

Care and Support for Adolescents Living with HIV/AIDS in School Settings: Perspectives of Teachers and Administrators in the Southern Highlands of Tanzania

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Abstract

Background: Adolescents living with HIV (ALHIV) encounter diverse challenges in school settings that impact their well-being and academic performance. This study sought to delve into the viewpoints of teachers and administrators regarding the care and support accessible to ALHIV in schools.

Methods: In 2021, a qualitative study was conducted employing focused group discussions (FGDs) and key informant interviews (KIIs). The study was conducted in the Njombe and Songwe regions, encompassing four districts and eight schools. FGDs were held with schoolteachers and matrons/patrons, while KIIs were conducted with coordinators at the regional and district levels. Thematic analysis was employed for data analysis.

Results: Various forms of support for ALHIV in schools were identified. Schools had designated health teachers/matrons/patrons responsible for addressing health-related issues, including those affecting ALHIV. Assistance for clinic visits and medication adherence was readily available. Peer clubs were established to combat stigma and discrimination while providing additional support. Nevertheless, challenges such as staff members' limited knowledge and skills, reluctance to disclose, inadequate nutritional support, and insufficient backing from regional and district administrators persist.

Conclusion: The study underscored the existence of care and support mechanisms for ALHIV in school settings while pinpointing areas for enhancement. Recommendations encompass capacity building for teachers and staff, bolstering support for disclosure, offering nutritious dietary options, reinforcing peer clubs, and fostering collaboration between the education and health sectors. These findings can inform the development of comprehensive interventions to support ALHIV in school settings better, ultimately advancing their well-being and academic achievements.

Keywords: Adolescents, HIV, School health services, Tanzania

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1. Introduction

The World Health Organization (WHO) defines adolescents as individuals aged between 10 and 19 years (1). They constitute a significant demographic group, comprising approximately 23% of the population in Sub-Saharan Africa (SSA) (2). With the widespread availability of antiretroviral therapy, many children infected perinatally now survive into adolescence, young adulthood, and beyond (3). This implies that most of them can attend school and pursue tertiary education. In addition to perinatal infections, adolescents are also vulnerable to sexually transmitted infections. UNAIDS estimates that half of all new infections

occur among youth aged 15-25 years, further increasing the number of Adolescents Living with HIV (ALHIV) in educational settings (4). Tanzania, in particular, grapples with a generalized HIV epidemic, boasting a prevalence rate of 4.5% and an estimated 1.7 million individuals living with HIV, among whom 96,000 are below the age of 15 years. Youth aged 15-24 accounted for 28% of the 54,000 new infections (4).

Schools serve as vital developmental environments for children and adolescents, influencing their social, emotional, cognitive, and behavioral development. Within the school context, they also acquire values and skills applicable to life (5).

Moreover, schools have the potential to function as hubs for comprehensive HIV/AIDS response, as they bring together educators, caregivers, and others committed to caring for vulnerable youth (6). However, children and ALHIV often face challenges in school enrollment, attendance, and academic achievement due to various factors such as illness and economic hardship stemming from ill or deceased caregivers (7).

Various interventions have been implemented to enhance support for children and adolescents attending school. These encompass school-based counseling, initiatives to combat stigma and discrimination, support for treatment adherence and medication retrieval, and, in some cases, the provision of food (7). Additionally, social support networks, such as peer clubs, have been recognized as valuable sources of assistance (8). In boarding school settings, support mechanisms such as treatment adherence monitoring, psychosocial support, and linkage to healthcare facilities are in place (9).

