

Ethical challenges of the healthcare transition to adult Antiretroviral therapy (ART) clinics for HIV infected adolescents and young people in Uganda

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Abstract

Introduction

Many HIV infected adolescents require transfer of care from paediatric/ adolescent clinics to adult ART clinics. Transition is beset with factors that hinder or facilitate the process, thereby raising ethical challenges of the transition process. Decisions made regarding therapy, such as when and how to transition to adult HIV care, should consider ethical benefits and risks. Understanding and addressing ethical challenges in the healthcare transition could ensure a successful transition. The purpose of this study was to analyse the ethical challenges of transitioning HIV care for adolescents into adult HIV clinics.

Method

We conducted 18 focus group discussions among 191 adolescents attending 9 different health facilities in Uganda. We explored facilitators and barriers regarding adolescent transitioning to adult HIV clinics. Thematic data analysis was used to analyze the data. The Silences Framework guided the data analysis and interpretation. The principles of Bioethics and the four-boxes ethics framework for clinical care (Patient autonomy, Medical indications, Context of care and Quality of life) were used to analyze the ethical issues surrounding the transition to adult HIV care.

Results

The key emerging ethical issues were: reduced patient autonomy; increased risk of harm from stigma and loss of both privacy and confidentiality; unfriendly adult clinics induce disengagement and disruption of the care continuum; patient preference to transition as a cohort; and contextual factors are critical to successful transition.

Conclusion

The priority outcomes of the healthcare transition for adolescents should address ethical challenges of the healthcare transition to ensure retention in HIV care, facilitate long-term self-care, provide ongoing holistic healthcare and support in order to promote health and wellbeing, and build trust in the healthcare system. Identifying what facilitates successful transitions, and the gaps that interventions can target, may ensure HIV-infected youth remain healthy across the healthcare transition.

Background:

Perinatally or behaviorally HIV-infected adolescents (10–19 years) and young adults (20–24 years) are an increasing proportion of the HIV-infected population in Uganda (1) with over 110,000 HIV-infected adolescents in Uganda in 2012. There is a growing number of adolescents and young adults with HIV who require transfer of care from pediatric and adolescent care to adult careers (2). Current patient management can assure that many HIV-infected children and adolescents the possibility of decades of

health and wellbeing, making HIV a chronic, manageable illness, but this requires a streamlined process of care continuum that ensures that healthcare is accessible and sustainable as adolescents and young people transit to adulthood.

Healthcare transition (HCT) is the planned and purposeful movement of youth from child-centered to adult-centered care (3). Currently, adolescents are largely in the care of pediatricians; but as they grow, they need to transition to adult HIV clinics. It is important for both individual- and population-level health that HIV-infected adolescents progress through the care continuum through a smooth transition process, to avoid disengagement from care or loss to follow up during the healthcare transition. However, HIV-infected youth frequently disengage from care during transition from pediatric/adolescent to adult care. Globally, many young people experience barriers (such as services, infrastructure, competent healthcare providers) which constrains this transition process. Yet, attention to this transition is critical to ensure continuity of complex care and can help mitigate potential adverse physical and psychological complications resulting from their HIV-infection or use of long-term medication therapies.

Adolescent transition successful outcomes have been reported in high- and middle-income countries in North America, Europe, and Asia (4–9). The four components critical to successful transition (10) include: (i) favorable clinical outcomes (such as medication adherence and viral suppression); (ii) capability of the adolescents and young people to complete treatment-related activities (such as seeking prescriptions and making appointments); (iii) youth taking responsibility for treatment-related activities and their overall health (for instance “when they stop reaching out to the adolescent to solve all their problems.”); and (iv) and youth establishing a connection (trust relationship) toward the adult clinic (that is feeling “safe”) with providers and even prioritizing connectedness over clinical outcomes (Success is registered even if patients are not taking medicines but are connected to care). Identifying what facilitates successful transitions, and the gaps that interventions can target, will help to ensure HIV-infected youth remain healthy across their lifespan. Indeed, identification of key components of successful transition and mitigating the ethical challenges associated with the transition can guide focused interventions and resources to strengthen the HIV care continuum as they transition to adult care.

Transition is “a planned process by which HIV-infected adolescents and young adults, and their caregivers, are empowered with knowledge and skills to enable them to independently manage their health.” (11). The main goal of transitional care is for young people living with HIV infection (YPLHIV) is to nurture confidence, autonomy, and responsibility for their HIV care by the time they are required to attend adult clinics. A good transition process builds life-skills and reduces risk-taking behaviors that can interfere with adherence to treatment and retention in care. Additionally, keeping YPLHIV on ART continuously and preventing transmission to others is critical to any transition program (1, 12). Adolescents have expressed the need for an improved transition process. Assessment of adolescent HIV care found “the need for better planning and preparation for clinical providers and adolescents to improve the transition process, with a focus on improving both clinical and psychosocial support throughout the process”(1). However, there is no clear process of transitioning to adult care in Ugandan health clinics. Ensuring effective transition from pediatric/adolescent to adult care is a national priority for optimizing

the health of YPLHIV, and also critical for prevention of HIV transmission to wider communities. The objective was to analyze the ethical issues associated with the process of adolescent transition to adult HIV care.

