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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

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ABSTRACT

Despite global improvements in antiretroviral treatment (ART) access, little is known about how young people with HIV initially enter treatment. This article explores young people's trajectories towards HIV treatment: how, when, and with whom testing and treatment decisions are made and the role of adolescents themselves in this process. In 2009, we conducted 20 in-depth interviews with male and female adolescents attending the HIV/AIDS Transition Clinic at the Infectious Diseases Institute in Mulago Hospital, Kampala, Uganda. Interviews were audio recorded and transcribed. The authors read the transcripts, developed codes and synthesized themes. Though many respondents were likely infected with HIV at birth, most tested and learned their serostatus as teenagers after repeated illnesses or perceived risky sexual behaviour. Young people encountered both obstacles and opportunities in their HIV treatment-seeking efforts. Caregivers' decisions and actions or an absence of specialist HIV services and skills caused delays in ART enrolment. Health workers played an important role in referral and connecting young people to care. The agency of young people themselves, once they realised that their illness could be HIV, was also crucial in ensuring prompt HIV testing and treatment-seeking. Young people who believed they were infected through mother-to-child transmission saw themselves as innocent victims and appeared motivated to combat HIV, while those suspecting sexual transmission found disclosure to parents difficult and described feelings of guilt, regret, and self-blame. Understanding pathways to HIV testing and treatment can inform care and support services for young people in Uganda. In particular, earlier disclosure may facilitate positive coping strategies and engagement in care.

1. Introduction

Approximately 2.6 million children and 2 million adolescents (10–19) are living with HIV worldwide, 88% of whom live in sub-Saharan Africa (SSA) (UNAIDS, 2015). In 2014, about 170,000–230,000 new HIV infections occurred among children under 15 years of age in sub-Saharan Africa (UNAIDS, 2015). In Uganda, although the number of new infections among children reduced significantly from 31,000 in 2010 to 5200 in 2014, the number of children and young people currently living with HIV remains unacceptably high at 150,000 (Republic of Uganda, 2015). Sexual transmission among young people and the success of antiretroviral treatment (ART) largely account for increased number of young people living with HIV (UNAIDS, 2015).

By 2014 Uganda among the most successful countries of the Global Plan to Eliminate new infections among children, with 90% ART coverage among pregnant mothers (UNAIDS, 2015), but testing of newborns exposed to HIV also remains low: only half test for HIV in the first 18 months and there is a significant loss to follow-up of children (Republic of Uganda, 2015). The implication is that many children infected perinatally are not on antiretroviral therapy (ART) and a significant proportion of young people in Uganda may live unknowingly with HIV. As a result, many young people with HIV are entering care and treatment at an older age after identification in acute and chronic care facilities. HIV diagnosis among adolescents in SSA is often delayed: 97% of adolescents received diagnosis after presentation with clinical disease, and more adolescents had advanced HIV disease at presentation than adults (Shroufia et al., 2013).

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Recently, adolescents living with HIV have been identified as a unique population which has received relatively little attention from policymakers, programme planners, and service providers despite having unique health and social support needs (USAID, 2012a, 2012b). As perinatally-infected children reach adolescence, it is important that they learn their HIV and are linked to services that promote HIV self-management independent of a paediatric provider, case manager, or significant community/family support (Ross, Camacho-Gonzalez, Henderson, Abanyie, & Chakraborty, 2010). Self-awareness of HIV infection status is associated with delayed or reduced HIV disease progression and death. Yet in many parts of SSA, including Uganda, parents, caretakers, and health providers are reluctant to reveal to children details of their HIV disease, often because they fear that children are not old enough to understand the illness or will not keep it a secret (Rujumba, Mbasaalaki-Mwaka, & Ndeezi, 2010; Kyaddondo, Wanyenze, Kinsman, & Hardon, 2013).

Studies aimed at improving young people's HIV treatment outcomes in Uganda and other resource-limited settings tend to focus on the factors that influence adherence to HIV treatment (D'Angelo, Abdalian, Saar, Hoffman, & Belzer, 2001; Angevine, 2007) or on experiences with HIV serostatus disclosure (Bikaako-Kajura et al., 2006; Vreeman et al., 2010). However, with the exception of a few studies (Boender et al., 2012; Luyirika et al., 2013), little is discussed about the experiences of young people with HIV in their quest to access testing, treatment and care in Uganda. In view of limited disclosure to children, it is vital to learn how and why young people exposed to HIV get tested and consequently enter into treatment and care, their illness trajectories, and their personal experiences negotiating access to HIV-related services. Using the narratives of young people themselves, this paper describes how, when, and with whom testing and treatment decisions are made and the role of young people themselves in these endeavours.

