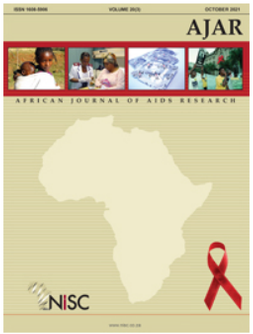

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Research Article

Barriers to ART adherence among school students living with HIV in Kenya

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HIV has transformed from a serious acute illness with high rates of morbidity and mortality to a fairly easily managed chronic disease. However, children and adolescents living with HIV are yet to achieve similar improvement in their HIV care outcomes compared to adults. There have been a number of studies assessing the reasons for slower improvement in these age categories, mainly focusing on health systems, drug- and family-related barriers to ART adherence in children. We sought to explore school-related barriers to adherence through in-depth interviews with students living with HIV (SLHIV) aged 13–17 years who had fully disclosed their HIV status in western Kenya. Data was analysed using NVivo 8™. The study found that stigmatisation in the form of negative discussions and alienation, fear of unintended disclosure (due to the drug packaging and lack of privacy while taking their pills) were barriers to ART adherence among these SLHIV. Other barriers included challenges with drug storage while in school and the complexity of coordinating school and clinic-related activities and a lack of structured support systems in schools. In addition to hindering their adherence to ART, these barriers resulted in negative emotions (anger, sadness, frustration) and affected school performance. This study found fairly serious barriers to ART adherence among SLHIV, which calls for structured communication and coordinated support between government ministries of health and education in Kenya.

Keywords: adolescents, disclosure, schools, stigma

Background

Desired HIV treatment outcomes such as reduced morbidity and mortality, reduced HIV transmission and increased quality of life requires that people living with HIV (PLHIV) achieve viral suppression. To achieve viral suppression, there is a need for near perfect adherence to anti-retroviral therapy (ART) (Chesney, 2003). Adherence to ART is affected by many factors including drug-related factors such as access to the drugs, pill burden and drug and health systems factors such as distance to clinics, unfriendly clinic hours and staff attitudes (Desmonde et al., 2018; Mehta et al., 2016; Shubber et al., 2016; UNAIDS, 2017). Most of these factors have greatly advanced over the years thus improving treatment outcomes. The magnitude of the improvement is, however, not uniform across age groups. A meta-analysis of data from low and middle income countries revealed an average viral suppression of 64.7% among children 18 years and below, compared to adults who had managed over 80% viral suppression (Boerma et al., 2016).

Studies describing barriers to ART adherence in children have largely focused on the health system and the home environment (Shubber et al., 2016). These barriers include the complexity of dosing, palatability of drugs, pill burden and dependence on other persons for administration (Garcia et al., 2015; Lockman et al., 2007; Sigaloff et al., 2011). As a result, most of the strategies for improving adherence to ART in children have had limited consideration that children over five years old spend most of their time in school with their peers and school staff.

In Kenya, the schools usually require a medical report on chronic and infectious diseases for each student at school admission. These forms are filled by authorised government health facilities. However, this is often disregarded for HIV due to the associated stigma. In addition, the caregivers fear doing personalised disclosure of the students' HIV status to the school staff for the same reasons as fear of stigmatisation. The school staff rarely come to the clinics and in many cases do not even know which clinics the children attend. The disconnect between the health systems and the schools with regard to the HIV care of students living with HIV (SLHIV) remains largely unexplored. We therefore sought to learn from the adolescents about the school-related barriers to adherence to medication.

Method

Study setting

We conducted this study at the Academic Model for Providing Access to Healthcare (AMPATH*plus*) health facilities. AMPATH*plus* is a partnership between Moi Teaching and Referral Hospital (MTRH), Moi University, and a consortium of North American universities focused on delivering HIV care in western Kenya. We targeted primary and secondary schools in four counties (Uasin Gishu, Busia, Kisumu and Trans-Nzoia) supported by AMPATH*plus*. These sites were selected because they have the highest coverage of children and adolescent living with HIV on the programme.