Methods

Setting and participants

The study was conducted from August 2019 to January 2020 in 9 facilities at various health care system levels, (three regional referral hospitals; 2 district hospitals, four health centers. Data was collected through 18 focus group discussions with young people living with HIV in nine facilities. Participants were selected purposefully by maximum variation sampling to represent a variety of age group, education level, and socioeconomic status. All the interviews were conducted in one of the private offices on the ward by the first Author (SNM). We explored the following issues concerning transitioning of adolescents to adult clinics (Responsibility of their own health, Knowledge about their health, responsible behavior, introduction of transitioning process, Experiences of adolescents who had transitioned and now they were back in the adolescent clinics, facilitators and barriers in transitioning to adult clinics). These participants were identified through the peer educators who were approached at the beginning of the study. All participants gave verbal informed consent and were assured that the information given was confidential, that they were not obliged to join the study, and that their views would be anonymous.

Conceptual framework

In Uganda, all ART service delivery they created an adolescent clinic or a day which provided Adolescent living with HIV (ALHIV) a comprehensive Service package in addition to adolescent friendly services. This is because they are a unique group and require additional support. While the components of the adolescent package of HIV care closely resemble those of the adult package of care, how they are delivered has an impact on uptake and success. To be effective, the adolescent package of care ensured: Integration of services, that services are age and development age appropriate, responsive to the needs of both perinatally infected adolescents, as well as those infected later in childhood or adolescence, emphasis on both care and treatment, and services are family-centered.

Data collection and analysis

An explorative qualitative approach was utilised for this study using eighteen (18) focus group discussions. Data was collected from 9 health facilities in all the four regions of Uganda. The study participants were selected through purposeful sampling based on sex and age. Eighteen focus group discussions were held, nine for the females and nine for males with an average of 10 young people in each focus group. Components of the HIV Care and Treatment service package for adolescents include the following: HIV Counselling and Testing, HIV prevention service, Growth and development monitoring, nutritional counselling and support, opportunistic infection screening and management, Sexual and reproductive health, Counselling and Psychosocial support, ARV preparation, initiation and monitoring,

Adherence and retention into care and mental health. A facilitator was conceptualized as a factor that was perceived to enable smooth transition, while a barrier was conceptualized any perceived factor that deters smooth transition.

The focus group interviews were initially reviewed to by the first author during data collection to assess point of data saturation. After data collection, all the FGDs were transcribed verbatim. The transcribed text was then translated from local language into English. As the researchers aimed at exploring experiences, barriers and facilitators to transitioning. thematic analysis approach was chosen (13). The interviews were read through several times by all authors and the different statements were grouped, resulting in the construction of a map, in accordance with the description by Braun and Clark (13). Different themes and sub themes were identified and discussed and rearranged until a final pattern was distinguished. The themes that were relevant to our research questions were considered and reported.

Theoretical Framework

The Silences Framework (14) guided this research. The Framework asserts that reality is not objective or fixed but rather human beings scripts the social world in communities at a particular time(14). The Framework put an emphasis on the 'Screaming Silences' in individual and group interpretations of experiences that can be qualified as 'truth'. In this paper silences are explored in relation to facilitators and barriers of transitioning among the adolescents in ART clinics in 9 facilities (3 regional referral hospitals, 2 District hospital, 2 Health Center IV and 2 private facilities). in Uganda. The Screaming Silences in relation to facilitators and barriers with in adolescents were explored to ascertain barriers and facilitators for transitioning of adolescents into adult clinics in 9 health facilities in Uganda.

The focus group discussions with the research participants lasted for one hour. All focus group discussions were audio tapped and transcribed verbatim and the transcribed data was subjected to the four phases of the Silences Framework shown below (14) .

- **Phase 1** - After transcription, the outputs from the focus group discussions were analysed by the researcher and recurrent themes were identified as the preliminary findings from the study.
- **Phase 2** - The preliminary findings from phase 1 were reviewed by the research participants. Reflections on the early findings from the participants were used to enhance further critique, confirming or refuting the findings from phase 1. A discussion of the silences (Findings) was formulated.
- **Phase 3** - A further analysis of the findings from phase 2 was undertaken in this stage by research participants. The participants in this phase were drawn from the ART clinics that had not taken part in the focus group discussion with a critical indirectly associative eye.
- **Phase 4** - Finally the researcher reflected on the findings from phase 3, revisiting, reviewing and developing emerging themes which formed the final output of this study.

Analysis of the ethical issues of the transition process

Jonsen et al (15) have described an approach to clinical ethical case analysis known as the “four-quadrant” approach (15, 16). This framework, while relying on Beauchamp and Childress’ four principles ethics framework (17). These principles include Autonomy (Respect for the individual patient and his or her ability to make decisions with regard to own health and future; right to self-determination); beneficence (Doing and promoting good; preventing and removing evil or harm); non-maleficence (Doing no harm; avoiding harming); and justice (Maximizing benefit to patients and society while emphasizing equality, fairness, and impartiality).

The four-box or four quadrant approach takes a more practical and clinically oriented approach to ethical challenges. Within this framework, all ethical problems are analyzed in the context of four topics: medical indications, patient preferences, quality of life, and contextual features (that is social, economic, legal, and administrative) (18). Each topic can be approached through a set of specific questions with the goal of identifying various circumstances of a given case and linking them to their underlying ethical principle. Medical indications include diagnosis, prognosis, proposed measures for evaluation and treatment, and expected outcome of treatment. Patients’ preferences are relevant from both a medical and ethical standpoint. If the patient has decision-making capacity, his or her preferences should be respected and should guide medical care. If the patient does not have decision-making capacity, or is a minor, the patient’s presumed wishes or best interests, as conveyed by a surrogate, serve as the guide. Illness or injury can negatively impact quality of life (QOL), and since the goal in medicine is to preserve, restore, and improve QOL, it is important to analyze how the care transition might affect QOL. During this analysis, the principles of beneficence, non-maleficence, justice and respect for autonomy must be considered. Clinical issues do not exist in isolation but are part of a larger context that is relevant to ethical analysis. Contextual features that can affect decision making include patient-specific factors such as family dynamics, financial resources, or religious or cultural identity; legal ramifications of care; and personal bias the patient.