2. Methods

2.1. Sample and interviews

Between May and June 2009, we conducted in-depth interviews with 10 male and 10 female young people attending the HIV/AIDS transition clinic at the Infectious Diseases Institute (IDI) in Mulago Hospital, Kampala, Uganda. Since we aimed to obtain a rich qualitative representation of the lived experiences of young people, we chose a small, manageable sample size of 20 interviewees. They were purposively selected by the study coordinator, who was staff at the IDI and regularly interacted with adolescent clients. This sample was balanced on gender and age, and included youth who had various social challenges that sometimes posed threats to their ability to remain in care. All participants had been on HIV treatment for at least 4 weeks and were excluded if they were in poor health or deemed unable to participate due to poor psychological or emotional states. Interviews were conducted by a social scientist with relevant qualitative research experience and an IDI clinician who was familiar with the adolescent clinic programme and issues of interest to both the young people and the providers. The in-depth interview guide outlined topics such as life before and after learning their status, testing, entering HIV treatment, and disclosure. The interviews were conducted in either Luganda or English and lasted between 40 and 70 min.

2.2. Ethical considerations

The study was reviewed by the Makerere University Faculty of Medicine Ethical Committee and approved by the Uganda National Council of Science and Technology. Institutional clearance was obtained from the IDI to invite ART clients to enrol in this study. To ensure informed and voluntary consent to participate, a research coordinator contacted and briefed prospective participants about the study several days before the intended interview, and those under 18 years were asked to discuss participation with their parents/caregivers who verbally granted permission. All participants who gave initial consent/assent were referred to the research team for further information concerning the study. After getting briefed again by the interviewers, those willing to participate signed the consent form and were assured of confidentiality and anonymity. Transport compensation was provided to each participant. Participants who appeared to become distressed by the questions (four participants became emotional and broke down into tears or spoke bitterly about their experience during the interview) were offered encouragement and brief counselling by one of the researchers, a medical doctor with experience in paediatric HIV care. Those who had questions about ART were offered appropriate answers.

2.3. Data management and analysis

With permission from the respondents, interviews were audio-recorded and field notes were taken. The audio records of interviews were later transcribed and used for checking and validating the field notes. Transcription into English was done by an experienced translator. Following thematic content analysis procedures (Attride-Stirling, 2001), the texts were initially read in detail by the first author to develop a list of preliminary codes and themes. Themes that were explicit in the transcripts and addressed the research questions were prioritised. Additional themes were generated inductively, through discussion and synthesis of the preliminary themes by all three authors. The first author then coded the data manually and identified common patterns and differences across participants, while the other authors reviewed the initial analysis and together refined the main themes for the manuscript. To complement thematic analysis, we identified and developed three case studies of individual participants. These case studies provide detailed accounts of adolescents' lived experiences and exemplify various key themes. They also illustrate the diversity of experiences and trajectories towards HIV treatment. These cases are not representative of all young people receiving care at the IDI. All names reported in the paper are pseudonyms.

3. Results

3.1. Study respondents: from diverse walks of life

A sample of 20 young people on ART (10 male and 10 female) with a median age of 19 (range: 15–23) were interviewed. The characteristics of the sample are described in detail elsewhere (Siu, Bakeera-Kitaka, Kennedy, Dhabangi, & Kambugu, 2011). Our sample represented a wide range of participants from different walks of life: students, out-of-school adolescents, a market vendor, a hair stylist, parents, and unemployed young people. Most (17 out of 20) interviewees were single or double orphans, and 12 out of 20 were living with a relative, mostly grandmothers/aunties or older siblings, at the time of the interview. Only 2 lived with their biological parent(s). Most youth who lived with relatives had a history of very high geographical mobility and almost no permanent residency as demonstrated by Phoebe's (age 20) experience:

> I now stay with my uncle's wife. Before staying with my uncle, I stayed with my sister, Teddy. I moved to stay with Teddy from Masaka, where I used to stay in many places. After that I went to my auntie, then in Namasuba (in Kampala), and then to my rich Uncle. … But I want to be at my own home; I am going to get married.

With a few exceptions, participants recalled unhappy early years, especially those spent in both their natal and foster families after the death of either or both parents. They spoke of growing up under poor economic circumstances, lack of resources for their education, and some reported cruel treatment from guardians. However, the findings reported below do not suggest gender differences in experiences.

3.2. Three case stories

3.2.1. Joe: resentment of parental silence about his HIV

"*Since childhood, I had been on treatment of TB [tuberculosis] relapse, TB relapse, TB relapse or whatever it was. My mother always told people that I had a TB problem, TB problem, TB problem, TB problem, TB problem.*" Joe, a 22-year old university student, lived with HIV for much of his childhood without knowing that he had it. Joe lost his father in 1990 and his mother in 2008. Before his mother died, she attended the HIV clinic at the IDI.

