



Experiences along the HIV care continuum: perspectives of Kenyan adolescents and caregivers

Winnie K Luseno, Bonita Iritani, Susannah Zietz, Suzanne Maman, Isabella I Mbai, Florence Otieno, Barrack Ongili & Denise Dion Hallfors

To cite this article: Winnie K Luseno, Bonita Iritani, Susannah Zietz, Suzanne Maman, Isabella I Mbai, Florence Otieno, Barrack Ongili & Denise Dion Hallfors (2017) Experiences along the HIV care continuum: perspectives of Kenyan adolescents and caregivers, African Journal of AIDS Research, 16:3, 241-250, DOI: [10.2989/16085906.2017.1365089](https://doi.org/10.2989/16085906.2017.1365089)

To link to this article: <https://doi.org/10.2989/16085906.2017.1365089>



Published online: 05 Oct 2017.



Submit your article to this journal [↗](#)



Article views: 117



View related articles [↗](#)



View Crossmark data [↗](#)

Experiences along the HIV care continuum: perspectives of Kenyan adolescents and caregivers

Winnie K Luseno^{1*}, Bonita Iritani¹, Susannah Zietz^{1,2}, Suzanne Maman², Isabella I Mbai³, Florence Otieno⁴, Barrack Ongili⁴ and Denise Dion Hallfors¹

¹*Pacific Institute for Research and Evaluation (PIRE), Chapel Hill, North Carolina, USA*

²*Department of Health Behavior and Health Education, University of North Carolina, Chapel Hill, North Carolina, USA*

³*School of Nursing, Moi University, Eldoret, Kenya*

⁴*Kenya Medical Research Institute (KEMRI), Kisumu, Kenya*

*Corresponding author, email: wluseno@pire.org

To be effective, HIV programmes should be responsive to the unique needs of diverse groups of infected adolescents. We highlight a range of adolescent perspectives on HIV services, including those who acquired HIV perinatally or sexually and those who were either in care, had dropped out of care, or had never enrolled in care. We conducted semi-structured interviews with 29 adolescents (aged 15–19) and 14 caregivers in western Kenya. Data were analysed using a descriptive analytical approach. Adolescents who were successfully linked had a supportive adult present during diagnosis; tested during hospitalisation or treatment for a recurrent or severe illness; and initiated treatment soon after diagnosis. Barriers to retention included side effects from HIV drugs, pill burden, and limited access to clean water and nutritious food. Support in family, school, and health facility environments was key for diagnosis, linkage, and retention. We make recommendations that may improve adolescent engagement in HIV services.

Keywords: Kenya, social support, testing, treatment, youth

Introduction

Adolescence is a critical period for the prevention, testing, and treatment of HIV, particularly in sub-Saharan Africa where an estimated 82% of the world's 2.1 million HIV-infected adolescents reside (Idele et al., 2014). Kenya is among the world's top three countries with the highest numbers of HIV-infected adolescents, with an estimated 130 000 infected (ages 10–19) and 18 000 new infections occurring each year (ages 15–19) (UNICEF, 2016). Among those under 18 years, prevalence is largely driven by the survival of perinatally-infected children (Lowenthal et al., 2014).

Prevention of mother-to-child transmission (PMTCT) of HIV was introduced in Africa in 2004, in the wake of a long and severe epidemic that included widespread infant infection (Lowenthal et al., 2014). An estimated one-quarter to one-third of these children survived and are presenting with serious illnesses as adolescents who are either out of care (never initiated care after diagnosis or initiated care and subsequently dropped out) or previously undiagnosed (Ferrand et al., 2007; Ferrand et al., 2010; Lowenthal et al., 2014). Such youth are particularly vulnerable to poor health outcomes. For example, a recent Zimbabwe study found that compared to adults, adolescents registering for HIV care were at a more advanced disease stage, waited longer for antiretroviral therapy (ART) initiation, and were more likely to die while waiting for ART initiation (Shroufi et al., 2013; Shroufi et al., 2015).

Estimates of the number of adolescents living with HIV typically include both perinatally- and sexually-infected individuals. The proportion which is perinatally-infected compared with sexually-infected is unknown. It is known, however, that girls commence sexual behaviour before boys in much of sub-Saharan Africa, and are therefore disproportionately burdened by HIV than boys in their late teens and early twenties (Idele et al., 2014).

Although there have been improvements in recent years, gaps remain in adolescent HIV services. For example, adolescent HIV testing in Kenya is well below the World Health Organization 90% target at 35% and 27% among females and males aged 15–19 years respectively (UNICEF, 2016). Additionally, a growing number of studies in southern and eastern sub-Saharan countries have found that youth aged 15–24 years are less likely to enrol in care after HIV diagnosis and more likely to be lost to care after enrolment than either older or younger groups (Auld et al., 2014; Bygrave et al., 2012; Evans et al., 2013; Genberg et al., 2015; Hatcher et al., 2012; Koech et al., 2014; Lamb et al., 2014; Naik et al., 2015). They are also less likely than adults to adhere to ART after initiation and subsequently experience shorter time to viral rebound and lower rates of virological suppression and immunological recovery (Nachega et al., 2009). This suggests that adolescents are less likely to rebound after interruptions in care. Studies also indicate that young males are less likely to be in care than females and more likely to be lost to care if ART is initiated

(Hatcher et al., 2012; Lamb et al., 2014; Ndiaye et al., 2013).

Growing recognition of the high vulnerability of HIV-infected adolescents has led to several recent qualitative studies examining the lived experiences of sub-Saharan African youth as well as barriers to full engagement in care services (e.g., Denison et al., 2015 in Zambia; Mutumba et al., 2015 in Uganda; Mutwa et al., 2013 in Rwanda; Wolf et al., 2014 in Kenya). The common theme of these studies is that fear of stigma and isolation is a primary concern for adolescents and presents a major barrier to obtaining and adhering to care. Most of these studies, however, recruited participants from large urban clinics and therefore did not examine the experiences of youth who had never initiated care after diagnosis, were lost to care after linkage, or cycled in and out of care. An exception is the study by Wolf et al. (2014) who interviewed youth ages 15–21 who had dropped out of care in a western Kenya urban setting. Thus, there is limited information about experiences with HIV services of different groups of infected adolescents in rural settings.