Ethical approval

Ethical reviews and approval were obtained from the Research Ethics Committee of School of Health Sciences, College of Health Sciences at Makerere University #SHSREC REF: 2019-029 and the Uganda National Council for Science and Technology (SS 5063). Administrative clearance and permissions were also obtained from the management of each of the health facilities. Written informed consent was obtained from young people above 18 years. For adolescents below 18 years assent from the adolescents and consent from parents or guardians was obtained. Participation was voluntary and all the interviews were conducted in private settings to ensure participant’s confidentiality.

Results

From the ethical analysis, the key emerging perceived ethical issues of the transition to adult HIV care were: Reduced patient autonomy; Increased risk of harm from stigma and loss of both privacy and

confidentiality; Unfriendly adult clinics induce disengagement and disruption of the care continuum; Patient preference to transition as a cohort facilitates the process.

Patient preferences

Need for connectedness with the care providers and other patients

There was an attempt to transition the adolescents to adult clinics but most of them came back to adolescent clinics, because of what they perceived as unfriendly attitude by adults (both healthcare providers and patients) in the adult HIV clinics. The adolescents stated that one of the barrier for them to transition to adult clinics is the judgmental nature of the adults in the clinics. The adolescents found it hard to talk to adults because adults seemed “serious” or unwelcoming, appeared uninterested in the issues of young people and talked about issues that were of interest to them. The adolescents and young people feared to be ignored or discriminated against. Thus there was a perceived disconnect between the adults (patients and care providers). There was also perceived fear of loss of privacy and confidentiality, as were as felt stigma, yet these were cherished by adolescents in the adolescent clinics. Besides, the adolescents and young people had different expectations from those of adults (care providers and other patients). The patient preferences were in line with the principle of autonomy (respect for the individual patient and his or her ability to make decisions with regard to own health and future; right to self-determination). These perceptions and experiences are exemplified by the participants below:

“... the adult people are so judgemental, you hear them saying, “how did he get the HIV? such a young child! yet sometimes, you got it from your mother, like me I got it from my mother and they don’t end only here, they again take them to the community and the whole village knows and then you reach there when everyone has known” (male, 20–24 years)

“... when you go to the adult clinic, it may be so difficult to comfortably associate with the adults. So, it may not be easy for us. They have parental thoughts, yet for me I have adolescent thoughts. I don’t know if there are adults, that I will be able to converse with like it is here. So, I think it may be so hard for me to comfortably converse with them or fit in them. But maybe if I get a child, I will be able to fit in them knowing am a fellow parent.” (Female, 20–24 years)

Need for similar care as provided in adolescent clinics

The adolescents had been in the adolescent clinics since they were 10 years and have developed a routine, made friends hence identifying care in adolescent clinic as different and favorable to them. A typical adolescents’ clinic starts off with a reminder from the peer a day before the clinic. Those who confirm will be expected to attend the clinic and those who are not able reasons are given and if it is within the reach of the facility they are facilitated like transport. On the real day they start off with education session either from the peer, health providers or counselors depending on the schedule and experience. After the session if they are immunosuppressed (low CD4 counts or high HIV viral loads) they are fast tracked to the pharmacy and spend a maximum of 30 minutes. If they are not

immunosuppressed (normal CD4 and low HIV viral loads) they are taken to the counselors and then to the clinician and finally to the Pharmacy for refill. Besides, in the adolescent clinics, healthcare workers provide porridge and a bite every time they come to the clinic. The health workers hold psychosocial events quarterly for all the adolescents, mainly to share experience, have talks, dance eat and play with a health education with peers. The adolescents felt that they been favored in this adolescent clinic which they know won't happen in the adult ART clinics. Some adolescents had experienced what goes on in the adult clinic:

....at a certain point it comes back to the health workers. Health workers tend to treat adolescents and young people in a different way while in the adolescent clinic and therefore the adolescents don't wish at any one point to leave their clinic to go to the adult clinic where they will not be treated the same way" (female, above 24 years)

like another reason why we might be scared to leave this adolescent clinic, we think that our clinic is more confidential and secure than the adult clinic because we feel like our secrets are safe in the adolescent clinic than in the adult clinic. Yah, we feel that and we think that's what works for us because we feel we are the same age it's easy to understand each other but in the adult clinic adolescents fear to meet there their relatives, their aunts their uncles, who may expose their status outside. It's not okay because stigma is high, discrimination, some of us are still in school so, we fear those, so we find that it's hard for someone to be exposed outside in the adolescent clinic than in the adult clinic. (female, 18 years)

Perceived care in the adult clinic

The adolescents want to be treated the same way they have been treated in the adolescent clinics when they move to adult clinics and this could facilitate their transitioning.

"They should provide patients in adult clinic with the same privileges like those in the adolescent clinic for example giving them porridge, having adequate counsellors, short waiting time among others".(female 15–19 years)

"Treating adolescents well like children even when they are transitioned to the adult clinic, like being caring and kind to them while in the adult clinic". (Male ,15–19 years)

"Moving with the same health providers to the adult clinic whom the adolescents are used to and who know more about them". (Female, 15–19 years)

Some adolescents were ready to move to the adult clinics because of some of the benefits they anticipated receiving:

"For me, I would love to go to the adult clinic, such that I be able to meet adults with beneficial ideas and knowledge, and also to have sensible and mature conversations with them" (female, 20–24 years)

"I would love to go to the adult clinic because now when I get there obviously there are packages that are given in the adult clinic that I can't get here like practicing safer sex, family planning and by that time I will be engaged so they will be beneficial to me". (Female ,20–24 years).

