

Perceptions of Strategies and Intervention Approaches for HIV Self-Management among Ugandan Adolescents: A Qualitative Study

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Abstract

The heightened vulnerability of adolescents to poor HIV care outcomes underscores the need for interventions that create and promote HIV self-management behavioral skills. Adolescents living with HIV (ALHIV) experience a complex array of physical, emotional, and social challenges that constrain their self-care, but the majority of existing psychosocial programs focus primarily on medication adherence. Understanding adolescents' self-care needs, challenges, and preferences is necessary for developing effective culturally relevant interventions. The involvement of caregivers and stakeholders is also critical to realizing positive self-care outcomes. This article presents the findings from focus group discussions with ALHIV, caregivers, and healthcare providers on self-care. The data were collected as part of formative research in the development of a self-management intervention for Ugandan ALHIV. Participants' discussions on self-care strategies and intervention approaches provide valuable insights to guide the development of interventions to promote positive HIV care outcomes among Ugandan ALHIV.

Keywords

adolescents, self-care, interventions, Africa

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What Do We Already Know about This Topic?

Adolescents living with HIV have multiple complex self-management needs that undermine their health and require multifaceted approaches but few such interventions currently exist.

How Does Your Research Contribute to the Field?

This article highlights adolescents' self-management needs, challenges, and intervention preferences, in order to inform the development of developmentally and culturally relevant evidence-based interventions for Ugandan adolescents living with HIV.

What Are Your Research's Implications toward Theory, Practice, or Policy?

Findings highlight the potential viability of using eHealth interventions to promote HIV self-management among adolescents in resource-limited settings.

Introduction

Adolescence is a critical period for the establishment of effective self-care behaviors.¹ It is during this developmental period that adolescents with chronic conditions start to assume greater responsibility in managing their medication regimens and clinic visits, and increasing autonomy in partnerships with healthcare providers. This transition period is also characterized by heightened vulnerability to poor health outcomes: evidence from numerous studies indicates that adolescents living with HIV (ALHIV) experience numerous psychosocial challenges²⁻⁵ that reduce their levels of medication adherence, viral suppression, and retention in care and consequently, increase their risk of AIDS-related mortality.⁶⁻¹¹ Self-management

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skills are necessary for achieving successful health outcomes among adolescents with HIV.¹

Globally, there is a limited body of knowledge on the effectiveness of psychosocial interventions among adolescents.¹² There are even fewer psychosocial interventions targeting the needs of ALHIV in sub-Saharan Africa,¹³ despite a high prevalence of HIV among adolescents in the region.¹⁴ Developing an effective intervention requires consideration of developmental, cultural, and resource needs of adolescents, and knowledge of the effective strategies for engaging and promoting sustainable gains in their knowledge, cognitive skills, and behavior. However, adolescents' attitudes and preferences for self-care have not been widely examined. Previous research has shown that adolescents are rarely consulted about decisions regarding their care¹⁵⁻¹⁷ although children's perspective is necessary for developing child-centered care.¹⁸

The use of collaborative strategies to design, test, and deliver interventions has been identified as critical to developing culturally relevant client-centered interventions.^{19,20} Drawing on the principles of community-based participatory research,^{19,20} this study examined the perceptions of ALHIV, caregivers, and healthcare providers on current gaps and preferences for intervention approaches for promoting HIV care self-management among ALHIV. These findings will inform the design of a self-management intervention for Ugandan ALHIV.

Methods

Participants

Adolescents, caregivers, and healthcare workers were recruited from a large HIV care clinic in Kampala, the capital city. We recruited adolescents and parents or caregivers from the clinic during their scheduled clinic visits; pediatric clinic healthcare providers were approached individually during work hours. Criteria for inclusion of participants in the study were age of 12 to 19 years (inclusive), enrolled in HIV care at the clinic, fully aware of their HIV status, and without documented cognitive impairments. Caregivers (both male and female) were eligible to participate in the study if they had a child aged 12 to 19 years and were seeking HIV care at the clinic. However, parents and caregivers were not matched to the adolescent participants. Healthcare providers (doctors, nurses, counselors) were eligible to participate in the study if they worked in the HIV pediatric or transition clinics at the center.

Data Collection

We conducted focus group discussions (FGDs) with adolescents (3 groups), parents or caregivers (3 groups), and healthcare providers (1 group). All adolescents were required to provide written informed consent (if older than 18 years of age or emancipated), or written assent and parental consent (if younger than 18 years of age) prior to participating in the study. Caregivers and healthcare providers were also required to provide written consent. Two research assistants (having bachelors

degrees in social work), with experience conducting qualitative research, led the FGDs using a structured FGD guide.

Participants were asked to describe their perceptions of HIV self-management roles (for adolescents, caregivers, healthcare providers), including self-management needs and challenges of ALHIV, in order to provide suggestions on strategies for improving ALHIV's self-management and indicate their preferences regarding the following intervention approaches: group or peer support, individual counseling, joint parent-adolescent counseling, and eHealth technologies.

Focus group discussions were conducted in a private boardroom at the clinic and were audiotaped. The discussion for the healthcare providers was conducted in English, while those involving the adolescents and caregivers were conducted in either English or Luganda. Both research assistants were fluent in both languages. Participant confidentiality was maintained through use of numbers and deidentification of transcripts. Adolescents and caregivers received a transport reimbursement as a token of appreciation for their participation in the study, while healthcare providers received USD \$5 incentive.