Joe's illness had always bothered him and significantly affected his secondary schooling. Sometimes his condition was so bad that he could not reside in his boarding school and received special breaks. Even though he got sick often, he did not know that it was HIV; he believed he suffered from TB like most students in his school. His mother usually gave him Septrin in addition to his TB medicine. With incidents of medication failure, Joe's TB treatment process was prolonged and distressing. "*I have been on TB medicine for the rest of my life. It was like three times when on TB treatment.*"

Joe recalled that his TB treatment trajectory, which eventually led getting tested for HIV, involved back-and-forth referrals between two City Council Clinics in Kampala. "*I first had the eight months at Kiswa clinic, then at the KCC clinic at Nasser Road where they referred me again to Kiswa because they saw that the situation was getting complex, so I also had another eight months of TB treatment there.*" Joe said that a health worker in the clinic grew concerned about his slow improvement and suggested an HIV test. "*One day, the doctor at Kiswa Health Centre was also asking why [my condition] was like that, and so, he told me that the only thing was to do a sero-test.*"

Joe did not take the recommended HIV test. Instead, his mother revealed to him that he was infected with HIV on the same day. Joe described the disclosure event as follows: "*When I went back with my mum, because I failed actually to go to do the HIV test, so when we went back home, she called me and talked to me about HIV infection. She called me in her bedroom. Yeah she was like 'have a seat', and then we began chatting. She told me that 'since your childhood, you have been unwell; we have been going to Ebenezer [clinic] like every year. You have been doing blood tests so this means that from childhood you have been affected with HIV.'*" Joe was disappointed with his mother for being silent about his HIV status for a long time. "*I kind of cut for her [got angry at her]. I felt weak because we had been living in the same house and she had not told me. I had this burden of drugs; you know I was in boarding school and my friends would ask me why I was swallowing all those drugs every now and I usually told them that I had TB.*" "*I cut for her for something like two weeks until uncle intervened, convincing me to return home. I was living at his place actually, then after that we got back; we reconciled. She told me that she was sorry, but added that people who are HIV positive can still marry and produce. She was very encouraging about it.*"

After a short while, Joe's mother took him to the IDI, where she was receiving treatment, to enrol him in treatment as well. Joe recalled that his CD4 count was 64. Initially, he was given Septrin tablets and started on ARVs a month later. Although Joe accepted his treatment, he complained about the large size of the ARV pills and the side effect of dizziness. He wished to keep his treatment confidential, especially at his university, "*because people also have this attitude towards HIV, so you do not know how they will react; it is a challenge.*"

3.2.2. Jane: personal agency to get a test and enrol on treatment

Jane was 19 years and lived with her maternal aunt in a Kampala City suburb. Her parents separated when she was only 12. Several maternal relatives were involved her upbringing. She was born into a family of six siblings, three of whom had died. She stopped school in senior secondary two, at age 16, due to lack of school fees.

Jane learnt of her HIV status in September 2007, after receiving a HIV test following a bout of malaria. "*One day I fell sick with malaria. I went to Kampala City Council clinic in Kawempe and they run three tests on me; HIV, typhoid and malaria. So, I was told to wait for my results. The sister [nurse] called me and revealed to me the results, telling me that I did not have typhoid but I have malaria and HIV. I was asked to return to the clinic on the following Tuesday so that they would send me to where to get treatment from.*" But Jane did not follow this advice. "*No, I did not go back because I could not believe it; instead I went to Naguru Teenage Centre (a City Council Clinic with youth-friendly services) with my boyfriend. I told him to go and test with me. His results were negative but mine were again positive.*"

Here too, the counsellor advised Jane and her boyfriend to go back on a later date for her to be referred to further care. "*The counsellor gave me his phone number to call him later but when I called, he told me that he was not there because the hospital had been transferred to Kiswa. He then gave me a contact of one of the IDI doctors whom I called. When I met with this doctor, I was tested again. I was started on Septrin and I am still on Septrin.*" Jane was uncertain about how she contracted HIV. "*It could have been either through my mother or sexually through my first boyfriend, but I am not sure.*"

3.2.3. Simon: discrimination from church host family

After the death of his parents when he was a teenager, Simon had to seek work to support himself financially. He worked briefly as a goat herder for a pastoralist in his village. "*It was during that time,*" he said, "*that savedees [evangelical Christians] came to our village and asked us to become saved. I got saved and there was a pastor who got interested in me and asked me a number of questions. He then asked if I would like to work for him and I agreed…. He told me to meet him in a given place and time here in Kampala. I was a bit scared but I reassured myself that they were born again and that he was a pastor.*" Simon left his village to move to Kampala, where he stayed with the pastor's family and worked odd jobs at the church and around the house, including arranging the church programme, singing in the choir, collecting water, and doing laundry.