Study design

This qualitative study was conducted between April and May 2017 among 64 SLHIV aged 13–17 years. These adolescents had full knowledge of their status because it was fully disclosed to them. Purposive sampling was used to select a total of 64 SLHIV (Table 1) that allowed us to achieve saturation. Our protocol was reviewed and approved by Moi Teaching and Referral Hospital Institutional Research and Ethics Committee Eldoret Kenya.

Study procedures

The SLHIV were identified at their respective HIV clinics by the clinic staff who had been sensitised to the study. They linked them to the trained research assistants who provided participants with more information about the purpose of the study and obtained consent. Consent was also obtained from the parents of the students. All interview sessions were held in private rooms and participants' names were not used during the interview sessions.

The sessions had interview guides that included the following main domains: (1) Experience with adhering to HIV care while in school; (2) Challenges with adhering to HIV care while in school; and (3) Recommendation for supporting SLHIV while in school. All in-depth interviews were conducted in English or KiSwahili and took approximately 45 minutes. We audio-recorded all sessions. We offered participants an inconvenience fee of 500 Kenyan shillings (USD 5) at the end of the interview sessions. This amount is locally appropriate and is considered sufficient for lunch and transportation needs.

Table 1: Participants' characteristics

County	Education level	Gender		Total
		Female	Male	
Uasin Gishu	Secondary	7	7	14
	Primary	1	1	2
Kisumu	Secondary	7	6	13
	Primary	–	3	3
Trans-Nzoia	Secondary	3	6	9
	Primary	5	3	8
Busia	Secondary	5	3	8
	Primary	7	1	8
Total		35	30	65

Analysis

We transcribed audio recordings verbatim. We used NVivo 8™ (QSR International) for coding and analysis. For validation, three investigators (JW, CK and JO) conducted independent coding and identification of themes on twelve transcripts. These three investigators met regularly to discuss and agree on emerging and conflicting codes while revising the code book. Once the code book was finalised and consistency achieved, two additional trained research assistants assisted with coding. We used thematic analysis, with data coded under one or more themes. New themes were identified and added to pre-existing categories from the interview guide during the analysis. Data were scrutinised for differences and similarities within themes. The final results consisted of summaries, interpretations and textual excerpts.

Results

We present excerpts from the FGDs to illustrate the themes that emerged. These excerpts are parts of the responses from the respondents (R) of parts of conversations with both the moderator (M) and the respondent statements. We have described the respondents as being in either primary school or secondary school (either of which is day or boarding) to demonstrate the diversity of the schools of our study participants. We identified six main themes as barriers to adherence to ART among students living with HIV.

HIV-associated stigmatisation

Some students had experienced direct stigmatisation in school after their status was discovered by their peers or by school staff, while some experienced it through negative discussions around HIV while at school.

> Secondary boarding female: R: *…they opened my bag and then they removed all of my drugs so that is how the rumours spread…*
> M: *And then what happened?*
> R: *They started like…my friends started dispersing, they never wanted to stay with me again.*
>
> Primary day male: *They say that HIV is terrible and it kills…*
>
> Secondary boarding male: *Just the way the teacher usually says that it is a deadly disease so the pupils also come saying that there is one they saw so thin and so I just join the conversation saying that I also saw the thin person and laughed, then we begin to tease a bit.*
>
> Secondary boarding female: *They usually say that HIV is not a good disease and that we take very big medications.*
>
> Primary day male: *In fact, you will just be surprised to hear that other people are also aware of your HIV status. Sometimes maybe if you are in disagreement with your friend, he or she would begin talking about you and the medications you are taking and say that you are HIV infected so you end up not being happy that day.*

The stigmatisation influenced the feelings of the SLHIV about themselves, making them feel bad, angry, sad and frustrated.

Primary day female: *I always feel bad…It is because they usually talk like that, yet I too I am HIV infected so I end up thinking about myself.*

Secondary boarding female: *…Even me, I felt frustrated…*

Secondary boarding female: *Of course you will just get hurt although there isn't anything much you can do about it…*

Secondary day male: *Deep inside, I feel bad but there is nothing I can do.*

While some students reacted by keeping quiet and pretending not to listen to the negative discussions, some would walk away, while others would join in and pretend not to be living with HIV. However, the negative feelings made some of them drop in their school performance, and some had to change schools to cope.