"Differentiated Service Delivery model, they have privileges of getting drugs from home, in the community they don't have to come here and for the adolescents, it's the clinic and I would also love to be on those groups where you don't have to come to the clinic, I only have to come to the clinic when I have issues"
(Male ,20 years)

All the ART clinic had a peer support group and some of the facilities were implementing the new program from Ministry of Health called Young adolescent program Support (YAPS) which was assisting adolescents to adhere to their treatment. In peer support groups adolescents to help each other to improve and better manage their situation, share challenges and discuss solutions. Members support each other to implement decisions made to meet their psychological, social, physical and medical needs

I feel like they still need more help in the adolescent clinic from my peers (peer support) through their support groups and also from health care providers especially their counsellors and social support on adherence to medication among other challenges they face. (Female, 20–24 years)

The contextual factors of care during the transition

Transitioning preparation

The adolescents expressed concerns that they were not prepared for the transition of care. It is possible that even the healthcare providers in the adult HIV clinics are probably not prepared to handle adolescents who are transitioning in adult care. Such preparation would require orienting them to the needs and preferences of adolescents and young people, the need to respect adolescents' autonomy and decision making, the need to avoid undue harm through disclosure of HIV status or breaching confidentiality and privacy, and the need to provide attractive benefits aimed at keeping adolescents and young people in care. Preparing the adolescents earlier before being transitioned to the adult clinic, like first talking to them about transitioning and telling them everything about the adult clinic would facilitate transitioning:

"We should be having sessions with parents and the health workers and discuss with them to on how to treat the adolescents well when they are transitioned to the adult clinic, not to be judgemental, not to disclose their status in the village, not to talk about them, not to discriminate the adolescents among others such that the adolescents feel comfortable when they go to the adult clinic". (female 15–19 years)

"I think transitioning should be introduced to us from the point we step in and become their client so that we grow up with that in mind, it's not like an ambush, like the way they are doing it now. But if at a point we stepped in here during counselling, they added that point of transitioning each time I have a counselling session they tell it to me, it wouldn't be new to me and I will be feeling comfortable going

there because they will be telling me the advantages and why but now it's had for someone.” (Female, 20–24 years)

The health care providers in adult clinics

The adolescents expressed fear for the health care providers in the adult clinic, who may be unprepared to provide age-appropriate care for adolescents and young people. The adolescents thought that working with the new providers would not be favourable to them and providers in the adult clinics may not be friendly and kind like those in adolescent clinics. While any person of any age would fear a transition, what makes it important as a barrier that this was a recurrent point in the discussions, and participants gave examples on how this usually manifests.

“I fear to find different and new health providers in the adult clinic who do not know me and they don't know my story” (adolescent female, 15–19 years)

“Fear that the health workers in the adult clinic are not kind and caring as those in the adolescent clinic”. (female, 15–19 years)

Congestion and long waiting times

Some of the adolescents who had visited the adult clinic expressed that adults spend a lot of time in the clinic from morning to evening, whereas in adolescents' clinic they are seen very fast and they leave. The adult clinics have so many clients and are congested, Adolescents don't want to spend a lot of time in the clinics

“When I come putting on my uniform, they give me the medicine but there you have to wait until they finish those who came first but here, if I come putting on my uniform or even if I am not putting it on, I get my medicine fast”. (Male.15–19 years)

“Some of us are schooling going children, some are working so, someone will escape from school to come pick medications, some will escape from work to come pick medications, so, when we are transitioned for real, remember when you join adulthood, then, for them they know ounce I am going for medication I am going to make all that day for medication but for us we are always on a quick schedule. As you come you left school when having a test in the afternoon, you come rushing you say, aya ya ya, I am going for a test, they give you your medicine and you move but the adults stay here the whole day. We see, some of our parents we come with them and they expect to spend the whole day and you find you came with the parent for you you're done but she is still there. (female, 20–24 years)

Personal factors such as fear to lose friends

Since young people who were infected with HIV as children were initially not expected to survive until adulthood, relatively little attention has been given to issues associated with this transition to adult care. The participants preferred that the adult HIV clinics should ease and smoothen the transition process by

identified a fellow youth as a care provider to meet with the transitioning youth, to offer information, emotional support, and even just to provide company at medical visits. Such a staff may be conversant with the needs, preferences, and expectation of adolescents and young people, such as flexibility and friendliness, which go a long way toward helping adolescents make the transition to adult care and ensure continuity of care. Besides, the adolescents expressed that if they are transferred to adult clinics they will lose their friend since they will be given different appointments where as in adolescent clinics they had a special day when they met as adolescents, this scares them a lot, and was perceived as potentially harmful. Thus, with improved life expectancies, health professionals are increasingly faced with the new challenge of working with these young people as they grapple with the unique experience of being an HIV-infected adolescent transitioning into adulthood.:

"I don't want to go to the adult clinic because they will miss their age mates since they usually come to the clinic and share their experiences". (female, 15–19 years)

"I would not wish to go to the adult clinic, is because I will miss my friends. When you come here, you chat with this one and you have totally a different conversation with another person". (male, 15–19 years)