The pastor and his wife had three children and treated Simon well. However, Simon became ill and developed herpes zoster around his abdomen. The pastor told him to seek care at the hospital in town, where clinicians suggested an HIV test. Simon found out and accepted that he was HIV-positive. He was given medications to take, and he told the pastor and his wife about his diagnosis. While the pastor's family was supportive, they began to discriminate against Simon at home. "*By the time someone tells you, 'never put your plate amongst our plates, never put your cup amongst ours,' it means that you are being discriminated against,*" he said. "*And yet the Lord used him [pastor] to assist you and you are alive because of him.*"

Besides the pastor and his wife, Simon told no one of his diagnosis. However, he believed that one of the church elders also knew because of the timing of his sickness. He said it was difficult to tell others about his illness. "*If it is not a person of God, it is hard to tell someone that I am infected.*" He took his medication in private, slipping away from church duties to take each pill. When he had to take pills away from home, he would not take the entire pill bottle with him for fear of accidental disclosure. "*Why would the bottle be necessary? I take my medication from home. I move with (carry) my one tablet if I have to, then I devise means of swallowing the pill.*"

Simon said that he wasn't born with HIV but thought he might have gotten it through a relationship he had before moving in with the pastor. Although he was feeling healthier at the time of the interview, he warned other youth to "*be careful, because life is not easy.*" He worried about his future with the pastor and his family. "*What hurts me really bad is before I had no complaints with the pastor's family but now that they have started to discriminate against me. I don't know where to go if they chose to evict me from their home. Are they really doing the right thing? Does it help them, or is it me to try and understand why they are doing this to me?*"

3.3. Young people's beliefs about how they became infected with HIV

Although participants were not explicitly asked how they acquired HIV, several spontaneously discussed what they believed was the source of their infection. Many thought or had been told that they had acquired HIV from their mothers. Joe described: "*I do not think it was sexual because I have not been involved in any sexual activity; may be from my mother or sharp objects or at birth.*" Paul (age 19) said: "*I have been told of transmission through objects but I think it is from my parents; even my siblings died, it's only two of us who survived.*" Joan's (age 19) account also pointed to mother-to-child transmission: "*I think I was born with it because I have never played sex with a man, and that is how I was told.*" While some others were unsure where to attribute their infection, a number of interviewees believed they acquired HIV through sharing sharp contaminated objects. Some alleged that they could have been maliciously injected through sharp objects by their HIV-infected caretakers. Others, like Anne (age 18), attributed acquisition to an infected sexual partner:

> A man gave it to me. In 2005 we met in Masaka. We were both studying, he was in S4 and I was in S3 so we played sex. […] Because there is no one else who I have ever met (sexually).

The perceptions that these young people held about how they might have gotten infected appeared to significantly influence how they categorised themselves, their response to the symptoms of HIV, and what living with HIV meant for them. Some narratives suggested that those who considered the source of their infection to have been mother-to-child transmission or sharing sharp instruments with their infected carers tended to see themselves as 'innocent' victims. They felt blameless and appeared more motivated to address their HIV diagnosis, especially with regard to coping, disclosure and adherence. Joyce (age 19), for example, took solace in this fact and described her coping strategy as:

> I used to get hurt by insults but this is no longer an issue because I was counselled about mother-to-child transmission [and] I trusted the result because before mum died she was infected and even dad died of HIV. I would therefore not doubt if they told me I was sick.

In this particular case, this female respondent described being comfortable discussing her status with family and others and said she did not have thoughts about HIV at times because, as she put it, "I was not guilty." Joyce, and a few others like her, favoured universal testing and disclosure and believed that other people in her neighbourhood had benefited from her approach of openness by taking their children to test for HIV. Appealing to others not to discriminate against infected people like him, Paul (age 19), who also believed he got infected though mother-to-child transmission, acquitted himself, saying"*…even the infected didn't have a choice, like me, I didn't.*" In this account, too, we see the voice of an 'innocent victim.'

In contrast, participants who believed that they acquired the infection sexually related accounts portraying guilt, regret, and self-blame and found disclosure to parents and others more painful. Maria (age 19), who suspected heterosexual transmission, expressed her distress as follows:

> Worries often come. It just comes because I think about my status…. I wasted school fees and got HIV.