Our study describes adolescents' experiences with HIV services at different stages of the care continuum: HIV testing, linkage to care, and retention in treatment. Our paper is unique in its inclusion of different groups of adolescents living with HIV. We focus on 15–19-year-old HIV-infected adolescents in a high prevalence rural setting in western Kenya and highlight a range of perspectives, including from youth who were either in or out of care at the time of interview, or who had never enrolled in care. We also include experiences of youth who acquired HIV perinatally or sexually. Additionally, we interviewed a sample of caregivers to get a more ecological view of adolescents' experiences. Our study design allowed us to examine a broad sample of experiences and consider the implications for improving adolescent HIV services.

Methods

Setting and study participants

This study was conducted in Siaya county, Kenya. At 17.8%, the county has the third highest HIV prevalence in Kenya (Kimanga et al., 2014; NACC, 2014). Many people of Luo ethnicity reside in the area. Luos have the highest HIV prevalence among ethnic groups in Kenya (Kenya National Bureau of Statistics & ICF Macro, 2010).

Twenty-nine adolescents and 14 caregivers were recruited and interviewed between April and November 2014. Eligible adolescent participants were between ages 15–19 years of either gender who had tested positive for HIV infection and were aware of their HIV-positive status. They could be either currently receiving HIV care or not.

Procedures

The adolescents were recruited from two sources: (1) patients at public HIV and antenatal clinics under the jurisdiction of the Siaya County Medical Office; and (2) individuals who tested positive for HIV in a Kenya Medical Research Institute (KEMRI) home testing campaign. Selected staff affiliated with the recruitment sources informed potential participants about the study. Only those who were interested in participating were connected with trained research assistants (RAs).

Regardless of referral mode, the RAs used a study

script and screening questionnaire to recruit participants. Recruitment was conducted to ensure a purposive sample of older (18–19 years old) and younger (15–17 years old) adolescents, orphans and non-orphans, males and females, youth who were engaged in HIV care (compliant and non-compliant), and youth who were not currently in care. Of the participating adolescents, 17 were recruited from a clinic and 12 from the KEMRI testing campaign. Adolescents were contacted first (before their parents). If the adolescent gave permission for the study to invite his/her caregiver (parent, guardian, or spouse) for a caregiver interview, then the caregiver (identified by the adolescent) was invited to participate. A caregiver was defined as someone with whom the adolescents lived, who knew about their diagnosis, and who took care of them. Adolescents could participate even if they did not want their caregiver to be interviewed.

All study participation was voluntary. Informed written parent/guardian consent and written adolescent assent was obtained for minors aged 15–17 years old, except in 9 cases where a waiver of parental consent was applied because the adolescent was an emancipated minor (e.g., married), or did not want his or her parent/guardian to know about or be involved in the study. For these adolescents, written informed consent from the adolescent was obtained and they were asked a series of six questions to assess their understanding of consent. Incorrect answers were reviewed with participants. Written consent was obtained for adolescents aged 18–19 years old and for caregivers to participate in the study. All study procedures were conducted in either Luo or English. Adolescents and caregivers received KSh150 (about US\$2 at the time of the study) and KSh300 (about US\$4) respectively, as compensation for study participation. Study protocols were approved by the institutional review boards of the Pacific Institute for Research and Evaluation (PIRE) and Moi University, Eldoret, Kenya.

Interviews

The first author and a co-author trained the RAs in conducting face-to-face individual in-depth interviews in private rooms and other places that ensured privacy. For adolescent interviews, interviewer gender was matched to be of the same gender as the adolescent. Adolescents and caregivers were interviewed separately; they could choose to be interviewed in Luo or English. Interviews lasted about 60 to 90 minutes. All participants also answered a short demographic questionnaire.

RAs used semi-structured interview guides with open-ended questions and probes. Adolescents were asked about their experiences with HIV testing, treatment, and disclosure of their HIV status (e.g., to family, friends, school staff). They were also asked how they first learned their status, who accompanied them for HIV testing or told them about their status, and about their perceptions about how they were counselled during disclosure (see Box 1). Caregivers were asked about their experiences and perceptions regarding their child's HIV testing, treatment and care.

Data analysis

We used a descriptive analytical approach informed by the socio-ecological framework and conducted our analysis

Box 1: Examples of questions and probes included in the adolescent interview guide**Questions/Probes****Tell me about how you first learned you had HIV and your testing experience.**

Probes: Were you tested for HIV? Did someone in your family (like your mother, father, brother, sister) tell you that you had HIV? When and where were you tested for HIV? How did you come to be tested for HIV? Tell me what you know about how you came to be infected with HIV.

Tell me about your HIV testing experience.

Probes: Did you go alone or with someone? Were you glad or sorry that you tested for HIV? What do you think could have improved your testing experience?

After you were tested, what did the person counselling you tell you about HIV health care?

Probes: Did you talk with your counsellor about where and how to get treatment for your HIV? Did you get a referral form? Did you talk to family members, friends, or anyone else about your status? How did people treat you?

We have finished talking about your HIV testing experience. Now we want to talk about your treatment experience. Tell me what you have done about your HIV health care.

Probes: Have you gone to get HIV health care? Where did you go?

Tell me about your HIV treatment.

Probes: Who do you go with to this place? What do you like about your health care? What don't you like about your health care?

Tell me what happened the last time you went for your HIV treatment.

Probes: When was your last appointment? How did you get there that day? Who did you go with? Tell me what happened when you got there?

in a series of steps (Bronfenbrenner, 1977). All interviews were audio-recorded, and then transcribed in the interview language and translated into English. A random selection of English transcripts was read by an independent team member while listening to the audio-recordings to ensure accuracy and fidelity of translations. Transcripts were then read by the first author and a co-author, and any needed clarification was sought from interviewers.

In the first phase of coding, topical (deductive) codes based on the interview guides were developed by the first author. The first author and a co-author (coding team) read each transcript and used the codes to prepare one to two page summaries for each transcript (Miles & Huberman, 1994). Matrices were constructed containing information from the summaries. Summaries and matrices included participants' demographic information. The coding team also applied the topical codes to all transcripts using Atlas.ti (Version 7.5.0). The team initially coded the same transcript and then discussed and compared assigned codes. After using this process for a few transcripts, they each coded half of the remaining transcripts. Code reports were generated and reviewed by the authors to further examine themes.

The first author used the summaries, matrices, and code reports to interpret the data. In a second phase of coding, interpretive codes were applied to identify categories and patterns that emerged from the data. These interpretive codes facilitated our analysis of participants' experiences with HIV testing, linkage to care, and retention in care. Our analysis was also informed by making comparisons among three groups represented in our data: those who had not enrolled in care after diagnosis, those who had enrolled and remained in care, and those who had enrolled and dropped out of care. We also made comparisons between perinatally- and sexually-infected adolescents.