Medical indications

Health system factors and preparation for transitioning

The adolescents expressed that preparation is paramount for them to transition and it may hinder them from transitioning because they don't know what to expect to do there and what is expected of them. This could be that they are not prepared well or they don't know what to expect in adult clinics Some adolescents think they are still young and that they have not reached that age of going to the adult clinic. Initially the Ugandan guidelines said that the age of transitioning was 18 years and later moved it to 24 years. However, there are clients who are above 24 years still seen in the adolescent clinic. This was perceived as unfair to both affected young people and adolescents, as it was a form of unequal treatment, and therefore an injustice that adolescents are not well prepared for a smooth transition to adult HIV care. Besides, it was an indication of failure to provide age-appropriate care to HIV patients, which in itself is also an injustice. Yet Continuity of care is a major challenge for young people living with HIV, especially when transitioning from pediatric and adolescent care into adult HIV care.:

"We don't want to go to the adult clinic because they think they will be treated like adults yet they are still those vulnerable people who still need that care like that in the adolescent clinic". (female, 15–19 years)

"I didn't want to go to the adult clinic because I didn't know what they are going to do (there)". (male, 15–19 years)

Moving as a cohort

Adolescents expressed that taking them as a cohort to the adult clinic so that they move with their friends whom they have been with and are familiar with would facilitate the transitioning process instead of distributing them in the different adult clinic days. However, this may not always be possible, for adults, the patients may be different clinic days according to medical factors such as presence of ART complications, immunosuppression, reproductive health needs, or failure of a given treatment regimen. Creating a different day for the transitioned adolescents in the adult clinic and not mixing them with the adults was not always possible or feasible.

“If they are to change us to the adult clinic, they should take us as a group because now you are able to see your friends and age mates maybe they get like 10 adolescents and they take them there as a group but when you have been knowing each other. So, that helps”. (Male ,20–24 years)

“Like all of us as we are here, all of us should go at once because as we are here, we know our selves and we associate. So, even if they give us one day in a month, but we are as we are here when we are age mates but not sitting here next to a 70 year, grand mum” (Female 15–19 years)

Quality of life

Stigma and fear to disclose their status

For young individuals receiving treatment, transitioning to an adult model of care presents a potential stumbling block to achieving and maintaining viral suppression, and therefore portends poor quality of care. The adolescents expressed fear that if they went to the adult clinics, the adults would disclose their sero-status and this would create stigma in the communities they live in:

“I fear to find relatives and village mates in the adult clinic who might disclose my HIV status back in the village to their children and other people in the village” (female, above 24 year).

Moving as a cohort

Adolescents felt that they had stayed together for a long time with fellow adolescents, and had formed special bonds of friendship. For this reason, they wished that they could be transitioned to the same clinics for adult HIV care. Their view was that taking them as a cohort to the adult clinic would enable them maintain these friendships, which were deemed essential for a better quality of life, compared to if they were separated. To adolescents, taking them as a cohort of people who are familiar with each other would facilitate the transitioning process instead of distributing them in the different adult clinic days, and so would ensure a better quality of life. However, this may not always be possible, for adults, the patients may be different clinic days according to medical factors such as presence of ART complications, immunosuppression, reproductive health needs, or failure of a given treatment regimen. Creating a different day for the transitioned adolescents in the adult clinic would ensure better quality of life. In contrast, mixing adolescents with the adults was likely to lead to poor quality of life.

"If they are to change us to the adult clinic, they should take us as a group because now you are able to see your friends and age mates maybe they get like 10 adolescents and they take them there as a group but when you have been knowing each other. So, that helps". (Male, 20–24 years)

There is also more personal interaction with healthcare providers, some of whom are peers of the adolescents and young people. Adolescent clinics tend to have more resources to support youth, [such as] funds for transportation to clinics, smaller caseloads, and more on-site comprehensive services, and [they] do more personal interactions, such as sending text message appointment reminders, seeing youth even if they are late for their appointments, or accepting to see the youth on non-appointment days. Yet adult HIV clinics may not have these considerations. This 'hand-holding' by peers and healthcare providers can be extremely helpful for adolescents and youth to stay engaged in care at the adolescent clinic (as treatment buddies). However, such an arrangement or practices may leave youth underprepared to meet the behavioral expectations of the adult clinics, where they have to be in control of their destiny. This challenge is exemplified by one youth:

"I would not wish to go to the adult clinic, is because I will miss my friends. When you come here, you chat with this one and you have totally a different conversation with another person". (male, 15–19 years).

Discussion

There is scarce information on ethical challenges faced by HIV infected adolescents during the healthcare transition into adult HIV care. The factors that influence the care continuum can be linked to success of linkage and engagement during healthcare transition (10). Such success may be indicated by the number of clinic visits within a given time frame or evidence of a marker for a visit (such as blood draw for viral load and CD4 count). However, some argue that success should be defined based on an individual's viral suppression, which is a marker of adherence to care, including adherence to medication. To achieve this raises ethical challenges in the healthcare transition, which need to be addressed for a successful healthcare transition.

There are several ethical challenges of the adolescent-to-adult HIV care transition that have been identified in Uganda. A study done in both private and public clinics in Uganda caring for YPLHIV and found that only 3% of healthcare facilities had a specific health transition clinic (HTC) to support the transition from pediatric providers to adult providers (19). This indicates lack of preparedness for the adolescent-to-adult HIV care transition. With improved life expectancies, health professionals are increasingly faced with the new challenge of working with these young people as they grapple with the unique experience of being an HIV-infected adolescent transitioning into adulthood. Additionally, another study found that HTC use is less common in those who are older (age 20–24), male, live in rural locations, acquired HIV behaviorally, are not on antiretroviral therapy (ART), and have CD4 counts > 250 (12). Therefore, those at highest risk for health complications and transmission of HIV to others do not

have the HTC resources to support a successful transition. Efforts have been made by Ministry of Health to expand the 3% availability to 100% so that the Transitioning process is prioritized at the national level.