Maria, like others who expressed regret, was not only angry at her risky sexual behaviour, but was also keen to keep status secret and appeared to tolerate the blame and discriminating attitudes levelled against her by other people. Simon was another good example, as we saw from his detailed life story above. Reflecting on the discrimination by the pastor's family, Simon sometimes wondered whether the onus was on him to try to understand why they acted like that towards him. Here, too, we see a participant attempt to portray himself as guilty after all. However, one female participant (Ellen, age 19) who strongly suspected that she got infected through rape because the man who raped her was HIV-positive, expressed bitterness and described hating her treatment and not taking ARVs for eight months"*…because I thought I was making my mum suffer, so I asked her to take care of others.*"

3.4. When and how they learnt of their HIV status

Although the majority of participants might have been infected perinatally, most described learning their HIV status much later, often when they were already in their teens. Besides Joe, whose account is quite illustrative, there were other striking examples. Nineteen-year-old Rebecca, who believed that she was infected through mother-to-child transmission, reported that she did not get know the truth about her infection until she was about to enter university. Daniel believed that he was infected with HIV through mother-to-child transmission since both of his parents had HIV, although he said he only became aware of the type of illness he suffered from when he was 19 years old. Allan (age 19), whose parents were both on treatment, said he got to know "the truth" at 16 years, despite having been ill frequently and often being on treatment.

With the exception of two participants who were prompted to test because they believed that their sexual behaviour could have exposed them to HIV, all participants learned their infection during the process of seeking medical treatment for the recurrent illnesses they had suffered:

> I was very sick in the village… and my grandmother sent my sister to collect me. She brought me to Kampala and they took me to KCC hospital and the counsellor asked me if I would like to be tested. That was in 2006 (Allan, age 19).

> I leant of my HIV status at the beginning of this year 2009. I had swollen things behind my ears and we were very confused about it. We came for oral surgery and they told us to go for a blood test, which I did. The doctor gave me the results and I was [HIV] positive (Andrew, age 19).

3.5. Resentment towards parental/caretaker silence

The young people described their feelings when they learnt of their infection. Many believed their parents or caretakers were already aware of or suspected, from the symptoms, their infection long before they divulged this information to their children. Many respondents, particularly those who had suffered recurrent illnesses and had borne the burden of frequent treatment, expressed bitterness that their parents/caretakers took so long to reveal to them the nature of their health problem. As we saw, Joe was angry at his mother. His disappointment with his parent for concealing information about his HIV infection is neatly illustrated in his narrative. Rebecca (age 19), a university student, also wondered why her father had not told her earlier that she was infected: "*I am now free with him, I asked him and he told me [but] I also asked him why he did not let me know before.*" Kate (age 19), whose parents both died of HIV between 2004 and 2006, had also been sickly throughout that period but no one told her the disease she suffered. Though her grandmother eventually took her for a HIV test, she was concerned by the lack of early disclosure: "*For them they knew because they were aware of my mother's sickness and death which annoyed me.*"

Although many young people's accounts of their relations with parents and other members of their wider family suggested that they had generally enjoyed good relations with their caretakers, strong familial relationships did not guarantee early disclosure of HIV status to children. Joyce, a university student, described feeling disappointed that her father was in denial about her status despite knowing that her mother died of it and that he was himself HIV-positive. It was not until 8 years later that Joyce learned the true results of her diagnosis:

> When mum died, people said I was born with the sickness but dad would not accept it. I was ten years old [but] we would just keep quiet…. The following year I was screened four times in Mityana but Daddy said the HIV virus was not detected.

Annet (age 19) was also tested but never learned her status despite her father receiving the results: "*…after testing me, they gave the results to my father but they did not inform me.*" Participants' accounts also indicated that caretakers were reluctant to allow their children to discuss their infection with other people. Ellen (age 19), who enjoyed a great relationship with her aunt and mother, shared how her mother would often sanction her discussion of her HIV status with other visiting people. However, poor relationships between the child and other family members ensured earlier disclosure of HIV status to the child. In some cases, disclosure or referring to the child's HIV status, especially by non-biological parents and caretakers, was triggered by anger resulting from mistakes by that child, as revealed by Phoebe (age 20):

> My uncle's wife talks ill of me and the other people come and tell me. […] That she says that, "that one is sick but she does not want to eat".

3.6. Pathways to HIV testing and treatment

3.6.1. Illness symptoms, trajectories and help seeking prior to HIV diagnosis

Participants described in detail the illnesses and symptoms they experienced prior to HIV diagnosis and narrated various help-seeking and care experiences. Like Joe, Jane, and Simon, nearly all the other participants described having suffered multiple illnesses throughout childhood. Reported symptoms ranged from malaria to tuberculosis. Although participants recalled varying levels of severity, they all described that their illness experiences were characterised by frequent consultation with professional health providers. Some participants described being nearly incapacitated by their illnesses, seriously impacting their schooling and social lives. They attempted a range of treatment options. None reported using traditional medicine, but all tried self-medication and medical check-ups with health providers, although often at lower-level public and/or private sector facilities. However, the frequency and persistence of symptoms left most young people sceptical of the appropriateness of the treatments they received. Although medical check-ups were common, they rarely included HIV testing.