Results**Sample demographics**

Summary statistics for the 29 adolescent participants are presented in Table 1. The average age of the participants was 17 years; 16 were female, and 25 were orphaned (i.e., one or both of their parents had died before they were age

18). Of the participants, 21 were likely infected with HIV perinatally, while 7 appeared to have been infected sexually; the mode of infection for 1 was unknown. Most perinatally-infected adolescents were male and all who were sexually-infected or had ever been married were female. Eight females were pregnant and/or had ever given birth. Most of the participants who had ever been married and/or pregnant were sexually-infected. At the time of their interview, 20 adolescents were receiving HIV care and 9 were not receiving care. We also interviewed 14 caregivers for the study, including 7 parents, 5 other family members (e.g., grandmother, sibling, aunt, uncle), and 2 spouses.

How adolescents learned about their HIV status

Study participants reported first learning about their HIV status by testing at a health facility ($N = 19$), through home-based testing ($N = 7$), and by being told by family members ($N = 3$). Our interviews revealed differences in experiences with learning about one's HIV status based on mode of HIV acquisition and age at testing. Sixteen of the 17 who mentioned a supportive adult, for example, parent, grandparent, sibling, aunt or uncle, was present at the time of testing were perinatally-infected. Only one sexually-infected female said her husband was present when she was tested. Most of those who said they were alone when they were tested and told their HIV status were sexually-infected females.

Most of the sexually-infected participants and a few male adolescents who learned their status as older adolescents (age 15 and above), were less likely to believe their first diagnosis. Many described being shocked, surprised, scared, worried, or frightened about how they would be treated by others; felt sorry for themselves; and/or were bitter. Others described having "deep thoughts", wondering where or how they had acquired HIV, and thinking they would die soon. As illustrated by the following quote from a sexually-infected participant, these adolescents reported testing multiple times, which could be due to denial, and/or lack of trust in the test or providers:

I was tested at [name of clinic] near our home. [Then you did start taking the drugs from there?] No...I

Table 1: Participant demographics by treatment status

	Overall (N = 29)	Not enrolled in care (N = 6)	Ever dropped out/ not compliant (N = 6)	Retained in care (N = 17)
Age group				
15–17	16	3	4	9
18–19	13	3	2	8
Biological sex				
Female	16	5	3	8
Male	13	1	3	9
Orphan status				
Maternal orphan	3	1	0	2
Paternal orphan	9	3	2	4
Total orphan	13	1	4	8
Non-orphan	4	1	0	3
How learnt about status				
Facility-based testing	19	–	5	14
Home-based testing	7	6	1	–
Told by caregivers	3	–	–	3
Mode of HIV acquisition				
Perinatal (suspected)	21 (7)	3	6	13
Sexual (suspected)	7 (2)	2	1	4
Unclear	1	1	–	–
Marital status				
Single	22	3	5	14
Ever married/lived as married	7	3	1	3
Ever pregnant/partner ever pregnant				
Yes	8	3	1	4
No	21	3	5	13
Currently in care				
Yes	20	–	3	17
No	9	6	3	–

came here and was tested again, and found to have the same results and then I was put on medication. [Why didn't you take the drugs at (name of clinic)?] I thought that those people were cheating me about the result, then I transferred to this side but I just got the same results (18-year-old female; retained in care; sexually-infected).

Furthermore, some sexually-infected participants described being treated poorly by providers during HIV testing. One of these participants described two contrasting testing experiences, with the more positive experience facilitating her enrolment in care:

[T]here are some [providers] who are very rude when they are testing you, they don't explain to you very well, but there are some who talk to you nicely and explain to you the testing process in a polite manner, like when I went to [name of clinic] the sister was very rude such that after the results came out positive, she scolded me saying "How can a young girl like you have this disease!"...but when I was tested here the sister talked to me well and counselled me, and showed me the people attending PSC [patient support clinic] so that I don't be scared (19-year-old female; retained in care; sexually-infected).

Most perinatally-infected participants reported being tested and told their diagnosis when they were under age 15, while sick and admitted in hospital or after repeatedly experiencing infections such as pneumonia, typhoid, and

malaria for a long period of time. The adolescent's guardian corroborated that she never suspected HIV until hearing about the symptoms on a radio program.

I started getting sick in class four and I could be falling sick frequently. It went that way until I reached class 7 where I was admitted in the ward and I was staying with my guardians since my parents were not there [had died]. I think my guardian could not think that I should go for the HIV testing. ... Sometimes I could have malaria, typhoid and sometimes I had TB. When I was joining form one [Grade 9] my body started getting weaker and weaker and I could not do anything [any chores]. So one day we were just sitting in this house ... and we said we can go for the test ... and finally I was found to be HIV positive (17-year-old male; retained in care; perinatally-infected).

Most perinatally-infected participants were unsurprised when they received their diagnosis. Most had already known or suspected that their parents were HIV-infected and assumed on learning their diagnosis that was why they were HIV-positive as well. Among those who learned about their HIV status when they were young children, that is, under 15 years old, some mentioned that they did not yet understand what it meant nor did they understand the severity and therefore did not react harshly on learning their status:

I was still young and so I thought it was just something normal. I did not understand it was something big. I was thinking that it was just a

disease the way I used to be sick... So I thought maybe it was just going to the hospital and taking medicine, then I will be okay (18-year-old male; retained in care; perinatally-infected)

A few, however, were initially confused as to how they were HIV-positive because they had learned in school and in the community that HIV was sexually transmitted. They wondered how they acquired HIV without being sexually active and were worried that their caretakers and peers would think that they were promiscuous upon learning their status:

I was asking myself that if I am found with the disease, those who I am staying with there are going to hate me. They are going to look down upon me. That's what I was thinking (17-year-old male; dropped out of care; perinatally-infected).

Linkage and retention in HIV treatment and care services

Of the 29 participants in the study, 17 had initiated care soon after diagnosis and were still engaged in care at the time of the interviews. Six of the 29 had not enrolled in care at the time of their interview for this study. Although most participants who enrolled in care after diagnosis had remained engaged in care up to the time of the interviews, six reported dropping out of care at some point. Of these, three had re-enrolled at the time of the interviews.

Facilitators to linkage

Accounts given by study participants who were engaged in care at the time of their interview suggest important facilitators for successful linkage and retention in care after diagnosis. Three key facilitators for successful linkage, especially for perinatally-infected participants, were: 1) having an adult caregiver or support person present during diagnosis; 2) testing during hospitalisation or treatment for a recurrent or severe illness; and 3) initiating treatment on the same day or soon after diagnosis.