Secondary boarding female: *…I totally dropped in my school performance until I asked my mum for a transfer to another school…I transferred to another school.*

Fear of unintended disclosure from the drug packaging

Students feared that school staff or students may get to know their HIV status due to the packaging of the antiretrovirals (ARVs). They reported that the drug bottles were large, and that the pills made sounds that were distinctive while in the packaging. In addition they feared that the labelling on the packaging would reveal which drugs they were taking.

Secondary boarding male: *The noise from the bottles, people are like…these people of noisy bottles.*

Primary school day male: *Those bottles are too large and unique; my friends will wonder what I'm carrying…*

Secondary boarding female: *I think they should change the container of the medicine. It should not be written AMPATH or USAID because if it is so, most people know this hospital*.

The SLHIV said they would add some cotton wool or some tissue paper to the bottles to lessen the noise. Some students reported leaving the bottles at home and instead carrying the drugs in paper bags, envelopes, multivitamin bottles, lotion bottles and sometimes in their sanitary pads.

Lack of privacy to swallow drugs

The SLHIV reported that the school environment does not allow for privacy as often students do activities in groups and hang out in quorums.

Secondary day male: *Friends were following me everywhere, in the field, in the dormitory. When I open my box, they are right there, so I feel ashamed and ask myself what should I do? Because they could follow me, so it was difficult to take my medication hence I could skip and it became a habit.*

The students often have to make excuses to be alone to be able to take the drugs, causing anxiety and fear of the lie being discovered.

Secondary day female: R: *I may ask for permission to go to the toilet, and that's when I take my medicine.*

M: *So you take your medicine in the toilet?*

R: *Not the toilet.*

M: *Where?*

R: *Once I have told the teacher that I am going to the toilet, I leave and maybe hide behind the class and take the medicine.*

M: *…return to class?*

R: *No, I stay a while first so that the teacher believes I actually was going to the toilet. I wait around a minute, then I get back.*

The students reported having to carry their drugs around so that they swallow them whenever an opportunity to be alone arose. Sometimes the drugs would fall out and cause embarrassment or get wet from rain or sweat.

Secondary boarding female: *Other than putting it in our pockets and in case it rains it messes up the medicine so it is usually irritating to take that medicine*.

M: *are you rained on at times?*

R: *Yeah, with the medicine in my pocket, so it becomes wet.*

Difficulties with drug storage

Some students reported storing the drugs themselves, while others had their drugs kept with the class teachers or matrons. Both had advantages and disadvantages. Those who stored the drugs themselves did so mainly because they had not made any disclosure in the school and so reported that lack of privacy and fear of the drugs being discovered was a major challenge. Sometimes the student shared lockable cabinets or metallic boxes and sometimes, even if they had individual storage places, they were not lockable and accidental disclosure would happen from a peer looking though their bags or lockers.

Secondary boarding female: *I had my friend. We were putting things together in one box. She had her box but we decided to share because we were friends and then I had my cousin in the same school. So it was difficult for me to take drugs sometimes…I took drugs for almost three months and it reached a time when it was hard for me to take the drugs. The matron could come do the inspection, teachers* [too], *now I decided to leave the drugs.*

Secondary boarding female: *It was a mixed school so I couldn't go with the drug to class, so you just leave it in the box and it was easy for your bed mate to know. And if he knew, every person in the dorm will get to know…With time, they got to know I was taking the drugs but they never knew they were for HIV, they thought it was for diabetes.*

School checks were reported to be especially difficult for these students as school staff would then peruse every storage place for illegal drugs and items.

Secondary boarding female: *It once happened that there was a search in school. They suspected there were illegal drugs in school so we were told there would be a search everywhere. I feared they could find out I was taking HIV medication so I took my medicine and threw it behind the cupboard and then I went away. So we were checked, we went to class and came back. I looked for my medicine behind the cupboard but I couldn't find it, yet it was*

in the middle of the term and we are only allowed to make phone calls in school every now and then. So I missed medicine for about two months.