3.6.2. Decision to test and the process of getting connected to HIV care

It was evident from the narratives of most of these young people that HIV testing was not the first option, although most had suffered persistent symptoms suggestive of HIV and their parents or carers may have suspected HIV. For many caretakers, especially biological parents, the decision to seek an HIV test often appeared to be complicated and threatening, which led to delays in testing and treatment initiation. Almost all the stories suggest one thing in common: caretakers were indecisive, avoided seeking a HIV test for their child, or didn't suggest one to the health worker who often treated them until the symptoms became severe or until a highly trusted health worker recommended it. Textual responses also suggested that while many young people reported a wide network of social support and care after diagnosis, there was a far more limited lay consultation between caretakers and other members of the family or community with regarding their child's symptoms and where potential help may be sought.

For many of these young people, therefore, their most crucial link into an HIV treatment programme was the connection with a health worker. Yet this was not every health worker whom they encountered in their treatment seeking process; it was mostly those who were either previously exposed to HIV care or had links and personal relations with fellow health workers already employed in an HIV clinic which promoted HIV testing. Many of our participants underwent HIV testing following provider-initiated testing, not voluntary counselling and testing: HIV testing was often done at the initiative of the health worker. Annet (age 19), for example, described the role of health workers in ensuring she accessed HIV care:

> The doctor [from Naguru health centre] sent us to that… is it called what… the place where they treat kids [in Mulago hospital]. Those people told me to come to IDI. I do not know why but when we went there, that same day, they gave us an appointment date, then when I went back, I was started on Septrin and I am still on Septrin.

The positive role of counsellors in disclosing results and helping the patient accept their status and adhere to treatment was also discussed. Most young people mentioned at least one HIV counsellor they believed had played a fundamental role in the helping them cope with their infection. They attributed many of the positive gains from ART, such as adherence, to those counsellors and to the general supportive atmosphere in the transition clinic that they were attending.

However, some young people emphasised their personal efforts and agency in the course of treatment seeking. Some spoke of how they had initiated the decision to undertake an HIV test or to confirm their diagnosis before promptly enrolling for treatment. For example, as Jane grew increasingly concerned about the symptoms she suffered, she made a personal decision to get tested for HIV in one of the City Council's Health Centres. Because she distrusted her initial results, she sought confirmation from another City Council Health Centre before getting linked to the Infectious Diseases Clinic in Mulago Hospital for treatment. Other participants discussed how they made an extra effort to get into the particular AIDS programme they preferred, highlighting their sense of agency in their treatment efforts. Margaret (age 21) described her role as follows:

> They called us in one by one for our results. It was then that the medical staff told me that I was infected. After that, they told me about two options that is Mulago Hospital and any other hospital of my choice where I would go and get treatment from. The following day we went to Mulago. There they told me that I was not ready for ARVs but I could start on Septrin.

4. Discussion

This exploratory study examined young people's illness experiences and pathways to HIV testing and treatment. We define pathways as the sequence of contacts with individuals or organisations prompted by the distressed person's own effort, and/or those of his or her significant others, to seek help (Rogler & Cortes, 1993). Our main interest was to describe young people's experiences with symptoms and options of care, how decisions are made and with whom, and the role of the young people themselves in the course of their care-seeking. The young people's accounts of their experiences with HIV illness, from when they were unaware that it was HIV to when they discovered their seropositive status, were fascinating and provide insights into factors that may lead to the delay to seek HIV care among this population. Overall, no obvious patterns suggested gendered differences in the findings. Males and females expressed their experiences, challenges, and concerns in relatively similar ways. A larger sample may have provided better insights into gender patterns.

We found sparse research on the social context and pathways to testing and accessing ART treatment by young people. The convenience sampling procedures and small sample size of this study limit the generalizability of these in-depth interviews. Qualitative data were collected from the young people themselves, so the findings suffer from potential self-report and recall bias. Without talking with parents and caretakers, we cannot know the full extent of what occurred in these families and in the caretaker's efforts to seek HIV care, since these young people might have not recalled their early treatment-seeking experiences. However, the fact that these young people described consistent experiences suggests that these are not issues of individual differences in the response of specific families to the ill health of young people but rather a pattern that deserves more attention from HIV researchers and programmers. This exploratory study contributes to the sparse literature and opens avenues for further research on this area. It documents the experiences along the pathway between symptom onset, testing, and HIV treatment access. However, as Hausmann-Muela, Joan Muela, and Nyamongo (2003) note, pathways to care are not deterministic or direct, but rather are dynamic and variable trajectories involving multiple courses of action with back-and forth-movements.