Facilitators to retention

Support from family, providers, school staff, and peers was also mentioned by several perinatally-infected participants who were successfully retained in care. Several school-going participants talked about receiving encouragement to adhere to their drug regimens and assistance to collect medication during scheduled clinic appointments from family members. Thus, they did not have to miss classes or seek permission to attend appointments from school administrators as illustrated by the following quote:

When I was in boarding school, there were times when I could not leave school to come for the drugs so I just called her [mother] and tell her to go get drugs for me which she always did and bring the drugs to the school (18-year-old female; retained in care; perinatally-infected)

A male participant who was also in boarding school said the nutritional and transport support he received from family members helped him remain engaged in care:

The support from my sister and my parent. So that aspect of travelling from there [home] to here [health facility] [it is] them who offer me the transport. The diet like now when I am in school [it] is my sister who

has offered me milk that I take daily. So at least if I find any difficulties she sees how to chip in (16-year-old male; retained in care; perinatally-infected).

A few adolescents described school administrators as supportive because they escorted them for HIV testing, encouraged them to remain in care or re-engage after dropping out, provided secure storage facilities for drugs, reminded participants to take their drugs, and gave permission to seek treatment:

The nurse used to help me a lot, she is the one who kept my drugs because in school we are not allowed to keep drugs in the dormitory because someone can overdose and some can steal your drugs and take them not knowing what they are meant for. The school nurse kept the drugs in a cupboard and she gave me one of the keys so when time comes I just go open the cupboard and take my drugs and come back to class. And in case I forget she comes around the class and calls me outside to find out why I have not taken the drugs.... With the principal, there was a time I became ill when we were nearing exams and she gave me permission to go for treatment at home (18-year-old female; retained in care; perinatally-infected).

A few participants mentioned wanting to finish school as a strong motivator for remaining engaged in care:

I want to go to school and complete when I have someone who is still paying my fees...I was told that I can only go to school if I use those drugs. So I use them so that I finish my schooling (18-year-old male; retained in care; perinatally-infected).

Some also mentioned taking drugs once a day, not having side effects from the drugs, and a belief that the HIV medications have improved their health and/or kept them healthy as factors that keep them engaged in care:

It [HIV treatment] has helped me because I never knew I will be able to rise on my foot and walk. I use to be brought frequently to the hospital but I improved from the day I started my treatment (16-year-old male; retained in care; perinatally-infected).

Among participants receiving care at facilities with adolescent friendly services (e.g., adolescent-specific clinic days and/or support groups), most mentioned their attendance as a source of support. Several spoke positively about the good relationships that they had established with clinic staff. Many felt more secure in seeking treatment when they saw that they were not the only ones their age who were HIV-positive and in treatment. For example, upon joining the adolescent clinic, an 18-year-old perinatally-infected male participant who was still in care said he thought to himself: "Now I am not just alone. We are many in this problem and so we just have to learn how to live."

In contrast to their perinatally-infected peers, accounts given by the four sexually-infected participants who were enrolled in care did not include descriptions of support networks. Rather, they described getting encouragement to test and support to remain engaged in care from one source, either family (e.g., parents, siblings, husbands, in-laws), a close friend, or a community member. None were currently enrolled in school or mentioned having supportive relationships with their providers. Furthermore,

all in this group were receiving maternal and child health services in adult care clinics. However, similar to those who were perinatally-infected, two sexually-infected participants attributed improvement in their health to the drugs they were taking and one said she is encouraged by seeing other people at the clinic because then she knows she is not alone.

Barriers to retention

Similar to participants who had dropped out of care, those who were retained in care also mentioned challenges to remaining engaged in care. While some school-going participants reported having supportive relationships with school staff, others were uncomfortable disclosing their status and faced difficulties in obtaining permission to leave school to attend clinic appointments, especially for those who appeared healthy:

There was a time I was supposed to go to the clinic. There was no teacher to give me permission and any teacher if I went and told him that I was sick they could not agree. They would say that is a lie and I look healthy and I am not sick. I did not want to tell every teacher that I am sick because the duties [teachers on duty] change ... I told the deputy that I am sick and he did not believe. So I had to convince him because I had to go [to the hospital]. ... he asked whether I had the cards and I showed him the card.... (18-year-old male; retained in care; perinatally-infected)

Other frequently mentioned challenges were related to difficulties with taking drugs in school and/or at the same time every day. Participants faced difficulties in taking their drugs in school because of poor nutrition, water shortages, and fear of disclosure:

There are times we have water shortage in school. So you start wondering how you will take the drugs. ... But if it is impossible to get water I take my drugs the following day. Again sometimes, you know I always take my drugs when [I] am going to sleep. So there are times when people [students] are required to sleep [lights off] and they [school prefects] don't want to see any movements yet I want to take my medication. That is when it is hard and I have to wait for at least two hours for me to take the drugs when there are minimal movements. Again friends, I don't want them near my stuff ... there are some who have come across my containers containing the drugs and asked me what they were for. But I faked that this is another disease. I faked and it ended there (16-year-old male; retained in care; perinatally-infected)

Traveling for school-related activities or to visit family was another reason given for missing doses, as illustrated by the quote below:

There are days we go for the school games and this time we went up to the district level and so we spent two days there and you know when you are going somewhere, even someone can see you carrying drugs. And also someone can say that so and so is taking drugs daily. Someone can have comments like "what is it?" (17-year-old male; retained in care; perinatally-infected).

Additionally, participants who were currently in care and those who had dropped out said that the tablets were too big and difficult to swallow, and that taking pills twice a day was challenging. Two participants who had not enrolled in care mentioned similar concerns, noting that they had heard about these challenges from others. Others who had not enrolled in care also expressed concerns about dire consequences if one missed a dose.

Another challenge frequently mentioned by participants from all comparison groups, especially those who had dropped out of care, was side effects associated with taking HIV drugs (i.e., ART and septrin, which is used as a prophylactic before initiation and sometimes in conjunction with ART). These included skin rashes; and nausea (vomiting), dizziness, drowsiness, lethargy, and weakness (unable to walk), which participants often associated with not having eaten well or taking the drugs on an empty stomach. Side effects were often experienced when participants first started taking drugs. For some, the side effects either disappeared after some time or were resolved with drugs prescribed by health providers. Others resorted to missing doses to cope with the side effects:

She gave me septrin and some drugs in a bottle and some small yellow ones, and she told me "these drugs there are some you take one in the morning and one in the evening" and I also just continued with the drugs that way but the one I take twice in a day give problems. When I take it in the morning, and evening I cannot walk, so I just take it only in the evening (18-year-old female; retained in care; sexually-infected)

A 19-year-old sexually-infected participant who had dropped out of care talked about successfully taking drugs during her pregnancy, but then discontinuing them due to nausea after giving birth. While she was encouraged to talk to a provider about the side effects by family members, she did not follow through because she disliked the providers at the clinic.

