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Article in *AIDS and Behavior* · September 2022

DOI: 10.1007/s10461-022-03856-6

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Challenges and Fears of Adolescents and Young Adults Living with HIV Facing Transition to Adult HIV Care

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Accepted: 2 September 2022

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Abstract

Adolescents and young adults living with perinatally-acquired HIV (AYLPHIV) have poor outcomes along each step of the HIV care continuum due to challenges in seeking care and advocating for themselves. The transition from paediatric to adult HIV care is a particularly high-risk period for AYLPHIV in rural Uganda. We conducted in-depth interviews with AYLPHIV (n=30), caregivers (n=10), and healthcare providers (n=10) to understand challenges facing AYLPHIV during the transition from paediatric to adult HIV care. Themes were identified by thematic content analysis. Transition-related challenges and fears included difficulty navigating the adult HIV clinic; loss of informational support; long wait times at the adult HIV clinic; lack of privacy, and fear of HIV status disclosure and stigma; and loss of support from caregivers, and health care providers. Before transitioning to adult HIV care, AYLPHIV should be adequately prepared and given appropriate information to help them navigate adult HIV care.

Keywords Adolescents · HIV care cascade · transition · challenges · sub-Saharan Africa · Uganda

Background

There are 170,000 adolescents and young people (15–24 years of age) living with HIV in Uganda accounting for 12% of the 1.4 million people living with HIV in the country [1]. Adolescents and young people living with perinatally acquired HIV (AYLPHIV) face myriad challenges that complicate their ability to seek care and advocate for themselves [2, 3]. The HIV-related challenges are complicated

by their developmental stage, further compromising their ability to seek care [4]. Stigma and discrimination are common, especially among peers, yet adolescence is a stage of development during which adolescents value peer relationships [5, 6]. The rates of disengagement from care, loss to follow up, viral failure, and death are highest in this age group compared to younger children and older adults in HIV care, and these discrepancies in health outcomes are even worse during transition from paediatric care to adult HIV care [7, 8].

Despite the need to transition AYLPHIV to adult HIV care for age- and developmentally appropriate care, the majority of AYLPHIV do not feel ready to make the transition because they continue to have close attachments with their peers and healthcare providers in adolescent- and youth-friendly HIV clinics and because they lack any preparation to successfully achieve such a transition to adult HIV care [5, 9, 10]. Other challenges to successful transition include a lack of, or failure to implement, available guidelines for the transition process in most sub-Saharan African countries. As a result, most AYLPHIV are transitioned to adult HIV care with minimal or no preparation [11]. Numerous challenges facing AYLPHIV during the transition have been documented in high-income countries and in urban settings

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in sub-Saharan Africa: stigma and discrimination, disruptions associated with changing care providers, challenges navigating the adult HIV clinic, lack of support from health care providers and caregivers, unfavourable scheduling of appointments (e.g., that interfere with schooling responsibilities), and poorly coordinated HIV care [9, 10, 12–16]. On the other hand, there are some factors that could facilitate successful transition: having a good understanding about their illness and treatment, mental health, and being actively engaged in or adherent to HIV care [17, 18]. AYLPHIV who are given preparation for their transition to adult HIV care have more favourable treatment outcomes [19, 20]. Due to staff shortages at the study site, the relevant transition guidelines from the national HIV care guidelines [21] have not been implemented, which has affected AYLPHIV transition preparation. Nonetheless, attempts are often made to provide health education to AYLPHIV who are ready for transition, though this is done hastily and thus does not effectively address AYLPHIV concerns prior to their transfer. In addition, the transition to adult HIV care at this site usually occurs at the request of AYLPHIV patients who feel ready and who prefer to be seen in the adult HIV clinic. Moreover, providers in this setting lack access to appropriate scales to measure transition readiness; the only applicable instrument provided in the national HIV care guidelines [21] does not capture the domains that have been established in the literature to suitably assess transition readiness [22, 23]. There is also no follow-up after AYLPHIV are transferred to an adult HIV clinic, and the transitioned patients are left to manage on their own.

Despite a number of challenges reported in high-income countries and in urban settings of sub-Saharan Africa by AYLPHIV who have attempted to transition to adult HIV care, these challenges have not been well studied in rural settings in sub-Saharan Africa. Our analysis was therefore aimed at understanding challenges and fears associated with the transition to adult HIV care among AYLPHIV in a rural region of southwestern Uganda.