Despite progress in improving support and care for HIV-positive students, several studies have identified multitudes of challenges. Stressors; including stigma and discrimination, a lack of counseling and psychosocial support, limited treatment support, and inadequate access to nutritious food at school were identified in Uganda (10). Insufficiencies in organized or comprehensive care for children and ALHIV, challenges related to disclosure management, and issues with treatment adherence have also been highlighted in other research (11). Furthermore, a study involving adolescents in Tanzania revealed a multitude of gaps in care and support for HIV-positive students in schools; only 33% of disclosed students received support, confidentiality concerns were noted, and treatment adherence support was limited. Inconsistencies in obtaining permission to attend clinics for treatment and medication pick-up were also observed (12). Importantly, this study primarily focused on adolescents' perspectives, while other critical stakeholders in the school environment, such as teachers, were omitted. Building upon these findings, the present study aims to investigate the perspectives of teachers and administrators regarding the care and support provided to ALHIV in school settings in the Southern Highlands region of Tanzania.

2. Methods

2.1. Study Design, Setting, and Participants

A qualitative research design was employed to gain insights into the care and support received by ALHIV in school settings. Two primary data collection methods, Focused Group Discussion (FGD) and Key Informants Interviews (KII), were utilized. Specifically, two regions in the Southern Highlands region, namely Njombe and Songwe, were selected for the study. These regions were purposefully chosen due to their higher HIV prevalence rates, coupled with low levels of HIV prevention knowledge among youth (13).

Within each selected region, one urban and one rural district were deliberately chosen, resulting in four selected districts for the study. In each of these districts, one primary and one secondary school were included as participants in the research. All four primary schools were public institutions, while three of the secondary schools were public, with the remaining one being a private school. A more comprehensive overview of the schools' characteristics can be found in Figure 1.

At the regional and district levels, interviews were conducted with coordinators overseeing school health and HIV-related activities. At the school level, FGDs involve schoolteachers, head teachers/masters, and matrons/patrons responsible for supervising health activities within the school environment.

2.2. Data Collection

Semi-guided interview tools were developed for KII and FGD to capture data adequately. At the regional and district level, KII focused on the implementation of national policies, plans, and guidelines to improve access to HIV services among ALHIV. A total of 13 coordinators were interviewed. FGDs were conducted with 8 groups and involved 48 participants with an average of 6 participants per group/school. The first author was supported by two trained research assistants in data collection. At each school, we sought permission from the headteachers. After explaining the purpose and procedure of the study and obtaining their permission, they convened a group consisting of teachers and matron/patron. FGD had a broader context involving participants from rural and