While HIV medication is free in public facilities in Kenya, medications to address side effects sometimes come at a cost, as described by one participant who was told that the drugs he needed to resolve side effects were unavailable at the hospital and he had to purchase them at the pharmacy. This frustrated him and he ended up discontinuing his care altogether:

Sometimes you don't have that money and you are being told to buy drugs. You have malaria [a catch-all term for undiagnosed ailments and malaise] ... if you come you are told that this and that drug is not there, go and buy those malaria drugs [at a pharmacy] (17-year-old male; dropped out of care; perinatally-infected).

The most frequently mentioned facility-related challenge by those retained in care as well as those who had dropped out of care was that clinic appointments took a long time. Although some participants talked about being able to negotiate with providers to speed up the process, most complained about long wait times, long queues, the slow processes at the clinic, patients having to come early for appointments while clinic staff came late, and clinic staff taking breaks while patients waited. This was especially

problematic for school-going adolescents whose first hurdle was to get permission to attend appointments from school administrators, who adolescents may not have disclosed their status to and/or were sometimes sceptical about their health status. Participants were concerned that long appointments not only affected their school attendance, but also put them in a position of further unwanted scrutiny by school administrators and adult clients at the clinic. In the following quote, the participant encapsulates some of these issues well and implies that improvement in these areas may engender more positive attitudes toward providers.

The queue, sometimes you can come early but you find you are waiting for the doctors. ... You come at 8.00am and the doctors come around 9.00am and yet there are other procedures to be done first and they are not yet opened. So you came and you find women [adult patients] sitting and they start looking at you and paying attention. So you don't even feel comfortable. So even when they come [doctors and other staff] they are slow. ... Even the pharmacist, there are times she sees a long queue but she leaves for tea and we are feeling hungry in the queue (16-year-old male; retained in care; perinatally-infected).

Among those in care and those who had dropped out of care, some adolescents and caregivers described having poor interactions with health providers, including being treated harshly, spoken to rudely, or being “punished” by clinic staff for missing their scheduled appointment:

If you had missed your appointment, say last week and you attend the clinic today your procedure will be different. You will remain until everyone is served. This is your punishment. And the way people are many! Imagine you come at 7 am and you may leave at around 3pm, 2pm, it depends (16-year-old male; retained in care; perinatally-infected).

... there was a doctor who was rude to me because sometimes I struggled in school to get permission to attend clinic, on arrival he would dismiss me because [I] am late, referring me to the next day. It was hectic (15-year-old female; dropped out of care; perinatally-infected).

In other instances, punishment involved being given a one-month return appointment rather than the preferred two or three months. Similarly, a frustrated caregiver of a non-adherent adolescent recounted being treated harshly by a provider when he escorted his nephew to the clinic after learning he had dropped out of care.

Barriers to enrolment in care

Among those who had not enrolled in care at the time of the interviews, an important barrier to linkage was not disclosing HIV test results to an adult caregiver. According to the national HIV testing guidelines in place when many of our participants were tested, post-test counselling was to be offered to youth and caregivers together, after which the youth was to be offered individual post-test counselling by the HIV testing and counselling (HTC) provider (NASCO, 2008). However, we found many cases where minors were tested alone or, even if an adult caregiver was present, s/he was not told his/her child's test result.

Other barriers to linkage were inadequate post-test counselling and ineffective referrals to treatment by HTC providers. For example, a 19-year-old perinatally-infected male adolescent who had not enrolled in care described being tested at home twice during voluntary medical male circumcision (VMMC) campaigns: first, when he was 12 years old and, the second time, when he was 15 years old. Both times, the HTC providers did not effectively communicate his test results to him: “... *they told me the results, however, they never showed me [the test strip] to see...*” This may have resulted in the adolescent not accepting his diagnosis and testing multiple times.

Additionally, two 16-year-old female participants who were not enrolled in care said they were not told about HIV treatment and care services by the providers who tested them. In one case the provider spoke with a caregiver who in turn was unable to convince her daughter to enrol in care. According to this perinatally-infected adolescent, who was tested when she was 15 years old, the HTC provider: “*did not tell me anything [about treatment] They told my mother.*” When asked if her mother talked to her: “*she told me that she wanted to take me to the hospital then I asked her why and she told me she was taking me so that I can start taking drugs but I told her that I don't want to take the drugs now.*” The other, who was sexually-infected and tested with no adult present, said: “*they [the HTC providers] did not talk to me [about treatment] they just took their things and left.*” Furthermore, several participants said they had not been followed up by the HTC provider or staff from the facility to which they were referred to ensure successful linkage to treatment and care services.

Although some youth were amenable to treatment because they could see how helpful it was to their health, as described earlier, others who had not enrolled in care were not prepared to take drugs every day because of negative perceptions and misinformation about HIV treatment due, in some cases, to information obtained from family members. Some said they were too young to take HIV medications, in good health, not susceptible to HIV-related infections, and not at risk of transmitting the disease:

Right now I am seeing that I have no problem [sickness] and there is not even a disease that has attacked my body. So that is why I am seeing that right now I should not start medication (19-year-old male; not enrolled in care; perinatally-infected).

Discussion

The continuing lack of clarity about effective HIV programmes for adolescents underscores the need for better understanding of contextual factors that encourage or discourage their engagement at various points along the continuum of care. Adolescents living with HIV, however, consist of diverse groups of individuals. Thus, to be effective, programmes need to be responsive to the unique needs and contextual realities of the different sub-groups of HIV-infected adolescents. Our qualitative study is among the first of such studies to describe experiences of a range of adolescents living with HIV. We included insights from adolescents living with HIV who were infected perinatally and sexually, and who were engaged and disengaged from

care at the time of the interviews. We use these experiences to identify factors that influence linkage and retention among different HIV-infected adolescent groups in a rural high prevalence region of western Kenya.