Methods

Study Setting

The study was conducted at the HIV clinic attached to Mbarara Regional Referral Hospital (MRRH) in the city of Mbarara, 280 km from the capital Kampala. Mbarara has a population of 195,013, according to the last census from the Uganda Bureau of Statistics [24]. The majority of people who attend the HIV clinic live in the rural areas outside of the city, earning their livelihood through subsistence farming, animal husbandry, and small scale trading. Many

residents experience challenges of food and water insecurity [25, 26]. The prevalence of HIV in Mbarara is estimated to be 13% among those aged 15–49 years, which is higher than the national prevalence of 5.8% [27]. To date, the MRRH HIV clinic has cared for a cumulative total of 583 adolescents (10–19 years) and 603 young adults living with HIV (20–24 years of age). The adolescent and young people's HIV clinic is attached to the paediatric HIV clinic and all care for AYLPHIV and children is handled by the same HIV care team.

Study Participants

We enrolled a consecutive sample of AYLPHIV aged 15–24 years ($n=30$), caregivers ($n=10$), and health care providers ($n=10$). We included those who were accessing care at the MRRH HIV clinic and who lived within 60 km of the clinic, were fully aware of their HIV status, and were willing to provide informed consent or assent to participate. We purposively sampled AYLPHIV who were at different stages of the transition cascade: those who had not yet transitioned, those who had attempted to transition but did so unsuccessfully, and those who had successfully transitioned. We also considered HIV care status (i.e., actively engaged in care vs. not actively engaged in care, as determined by missing at least one clinic appointment in the last 6 months). For the sample of caregivers of AYLPHIV, we considered only women who were caring for adolescents aged 15–19 years (and accessing care at the MRRH HIV clinic) or women who lived with and were supporting a young person living with HIV aged 20–24 years (and accessing care at the MRRH HIV clinic). For the sample of healthcare providers, we enrolled healthcare providers who had been providing care to AYLPHIV at the MRRH HIV clinic for at least 6 months (i.e., we excluded new hires). Exclusions were for those with cognitive impairments (assessed in consultation with a certified psychiatrist) and those who were too physically ill to remain present and engaged for the duration of the interview.

Sampling

Existing literature suggests that saturation can be reached with as few as 12–16 interviews [28, 29], however we conducted 50 interviews to obtain a range of opinions on how AYLPHIV transition from pediatric to adult HIV care. A diverse sample of participants, including adolescents living with HIV (15–19 years of age), young adults living with HIV (20–24 years of age), women caregivers of AYLPHIV, and health care providers with experience in the care of AYLPHIV, was recruited through purposeful sampling. As suggested by Galvin [30], it was expected that

the diversified sample would provide us with a variety of insights to explore regarding the transition of AYLP HIV from pediatric to adult HIV care.

Data Collection Procedure

We conducted one-on-one in-depth interviews with each of the AYLP HIV, caregivers, and health care providers. AYLP HIV and caregivers were approached for enrolment when they presented for their routine care in the HIV clinic. Their clinician assessed them for eligibility based on the inclusion criteria and referred them to the research assistant for possible enrolment. We used an interview guide that we developed through a review of the literature on transitioning from adolescent to adult HIV care and with input from those with expertise in the management of AYLP HIV. The interview guide included questions about transition concerns, challenges associated with transitioning to adult HIV care, preparation (whether experienced or hypothetical) for transition, and the timing of transition. The interview guide was written in English by a native speaker of Runyankore (the local language widely spoken in the southwestern part of Uganda), translated into Runyankore, and then back translated to English to ensure fidelity to the original text. The interview guide was pretested on a small convenience sample of participants and revised before use. Each interview lasted between 60 and 90 min. Interviews were conducted by two research assistants who are fluent in both English and Runyankore. All interviews were audio recorded and transcribed directly into English by the research assistants for subsequent review and analysis by the study team.

Ethical Considerations

The study was approved by the Research Ethics Committee of the Mbarara University of Science and Technology (#20/08–19) and the Partners Human Research Committee (#2019P003451). The study also received clearance from the Uganda National Council for Science and Technology (#HS512ES) and from the Office of the President. Participants aged 18 years and older, emancipated minors (those below 18 years of age but who were either living on their own or were married or had a child), and empowered adolescents (those below 18 years of age but who have been empowered to take control of their own HIV care) [31] were permitted to provide written informed consent without involvement of their caregivers. Those who were below 18 years of age and still under the care of their caregivers provided written informed assent after their parents/guardians provided written informed consent. All participants received 25,000 Ugandan Shillings (approximately 7 U.S.

