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Perspectives About Transition Readiness Among Adolescents and Young People Living With Perinatally Acquired HIV in Rural, Southwestern Uganda: A Qualitative Study

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ABSTRACT

Despite the availability of antiretroviral therapy, treatment outcomes are worse among adolescents and young adults living with perinatally acquired HIV (AYLPHIV). These disparities are magnified during the transition from pediatric to adult-based HIV care. We conducted in-depth interviews with AYLPHIV aged 15–24 years ($n = 30$), their caregivers ($n = 10$), and health care providers ($n = 10$). All participants provided written assent and/or informed consent to enroll. Thematic content analysis was used to identify and analyze themes relevant to transition readiness. We grouped perspectives on transition readiness into 4 themes: preparation for transition, communication between stakeholders, social support, and timing of transition. AYLPHIV in sub-Saharan Africa who are facing a transition to adult HIV care should be equipped with relevant information about their illness, self-advocacy skills, and support from caregivers and health care providers to remain engaged in HIV care.

Key words: adolescents, HIV care, HIV care cascade, sub-Saharan Africa, transition, treatment outcomes, Uganda

Sub-Saharan Africa is home to about 85% of adolescents living with HIV (UNICEF, 2018); however, in Uganda, 12% of the 1.4 million persons living with HIV are adolescents and young adults aged 15 to 24 years (Ministry of Health of Uganda, 2021). Although the availability of antiretroviral therapy (ART) has enabled children born with HIV to grow into adolescence and young adulthood (UNAIDS, 2018), there is a need to shift

from medically focused care to more broadly focused care to address the social and psychological challenges to health that are associated with HIV in this age group. Rates of disengagement from care and loss to follow-up, both of which contribute to high rates of mortality, are highest among adolescents and young adults living with perinatally acquired HIV (AYLPHIV) compared with those in other age groups (Dahourou et al., 2017; Kariminia et al., 2018). Poor treatment outcomes in this age group have been observed to be highest when they make the transition from pediatric to adult HIV care, so that they can receive age and developmentally appropriate HIV care (Machado et al., 2016; Mofenson & Cotton, 2013; Schwartz et al., 2011). Among AYLPHIV transitioning to adult care, HIV outcomes are worse in sub-Saharan Africa due to a lack of policies and programs to govern the transition process (Badejo et al., 2018; Lee & Hazra, 2015).

Most AYLPHIV do not transition to adult HIV care successfully due to the ongoing attachment they have to the pediatric HIV clinics and also due to other psychosocial challenges, including lack of preparation, lack of transition planning, and HIV stigma (Jones et al., 2019; Newman et al., 2014). Moreover, AYLPHIV are often dependent on their health care providers or family members for care and lack the necessary skills to navigate HIV care on their own following this care transition (Lanyon et al., 2020; Mbalinda et al., 2020). In addition, AYLPHIV face

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psychosocial challenges that are compounded by their developmental stage, making it even harder for them to seek care (Ashaba et al., 2018, 2019). The need for peer acceptance and approval, which can be further undermined by the stigma attached to HIV, is another element that hinders the ability of AYLP HIV to seek care, advocate for themselves, and cope with their condition (Lanyon et al., 2020; Machado et al., 2016). AYLP HIV should be provided with psychosocial skills in order for them to successfully navigate adult HIV care following their transition to adult HIV clinics and therefore achieve better outcomes (Hussen et al., 2019; Lanyon et al., 2020; Tanner et al., 2017). Despite the availability of care transition guidelines from the Ministry of Health of Uganda that advocate for facilitating successful transition through the provision of social support, skills development for AYLP HIV and health care providers, transition readiness, and multidisciplinary teams (Ministry of Health of Uganda, 2020), these guidelines have not yet been implemented at most HIV clinics in the country.

Although a number of studies have documented barriers to transitioning to adult HIV care among AYLP HIV across sub-Saharan Africa (Dahourou et al., 2017; Mbalinda et al., 2020; Zanoni, Archary, Sibaya, et al., 2021), few studies have elicited the perspectives of AYLP HIV (or their caregivers) about their transition readiness in rural settings in sub-Saharan Africa. Moreover, AYLP HIV in rural settings face multiple challenges, including economic and structural challenges, that may complicate their ability to transition successfully to adult HIV care (Bermudez et al., 2016; MacCarthy et al., 2018). Thus, this qualitative study sought to better understand, from multiple perspectives, the factors that influence the transition of AYLP HIV from pediatric to adult HIV clinics in rural, southwestern Uganda.