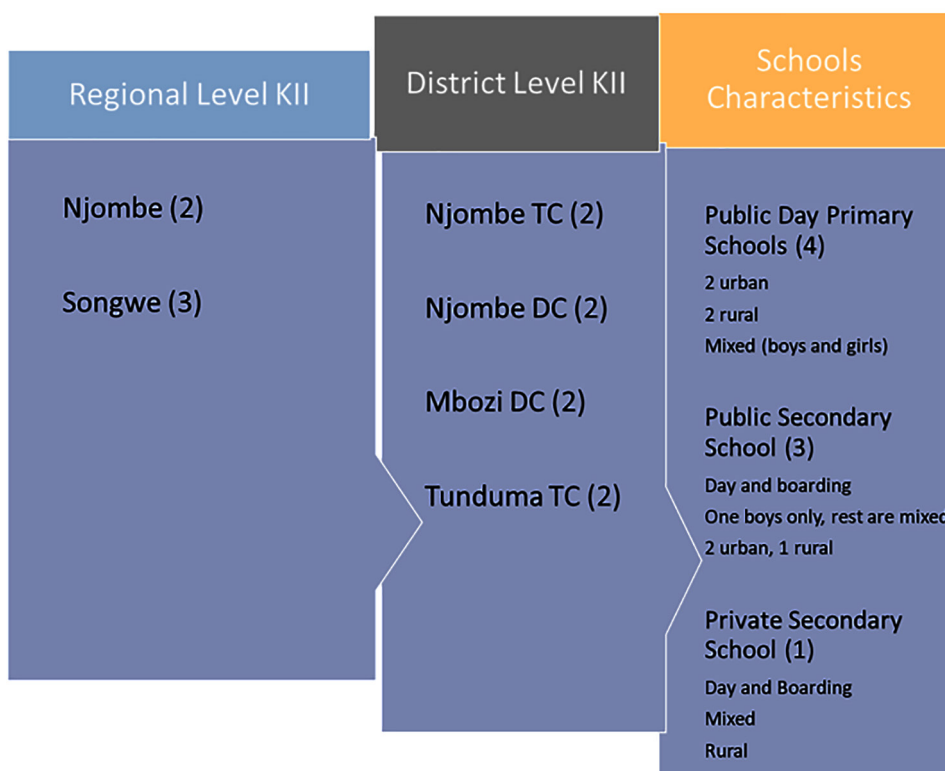


Figure 1: The figure shows the regions, districts/councils, and schools engaged in the study.

urban schools and private and public schools; this helped to understand the dynamics involved in addressing stigma and supporting ALHIV. FGD also explored how the councils support the school health program through funding, capacity building, and supervision. Each session of FGD lasted for 60 to 90 minutes. FGDs and interviews were audio recorded with consent from participants. Note-taking was also done to capture the main ideas that arose and the non-verbal information. FGDs were conducted in Swahili, an official national language. Data collection was conducted in November and December 2021.

2.3. Ethical Approval

The assessment represents a subsequent investigation building upon prior research (12), which received approval under reference number 3049 from the National Institute for Medical Research (NIMR). The assessment protocol underwent rigorous scrutiny and received endorsement from both the ministries of health and education. Prior to commencing the interviews, explicit consent was actively pursued, and the participants duly executed consent forms. It is essential to note that no personally identifiable information was gathered; instead, serial numbers/

codes were implemented to designate each questionnaire/interview guide. As an expression of gratitude for their participation, participants were remunerated with an equivalent sum of 5 United States Dollars (USD) for transportation expenses.

2.4. Data Management and Analysis

Data in audio files were transcribed verbatim by first author and research assistants fluent in Swahili and English. FGDs and KII were translated into English, and all transcripts were checked against the original audio recordings for accuracy. Thematic data analysis was conducted using an inductive coding approach. First and second authors independently read through two FGD and two interview transcripts to become acquainted with the data and formulate initial coding ideas. The research team reviewed and reached a consensus on the code book.

First author used the developed codebook to code all the transcripts in conformity with the research questions while remaining open to new emerging codes. Coding was done using Dedoose, web-based software for analyzing qualitative and mixed-method research. Next, the codes and all extracts of data coded concerning them were

collated into potential themes and overarching themes. To ensure study rigor, we applied Lincoln and Guba criteria to address study rigor. The criteria are focused on credibility, dependability, confirmability, and transferability (14).

3. Results

During the FGD conducted at the school level, an evaluation was carried out to assess the support and care provided by the school for ALHIV while they attend the educational institution. The primary topics arising from the discussion and subsequent analysis encompassed the following aspects: the presence of health educators, matrons, or patrons; provision of assistance for clinic appointments and medication management; the role of peer support; and the strategies employed by schools to combat stigma and discrimination against ALHIV.

3.1. Availability of Health Teacher/Matron/Patron

In all the schools we interviewed, at least one teacher was chosen to serve as a health educator. Typically, these individuals are science teachers responsible for addressing various health-related issues affecting students, including ALHIV. This role was unanimously agreed upon in all eight FGDs.

One participant in FGD8, a secondary school, shared the following insight:

“There is a designated health teacher who handles the health concerns of our students. All students with different health problems seek special attention from this teacher because we lack a nurse.”

Certain schools have a single health teacher responsible for this role, while others have separate health teachers for each gender. Coordinating school health activities and providing care for ALHIV are additional responsibilities alongside their regular teaching duties.

3.2. Support for Clinic Appointments and Medication

Support for clinic appointments and medication is available in all the schools we interviewed, with some variations depending on whether the school is a day school or has boarding facilities. Day school students typically take their medications at home and are allowed to arrive at school later to ensure they can take their medications and have breakfast

comfortably.