Adolescents' perceptions about their source of HIV infection shaped how the young people categorised themselves and influenced how they dealt with the news about their infection. Young people who believed they were infected through sexual transmission felt guilty, blamed themselves, and regretted their experience, often feeling that they had betrayed themselves and their caretakers who did not expect them to be infected with HIV. Some in this category feared disclosing their serostatus to their caretakers. On the other hand, those who suspected mother-to-child transmission did not convey a peculiar sense of guilt and regarded themselves as innocent victims. Adolescents infected perinatally and behaviourally tend to have different clinical and psychosocial support needs, including concerns about disclosure and stigma (USAID, 2012a, 2012b). They observed that behaviourally infected adolescents compared to perinatally infected adolescents are more likely than to live in denial and fear of HIV, are more likely to be misinformed about HIV, experience more adherence challenges, and lack familial, clinical and social support. These findings appear to support that observation and underscore the precarious situation of this category of young people living with HIV and suggest the need for this group not to be overlooked in adolescent transition programmes.

Some young people expressed a sense of frustration, resentment, and disappointment with their caretakers, who they believed had knowingly withheld from them true information about their illness. It is well established that more than 90% of children living with HIV are infected perinatally through mother-to-child transmission during pregnancy, around the time of birth, or through breastfeeding. The fact that many young people in this study learnt of their infection with HIV well in their teens suggests that their diagnosis took long to be discovered or disclosed. But widespread parental and caretaker 'silence' about the diagnosis, whether deliberate or unintentional, appeared to have negatively impacted on the young people's own efforts, personal agency, resilience in their therapeutic itinerary, and psychological distress. Yet, as some accounts have showed in this study, when the young people learnt of their infection, some promptly sought HIV treatment and remained adherent, demonstrating their ability to help themselves when confronted with an illness whose diagnosis and treatment they understood.

These findings also demonstrate that some young people immediately effected some behavioural changes, including disclosing to their sexual partners and abstaining or adopting condom use when they found out that they had HIV. Delaying disclosure of an HIV diagnosis to young people, especially sexually active ones, might undermine HIV prevention as well as treatment. Family support and relationships have been found to influence sexual behaviour of young people living with HIV, with those reporting family support more likely to have no or fewer sexual partners after their diagnosis compared to those without (Mhalu, Leyna, & Mmbaga, 2013).These findings thus contribute to the growing literature from diverse social contexts that report that when disclosure is done appropriately, followed with adequate counselling, children's reactions to their HIV infection tends to be favourable, with minimal long-term psychological and emotional consequences (Butler et al., 2009; Domek, 2010; Ishikawa, Pridmore, Carr-Hill, & Chaimuangdee, 2010) and good adoption of preventive behaviour (Bakeera-Kitaka, Nabukeera-Barungi, Nöstlinger, Addy, & Colebunders, 2008; Busza, Besana, Mapunda, & Oliverasd, 2013). However, Moyer, Kageha, Both, Cherutich, and Hardon (2013) note that disclosing in a manner likely to result in positive benefits for the infected individual is rarely straightforward.

The findings from this study highlight the importance of familial, institutional, and individual influences in facilitating or delaying access to HIV testing and/or ART among young people with HIV. Three possible factors were found to be important in the decision to delay versus promptly seek a test and/or get connected to a treatment provider. First was the role of the parents and caretakers. It appeared that many had difficulties realising or accepting that their child was infected with HIV. Transmission of HIV from a mother to her child during pregnancy, childbirth, or breastfeeding, commonly referred to as mother-to-child transmission (MTCT), remains one of the most frequent modes of HIV transmission in sub-Saharan Africa. Six percent of pregnant women receiving antenatal care (ANC) in Uganda are HIV-infected. To reduce transmission risk, these women and their infants need both antiretroviral (ARV) drugs and the appropriate care and support services to help them adopt risk-reducing behaviours. The Ugandan Ministry of Health (MOH) has made the bold decision to roll out the World Health Organization (WHO) prevention of mother-to-child transmission (PMTCT) Option B+, which calls for all HIV-infected pregnant women to be put on antiretroviral therapy (ART) for life. This roll-out began in September 2012.

