Immune Defic Syndr*. 2008; 49(2):163–170. [PubMed: 18769353]
- AUTHOR. A systematic review of pediatric adherence to antiretroviral therapy in low- and middle-income countries. *Pediatric Infectious Disease Journal*. 2008; 27(8):686–691. [PubMed: 18574439]
- AUTHOR. A systematic review of pediatric adherence to antiretroviral therapy in low- and middle-income countries. *Pediatr Infect Dis J*. 2008; 27(8):686–691. [PubMed: 18574439]
- Wiener L, Mellins CA, Marhefka S, Battles HB. Disclosure of an HIV diagnosis to children: History, current research, and future directions. *Journal of Developmental and Behavioral Pediatrics*. 2007; 28(2):155–166. [PubMed: 17435473]
- Williams PL, Storm D, Montepiedra G, Nichols S, Kammerer B, Sirois PA, et al. Predictors of adherence to antiretroviral medications in children and adolescents with HIV infection. *Pediatrics*. 2006; 118(6):e1745–1757. [PubMed: 17101712]
- World Health Organization. 10 facts on adolescent health. 2008. Retrieved September 30, 2011, from http://www.who.int/features/factfiles/adolescent_health/en/index.html
- World Health Organization. *Global summary of the AIDS epidemic, 2008*. 2009.

Table I

Adolescent-Reported Themes for ART Adherence

Emerging Themes	Sample Excerpts from Focus Group
Secrecy	
Minimize the number of people that know	"My head teacher and class teacher know because I have to ask for permission to come to clinic."
Covert storage of medication	"Mine I keep in my box and lock and put my key inside my clothes..."
Beware of the risk of information-sharing	"Sometimes if you use [medicines] when people are seeing you, they go out and broadcast you, they spread that you use." HIV medicine."
Other Barriers to Adherence	
Responsibility for medication adherence	"Maybe reminding me sometimes when I come home late from school. May be reminding, but taking I do it on my own."
Pill burden	"They are too big in size so they get stuck in the throat."
Interpersonal conflict	"You forget to take the drugs in the morning and in the evening you delay a bit. Then the guardian quarrels you, abuses you, and forces you to take them. So you get angry and say I am not even taking them. Let them stay and the day ends like so."
Just forgetting to take medications	"At times you just forget to take your medicines."
Delaying doses because of school or work	"I reach home late and I can't carry the medicine to school to take at six because it will be known."
Rejection, discrimination, and blame	"Sometimes when you tell people, they will know that you have AIDS. Then after one year or so they go and misbehave outside. Then they get AIDS, and they come around and say it's you who brought it on them and infected them. They get angry at you forever." "It is important to keep it secret because when everybody knows, they will be just abusing your name."
Growing tired of taking medicines	"You become tired. Some of them are bitter, they are many. If there is medicine that can be swallowed once per day, it would be better."
Not knowing why they are taking medicines	"I would take for a week and miss two days because I didn't know why I was taking it... But after I was told why, I became strict in taking."
Delaying in front of others	"We are many in the house, and it is only the parents who know, so if they are not there and the others see me removing these drugs, they will be anxious to know what they are for and why I am taking. So it forces me to wait if they are around, and at times, I even forget and the time for taking (the drugs) passes. I swallow late."