Our data suggest that mode of HIV acquisition and age at testing are important factors that influence adolescent enrolment and retention in care. However, like Siu, Kennedy and Bakeera-Kitaka (2016) who conducted a qualitative study among male and female Ugandan HIV-infected youth aged between 15 and 23 years, we did not observe clear patterns in experiences that differed by gender among perinatally-infected adolescents, or among those who were retained in or dropped out of care. Most perinatally-infected adolescents in our study reported being tested at younger ages, while in poor health, with a supportive adult present, and not being surprised about their diagnosis. Most in this group linked to care soon after diagnosis. However, those who were tested at older ages, particularly sexually-infected female adolescents, tended to be alone during testing, had trouble accepting their diagnosis, tested multiple times, reported harsh treatment by providers, and did not always enrol in care after diagnosis. In their study, Siu et al. (2016) found that youth who believed they were infected perinatally felt blameless about their diagnosis and were more motivated to enrol in care. In contrast, accounts given by those who believed they were infected sexually portrayed guilt, regret, self-blame, and difficulty disclosing their status to their caregivers. In our study, interviews with adolescents who did not enrol in care after diagnosis revealed shortcomings in post-test counselling, disclosure of results, referral to care, and follow-up which may have influenced individuals' motivations to enrol in care. Other studies have documented similar findings among adults (Wachira et al., 2014).

These findings suggest that improving HTC service delivery models, particularly for older and sexually active youth, may improve adolescent linkage to HIV care. For example, there may be advantages to changing current practice and encouraging emancipated, older, and sexually active adolescents to have a caregiver or trusted supportive adult accompany them for HIV testing. Although not in the current Kenya HIV testing guidelines, which allow for adolescents to be tested alone (NASCOP, 2015), this premise is supported by other recent study findings (Groves et al., 2017; Hallfors et al., 2017). Thus, additional research is warranted to investigate whether having a caregiver or trusted companion during testing would help this group of adolescents to cope better with their diagnosis and, in turn, facilitate linkage to care sooner.

Some participants who had remained engaged in care after diagnosis attributed their improved health to their HIV treatment. However, among those who had not enrolled in care, barriers to linkage included perceptions of being healthy and at low risk of onward transmission, and having misinformation and negative perceptions about treatment. These findings imply that enrolment in care soon after diagnosis may not be attainable for all youth because some may need time and continued counselling to process, understand, and accept their diagnosis. For these youth, a more achievable goal may involve identifying innovative approaches to keep them in the system to monitor their health, routinely counsel them about the benefits of HIV

treatment, and address their perceptions and concerns about treatment. In other analyses focusing on pregnant or parenting adolescents, we found that contact with our RAs, who were university-trained registered nurses, encouraged some who were not in care to enrol (Hallfors et al., 2017). This suggests that follow-up nurse visits at prescribed times until they enrol in care may be an effective approach that should be explored.

Consistent with other studies (Denison et al., 2015; Mburu et al., 2014; Mutumba et al., 2015; Mutwa et al., 2013; Wolf et al., 2014), adolescents in our study who had access to one or more supportive environments including family, school, and/or health facility were successfully retained in care. For some, however, lack of support at school and health facilities was especially problematic resulting in missed medication doses and/or cycling in and out of care. Perinatally-infected adolescents described challenges at school in trying to adhere to their drug therapy and obtain permission to attend appointments, while also limiting disclosure of their status. They and their caregivers also described facing rigid rules at health facilities regarding appointment attendance and, in some cases, unfriendly and unyielding providers who spoke harshly to them and "punished" them if they missed or were late for an appointment.

Unlike perinatally-infected adolescents, those who were infected sexually were less likely to report having access to a network of support. Rather, they tended to rely on one person. Additionally, none of the sexually-infected adolescents spoke positively about their providers in the way most perinatally-infected adolescents did. Our data suggest that research is needed to examine whether national and institutional policies can be better crafted to encourage reliable sources of support for sexually-infected adolescents to improve ART adherence and retention (Lowenthal et al., 2015). Furthermore, implementation research is needed to determine whether more flexible school rules and clinic appointment schedules to help school-going adolescents adhere to their treatment and care can be developed and consistently implemented while maintaining sufficient student privacy.

Our study findings also highlight the continuing importance of actual and anticipated side effects from HIV drugs, pill burden, and lack of access to clean water and nutritious food as barriers to engagement in HIV care among adolescents. As noted by other researchers, approaches by providers and school administrators that may help to improve engagement in care and warrant further study include having open conversations and acknowledging challenges faced by adolescents in adhering to their drug regimen, and working together to identify solutions (Bernays, Paparini, Gibb, & Seeley, 2016; Denison et al., 2015). Additionally, development of new drug formulations that are long-acting, more tolerable and less burdensome (e.g., smaller tablets, chewable or liquid alternatives, once-a-day pills) may make a significant contribution toward improving engagement in care for adolescents living with HIV in resource-poor settings with limited clean water availability (Adejumo, Malee, Ryscavage, Hunter, & Taiwo, 2015; Bygrave et al., 2012).

An important limitation of our study is due to the challenges we faced in recruiting 15–19-year-old males who were infected sexually and who had never enrolled in

care. Thus, we were unable to make gender comparisons for these groups and caution is warranted in generalising our results to these groups of adolescents. All in our male sample were perinatally infected and, except for one, had at some point enrolled in care. A key strength, however, is that our findings corroborate other research findings while also highlighting important differences and similarities between different adolescent groups.

Conclusions

While HIV incidence rates and poor outcomes are decreasing among adults and young children, they continue to worsen among adolescents. Indeed, HIV-infected adolescents are at particular risk of mortality, morbidity, and onward transmission. Several studies in sub-Saharan Africa have found that youth aged 15–24 years are less likely to enrol in care after HIV diagnosis, more likely to be lost to care after enrolment compared to either older or younger groups, and are also less likely than adults to adhere to ART after initiation. In this paper, we examined experiences with HIV services among a diverse sample of infected adolescents in a rural region of Kenya with the highest prevalence in the country, and considered implications for improving engagement in treatment and care among this vulnerable population. The key cross-cutting theme in our data is the critical importance of supportive relationships in family, school, and health facility environments in motivating infected adolescents to enrol and remain engaged in HIV treatment and care after diagnosis. Compared to older and sexually-infected adolescents, accounts given by those who were younger and perinatally infected were more likely to mention support from a caregiver, teacher, or health provider as key for their diagnosis, linkage and retention in care, and adherence to ART. We note that emancipation and older age do not negate the need for supportive relationships among adolescents to help cope with an HIV diagnosis or challenges associated with HIV treatment and care. Our findings provide additional evidence in support of research to identify effective interventions to improve HIV services delivery models for adolescents and enhance their engagement in these services. We add to this a call for research to develop less burdensome drug therapies, flexible institutional policies, and effective strategies to enhance support networks for HIV-infected adolescents, including those who are sexually infected.