The students who had their drugs stored for them reported that the fear of being noticed making frequent trips to the drug stores was a major challenge as well as sometimes being unable to access the drugs if the keeper of the stores was away.

Complexity of coordinating clinic schedule with school activities due to strict school schedules

SLHIV reported constantly having to weigh between missing a school activity over a clinic-related activity and often having to choose a school-related activity over a clinic visit, for instance, in cases where examinations are due yet the student has run out of pills. This was also mirrored in the timing for taking the drugs; sometimes students are forced to skip or delay taking their pills. The students sometimes have to make an excuse to get out of class to be able to take their medication, creating constant anxiety.

Primary day male*: On that day, there was a certain teacher in class whose lesson normally lasts from 6.00 a.m. up to 8.00 a.m. So during such times I usually just take my medications late.*

The students also reported difficulties coordinating getting out of school for clinics if the persons to whom they had made disclosure were not available or if they had not made disclosure to the schools.

Primary day male: *At times in school, maybe that particular teacher who was informed about my HIV status is not in school, so whenever you want to seek permission from another teacher, it becomes difficult because they don't agree since they don't understand your condition. So, such would make you relapse.*

Primary boarding female: *You know, sometimes they usually give a return visit after every one month, however, recently, I was told to come back on 2 March although I couldn't attend because I was in school and the teachers were strict and didn't want anyone to miss classes, so that's why I couldn't attend clinic, however, I still had medications…*

The students thought that clinic visit dates would be more convenient to them if they were given in consultation with them, and especially if they were given over the holidays.

Secondary boarding female: *If maybe the clinician sent you to draw blood and yet you are also about to re-open school, maybe the following month, so you are forced to come back for results after a short time and maybe it finds you in school.*

Inadequate support structure in schools

The adolescents reported not being aware of any support structures available to them in school. They reported that for children with other problems and diseases such as ulcers and diabetes there were some support structures such as optional meals or being exempted from some activities that worsen their condition and that the school nurses or sanatorium were often available for help. But, for the SLHIV, there was nothing in place. They said that support with drug storage was an issue:

Secondary day male: *I was in a boarding school when I was in form one, form two but I couldn't cope because I interacted much with friends in school so it was very difficult to take medicine. The person who was supposed to keep my medication was not so much concerned and was rarely in school, so I had to keep medicine in my box and sometimes it was difficult to take medicine.*

There was also a lack of support for clinic visits in circumstances where they needed someone to pick up their drugs on their behalf:

Secondary day male: *I have missed maybe because of exams, so there is no one to come and represent me here. Mostly I experience the challenge when I have no one at home to go, maybe we had exams or we went for games, so when you come, you are late.*

Discussion

Children and adolescents living with HIV (CALHIV), like other PLHIV, must have near perfect adherence to the drug programmes if they are to achieve viral suppression and subsequently have improvement in their treatment outcomes. The benefits of good treatment outcomes for this group include improvement in their academic achievements, their physical and mental development and their socialisation. We, however, currently see a lag in the improvements in viral suppression rates in these age groups in low and middle income countries (Boerma et al., 2016). School-related barriers are scarcely described in the existent literature, yet we know that this age cohort is largely in school and bound to be affected by the school environment.

HIV education was incorporated into the Kenyan school curriculum in 2003, followed by the publication of an HIV education policy in 2013 aimed at guiding the school staff on prevention, care and support for PLHIV and reducing HIV-associated stigmatisation (USAID, 2013). In addition, the Ministry of Education, through reviews of its curriculum, has made great progress in building life skills necessary for making reproductive health choices and reducing risky behaviours among students, albeit with many implementation challenges (Sidze et al., 2017; UNESCO, 2009; United Nations Population Fund, n.d.).