Materials and Methods

Study Design and Rationale

This was a qualitative study in which in-depth interviews were conducted with a purposive sample of AYLP HIV, women caregivers, and health care providers in accordance with the Consolidated Criteria for Reporting Qualitative Research [Appendix A, Supplemental Digital Content 1, <http://links.lww.com/JNC/A26>] (Tong et al., 2007). The aim of the study was to obtain participants' perspectives on how AYLP HIV transition from pediatric to adult HIV care.

Study Setting

The study was conducted at the HIV clinic attached to Mbarara Regional Referral Hospital (MRRH) in

Mbarara city, located in southwestern Uganda, between November 2020 and March 2021. Mbarara city is located approximately 270 km from Kampala, the capital city, and has a population of 195,013 (Uganda Bureau of Statistics, 2014). The majority of the people who attend the HIV clinic reside in rural areas outside of the city, and their families rely on subsistence agriculture, animal husbandry, and small-scale trading to earn a living, alongside documented challenges of water and food insecurity (Mushavi et al., 2020; Tsai et al., 2012). By the end of 2020, the prevalence of HIV in Mbarara was estimated at 13% among those aged 15–49 years, which is more than twice that of the national prevalence of 5.8% (Ministry of Health of Uganda, 2021). The Pediatric and Adolescent Care Section of the clinic currently cares for 3,500 children, adolescents, and young adults living with HIV and has cared for nearly 4,000 HIV-exposed infants since its establishment in November 1998. The adolescent HIV care clinic at MRRH (which cares for children 10–19 years of age) is closely linked to both the pediatric HIV care clinic (which cares for children 0–9 years of age) and the young people's HIV care clinic (which cares for young people 20–25 years of age). All three clinics are operated by the same team of clinicians. The clinic provides care following the National HIV Prevention and Care and Treatment Guidelines (Ministry of Health of Uganda, 2020), which were adopted from the World Health Organization guidelines/recommendations for the management of HIV care for adolescents living with HIV and young people living with HIV (World Health Organization, 2013). Like many other institutions in sub-Saharan Africa, the HIV clinic at MRRH has no structured plan or guidelines in place to guide AYLP HIV transitioning to adult HIV care.

Study Participants

We enrolled a purposive sample of AYLP HIV aged 15 to 24 years ($n = 30$), women caregivers ($n = 10$) of AYLP HIV in same age group of interest (15–24 years old), and health care providers ($n = 10$) experienced in care delivery for AYLP HIV at the study site. We enrolled a mixed sample of AYLP HIV, including those who had not transitioned to adult HIV care ($n = 18$), those who tried but failed to transition to the adult HIV clinic (i.e., made an attempt to access care in the adult HIV clinic but returned to the pediatric HIV clinic; $n = 8$), and those who had successfully transitioned to adult HIV care ($n = 4$). AYLP HIV or their caregivers also had to be receiving care at the study site and living within 60 km of the clinic to be enrolled in the study. For health care

providers, we interviewed pediatric HIV care team members who had been serving at the study site for at least 6 months. We excluded AYLPHIV who were not fully aware of their HIV status despite being on ART. We also excluded those who were too physically unwell to tolerate the length of the interview (e.g., due to an underlying physical illness), as assessed by the attending clinician in the HIV clinic. Those who exhibited cognitive impairment after screening by a certified psychiatrist were also excluded from the study. No participants who met the inclusion criteria declined to participate in the study. Interviews were conducted by two research assistants (graduates in social work and social administration) who were fluent in English and the local language (Runyankore).