The ethical issues can be derived from the care process, using the ethical principles (20), which need to be balanced through specification. Autonomy refers to the right of the patient (the adolescent, youth or their guardians/parents) to retain control over his or her body, such that a healthcare provider may just suggest or advise, and any actions that attempt to unduly persuade, coerce or limit the patient's ability to make a voluntary choice are violations of this principle. From this principle, the patient should be allowed to make his or her own decisions – whether or not the healthcare provider believes these choices are in that patient's best interests – independently and according to his or her personal values and beliefs. The principle requires respecting patients' preferences, decisions and choices, as long as they do not conflict with other principles, such as curtailing patient benefits, inducing harm or reducing fairness.

From the principle of beneficence, health care providers must do all they can to benefit the patient in each situation during the transition (including providing age-appropriate care and adolescent-friendly services). Besides, all procedures and treatment plans recommended must be with the intention to achieve the best for the adolescent and young person in the HIV care transition. Additionally, to ensure beneficence, healthcare providers should develop and maintain a high level of skill and knowledge, including providing acceptable age-appropriate care for adolescents and young people. An additional competence is the need to consider the patients' individual circumstances, with the understanding that what is good for one patient will not necessarily benefit another.

The principle of non-maleficence requires that healthcare providers should primarily consider whether anyone (including other people or society) could be harmed by a decision made, even if it is made for the benefit of an individual patient. For instance, failure to transit individuals as a cohort, which the adolescents and young people prefer, may lead to disengagement and loss of linkages and therefore affect transition success. Also, breach of confidentiality and privacy and stigma lead to harm to the individual, but may lead to society harm if it leads to loss of continuity of care, with potential risk of HIV transmission in case of sexually active adolescents and young people. Still, lack of a formal process of preparedness for patients and healthcare providers constitutes harm to the healthcare transition.

The principle of justice requires ensuring fairness in all medical decisions, to consider fairness in decisions that burden and benefit individuals (as well as equal distribution of scarce resources and treatments). Justice also requires upholding applicable laws and standards when healthcare providers are making decisions that affect adolescents and young people during the healthcare transition. Still, justice is required in allocation of resources, including time, space and other resources needed to provide HIV care during the healthcare transition.

One of the ethical issues identified in this study is patient preferences for adolescent-friendly services over adult HIV care. The former services are accessible, acceptable, appropriate, effective and equitable (21); they are flexible and tend to provide more personal and age-appropriate care for adolescents (22). In these clinics, the health care providers are sensitive to their young clients' needs, they encourage

autonomy and demonstrate respectful and non-judgmental attitudes (which are perceived as harmful by adolescents and young people) (22). In this study one ethical challenge of the patient preferences during the care transition is that since the care provided in the adolescent clinics was very satisfactory to the adolescents, they seemed unprepared and unready to transition to adult HIV care, and some did not even see the need to transfer to care.

There is need to progressively provide age-appropriate HIV and sexual and reproductive health services to meet the needs of the adolescents and young people as they grow up. Adolescent HIV care is characterized by an emphasis on multidisciplinary on-site care with a youth friendly environment, a family-centered focus, and psychosocial support which attends to adolescent developmental needs (23). From the views of participants, these contextual factors were lacking in adult HIV clinics. Many adolescents with HIV (both perinatal and behaviorally acquired) develop strong and longstanding relationships with their care team, often seeing them as members of their family, especially in the context of prior parental loss (24, 25). However, most of these adolescent and young people have grown and need to move to adult clinics to create space for those patients in pediatric clinic, as well as to access specific age appropriate services such as sexual and reproductive health services, which may be missing in the adolescent and pediatric clinics. Such adolescents may be reluctant to disengage from health care providers in the adolescent clinics out of patient preferences, yet this portends discontinuity of care and even risk of missing age-appropriate services for elder adolescents and young people. Integrating adolescent friendly days or clinics in ART care, and progressive introduction of sexual and reproductive health services in the pediatric and adolescent clinics may smoothen this transition and eventually improve retention in care (26). Such initiatives potentially improving health outcomes and patient quality of life during the healthcare transition.

To ensure quality of life for adolescents, there is need to engage adolescents or peers in the care provision for them in the adult HIV clinics. In this study most of adolescents saw the unfriendly adults in the adult clinics as a barrier to transitioning. The benefits of engaging adults in the adult ART clinics to support adolescents in transitioning cannot be underestimated, as it ensures that they feel acceptable and welcome. It is important to explain the transitioning process and its importance to the adults (both patients and healthcare providers) in adult clinics so that they can support these adolescents and young people in the care transition. The role of care givers and adults has been documented in many studies as these individuals are important resource to find potential solutions to guide the transition process (27, 28) to ensure continued engagement of adolescents and young people in the adult HIV clinics to which they are transferred.