Dollars at the time the study was conducted) to reimburse them for transportation to the clinic/study site.

Data Analysis

The study followed the Consolidated Criteria for Reporting Qualitative Research procedures [32]. Using the inductive theory technique, we performed thematic content analysis to identify themes relevant to the challenges and fears of AYLP HIV facing the transition to adult HIV care. The four members of the research team (SA, PT, GN, and CB) read the first four transcripts iteratively, taking notes on the emerging themes until they reached consensus on the key themes that were used to guide the development of a codebook that we used to categorize the data [33, 34]. The iterative process involved reading transcripts, comparing notes, revising the themes and subthemes, and eliminating duplicates, until consensus was reached about the extent to which the themes and subthemes accurately reflected the data contained in the transcripts. Themes relating to fears and challenges of AYLP HIV emerged from the data as independent themes and were explored through an iterative process following techniques by Miles and Huberman [35]. The codebook guided the coding process that was completed by three members of the research team (SA, TPT, GN) who coded the first 5 transcripts in duplicate and compared their findings until they were in agreement with each other. The remaining interviews were then divided and each member of the research team coded a subset of interviews individually. MAXQDA software version 20 [36] guided the data analysis process.

Results

Among the 30 AYLP HIV who participated in the in-depth interviews, the mean age was 20 years (standard deviation [SD] 3.1), and the mean age at which they had initiated ART was 6.6 years (SD 5.2). Characteristics of the AYLP HIV, caregiver, and health care provider samples are shown in Table 1.

Challenges and Fears of Transitioning to Adult HIV Care

Navigating the Adult HIV Clinic

According to the participants in the study, navigating the adult HIV clinic after transfer of care is difficult, owing to a lack of preparation prior to the transition. The fear of navigating care in an unfamiliar environment and approaching adult health care providers without prior introduction were

Table 1 Summary characteristics of the study participants

	Mean (SD) or n	%
AYLPHIV participants (N = 30)		
Age, years	20 (3.1)	
Age started ART, years	6.6 (5.2)	
Years on ART, years	13.7 (6.1)	
Female	14	47%
<i>Level of education</i>		
Primary level	6	20%
Secondary	16	53%
Tertiary	8	27%
<i>Marital status</i>		
Married	1	3%
Not married	29	97%
<i>Transition status</i>		
Not yet transitioned to adult care	18	60%
Failed transition to adult care	8	27%
Transitioned successfully	4	13%
Caregiver participants (N = 10)		
Age, years	47.3 (7.2)	
Female	10	100%
<i>Level of education</i>		
Primary	2	20%
Secondary or more	8	80%
<i>Marital status</i>		
Married	4	40%
Not married	6	60%
<i>Employment</i>		
Business	5	50%
Professional (teacher, nurse)	3	30%
Farmer	2	20%
Number of children	3.5 (2.3)	
Number of children in HIV care	1.2 (0.63)	
Health care provider participants (N = 10)		
Age, years	38 (11.0)	
Years providing HIV care	7.8 (5.5)	
Female	6	60%
<i>Marital status</i>		
Married	8	80%
Not married	2	20%
<i>Employment designation</i>		
Medical officer	2	20%
Clinical officer	3	30%
Counselor	5	50%

the most frequently voiced challenges. Health care providers in adult HIV clinics were described as unapproachable and unfamiliar with the challenges faced by AYLPHIV, as well as lacking in knowledge about how to address these challenges.

First of all, in the adolescent clinic, when you get there, the doctors welcome and talk to you very well, they call you by your name, greet you and generally treat you very well. At the adult clinic... the first time

I went there, from nowhere they just started addressing me as sir, yet I was not used to that. I was asked a number of questions whether I had any complaints but I said no, yet I had them ... I had some cough but I could not say anything. In most cases, the doctors are so serious, when you get there, they do not bother to talk to you or encourage you... actually he just gave me the medicine and I went out, I did not even take ten minutes with him in his office

- 24-year-old man, failed to transition successfully to adult HIV care

“When they [AYLPHIV] get there [adult HIV clinic], they really get disturbed because they do not know anything at the adult clinic, not even the doctors they are going to interact with. They do not know the clinic procedures, whom to consult in case of anything, and how to go about it. They also get scared of being talked to in a rude and harsh manner unlike where they came from at the children’s clinic which they were used to.”