“Most of the adolescents here take their ARV drugs at home in the morning because it is a day school.” (FGD1, an urban public primary school)

In boarding schools, students keep their medications in their dormitories, and they are responsible for taking them, especially if they have not disclosed their HIV status. Students who have disclosed their status can store their medications in the mini dispensary or a designated room for drug dispensing.

“They keep their medicines themselves. They ask for permission from their class to come and swallow their medicine in the dormitory.” (FGD8, a public urban secondary school)

For those who have disclosed their status, teachers typically provide support.

“They have the opportunity, and any student who needs to take medications can simply request permission from the class teacher and go to the health office to receive their ARVs from the health teacher in charge.” (FGD7, a private rural mixed-gender secondary school)

Regarding permission to attend the clinic, all FGDs agreed that pupils can attend the Care and Treatment Centre (CTC) upon request.

3.3. Peers' Clubs

Peer clubs play a pivotal role in the national school health program and comprehensive sexuality education by allowing students to engage in discussions extending beyond the classroom, all under the guidance of trained peers and/or teachers. During our visits to various schools, it was noted that all schools except one private secondary school had established peer clubs specifically focused on health and HIV prevention. These clubs are meticulously overseen and supported by dedicated teachers.

“All of these clubs are under the watchful eye of appointed guardians. These guardians deliver HIV training sessions to students every Friday at a designated time, covering a range of topics, including methods of protecting oneself from HIV/AIDS. The subjects covered in these sessions are refreshed every Friday.” (FGD8, a public urban secondary school)

These clubs also serve as a platform to combat discrimination and stigma against People Living with HIV (PLHIV).

“We are confident that such occurrences will be rare, as club members receive comprehensive training. If such incidents arise, our commitment to educating individuals will persist, as it signals a lack of understanding of the crucial information being imparted.” (FGD8, a public urban secondary school)

A collaborative initiative has been proposed to engage youth from NACOPHA clusters and the Network of Young People Living with HIV to support specific club sessions as peer facilitators. This collaboration will equip students with essential knowledge and skills for addressing stigma, HIV care, and prevention.

“In the school environment, we have existing Youth clubs that can serve as a conduit to establish connections with schools. Furthermore, some schools have already integrated youth clubs, which include members living in challenging environments similar to the ones we engage with.” (K9, National Council of People Living with HIV)

3.4. Addressing Stigma and Discrimination

The approaches include using peer clubs to address stigma and discrimination, as described earlier. Teachers usually call both parties for an educative discussion and resolution when it happens.

“We will call both students. The one that has been stigmatized and the other that stigmatized him. We will counsel and educate them and make a note to conduct a seminar for the other students.” (FGD8, a public urban secondary school)

3.5. Challenges

Despite the availability of support for ALHIV in school settings, the discussions also revealed several challenges in caring for ALHIV. Some of the emerging themes include the following:

3.6. Essential Knowledge and Skills in Care for People Living with HIV/AIDS

Many matrons and patrons did not undergo

formal training, resulting in a deficiency of counseling, adherence follow-up skills, and the ability to refer children for additional care appropriately. Within the context of school-based FGDs, it was revealed that 5 out of 8 FGDs noted that the personnel responsible for health services lack the necessary training, consequently impacting the delivery of health services, particularly in the care of ALHIV.

3.7. Disclosure

Disclosing HIV status is the first step toward receiving appropriate care for clients living with HIV. However, due to fear of stigma and discrimination, many adolescents hide their status from their teachers.

“Let me add something: we cannot identify those students if the parents have not told us. Many of the parents are very secretive and do not tell us the truth.” (FGD8, a public urban secondary school)

Not disclosing their HIV status hinders access to various available support existing in school settings.

3.8. Availability of Food

Many respondents expressed the view that children taking HIV medication require food in the morning and afternoon due to the potent nature of the drugs on an empty stomach. One of the significant challenges addressed during the FGD and KII sessions is the availability of food for pupils on long-term medications, including ART, and how it impacts their well-being.