Sampling

Existing literature suggests that saturation can be reached with as few as 12–16 interviews (Hagaman & Wutich, 2017; Weiss, 1995); however, we conducted 50 interviews to capture different perspectives on how AYLPHIV transition from pediatric to adult HIV care. Purposive sampling was used to include a varied sample of participants, including adolescents living with HIV (15–19 years old), young adults living with HIV (20–24 years old), women caregivers of AYLPHIV, and health care providers with experience in the care of AYLPHIV. It was envisioned that the diverse sample would provide us with a number of insights to consider, as suggested by Galvin (2015), in relation to the transition of AYLPHIV from pediatric to adult HIV care.

Data Collection Procedures

AYLPHIV were enrolled because they came for their routine care appointments in the HIV clinic. A clinician attending to the AYLPHIV screened them for eligibility and then referred them to the research assistants trained in qualitative research methods. Research assistants approached potential participants, provided details about the study, and asked for their assent and/or consent before enrolment. We used an interview guide that we developed through reading literature on transition of AYLPHIV to adult HIV care and with input from health care providers with experience caring for AYLPHIV. The aim was to elicit a range of views about transitioning AYLPHIV to adult HIV care. The interview guide was composed of open-ended questions, followed by probes, aimed at facilitating participants' free expressions of their views. The interview guide was developed in English by one of the coauthors (SA), translated into

Runyankore, and then back translated to English to ensure fidelity to the original text. The interview guide included questions about transitioning to adult HIV care, attitudes and expectations about the transition, transition preparation, perceived benefits of transitioning, and transition readiness. Three members of the study team (SA, PT, and GN) evaluated the initial interview transcripts to find emerging areas of inquiry that required further investigation or new ideas emerging from the initial transcripts; new questions and probes about these domains were then included into later interviews. Interviews were conducted by two research assistants (PT and GN) either in Runyankore or in English, depending on participant's preference, and were audio recorded. Field notes were not taken and interviews lasted between 60 and 90 min. No repeat interviews were conducted. All participants who were approached agreed to participate in the study.

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). Following Ugandan guidelines, clearance was also received from the Office of the President. Participants below the age of consent provided assent after their parents/caregivers provided written informed consent. Emancipated minors (i.e., adolescents below 18 years of age who are either pregnant, have a child, or are responsible for their own livelihood) and empowered adolescents (i.e., adolescents below 18 years of age who are empowered to take responsibility for their own health) were allowed to provide written informed consent without involving their caregivers, consistent with Ugandan national guidelines (Uganda National Council for Science and Technology, 2007). 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

Interviews were transcribed from the audio recordings. Interviews conducted in Runyankore were directly translated and transcribed into English. We then conducted a thematic content analysis using an inductive approach. The interviews were first read iteratively by four members of the study team (S.A., C.B., P.T., and

G.N.) to identify themes relevant to transition readiness (e.g., preparation for transition, health literacy, self-advocacy skills, transition timing, and the role of social support during transition). All four team members took notes while reading the transcripts. The notes were shared among all team members, and selected themes and subthemes were used to create a codebook through an iterative process of reading, sharing information, and revision until an agreement was reached by combining themes and subthemes to ensure that there were no duplicated themes. The team (S.A., C.B., P.T., and G.N.) then coded the first 5 interviews in duplicate and compared/contrasted their coding, resolving discrepancies through consensus, until all 4 coders were in agreement with each other. The remaining interviews were divided, and each member of the coding team coded a subset of interviews individually. MAXQDA software (VERBI GmbH, Berlin, Germany) was used for data analysis.

Results

Among the 30 AYLPHIV who participated in the in-depth interviews, the mean age was 20 years (*SD* 3.1), and the mean age at which they had initiated ART was 6.6 years (*SD* 5.2). Characteristics of the AYLPHIV, caregivers, and health care provider samples are shown in Table 1.

Perspectives About Transition

Participants provided various perspectives on transition readiness among AYLPHIV that we grouped into 4 themes: preparation for transition, communication between stakeholders, social support, and timing of transition.

Theme 1: Preparation for Transition

Although most AYLPHIV who had not yet transitioned to adult HIV care reported that they were willing to transition to adult HIV care, a dominant theme was that they needed to be prepared for the transition so that they could manage their own care in an adult HIV clinic. They felt that they required health literacy and self-advocacy skills to successfully negotiate their own care following their transfer to an adult HIV clinic.