Acknowledgement — We are grateful to the adolescents and caregivers who participated in this study. This study was funded by the National Institute of Mental Health, National Institutes of Health (R21MH099923, Winfred (Winnie) K Luseno, PI). The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institute of Mental Health, or the National Institutes of Health.

References

- Adejumo, O. A., Malee, K. M., Ryscavage, P., Hunter, S. J., & Taiwo, B. O. (2015). Contemporary issues on the epidemiology and antiretroviral adherence of HIV-infected adolescents in sub-Saharan Africa: A narrative review. *Journal of the International AIDS Society*, 18(1), 20049. <https://doi.org/10.7448/IAS.18.1.20049>
- Auld, A. F., Agolory, S. G., Shirashi, R. W., Wabwire-Mangen, F., Kwasigabo, G., Mulenga, M., ... Ellerbrock, T. V. (2014). Antiretroviral therapy enrollment characteristics and outcomes among HIV-infected adolescents and young adults compared with older adults—seven African countries, 2004-2013. *Morbidity & Mortality Weekly Report*, 63(47), 1097–1103.
- Bernays, S., Paparini, S., Gibb, D., & Seeley, J. (2016). When information does not suffice: Young people living with HIV and communication about ART adherence in the clinic. *Vulnerable Children and Youth Studies*, 11(1), 60–68. <https://doi.org/10.1080/17450128.2015.1128581>
- Bronfenbrenner, U. (1977). Toward an experimental ecology of human development. *The American Psychologist*, 32(7), 513–531. <https://doi.org/10.1037/0003-066X.32.7.513>
- Bygrave, H., Mtangirwa, J., Ncube, K., Ford, N., Kranzer, K., & Munyaradzi, D. (2012). Antiretroviral therapy outcomes among adolescents and youth in rural Zimbabwe. *PLoS One*, 7(12), e52856. <https://doi.org/10.1371/journal.pone.0052856>
- Denison, J. A., Banda, H., Dennis, A. C., Packer, C., Nyambe, N., Stalter, R. M., ... McCarraher, D. R. (2015). “The sky is the limit”: Adhering to antiretroviral therapy and HIV self-management from the perspectives of adolescents living with HIV and their adult caregivers. *Journal of the International AIDS Society*, 18(1), 19358. <https://doi.org/10.7448/IAS.18.1.19358>
- Evans, D., Menezes, C., Mahomed, K., Macdonald, P., Untiedt, S., Levin, L., ... Maskew, M. (2013). Treatment outcomes of HIV-infected adolescents attending public-sector HIV clinics across Gauteng and Mpumalanga, South Africa. *AIDS Research and Human Retroviruses*, 29(6), 892–900. <https://doi.org/10.1089/aid.2012.0215>
- Ferrand, R. A., Luethy, R., Bwakura, F., Mujuru, H., Miller, R. F., & Corbett, E. L. (2007). HIV infection presenting in older children and adolescents: A case series from Harare, Zimbabwe. *Nephrology, Dialysis, Transplantation*, 44(6), 874–878. <https://doi.org/10.1086/511873>
- Ferrand, R. A., Munaiwa, L., Matsekete, J., Bandason, T., Nathoo, K., Ndhlovu, C. E., ... Corbett, E. L. (2010). Undiagnosed HIV infection among adolescents seeking primary health care in Zimbabwe. *Nephrology, Dialysis, Transplantation*, 51(7), 844–851. <https://doi.org/10.1086/656361>
- Genberg, B. L., Naanyu, V., Wachira, J., Hogan, J. W., Sang, E., Nyambura, M., ... Braitstein, P. (2015). Linkage to and engagement in HIV care in western Kenya: An observational study using population-based estimates from home-based counselling and testing. *The Lancet. HIV*, 2(1), e20–e26. [https://doi.org/10.1016/S2352-3018\(14\)00034-4](https://doi.org/10.1016/S2352-3018(14)00034-4)
- Groves, A. K., Hallfors, D. D., Iritani, B. J., Rennie, S., Odongo, F. S., Kwaro, D., ... Luseno, W. K. (2017, July). “I think the parent should be there because no one was born alone”: Kenyan adolescents’ perspectives on parental involvement in HIV research. Poster presented at the 9th International AIDS Society (IAS) Conference on HIV Science, Paris, France.
- Hallfors, D. D., Iritani, B. J., Maman, S., Mbatia, I., Ongili, B., Anyango, F., & Luseno, W. K. (2017). *Challenges in promoting the health of HIV-positive pregnant/parenting adolescents and preventing maternal to child transmission in Western Kenya*. Manuscript submitted for publication.