As much as possible, the contextual factors that may lead to unintentional harm, such as disclosure of HIV status or breach of privacy and confidentiality should be addressed during the healthcare transition process. Stigma affects an individual's sense of self-worth and self-esteem, reducing ability to seek emotional and psychosocial support through disclosure to others, limiting confidence to adhere to treatment at school or in the workplace, and affecting willingness to seek health services on a continual basis (31). Stigma thus violates all the ethics principles. There is thus need to create clinic-wide strategies

to eliminate stigma towards adolescent and young patients in the clinical setting during the healthcare transition (31). HIV is a highly stigmatized illness and many adolescents and young people living with HIV face HIV-associated stigma and disclosure to sexual partners, friends, and family, which is a major barrier to engagement in adult care (29, 30) Many adolescents expressed fear that if they went to the adult clinics, the adults would disclose their sero-status and this would create stigma in the communities they live in. Adults, parents and care givers need to understand that stigma can affect an adolescent's ability to live positively with HIV, and thus continuing engagement and continuity of HIV care after transitioning.

Another contextual factor mentioned by participants was congestion and long waiting times in adult clinics. Adult HIV clinics are often more formal with limited scheduling flexibility, large numbers of patients and more patient- and disease-focused care, less co-located specialty care, and fewer youth-friendly services (6). These characteristics may explain the poor outcomes of ALHIV seen in adult HIV care(32). Adolescents and young people transitioning to adult clinics identify fear of such an adult clinic environment as a barrier to smooth and successful transition and have described difficulties after transfer to adult clinics in dealing with congestion and longer wait times (25, 27). Engaging and training adult providers in adolescent -friendly HIV care models may be useful as many adult providers lack the expertise or will to provide youth-friendly services in the adult setting(24, 33).

Another contextual factor is that adolescents who had grown up while attending ART clinics are comfortable in these clinics with their peers and their providers, and preferred to be transitioned (as a cohort) into a specific HIV clinic. Separation from the group they have known for a long time is a major ethical challenge. Still, transitioning the group as a cohort is in itself a major ethical challenge, as the transition care may depend on medical indications (that is, the adolescents and young people may need different care depending on factors such as age, medical complication and social factors). Besides, transitioning as a cohort may limit provision of age-appropriate HIV and Sexual and Reproductive Health services. Age-appropriate services, in a carefully planned healthcare transition, recognize and are responsive to the evolving physical, developmental, cognitive, medical, emotional, educational and social needs, such that they provide close to individualized care. This may not be possible if adolescents transition as a cohort. Yet adolescents feel like they have lost a family when they talk about separation during the healthcare transition (28). It is imperative to assist adolescents identify barriers (real or perceived) to transitioning process so that the providers, care givers and adolescents can explore potential strategies to overcome them. This necessitates flexibility in allowing transition as a cohort, as long as it does not lead to loss of potential benefits such as age-appropriate care or does not lead to inadequate HIV care.

Sill, another identified contextual factor that portends harm is the preparedness and preparation for transition for both healthcare providers and patients. Carefully planned transition recognizes the evolving developmental, medical, emotional, educational and social needs. Lack of preparedness portends harm to both patients and providers and is a major ethical challenge. Strong attachment between adolescents and the paediatric providers is a major hindrance to HIV care transition, and may limit initiatives for

preparedness (34–37). Since lack of transition preparation is barrier for effective transitioning, it may affect care outcomes and thus quality of life, especially if it leads to stigma or results into discontinuity of care. Such preparedness requires that transition is carefully planned and managed, taking into consideration the adolescent's medical, psychological and social needs (38, 39). Even then, transition should be a gradual process of preparing and supporting the adolescent to make the shift from dependence on caregivers to self-management and autonomy, and into more developmentally and medically appropriate care (27, 28, 34, 35).

Finally, another contextual factor that needs to be addressed is standardization of the process of preparedness for the healthcare transition through a process that recognizes the ethical principles of respect for autonomy, beneficence, non-maleficence and justice. In order to improve the transition process for HIV-infected youth, the American Academy of Pediatrics (2013) recommends that (i) written policies and protocols should developed to guide transition; (ii) a transition plan needs to be created jointly by the youth, family members and healthcare providers; (iii) the transition plan should facilitate connectedness of the youth to the adult HIV clinics during the transition, and (iv) there is need for regular communication between adolescent and adult HIV clinics during the transition process for quality assurance (40). The latter calls for understanding adult providers' attitudes and comfort in treating youth, who are often dealing with other challenges (such as challenges of the developmental stage), and that this is critical for ascertaining preparation gaps and needs (41).

The health system should develop and monitor behavioral and other indicators of successful transition, so monitoring and evaluation of data are critical. These indicators should recognize that adolescents living with HIV largely belong to two distinct groups—those who acquired HIV perinatally and may have more experiences of HIV care including ART, and those who acquired HIV more recently during their teens. These groups may have different needs and challenges and different approaches to healthcare transition. In addition, adolescents with HIV represent a heterogeneous group in terms of socio-demographics, mode of HIV acquisition, sexual and substance abuse history, clinical and immunologic status, psychosocial development, and readiness to adhere to medications. Many of these factors may influence decisions concerning when and how to transition to adult HIV care. The indicators may be immunological (viral suppression, improved quality of care, maintaining normal CD4 counts and suppression of opportunistic infections). Behavioral indicators identified for success of the HIV care transition include keeping appointments, medication adherence, and demonstrating ownership of medical care, and serological markers (viral load and CD4 count) (42). Besides, adolescents' readiness and ability to take charge of their healthcare, such as to adhere to therapy within their psychosocial context need to be carefully considered as part of therapeutic decision making, and is a critical indicator of success of the healthcare transition. Also, peer and family support are crucial for a smooth healthcare transition, as adolescents help each other to improve and better manage their situation, share challenges and discuss solutions. Members support each other to implement decisions made to meet their psychological, social, physical and medical needs. Other important data is on sexual and reproductive health indicators, especially on morbidity outcomes.