We found that HIV-associated stigmatisation existed in the school environment in Kenya among fellow students and among school staff and was expressed in negative discussions around HIV and in alienation. Students who had not disclosed their status largely experienced the stigmatisation through the negative discussions, while those that had disclosed their status, or had an accidental disclosure, experienced alienation in addition to the negative discussions. Stigmatisation has been shown to worsen care outcomes for marginalised groups by impairing their access to quality care (Ammon et al., 2018; Ayieko et al., 2018; Boyes et al., 2018).

School-related, HIV-associated stigmatisation may be from inadequate knowledge of the improvements in treatment outcomes of HIV among students and school staff. This may be due to infrequent school curriculum reviews that prevent the curriculum from keeping up with the constant changes in the HIV field. The students reported that teachers still described HIV as a killer disease, and

associated HIV with severe wasting of the body. HIV was also being associated with large and scary pills. The SLHIV also experience self-stigmatisation, which points to the need for psychological counselling and resilience building.

In addition to stigma reduction, an HIV education policy was published to give guidance for the support of PLHIV in the ministry. However, we found that SLHIV are facing challenges, particularly in the lack of privacy for swallowing pills, difficulties with drug storage, strict school schedules that complicate their clinic appointments and lack of structured school support systems. This mirrors findings in Zimbabwe and Uganda where teachers reported lack of knowledge and structures for supporting their SLHIV. They said that often support was based on individual teachers who were empathetic, and that often the support was insufficient (Campbell et al., 2016; MacCarthy et al., 2018). Unsafe packaging and a lack of privacy for swallowing drugs were also mentioned in Uganda (MacCarthy et al., 2018). One 2005 study in the USA, which assessed adherence among adolescents who had horizontal acquisition of HIV and who had high alcohol abuse and mental health disorders, found that being in school offered them a structured schedule thus it improved adherence. This shows that schools can be modified to offer great support to CALHIV, even though this population differs from that of children with perinatal infections who may not be engaged in high-risk behaviours (Murphy et al., 2005).

It is notable that there was a scarcity of school-related data in our literature search. One large systematic review of over 5 000 abstracts extracted globally and which included about 2 000 children found that forgetting to take drugs, being away from home, change of daily schedule as well as health service-related barriers such as distance to clinic and drug stock-outs were barriers to drug adherence in children (Shubber et al., 2016). Other barriers reported in India were mothers' fear of giving medication in the presence of other people, adverse events, drug stock-outs, inconvenient clinic hours, difficulties with transport and the distance to clinic (Mehta et al., 2016). Patient-provider relationships have also shown a significant effect on adherence in a number of studies (Shubber et al., 2016). Because of the robustness of the studies evaluating the effect of these factors, significant strategies have been made to address them. These include the promotion of simplified paediatric regimens, support for caregiver/family education and economic empowerment, support for training of health personnel on child communication and setting up of adolescent-friendly clinics (AIDSinfo, n.d.).

In 2009, Haberer and Mellins published a comprehensive framework for analysing barriers to adherence to ART in children. This framework omitted school-related factors, likely because this was hardly mentioned in the existing literature.

Our study fills the gap in the data available on the barriers to ART adherence in children and adolescents living with HIV, and could help support the WHO target of achieving 95% viral suppression in CALHIV by 2030. In general, the SLHIV who had disclosed their status to some school staff and/or students reported fewer difficulties with these issues. Students need to be given skills on how to properly disclose their status to ameliorate negative reactions from those to whom they disclose this information. In addition, there is a need to support building resilience among SLHIV by the clinic, the family and the Ministry of Education. SLHIV also need to be educated on their rights as PLWHIV as do the schools. This is not in the current education curriculum, and many rights are unknowingly violated and unreported.

Conclusion

HIV-associated stigmatisation, lack of privacy for taking drugs, difficulties with drug storage, strict school schedules that complicate coordination of school and clinic activities and lack of structured school support systems are common barriers to adherence to ART in SLHIV .

Recommendations

The Ministry of Health together with the Ministry of Education should work closely to put in place structures for support of adherence to medication among SLHIV and to reduce HIV-associated stigmatisation in schools.

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