- 34-year old woman, mother to a 19 year-old AYLPHIV

Loss of Informational Support

Related to the theme of navigating the adult HIV clinic, most AYLPHIV expressed that they felt unsure about how to access care in the adult HIV clinic due to lack of preparedness prior to transition. They expressed worry about approaching adult health care providers, lack of familiarity with the procedures at the adult HIV clinic, and knowing little about whether their medicines will stay the same or change. This fear of the unknown contributed to their failure to keep their clinic appointments following transition, resulting in non-adherence to ART and a potential decline in health.

The most common effect is failure to get information that they are expected to get while at the health facility. Some of them will fear to disclose to the doctors the health challenges they are going through and instead they make things worse.

- 19-year old man, failed to transition successfully to adult HIV care

Another challenge is that in the children’s clinic, we always have health education, and it is sometimes delivered by fellow peers who give us their own life experiences and tell us what we are supposed to do whenever we get challenges. But in the adult clinic, we may miss getting such health education and even if we do, they may not invite peers to talk to us. It is a big mistake when we fail to get health education to

guide our lives on what exactly we are supposed to do, in this case we may start taking our medication poorly, miss clinic appointments, and sometimes engage ourselves in bad behaviors that may affect our viral load.

- 24-year-old man, failed to transition successfully to adult HIV care

I fear that they [health care providers] are going to change the type of HIV medication I take, and there is a likelihood that I may fail to swallow it. I overheard the doctor say that if they discover that you have poor adherence, they give you another line of medication that is more than six tablets.

- 15-year-old girl, not yet transitioned to adult HIV care

Long Wait Times at the Adult HIV Clinic

Aside from being anxious about their HIV status being revealed without their consent, AYLPHIV voiced concerns about the much higher volume of patients seen in the adult HIV clinic and the associated longer wait times. Furthermore, many AYLPHIV were still in school and stated that extended wait times would not be compatible with their schedules. Many of them had limited time and had to rush back to school, and waiting in line often caused them to miss classes, adversely affecting their academic progress. Participants also felt that care in the adult HIV clinic was not adolescent friendly, the appointments were too short, and care in general was not individualized to the needs of AYLPHIV.

They [AYLPHIV] are not used to the waiting time, they are also not used to sitting and interacting with old people in the adult clinic. Some of these adolescents fear to be judged by the old people when they are in the adult clinic. We have heard comments like ‘where did this young girl get infected with HIV from?’ Such comments are so hard for them. They are stigmatizing, demotivating, and make these adolescents living with HIV lose hope.

- 29-year-old healthcare provider

My biggest concern about the adult clinic is the issue of time. The amount of time patients take going through the clinic procedure is too much. If you go there, you have to make sure that you go very early in the morning, because if you get there late, you may not receive sufficient services.

- 22-year-old woman, not yet transitioned to adult HIV care

When I went there [the adult HIV clinic] ... the first thing I experienced was that I was delayed so much

at the adult clinic. Secondly I met doctors that I had never seen before, and I was generally scared about the new place and new environment. The fact that I am still a student also affected me so much, there was so much delay because of the big crowds.

- 24-year-old man, failed to transition successfully to adult HIV care

Lack of Privacy and Fear of HIV Status Exposure and Stigma

Participants in the study were concerned about transferring care from the adolescent and young people’s HIV clinics to the adult HIV clinic because they felt their HIV status risked being involuntarily disclosed. AYLPHIV reported that they keep their HIV status a secret and that transitioning to adult HIV care could increase the risk of unintended HIV status disclosure. The reason they gave for believing disclosure in the adult HIV clinic to be a greater risk is that the adult clinic has a larger number of patients. They expressed fear that they could encounter people they know, who would then reveal their HIV status to the rest of the community, exposing them to stigma and discrimination if their HIV status became known.

They first of all get stigmatized, meeting people you know and at the same time meeting people you don’t know, when they look at you they start talking a lot, blaming you for getting involved in bad behaviors that got you infected with HIV ... as a result, you may start dodging and even miss getting your HIV treatment because if you notice there are some people who know you, that day you do not show your face, you have to hide yourself or at worst just move out from the clinic.