Health literacy. To ensure a successful transition, AYLPHIV stated that health care providers should comprehensively assess the AYLPHIV who will be transitioning to ensure that they understand their illness and their medications—including the benefits accrued

Table 1. Summary Statistics

Variables	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%
Level of education		
Primary level	6	20%
Secondary	16	53%
Tertiary	8	27%
Marital status		
Married	1	3%
Single/not married	29	97%
Transition status		
Not yet transitioned	18	60%
Failed transition	8	27%
Transitioned successfully	4	13%
Caregiver participants (=10)		
Age, years	47.3 (7.2)	
Female	10	100%
Level of education		
Primary	2	20%
Secondary or more	8	80%
Marital status		
Married	4	40%
Widowed/separated	6	60%
Employment		
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 providers (N = 10)		
Age, years	38 (11.0)	
Years providing HIV care	7.8 (5.5)	
Female	6	60%

Table 1. (continued)

Variables	Mean(SD) or n	%
Marital status		
Married	8	80%
Other	2	20%
Employment designation		
Medical officer	2	20%
Clinical officer	3	30%

from taking ART and the likely side effects—and to provide general knowledge about accessing care in an adult HIV clinic.

“First of all, they should know their HIV status, that you are HIV positive and that you are supposed to take your medicine without fail as instructed by the doctors. They should know that they are supposed to take good care of themselves, drink and eat very well. HIV medicine has a lot of side effects, if you take medicine and you do not eat very well, you will start getting opportunistic diseases like cough, constant fever, wounds all over and pimples.”

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

“They should know how to manage on their own, they should be taught on not missing their medicines because when you are still young there is someone to watch over you, care for you, and encourage you to always take your medicines as prescribed, but when you grow you should be fully responsible for your health; you should know the consequences when you misuse your drugs, like when you miss taking drugs or when you miss eating. So, you should learn how to care for your health.”

—23-year-old woman, failed to transition successfully to adult HIV care

Self-advocacy skills. Participants indicated that before transitioning to the adult HIV clinic, health care providers should ensure that AYLP HIV have the necessary skills to navigate the HIV clinic, advocate for themselves at the adult HIV clinic, communicate with health care providers and explain their needs without fear, approach health care providers in the event of a need, and plan for and keep clinic visits.

“They need to know how to take their medicine properly without being reminded all the time; they should learn to be independent. They should know that they should take their medicine properly as prescribed because medicine is their life. They should know that HIV illness has no cure so they should know that they will take the medicine for life.”

—23-year-old woman, transitioned successfully to adult HIV care

“You see, most of the times we depend on our parents, and if something happens you run to them for help; but as we grow, we should learn to be independent—that is why I encourage adolescents to learn how to make their own appointments with doctors instead of depending on parents to do it for them.”

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

They indicated that, although transition sensitization meetings can start a few months before the transfer, the process of providing people with the necessary skills for a successful transition should begin several years before the planned shift. They stated that empowering AYLP HIV should be a collaborative effort between parents and health care providers at both the children’s and adult HIV clinics.

“Health workers in the children clinic should start preparing adolescents early enough, they should make them understand that transitioning to the adult clinic is inevitable. But they should not only stop there, they should also tell them the truth and what they should expect when they get there. It should be a daily communication especially during the health education and sometimes when they are with the counselors.”

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

I think we should start preparing these adolescents [for transition] very early from the age of 12, that’s what the MOH tells us [age of 12]. Not preparing our adolescents early only but plus their parents.”

—Health care provider

This was emphasized further by health care providers who indicated that, before transitioning their patients, they look for AYLP HIV who are stable in treatment and have demonstrated some degree of independence. Suggestive evidence would include their coming to the clinic on their own and showing up on time. Providers believed that by doing this prescreening, they would be assured that such AYLP HIV would not drop out of care following transition.

“I will also consider stability of patients in accessing care... here I mean adherence, keeping clinic appointments, ability to make independent decision regarding care, if they are able to come to the clinic by themselves and not being escorted to the clinic. I also look at the ability to use self-skills to access and maintain HIV care. For example, the ability to take their HIV medicine without being reminded, respecting clinic appointments and be able to defend and understand their rights to care and not being left behind.”