“I used to observe students coming to school with extreme hunger, taking their medications, and then struggling to concentrate during their classes because of the potent nature of the medicines. Later, they are still hungry when they return home; perhaps their parents have not yet returned from work. They must wait for their parents to return, which presents a considerable challenge.” (KR11, District School Health Coordinator (DSHC))

The proposal was raised to provide support through school feeding programs or other social safety nets.

“Supporting these families in obtaining food for their

children through programs like TASAF is essential, as some of them are unable to afford even a single meal despite their children being on medication.” (FGD6, a public urban secondary school)

3.9. Support from Regional and District Administrators/Coordinators

At the sub-national level, President’s Office Regional Administration and Local Government (PORALG) oversees the implementation of the school health program and HIV interventions, operating under the technical guidance of the Ministry of Education, Science and Technology (MoEST). Within the sub-national context, the education and health departments have designated school health coordinators responsible for executing school health initiatives within educational institutions. These initiatives encompass immunization, nutritional support, water, sanitation and hygiene (WASH) programs, life skills education, HIV/AIDS prevention, and the management of Gender Based Violence (GBV) issues.

In all regions and districts we surveyed, at least one school health coordinator was affiliated with the education department at each administrative level. Their primary duty is coordinating all health-related activities within educational institutions in conjunction with the health department. Additionally, council HIV and AIDS control coordinators actively participate in these endeavors due to their roles as coordinators for HIV/AIDS initiatives within the community.

“At the regional level, we have school health coordinators representing the education department, extending their presence from the school level to the regional level.” (KR7, Regional AIDS Control Coordinator (RACC))

In order to facilitate the effective implementation of policies and guidelines within schools, school health coordinators are tasked with conducting regular visits to educational institutions. These visits provide supportive supervision mentorship programs and address students’ health-related challenges, particularly ALHIV. The scheduling of these activities is meticulously outlined in annual work plans, albeit their irregular execution due to budgetary constraints.

“We are expected to conduct reviews and

supervision visits every three months. However, on occasion, budgetary limitations impede our ability to reach all schools as planned.” (KR11, DSHC).

Furthermore, there is a notable scarcity of health-related supportive supervision visits at the school level. Six out of seven FGDs revealed that they had not received any form of support in the form of supervision or mentorship about health or HIV services over the past six months. The lone exception was a school that received a visit related to WASH in October 2021.

“We have never received any form of assistance. We operate independently, as we lack comprehensive guidelines, training, or seminars provided by the relevant authorities.” (FGD1, Primary School)

Moreover, at the school level, there is a resounding call for guidance and support from the district and regional levels.

“Secondly, we urgently require support from the district level. Their visits can provide us with much-needed guidance.” (FGD6, Secondary School)

4. Discussion

Investigating the care and support available for ALHIV in primary and secondary schools in the Southern Highlands of Tanzania, we examined the perspectives of schoolteachers and administrators. Their suggestions for further enhancing the care provided to ALHIV were also sought. Various forms of support, including the presence of a health matron/patron, addressing stigma, support for clinic attendance, and adherence, were observed across the schools. Peers’ clubs were also in place, reinforcing sexuality education and moral values and addressing stigma and discrimination.

In each of the visited schools, at least one teacher was designated as the health teacher (also known as matron/patron). These individuals are responsible for all health-related matters in the school, offering support to ailing children or those with chronic illnesses. Furthermore, they collaborate with nearby health facilities and departments to coordinate various health interventions. Their roles are comprehensively outlined in the national school health program guidelines (15). In Uganda, school staff (teachers, school nurses, and matrons) provide general guidance and counseling to all

students, focusing on career growth, life skills, personal hygiene, general health, and sexual and reproductive health (8). Similarly, selected health teachers assume similar roles in Kenya, with support from school health committees (9).