- Hatcher, A. M., Turan, J. M., Leslie, H. H., Kanya, L. W., Kwena, Z., Johnson, M. O., ... Cohen, C. R. (2012). Predictors of linkage to care following community-based HIV counseling and testing in rural Kenya. *AIDS and Behavior*, *16*(5), 1295–1307. <https://doi.org/10.1007/s10461-011-0065-1>
- Idele, P., Gillespie, A., Porth, T., Suzuki, C., Mahy, M., Kasedde, S., & Luo, C. (2014). Epidemiology of HIV and AIDS among adolescents: Current status, inequities, and data gaps. *JAIDS Journal of Acquired Immune Deficiency Syndromes*, *66*(Suppl 2), S144–S153. <https://doi.org/10.1097/QAI.0000000000000176>
- Kenya National Bureau of Statistics & ICF Macro. (2010). *Kenya Demographic and Health Survey 2008-09*. Calverton, MD: Kenya National Bureau of Statistics and ICF Macro.
- Kimanga, D. O., Ogola, S., Umuro, M., Ng'ang'a, A., Kimondo, L., Murithi, P., ... Kim, A. A. (2014). Prevalence and incidence of HIV infection, trends, and risk factors among persons aged 15-64 years in Kenya: Results from a nationally representative study. *JAIDS Journal of Acquired Immune Deficiency Syndromes*, *66*(Suppl 1), S13–S26. <https://doi.org/10.1097/QAI.0000000000000124>
- Koech, E., Teasdale, C. A., Wang, C., Fayorsey, R., Alwar, T., Mukui, I. N., ... Abrams, E. J. (2014). Characteristics and outcomes of HIV-infected youth and young adolescents enrolled in HIV care in Kenya. *AIDS (London, England)*, *28*(18), 2729–2738. <https://doi.org/10.1097/QAD.0000000000000473>
- Lamb, M. R., Fayorsey, R., Nuwagaba-Biribonwoha, H., Viola, V., Mutabazi, V., Alwar, T., ... Elul, B. (2014). High attrition before and after ART initiation among youth (15-24 years of age) enrolled in HIV care. *AIDS (London, England)*, *28*(4), 559–568. <https://doi.org/10.1097/QAD.0000000000000054>
- Lowenthal, E. D., Bakeera-Kitaka, S., Marukutira, T., Chapman, J., Goldrath, K., & Ferrand, R. A. (2014). Perinatally acquired HIV infection in adolescents from sub-Saharan Africa: A review of emerging challenges. *The Lancet Infectious Diseases*, *14*(7), 627–639. [https://doi.org/10.1016/S1473-3099\(13\)70363-3](https://doi.org/10.1016/S1473-3099(13)70363-3)
- Lowenthal, E. D., Marukutira, T., Tshume, O., Chapman, J., Nachega, J. B., Anabwani, G., & Gross, R. (2015). Parental absence from clinic predicts human immunodeficiency virus treatment failure in adolescents. *Journal of the American Medical Association Pediatrics*, *169*(5), 498–500. <https://doi.org/10.1001/jamapediatrics.2014.3785>
- Mburu, G., Ram, M., Oxenham, D., Haamujompa, C., Iorpenda, K., & Ferguson, L. (2014). Responding to adolescents living with HIV in Zambia: A social-ecological approach. *Children and Youth Services Review*, *45*, 9–17. <https://doi.org/10.1016/j.childyouth.2014.03.033>
- Miles, M. B., & Huberman, A. M. (1994). *Qualitative Data Analysis: An Expanded Sourcebook*. Thousand Oaks, CA: Sage Publications.
- Mutumba, M., Bauermeister, J. A., Musiime, V., Byaruhanga, J., Francis, K., Snow, R. C., & Tsai, A. C. (2015). Psychosocial challenges and strategies for coping with HIV among adolescents in Uganda: A qualitative study. *AIDS Patient Care and STDs*, *29*(2), 86–94. <https://doi.org/10.1089/apc.2014.0222>
- Mutwa, P. R., Van Nuil, J. I., Asimwe-Kateera, B., Kestelyn, E., Vyankandondera, J., Pool, R., ... Boer, K. R. (2013). Living situation affects adherence to combination antiretroviral therapy in HIV-infected adolescents in Rwanda: A qualitative study. *PLoS One*, *8*(4), e60073. <https://doi.org/10.1371/journal.pone.0060073>
- Nachega, J. B., Hislop, M., Nguyen, H., Dowdy, D. W., Chaisson, R. E., Regensberg, L., ... Maartens, G. (2009). Antiretroviral therapy adherence, virologic and immunologic outcomes in adolescents compared with adults in southern Africa. *JAIDS Journal of Acquired Immune Deficiency Syndromes*, *51*(1), 65–71. <https://doi.org/10.1097/QAI.0b013e318199072e>
- Naik, R., Doherty, T., Jackson, D., Tabana, H., Swanevelder, S., Thea, D. M., ... Fox, M. P. (2015). Linkage to care following a home-based HIV counselling and testing intervention in rural South Africa. *Journal of the International AIDS Society*, *18*(1), 19843. <https://doi.org/10.7448/IAS.18.1.19843>
- NACC. (2014). *Kenya AIDS Response Progress Report, 2014. Progress Towards Zero*. Nairobi: National AIDS Control Council of Kenya (NACC).
- NASCOP. (2015). *Guidelines for HIV Testing Services in Kenya*. Nairobi, Kenya: National AIDS and STI Control Programme (NASCOP), Ministry of Health.
- NASCOP. (2008). *Guidelines for HIV Testing and Counselling in Kenya*. Nairobi, Kenya: National AIDS and STI Control Programme (NASCOP), Ministry of Health.
- Ndiaye, M., Nyasulu, P., Nguyen, H., Lowenthal, E. D., Gross, R., Mills, E. J., & Nachega, J. B. (2013). Risk factors for suboptimal antiretroviral therapy adherence in HIV-infected adolescents in Gaborone, Botswana: A pilot cross-sectional study. *Patient Preference and Adherence*, *7*, 891–895. <https://doi.org/10.2147/PPA.S47628>
- Shroufi, A., Gunguwo, H., Dixon, M., Nyathi, M., Ndebele, W., Saint-Sauveur, J. F., ... Ferrand, R. A. (2013). HIV-infected adolescents in southern Africa can achieve good treatment outcomes: Results from a retrospective cohort study. *AIDS (London, England)*, *27*(12), 1971–1978. <https://doi.org/10.1097/QAD.0b013e32836149ea>
- Shroufi, A., Ndebele, W., Nyathi, M., Gunguwo, H., Dixon, M., Saint-Sauveur, J. F., ... Ferrand, R. A. (2015). Risk of death among those awaiting treatment for HIV infection in Zimbabwe: Adolescents are at particular risk. *Journal of the International AIDS Society*, *18*(1), 19247. <https://doi.org/10.7448/IAS.18.1.19247>
- Siu, G. E., Kennedy, C. E., & Bakeera-Kitaka, S. (2016). Young people with HIV attending a transition clinic in Kampala, Uganda: An exploratory study of social context, illness trajectories, and pathways to HIV testing and treatment. *Children and Youth Services Review*, *65*, 9–16. <https://doi.org/10.1016/j.childyouth.2016.03.015>
- UNICEF. (2016). Key regional charts and figures — Eastern and Southern Africa [Data file]. Retrieved from <https://data.unicef.org/topic/hiv/aids/adolescents-young-people/>
- Wachira, J., Naanyu, V., Genberg, B., Koech, B., Akinyi, J., Kamene, R., ... Braitstein, P. (2014). Health facility barriers to HIV linkage and retention in Western Kenya. *BMC Health Services Research*, *14*(1), 646. <https://doi.org/10.1186/s12913-014-0646-6>
- Wolf, H. T., Halpern-Felsher, B. L., Bukusi, E. A., Agot, K. E., Cohen, C. R., & Auerswald, C. L. (2014). "It is all about the fear of being discriminated [against]...the person suffering from HIV will not be accepted": A qualitative study exploring the reasons for loss to follow-up among HIV-positive youth in Kisumu, Kenya. *BMC Public Health*, *14*(1), 1154. <https://doi.org/10.1186/1471-2458-14-1154>