—Health care provider

“When transitioning adolescents, they should be handled individually, case by case at a certain age. They should first be

sensitized, educated, and told everything about the transitioning and why it is done. Considering the age factor only may not be helpful. Some may take a shorter time to be prepared while others may take a longer time, depending on their levels of understanding. So, you have to first look at the age and then their level of understanding.”

—Health care provider

Theme 2: Communication Between Stakeholders

Communication between health care providers in the pediatric and adult HIV clinics. According to the study participants, the transition process should not be handled solely by the HIV care team at the children’s clinic. They felt that adult health care providers should be involved in transition planning so that they may become acquainted with AYLP HIV who are going to transition to enable the entire team to plan how to collaborate to achieve a smooth transition. They stated that doing so would also allow the AYLP HIV to meet the health care providers in the adult HIV clinic, which would decrease transition-related anxiety by introducing them to the clinicians who will be treating them and addressing their health concerns when they transition. Meeting with the health care providers at the adult HIV clinic prior to the transfer would also make it simpler for them to adjust to the new environment once it occurs.

“Before they change them [AYLP HIV] to adult clinic they should give them time and explain to them why they are transitioning them to adult clinic. They should even involve doctors for adults and orient them, like encouraging them to give them services first before others to avoid delays. Let them [health care providers] treat them the way they were treated at children’s clinic for some few months such that they first get used to the new environment.”

—Mother of an adolescent living with HIV

“Health workers in the adult clinic should link up with those in the children clinic and hold a discussion, find out the challenges of these adolescents and how they were treated in the children clinic... and also adjust accordingly.”

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

“The doctors in the adult clinic should be able to work together with those in the children’s clinic so that they can understand challenges of adolescent patients and be able to handle them better.”

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

Communication between health care providers and caregivers. Along with regular communication

among health care providers, consistent communication between health care providers and parents/caregivers was also described as necessary to organize the transition process. AYLP HIV generally stated that they wished for their parents/caregivers to be involved in transition planning because they were more familiar with the children’s health care issues.

“Parents should liaise with the health care providers and discuss the condition of the child before they change [transition] because it’s a parent who knows better about the child, so they should tell the doctors everything concerning the child’s character and how they can work together to make the change [transition] smooth.”

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

“You know our parents may understand us better than doctors, like my parent knows that I do not like the medicine but for the doctor she sees me here, I am okay, she gives me the medicine to take, then I go back home, but my mother knows that taking medicine is a tug of war. Really they [parents/caregivers] should also express their problems concerning our health to the health care providers, like ‘you see my daughter has this problem, since she started taking this medicine, she got this effect’.”

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

Theme 3: Social Support

Social support from caregivers. Along with the ability to navigate an adult HIV clinic, AYLP HIV noted that caregivers and family members needed to provide support. Many AYLP HIV feared that their caregivers would abandon them once they transitioned to an adult HIV clinic, even if they still needed their caregivers’ support as they navigate and become acquainted with the adult HIV clinic. Some argued that caregiver support may help AYLP HIV gain greater self-confidence, thereby motivating them to remain in care.

“They [parents/caregivers] should support them [AYLP HIV] by giving them time in caring for them, and ensure that change does not affect their wellbeing in any way. They should encourage them that though they change [transition] the health care they receive will remain the same; they can even still consult their previous health care providers where necessary.”

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

“They need to get appropriate guidance and counselling, advice, and parental care. There is a common practice for patients living with HIV to be isolated in families, and in this case, the doctors should work together with parents so that

they can overcome that challenge of isolating HIV patients in their homes and they start taking care of them appropriately.”

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

Social support from health care providers. Participants noted that in addition to the support required from caregivers during the transition phase, health care providers should extend their support to AYLP HIV beyond simply providing medications. Although health care providers in children’s HIV clinics have known their AYLP HIV patients for nearly their entire lives and are generally supportive, AYLP HIV felt that health care providers in adult HIV clinics should be available to guide decisions regarding transitioning prior to and during the transition process.

“Doctors at the children’s clinic should support the child in orienting and introducing him or her to the new doctors such that when they reach there [adult HIV clinic] they do not see new faces but rather the people they met before.”