Our study revealed that despite their roles, teachers required comprehensive capacity building to equip them with the necessary knowledge and skills for providing counseling, HIV care, and addressing discrimination. These teachers already have regular teaching responsibilities, so health activities were perceived as an additional burden. The need for capacity building for teachers and staff on how to support ALHIV was also identified in a study conducted in northern counties in Kenya, with training being conducted before the implementation of adolescent-friendly services in school settings (9). Similar findings were observed in Kisumu (16). In urban schools in western Uganda, professional counselors are hired to provide counseling services and minimize the burden on teachers (8).

Our study noted that in all the visited schools, ALHIV received various forms of support to ensure they maintained drug adherence and attended clinics. Students could arrive late in the morning if they needed to take their medications. In boarding schools, students who had disclosed their HIV status could keep their drugs at the teacher's office. There were no restrictions on attending clinic appointments and picking up medications; when students requested permission to attend clinics, it was readily granted. It is noteworthy that in Tanzania, an HIV care clinic for children and adolescents operates on Saturdays to ensure that students can attend school programs without interference. Similar support was observed in a study conducted in Western Uganda, where teachers and school nurses provided treatment adherence support to children on antiretroviral therapy (ART) (10, 17). Referrals to health facilities for further care were also available (10). In the context of the Red Carpet Program, intervention ARVs storage and adherence support were provided to students on ART (9).

However, it is essential to highlight that the lack of HIV status disclosure limits access to the support available at school. Undisclosed students are not monitored for drug adherence and often keep their medications at home or in the dormitory.

They also face challenges in obtaining permission to attend clinics. This issue was similarly identified in a study conducted in Tanzania, where clinic attendance for drug pick-up and adherence support was challenging for undisclosed children (12). ALHIV were reluctant to disclose their status due to fear of stigmatization and discrimination from teachers and their peers (12, 16). For undisclosed adolescents, the absence of privacy for taking medications was cited as a reason for non-adherence to the medication schedule in Namibia (18) and other settings (7, 10, 19). To address this challenge, one program implemented measures such as providing drug storage cabinets and safe spaces for taking medication to improve adherence (9). Lack of disclosure also posed a hurdle to receiving support for ALHIV in a study conducted in Kisumu, Kenya, where support included being allowed to go to the clinic without facing reprisals, being excused from labor-intensive activities, or receiving nutritional supplementation (16).

Stigma and discrimination against PLHIV remain prevalent within our context. The Stigma Index Report 2.0, published in 2021, revealed that approximately 6% of PLHIV experienced external stigma (20). Within educational settings, ALHIV encounters stigmatization from both educators and their peers (12, 16). While our study primarily focused on interviewing teachers, it is essential to acknowledge that ALHIV perspectives on stigma and discrimination were not explored. Nonetheless, the participants we interviewed concurred that such issues persist within schools. Multiple studies have extensively documented stigma and discrimination in educational settings (7, 10, 16, 18, 19, 21).

Regarding strategies to address stigma and discrimination, our study has documented several approaches, primarily involving civics and moral education subjects. Whenever an incident of discrimination is reported, teachers utilize the opportunity to educate the offender and counsel the victim. Peer clubs exist in all the schools we visited, except one private secondary school. These clubs offer a platform for reinforcing classroom knowledge within a friendly and interactive environment guided by teachers. The topics covered by these clubs include sexual and reproductive health, HIV/AIDS, stigma, and discrimination. Research indicated that peer clubs are effective in increasing awareness about HIV/AIDS and its prevention (22).

In various contexts, peer clubs not only help ALHIV to make friends and socialize but also serve as a means to address stigma and discrimination (8). In addition to anti-discrimination measures, peer clubs can offer peer counseling and support (9). Teachers who participated in our interviews suggested that disclosed ALHIV should be connected with networks of young people living with HIV to provide them with close support. The school is regarded as having the potential to equip all learners, including those living with HIV, with knowledge and life skills through mentorship discussions, clubs such as peer education clubs, regular guidance, and counseling from teachers, as well as awareness campaigns facilitated by external HIV/AIDS support organizations (10).