- 24-year-old man, failed to transition successfully to adult HIV care

...the general public also may look at them [AYLPHIV] as if they are not capable of being productive because of their condition. It also affects them in the community and the society as a whole, they feel discriminated, isolated and as if they are hated, as if they are not going to get married or employed and as if they are a disgrace in society... all this is so stigmatizing.

- 48-year-old healthcare provider

In the adult clinic, we fear to be seen and identified by those adults because there is a likelihood that they might disclose your status, bully you and expose your HIV status without your consent and knowledge which is very bad and it may affect you all the more.

- 20-year-old woman not yet transitioned to adult HIV care

Relatedly, in addition to the larger volume of patients at the adult HIV clinic, study participants felt that the adult HIV clinic was in an open area with relatively little privacy and that passersby could easily identify them as someone living with HIV. They felt more comfortable attending the children's HIV clinic, which they felt did a better job of ensuring privacy and confidentiality. Many AYLP HIV were concerned that after transfer to the adult HIV clinic, their HIV status would be revealed to the public, thereby exposing them to stigma and discrimination. Their greatest concern was that other people would find out they were HIV positive.

The adult clinic is too open, wide and there is no privacy. When you are in there, people across the main gate [hospital entrance] may easily see you and identify you as an HIV positive patient.

- 15-year-old boy, not yet transitioned to adult HIV care

... in adult clinic I will be exposed because it is in an open place, you may be seen by very many people who are actually HIV patients but can spread rumors about you.

- 21-year-old man, not yet transitioned to adult HIV care

... the adult clinic is in an open place, they [AYL-HIV] fear that their privacy and confidentiality will be exposed and people will discover that they are HIV infected.

- 24-year-old woman, transitioned successfully to adult HIV care

Loss of Support from Peers

Many AYLP HIV described losing support from peers and becoming socially isolated after being transferred to the adult HIV clinic. They reported that they are intimidated by adults and cannot engage in conversations with them. They also reported that adults living with HIV have a tendency to engage in conversations that portray a negative picture of their lifestyles, which increases anxiety among AYLP HIV. They felt that adults often express judgment, questioning the morality of their behavior, and blaming them for acquiring HIV at such a young age.

At adult clinic, adult patients are not friendly and because of the age difference you find you don't have anything in common; no interactions, no connections at all. You find you don't belong in that category. You sit with the adult patient and even fear to ask anything

because they are not close to us; they don't give us time to interact with them.

- 24-year woman, transitioned successfully to adult HIV care

Loneliness. Remember, you have left your friends at the children's clinic. You will be there alone and may end up getting stressed when you do not have anyone to talk to because those adults do not have time for you.

- 19-year-old woman, not yet transitioned to adult HIV care

It [transition] should be organized in a way that a group of adolescents who joined [care] together are prepared and transferred together to the adult clinic so that when they get in the adult clinic, they feel like they are still in the company of the people they know, the adolescents they are used to. This helps them to stay together instead of finding yourself alone in the adult clinic ... in fact, some adolescents start feeling discriminated against, especially when they find themselves alone in the adult clinic when some of their colleagues are left behind.

- 22-year-old woman, not yet transitioned to adult HIV care

Loss of Support from Caregivers and Health Care Providers

In addition to the aforementioned loss of support from peers, study participants also described a loss of support from caregivers and health care providers after transitioning to adult HIV care. AYLP HIV stated that, while in the children's HIV clinic, they felt their caregivers supported them in various ways (e.g., by transporting them to the HIV clinic and at times personally escorting them to the clinic for their appointment). However, after transitioning to the adult HIV clinic, AYLP HIV anticipated that their caregivers will discontinue such support, either because the caregivers feared being associated with the AYLP HIV at the adult HIV clinic or because the caregivers would then view the AYLP HIV as adults and now capable of assuming their own care. At the same time, other AYLP HIV noted that health-care workers in the children's HIV clinic are more helpful than healthcare workers in the adult HIV clinic and are more concerned about children's well-being, and more empathetic and understanding, whereas they felt that healthcare providers in the adult HIV clinic would be more likely to blame AYLP HIV for their infection and associated problems.

... when they change to start seeing doctors for adults, their parents will not be free to accompany them inside, for fear of being identified by others at the

adult clinic, since there is no privacy. The child will be coming alone which may be difficult for him to access HIV care services easily.