Study limitations

The participants were selected by the peer leader from the ART clinic this could have posed a selection bias, which was reduced by asking the peer leader to select both females and males and also to have a representation of young people aged 10–19 and 20–24. There may have been some risk posed by selection bias, as the groups were constituted by all age groups. Because of this, power relations and different perceptions between young adolescents and older adolescents, as well as young adults (above 20 years) may have different perceptions, which may have required conducting FGDs with separate age groups. As much as possible, the facilitators of the FGDs ensured that all views of the different participants were captured, rather than only the views from the dominant participants.

Besides, the selection of participants did not consider whether the HIV was perinatally or behaviorally acquired, though most of the adolescents had acquired the HIV infection perinatally. Most adolescents with behaviorally acquired HIV infection acquired this through unprotected sex, and are in an early stage of HIV infection, which makes them ideal candidates for early interventions, such as prevention counseling, linkage to and engagement in care, and initiation of ART. In contrast, adolescents with perinatally-acquired HIV infection are long-term survivors, are usually heavily ART-experienced, may have a unique clinical course that differs from that of adolescents who acquire HIV later in life, and may have developed unique ways of coping with the infection. Yet, adolescents who acquired HIV perinatally or in infancy may have initiated ART early in life with mono- or dual-therapy regimens, and if adherence was poor, may have developed incomplete viral suppression, viral resistance, complications or ART therapy or opportunistic infections. Thus, different adolescents may have different perspectives and needs for the HIV care transition. However, all adolescent and youth have similar needs regarding needs for autonomy and independence, and have similar evolving decisional capacity and thinking processes, risk-taking behaviors, preoccupation with self-image, and need to fit in with their peers. Thus, it is likely that all adolescents and youth have similar focus on maintaining their health in the context of a chronic illnesses that needs lifelong treatment. These challenges are not specific to any particular transmission mode or stage of disease. Thus, irrespective of disease duration, stage of illness or mode of HIV acquisition, these individuals have similar needs and every effort must be made to engage and retain them in care so they can improve and maintain their health for the long term.

Lastly, the study did not get perspectives of healthcare providers to corroborate the experiences and perspectives of the adolescents and youth, neither did the study get view of adolescents in the adult HIV clinics. Adolescents may seek care in several settings, where healthcare providers may have different expertise. These include pediatric-focused HIV clinics, adolescent/young adult clinics, and adult-focused clinics. Regardless of the setting, the adolescents are likely to have similar views the context notwithstanding. Expertise in caring for adolescents irrespective of setting is critical to creating a supportive environment for engaging youth and retaining them in care. Therefore, the identified ethical issues may be applicable to all care settings.

Declarations

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Conclusion

Understanding the expectations and experiences of adolescents and young adults as they go through transitional care adult HIV care to will provide important knowledge to improve current practice. Several individual, social, health system and services-related factors raise ethical challenges that need to be considered if the barriers and facilitators are to be addressed so as to facilitate a smooth transition process. These ethical factors relate to patient preferences and need to maintain their autonomy, contextual factors of the transition and the patients' perceived quality of life. To achieve the priority outcomes of the healthcare transition necessitates addressing ethical challenges of the healthcare transition to ensure retention in HIV care, facilitate long-term self-care, provide ongoing holistic healthcare and support, and build trust in the healthcare system.

Abbreviations

ALHIV Adolescents living with HIV

ART- Anti retro viral Therapy

PHIV Perinatally HIV

HIV Human Immunodeficiency Virus

HC Health Center

HTC Health Transiting Clinics

MOH Ministry of Health

PNFP Private Not for Profit

RRH Regional Referral Hospital

YAPS Young adolescent Program Support

YPLHIV Young people living with HIV

Declarations

Ethics approval and consent to participate

Ethical review and approval were obtained from the Higher Degrees and Research Ethics Committee of the College of Health Sciences at Makerere University #SHSREC REF NO: 2019-029 and Uganda National Council of Science and Technology (SS5063). The administrative clearance and permissions were obtained from the nine health facility. Written informed consent was obtained from the adolescents and young people. Written informed consent was obtained from young people above 18 years. For adolescents below 18 years assent from the adolescents and consent from parents or guardians was obtained. Participation was voluntary and all the interviews were conducted in private settings to ensure participant's confidentiality.

Consent for publication

Not applicable

Availability of data and materials

The acquired and/or analyzed data are not publicly available because of the lack of authorisation from the children's legal guardians, and the agreement with the Research Ethics Committee that the database would remain with the corresponding author only. However, all data can be made available by the corresponding author upon reasonable request.

Competing interests

The author(s) declare that they have no competing interests.

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Authors' contributions

SNM designed the study, collected and analysed the data, drafted the paper; SBK contributed to the design the study and reviewed the paper. LD contributed to the collecting data, analysis, and reviewing

the paper; EM contributed to the reviewed the paper PM contributed to the reviewed the paper and DKK contributed to the design the study, analysed the data and reviewed the paper. All the authors approved the final draft of the paper.

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Table

Table 1
shows their socio demographic data

Variable	Numbers
Age	49
15–19	72
20–24	53
Above 25	
Education status	102
In school	72
Out of school	
Sex	84
Male	90
Female	
Mode of transmission	127
Perinatal	56
Horizontal	8
Don't know	
Living status	30
Alone	52
Parents	109
Guardian	

Supplementary Files

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