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

“They [health care providers] should continuously make adolescents get used to what happens in the adult clinic and make them feel comfortable and encourage them to come to the adult clinic for their treatment.”

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

When they [AYLP HIV] are transferred, the health workers should give them some kind of special attention, give them time and attend to them very fast, because adolescents do not want to be delayed. When delayed they may get demotivated... some of them are students and may be doing their exams... so they need to be given special attention.”

—Mother of an adolescent living with HIV, not yet transitioned to adult HIV care

Theme 4: Timing of Transition

Although the transition to adult HIV care has been based on chronological age in most HIV care settings, particularly in low-income countries, study participants reminded interviewers that chronological age is not a sufficient measure of maturity. According to the study participants, transition should be carefully timed to ensure that the AYLP HIV are prepared in advance. Aside from age, other factors mentioned by participants to consider included the number of years in HIV care, adherence to treatment, and one’s track record of keeping clinic appointments. Furthermore, before moving to

adult care, study participants also felt that AYLP HIV’s level of comprehension (i.e., in terms of cognitive development) should be assessed. Many study participants noted that it is essential to realize that each AYLP HIV is a unique person, with particular abilities, and that decisions to transition to adult HIV care should be made on an individual basis.

“I think age is not a very important factor. As for me, I was transferred when I was 23 years and the transfer was made just because I had given birth. What should be considered important is how serious the adolescent is with medication, the determination and the courage one has with HIV treatment, as consideration for a transfer.”

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

They [health care providers] should first of all consider the age factor, the time you have spent on your HIV treatment, and how serious you are in attending to your clinic appointments. Some adolescents cannot come alone to the clinic; they have to be escorted by their parents; such patients should not be considered for a transfer because they cannot handle [it] on their own. Consideration should be given to patients who are independent and can handle their treatment alone without anyone to escort them to their HIV clinics.”

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

“They [health care providers] should consider someone’s understanding, like someone’s knowledge about his illness and ability to care for himself. Also, they should make sure one is willing to change without forcing him.”

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

Discussion

In this qualitative study of AYLP HIV, caregivers, and HIV health care providers in southwestern Uganda, multiple perspectives were obtained on transition readiness among AYLP HIV. Participants agreed that appropriate transition preparation should include equipping AYLP HIV with self-advocacy skills and providing them with information about their illness, facilitating communication between health care providers in pediatric and adult HIV clinics, as well as between health care providers and caregivers. Additionally, study participants voiced that caregivers and health care providers must provide social support and transition planning that is not focused solely on age cutoffs to ensure the effective transition of AYLP HIV.

The emphasis on health literacy and self-advocacy skills, described by our study participants, is consistent

with previous research (Hansudewechakul et al., 2015; Jones et al., 2019). Preparing AYLP HIV for transition enables them to remain in care while also gaining the ability to advocate for themselves in health care settings when seeking care (Jao et al., 2016). Independence skills have also been described as essential for AYLP HIV transition success (Ryscavage et al., 2016; Westling et al., 2016). Additionally, participants indicated that transition preparation should begin early to give AYLP HIV adequate time to acquire essential skills and that, in addition to engaging AYLP HIV in the process of transition planning, AYLP HIV should offer their thoughts on what makes a successful transfer of care (Sharma et al., 2014). In Tanzania, increased awareness of transition through the involvement of AYLP HIV and their families was linked to transition success (Masese et al., 2019). Alongside equipping AYLP HIV with independence and social skills for transition, the transition process should involve the assessment and treatment of behavioral and emotional issues in order for AYLP HIV to develop the resilience necessary for a successful transition (Abrams et al., 2018; Masese et al., 2019). Lack of transition preparation for AYLP HIV has been identified as a significant barrier to successful transition (Tanner et al., 2017). Furthermore, it has been demonstrated that AYLP HIV who are prepared prior to transition have a higher likelihood of improved treatment outcomes (Gilliam et al., 2011; Vijayan et al., 2009). Programs focusing on health literacy and medication management among ALPY HIV have described improved outcomes (White et al., 2015).