- 21-year-old man, failed to transition successfully to adult HIV care

While still at the children's clinic, the caregivers are always there to help remind patients [AYLPHIV] to take their medication, but when you go to the adult clinic, that care reduces and the health workers expect you to know what to do... what happens next is that these adolescents lose morale, feel demotivated and start taking medication very badly, eventually the results may not be good... you may end up losing your life.

- 24-year-old woman, transitioned successfully to adult HIV care

When some parents get to know that you are transferred to the adult clinic, they thank God and they start relieving themselves of their responsibilities as parents because they think now you are a mature grown up. They start looking at you as an independent person and they think that you can take care of yourself.

- 16-year-old boy, not yet transitioned to adult HIV care

Discussion

In this qualitative study of adolescents and young adults living with perinatally acquired HIV, caregivers, and health care providers in rural Uganda, we found that AYLPHIV experience multiple challenges and have several fears related to transitioning to adult HIV care. Prominent themes included: difficulty navigating the adult HIV clinic; loss of informational support; long wait times at the adult HIV clinic; lack of privacy, and fear of HIV status disclosure and stigma; and loss of support from peers, caregivers, and health care providers. Addressing these structural and interpersonal issues will be needed in order to improve engagement in care among AYLPHIV in rural Uganda and thereby reduce HIV-related mortality in this key population.

Difficulty navigating the adult HIV clinic following the transition from pediatric to adult HIV care is similar to what has been reported in South Africa [37]. This phenomenon has been linked to lack of preparation prior to transition, coupled with lack of formal introduction to the new health care providers in the adult HIV clinics and lack of clear procedures to guide accessing care in the new clinic setting. Anxiety about meeting new health care providers and about building a new trusting relationship with new health care providers has been reported to complicate navigating the

adult HIV clinic following transition [38]. Although these challenges have been reported in high income settings, these challenges are further magnified in rural settings due to added challenges of poverty, low levels of formal education and health literacy, and orphanhood [39]. As a result, others have recommended that AYLPHIV should be transitioned only after first demonstrating that they have full understanding of their illness, are competent enough to negotiate clinic appointments, and have the ability to work independently with multiple health care providers [40]. Preparatory activities that involve healthcare providers in transition planning, accompanied by clear guidelines to navigate adult HIV clinics, have been documented to lessen the anxiety associated with transitioning care and to improve retention in care following the transition to adult HIV care [16–18, 41]. There is need for flexibility in offering adolescent- and youth-friendly services to AYLPHIV during their transition to the adult HIV clinic so that they can become more familiar with the new environment and maximally engage in care [42]. Finally, although assessment of readiness to transition should be done prior to transitioning care [43], most HIV care setting in sub-Saharan Africa lack validated scales to assess transition readiness [44]. Although the national HIV care guidelines in Uganda include a scale to assess transition readiness among AYLPHIV [21], this scale does not capture relevant domains that have been documented in literature to represent transition readiness [22, 23].

Similar to what has been documented in studies of adolescents and young adults living with chronic medical conditions, many AYLPHIV in our study anticipated stigma from adult health care providers following their transition to adult care [9, 14]. The anticipated involuntary serostatus disclosure and lack of privacy in crowded adult clinic settings contributed to these fears [15, 17, 41]. The anticipated stigma and discrimination, and moralizing about behavior, hinders the ability of AYLPHIV to seek care and assistance from unfamiliar adults in the adult HIV clinics [45–47]. To address this phenomenon proactively, interventions should empower AYLPHIV to live positively and provide them with the skills to selectively disclose their HIV status as a way of mobilizing support and enhancing their self-care [22, 48].

Anticipated loss of support from peers, caregivers, and health care providers has been reported as well [37]. Peer support has been associated with successful transition and retention in care among AYLPHIV in South Africa [49, 50], likely because AYLPHIV have engaged with other peers in the children's clinic since a young age, and these ties should not be eliminated with the transition to adult HIV care [45, 51]. The anticipated loss of support from caregivers and health care providers following transition is similar to what has been reported in previous studies, suggesting

the necessity for caregivers and health care providers to remain involved and supportive during the transfer of care [15, 45, 52]. Support that blends the needs of AYLP HIV has been documented as a major factor associated with successful transition [52]. Adult health care providers should also be part of the transition process and should be aware of the transition challenges so that they can better support AYLP HIV seeking to transition to adult HIV care [40]. Related to the psychosocial support, informational support has been documented as an important facilitator of successful transition among AYLP HIV as a component of transition preparation through provision of information on benefits of transition, as well as general information concerning accessing care in the adult HIV clinics [10, 18]. Information support has been associated with retention in care among adults living with HIV in Uganda [53]. AYLP HIV who are provided with information about their illness and about how to manage their illness are more likely to be ready for the transition to adult HIV care [18, 41].