However, ignorance of symptoms of HIV or stigma may lead caretakers to live in denial and not specifically seek for an HIV test for their children despite regularly seeking care for other symptoms, as found in a study in Kampala (Boender et al., 2012). Parents of perinatally infected children tend to face both moral and pragmatic dilemmas disclosing to them. Kyaddondo et al. (2013) found that alongside fear of stigma and fear that the knowledge of HIV will have serious psychological effects on the child, intense parental feelings of guilt often complicate disclosure of perinatally infected HIV. In addition, a mother informing her child that he or she is HIV-positive is tantamount to revealing her own HIV status. While caregivers may have the confidence or self-efficacy to take their HIV infected children to the clinic as required, lack of disclosure of the child's status is often a serious constraint, affecting access to health care by the child (Wachira, Middlestadt, Vreeman, & Braitstein, 2012).

Second was the role of health system and, specifically, the health workers. Young people's experience with health workers prior to and after ART was generally satisfactory. It seemed to these young people that the health workers not only understood their medical problem, but also appreciated the emotional and social context of their lives. Health workers appeared to influence uptake of HIV testing and ART in two different ways. On the one hand, although young people repeatedly sought care from health facilities for their symptoms, in many cases, the investigations rarely involved testing for HIV. The unavailability of specialist HIV services and skills in some health facilities, particularly in remote areas outside of Kampala, may have affected the HIV diagnosis and referral mechanism. Shortage of trained staff with appropriate counselling skills to work with children infected with HIV is a major obstacle to improving the quality of care for this group in many SSA countries (Rujumba et al., 2010; van Dijk, Moss, & Sutcliffe, 2011). Relying on health workers who are not trained to work with adolescents often leads the adolescents to feel unwelcome and misunderstood in care clinics (USAID, 2012a). However, the increased effort in recent years in Uganda to train medical workers in specific adolescent centred care and the policy emphasis to extend services for adolescents right to the lowest level (Health Centre Two's) may have alleviated this problem. For example, in 2014, the test and treat approach, in which ART should be initiated immediately for children below 15 years regardless of CD4 level or WHO clinical stage, was adopted in Uganda, and this has increased the number of adolescents initiating on ART. At the same time, the minimum CD4 counts for ART initiation were increased to <350 for those above 15 years, markedly reducing the delay to ART initiation. Although this represents a significant leap in the provision of adolescent and paediatric HIV treatment and care, there remains limited skills capacity in many facilities, especially the peripheral units (Republic of Uganda, 2015).

On the other hand, some health workers, especially those who appeared to have some links with specialist HIV care, were portrayed as important allies in HIV treatment-seeking because they helped identify the young people who may be exposed to HIV and enrolled them on ART. When given specific guidance and time, HIV programme implementers can play an important role in case-finding of HIV-positive youth and enhancing access to counselling and testing (Bell et al., 2003). Some health workers in this study, especially those working in facilities that provided HIV services or those who had direct personal contact with service providers at higher levels, promptly referred the young people to specialist care, counselled, and instilled hope as adolescents began to learn to live with HIV. For many young people, having gone through repeated episodes of illnesses and unexplained treatment mostly due to the silence by those who might have suspected HIV, the eventual contact with the specialist providers and the prompt testing and counselling received provided an opportunity for them to learn their serostatus and gave peace of mind. Future studies should focus attention on how children could be linked into specialised care by general health providers and assess factors associated with delay or prompt uptake of care as well as attrition from programmes among young people.

A third factor which is less reported in research among young people with HIV is personal agency by the young people themselves. Some of the adolescents in this study described their manoeuvres and self-determination to ensure they got tested and enrolled into the HIV care facilities they wanted, once they learned their diagnosis. This suggests that young people may benefit from early knowledge of their status as knowledge of their illness may invoke a certain degree of determination in their quest for therapeutic solutions (Mburu et al., 2013). WHO recommends that adolescents may access care in a variety of settings, including paediatric and antenatal care clinics as well as adult clinics (WHO, UNAIDS and UNICEF, 2010). However, since the Ugandan health system provides few paediatric -or adolescent-specific services (Boender et al., 2012), the challenges adolescents face to access health care and maintain adherence to treatment may persist.

5. Conclusion

The narratives of these young people reveal both obstacles and opportunities encountered in HIV treatment-seeking efforts. The delays to diagnose HIV and to enter into HIV treatment and care appear to be largely attributable to parent's decisions and actions and also to the absence of specialist HIV services and skills in some health facilities. However, health workers who were exposed to HIV care played an important role in referral and connecting the young people to care. The agency of the young people themselves, once they suspected that their illness could be HIV, was also crucial in ensuring prompt HIV testing and treatment-seeking. This study therefore suggests that understanding both the caretakers' roles and the agency of young people themselves in determining when to test for HIV and access ART may be vital in enhancing young people's HIV treatment efforts.

Competing interests

None.

Authors' contributions

GES conceptualized the study and drafted the manuscript. CEK and SBK reviewed the drafts. All authors discussed the analysis and drafted the case stories.

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