A second notable finding from our study is the importance of caregiver and health care provider support. This is consistent with prior research demonstrating that a successful transition is achievable if diverse systems, including patients, caregivers, health care providers, and health care systems, collaborate with each other (Wang et al., 2010). Although our study participants emphasized the significance of support from health care providers and caregivers, previous research has also identified peers as an important source of support in successful transition, resilience development, and treatment adherence (Inzaule et al., 2016; Zononi, Archary, Subramony, et al., 2021). Support from health care providers was linked to a high level of transition readiness in a study conducted in Cambodia (Yi et al., 2017). Conversely, lack of social support has been noted as a major concern for AYLP HIV both before and after transition (White et al., 2015). Participants in our study also recognized the coordination of pediatric and adult health care providers as an important aspect of transition planning. This was cited as critical in assisting

AYLP HIV to transition smoothly to adult HIV clinics because involving adult health care providers in the transition process allows AYLP HIV to become familiar with the health care providers, which facilitates their ability to navigate the adult HIV clinic after transition (Kung et al., 2016; Tanner et al., 2017).

Finally, it was emphasized by many study participants that age cutoffs should not be used as a sole criterion for defining transition readiness. Transition readiness goes beyond age and knowledge of the illness and should include barriers and facilitators, as well as a clear definition of the roles of various stakeholders involved in the transition process (Schwartz et al., 2011; Zononi, Archary, Sibaya, et al., 2021). This is consistent with earlier research that defines transition readiness as the ability of AYLP HIV, in collaboration with their support networks, to prepare for, initiate, and complete the transition process (Betz, 2004). Other criteria identified by participants as crucial to consider include emotional maturity and awareness of illness, status of care, health status, and responsibility (i.e., in terms of treatment adherence, keeping clinic appointments, and appreciation of health status; Masese et al., 2019). Individual self-advocacy skills and developmental level have also been identified as significant facilitators of successful transition among AYLP HIV (Wiener et al., 2011). In light of these findings, AYLP HIV should be assessed for developmental, behavioral, and psychological readiness before being transitioned to adult HIV care, taking into account their strengths and weaknesses (Straub & Tanner, 2018; Wiener et al., 2011).

When interpreting our findings, the following limitations should be considered. Given that we interviewed participants at a single HIV clinic in southwestern Uganda and used a purposive sample, our findings may not be applicable to all AYLP HIV in Uganda. This is mainly due to the fact that the majority of AYLP HIV who attend this clinic reside in rural areas of southwestern Uganda, and hence, their challenges associated with accessing HIV are complicated by challenges of poverty, food insecurity, cost of transportation to the clinic, and limited education opportunities (Ashaba et al., 2019; MacCarthy et al., 2018), which differ from the challenges facing AYLP HIV in urban areas. However, we interviewed a diverse sample of AYLP HIV, their caregivers, and their health care providers to obtain their perspectives on transitioning AYLP HIV from pediatric to adult HIV care. Additionally, we only interviewed women caregivers because women provide most of the childrearing and day to day care (Kipp et al., 2007; Russell & Seeley, 2010; Taylor et al., 1996), but missed the perspectives of male caregivers. Finally, health care

providers in the adult HIV clinic were not included in the study.

Conclusions

To improve treatment outcomes among AYLP HIV following their transition to adult HIV clinics, they should be empowered with health literacy and self-advocacy skills to enable them to navigate adult HIV clinics and advocate for themselves when seeking care. Additionally, active communication between health care providers in the pediatric HIV clinic and the adult HIV clinic is essential to familiarize the AYLP HIV with the adult HIV clinic prior to the transition.

Key Considerations

- Before transition to adult HIV care, adolescents and young adults living with perinatally acquired HIV should be prepared for transition and equipped with self-advocacy skills and information about their illness.
- Communication between health care providers in pediatric and adult HIV clinics, as well as communication between health care providers and caregivers, should be regarded as a crucial aspect of transition preparation for adolescents and young adults living with perinatally acquired HIV to adult HIV care.
- Adolescents and young adults living with perinatally acquired HIV should be involved in the transition process so that they can also provide feedback on what factors contribute to a successful transition to adult HIV care.
- To help adolescents and young adults living with perinatally acquired HIV to develop the resilience required for a successful transition, the transition process should include the assessment and treatment of behavioural and emotional challenges.

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