Similar to what has been documented in the literature [16, 17], long wait times at the adult HIV clinic were also reported as a challenge by study participants. Long wait times in the adult HIV clinic have been identified as a major barrier to successful transition and retention in care, particularly for school-going AYLP HIV who miss school while waiting in the clinic [16]. In addition, clinic attendance during school hours and long wait times mean that school-going AYLP HIV miss a complete school day in order to receive care, which negatively impacts academic performance, because many are forced to choose between health care and academics [16, 17, 37].

The following study limitations should be taken into account while interpreting our study findings. First, we enrolled a purposive sample of AYLP HIV and their caregivers from a single HIV clinic in southwestern Uganda. The findings may not be representative of the views of all AYLP HIV in Uganda. Adolescents and young adults with horizontal acquired HIV may have different views and experiences. Second, some of the views expressed were anticipated fears from AYLP HIV who have not transitioned. Some of these expressed fears (e.g., of adult health care providers) may not reflect the actual experiences of AYLP HIV who have transitioned to adult HIV care. Third, we only interviewed women caregivers due to the culture in southwestern Uganda where women provide most of the childrearing and day to day care [54–56]. It is possible that we could have missed important views from men caregivers on these important care related issues.

Conclusion

AYLP HIV facing the transition to adult HIV care report a number of related challenges and fears: difficulty navigating the adult HIV clinic; loss of informational support; long wait times at the adult HIV clinic; lack of privacy, and fear of HIV status disclosure and stigma; and loss of support from peers, caregivers, and health care providers. AYLP HIV should be provided with adequate preparation to successfully make the transition to adult HIV care. Critical next steps in the literature include the development of scales to assess transition readiness in a systematic way; and the developing, testing, and scale-up of adolescent friendly HIV services.

Supplementary Information The online version contains supplementary material available at <https://doi.org/10.1007/s10461-022-03856-6>.

Acknowledgements We would like to express our gratitude to the study participants who volunteered their time to participate and without whom this study would not have been feasible.

Author Contributions SA was responsible for conceptualizing the study including development of the methodology, secured funding, provided leadership, and wrote the original draft and oversaw revisions of the manuscript. PT and GN was responsible for data collection, data analysis and contributed to the final draft of the manuscript. CB was responsible for daily project administration and supervision of research and contributed to the original draft and revised version of the manuscript. DN and JK reviewed and edited the final version of the manuscript. SM supervised and guided the data collection procedures, and reviewed and edited the final version of the manuscript. BCZ guided the data analysis process, contributed to the original draft of the manuscript and revised the final version of the manuscript. ACT provided leadership and guidance during conceptualization of the study, data analysis, and contributed to the original draft and revised version of the manuscript.

Funding This research was made possible with help from the Harvard University Center for AIDS Research (CFAR), an NIH funded program (P30AI060354), which is supported by the following NIH Co-Funding and Participating Institutes and centers: NIAID, NCI, NICHD, NIDRCR, NHLBI, NID, NIMH, NIA, NIDDK, NINR, NIMHD, FIC, and OAR. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health. Dr. Ashaba also acknowledges salary support from grant number K43TW011929.

Data Availability Not applicable.

Code Availability Not applicable.

Declarations

Conflict of Interest Dr. Tsai reports receiving a financial honorarium from Elsevier, Inc. for his work as Co-Editor in Chief of the Elsevier-owned journal *SSM-Mental Health*. The other authors have no conflict of Interest to declare.

Ethics Approval The study was approved by the Research Ethics Committee of the Mbarara University of Science and Technology (#20/08–19) and the Partners Human Research Committee (#2019P003451). The study also received clearance from the Uganda National Council for Science and Technology (#HS512ES).

Consent to Participate All Participants provided written informed assent and /or consent to participate in the study.

Consent for publication Participants consented to having their data published.

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