The availability of nutritious food at home and school presents a significant challenge for students with limited resources, including ALHIV. The lack of adequate food adversely affects medication adherence, as observed in other studies conducted in Tanzania (12), Uganda (10), and Kisumu (16). Given that many schools do not have established school food programs, teachers sometimes have to provide food assistance to children who have disclosed their HIV status using their funds (12). Within the context of school health programs, it is imperative to provide support to ALHIV by ensuring access to nutritious food, particularly for those hailing from economically disadvantaged households. This recommendation aligns with findings from other studies (10, 12).

Schools operate within the framework of existing policies and regulations established by the health, education, and local government ministries. The school health coordinator and members of the council's health management team are tasked with visiting schools to offer mentorship, supportive supervision, and follow-up on implementation. However, our study has identified that these visits and other forms of support are infrequent due to budget constraints and limited collaboration between the education and health sectors. Similar findings were also reported in a study encompassing five regions in Tanzania, emphasizing the necessity for a multisectoral approach and closer cooperation between the education, health, and protection sectors (12). A similar approach to supporting schools in the development of HIV/AIDS care and support was also advocated for in Western Uganda (8).

4.1. Study Strengths and Limitations

Our findings are grounded in the responses provided by participants and are consequently susceptible to selective reporting. Particularly noteworthy is the potential for interviewees to purposefully omit self-incriminating events, such as instances of stigmatizing students. Additionally, the perspectives and prejudices held by the participants can influence their responses and viewpoints. To mitigate these potential biases, we adopted a larger sample size, consisting of 13 KII and 8 FGD, conducted in rural and urban settings. This strategic approach allowed us to cross-verify our findings and enhance the overall reliability of our study. Moreover, the diversity of schools selected across various geographical settings enriches the comprehensiveness and applicability of our findings to other educational institutions in Tanzania.

5. Conclusion

Our study has underscored the presence of care and support for ALHIV within school environments, notwithstanding certain limitations and challenges that have been identified. Given that adolescents spend a significant portion of their time in school, it represents an opportune platform for extending support to ALHIV and imparting essential HIV life skills and comprehensive sexuality education to all students while addressing issues related to stigma and discrimination.

To fully harness the potential of schools in this regard, we recommend enhancing teachers' and matrons'/patrons' capabilities through training. We propose adopting a hybrid approach incorporating physical and virtual options to ensure adequate capacity building. Collaborative efforts with health facilities and parents/guardians are essential to encourage ALHIV to disclose their status to health teachers, thereby facilitating the delivery of care.

Additionally, support for peer clubs is crucial, including the empowerment of their leaders and their connection with networks of people living with HIV. This collaborative effort will facilitate the acquisition of HIV life skills and the effective addressing of stigma and discrimination. Furthermore, we suggest capacitating regional and council school health coordinators and providing them with financial support to supervise and

mentor schools in school health matters, including the care of ALHIV.

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Ethical Approval

This is a follow-on assessment to an earlier study with approval number 3049. The assessment protocol was reviewed and approved by the ministries of health and education. Consent was sought and consent forms were signed before the commencement of the interviews.

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Authors' Contribution

Andrew Kigombola (AK): Substantial contribution to conception and design of the protocol, tools development, data analysis and interpretation, coordinated the research team and data collection, developed the first draft of the manuscript. John George (JG): Substantial contribution to conception and design of the protocol, tools development, data analysis and interpretation, developed the first draft of the manuscript. Mastidia Rutaiwa (MR): Design of the work, review the manuscript critically for important intellectual content. Betty Mwambembule (BM): Design of the work, review the manuscript critically for important intellectual content. Neema Mlote (NM): Design of the work, review the manuscript critically for important intellectual content, Edgar Lungu (EL): Design of the work, review the manuscript critically for important intellectual content. All authors approved of the final version to be published, and agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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