Data Analysis

Recordings were transcribed verbatim; Luganda text was translated to English first and back translated to verify accuracy of the translations. The analysis was conducted using Dedoose software, version 8.0.²¹ Inductive content analysis was used to identify emerging themes and examine patterns in the data. The first and second authors independently reviewed the transcripts using an open coding method to identify emerging themes; these themes were reviewed until consensus on meaning was reached. A codebook of emerging themes and sub-themes was then developed, along with a definition of each theme and supportive quotes. Three graduate students blind coded the transcripts, coding participant statements based on the identified themes. They also verified and added themes to the codebook developed by the first and second authors. Each transcript was coded twice, and the percent agreement between coders was calculated. The initial inter-rater agreement was 83%. Disagreements were largely found in categories with overlapping elements. The primary author also reviewed all disagreements in coding and assigned final codes as necessary. Following this reclassification, the final inter-rater agreement was 100%.

Results

Description of Participants

A total of 34 adolescents (10-12 participants per group), 34 caregivers (10-12 per group), and 12 healthcare providers participated in the focus group discussions. Of the adolescents interviewed, 56% were females, 40% lived with both parents, and 89% were currently enrolled in school. The median age of the adolescents was 15.2 (standard deviation = 2.8). Among the caregivers, 92%

were female; they included biological parents (52%), grandparents (35%), and aunts/uncles (15%). The healthcare provider group consisted of doctors (n = 2), nurses (n = 3), and counselors (n = 3), all working in the pediatric clinic.

Strategies for Strengthening HIV Self-Management

Counseling and Guidance

Study participants highlighted medication adherence, prevention of HIV transmission, self-disclosure of HIV status, management of HIV stigma and negative affective states (eg, self-hatred, self-rejection, self-isolation, fear, or worry about death), and preparing adolescents for the future as the most pressing needs and challenges related to HIV self-care. Participants highlighted the need for healthcare providers to provide guidance and counseling to ALHIV on issues related to medication adherence, prevention of transmission and to prepare ALHIV for self-disclosure of their HIV status. These discussions also included calls for early caregiver disclosure of HIV status to the adolescent, which was described as empowering and necessary for resolving challenges related to nonadherence and medication refusal, and for ALHIV to assume increased responsibility for their self-management:

The part that the health workers have to play—it is counseling these children. Telling them everything. Now like mine the stage she has reached, basing on the time I brought her here and the fact that they told them the truth about things that should be done—that is, taking their drugs. Because like my child, by the time we came she didn't know but now she knows. And she knows how to check on the medical forms, and tell me that do you know that you are going back to the hospital on such and such a day [Caregiver].

Open Communication with the Adolescent

Participants highlighted a need to foster open communication between caregivers and adolescents. Caregivers attributed the lack of open communication between caregivers and adolescents to cultural constraints:

You knows, as a society, we have been guided by culture. Some cultures don't allow open talk, to a certain level, to a certain age. For example, children, you are not supposed to disclose certain things above what they are supposed to know. So, you will find that as we are guided by the culture. You will find that those norms of the culture will dictate upon us—not to give the young one or empower them with the knowledge that they are supposed to get. I think that is what contributes to children lacking information to go about with the disease [Caregiver].

Healthcare providers also noted the lack of open communication diminishes an adolescent's trust and curtails opportunities to understand adolescent concerns and challenges.

We give them information, you explain to them the different options of the drugs you have, and the expected side effects. Because if the person knows that these are the options I have, they will be able to accept the side effects they will get and also they will be able to adhere. Because if I don't know, I will be thinking probably there is a better option, and they are hiding it from me [Healthcare provider].

As a service provider, we need to support these children. Number one, at least by giving them time, so that they can express themselves to us. We need to understand, whatever they are undergoing and we need to believe that whatever that they are telling us that is affecting their lives is really a true story that is affecting their lives. So, we need to give them care, and we need to give them support [Healthcare provider].

Discussions on open communication also included calls to encourage early disclosure to adolescents of their HIV status. All study participants emphasized that the parent/caregiver's lack of or delays in informing adolescents of their HIV status constrained adolescent self-care capabilities because ALHIV in such situations lacked understanding of why they have to engage in self-care tasks such as taking medications. The lack of disclosure was also perceived to foster mistrust between adolescents and their caregivers, often leading to rejection of medications.

The challenge that my child gets is that they started taking drugs [ART] when they didn't know [their status]. But after knowing, it affected them so much and the problem they have now is that they refuse to take drugs. The good thing is that the whole family knows their status and mine [Caregiver].

Most of them find themselves taking drugs (ART) yet they do not believe that they have HIV [Healthcare provider].

Sexuality Education

The emerging sexuality of adolescents and the associated risk of secondary transmission of HIV to sex partners was a concern largely shared by caregivers and healthcare providers. To a lesser extent, adolescent participants also reported concerns about unplanned pregnancies and risk of reinfections. Regarding prevention of HIV transmission, healthcare providers and caregivers lamented that ALHIV generally prefer dating persons who were HIV negative. They advocated for encouraging adolescents to date persons of similar status as this would eliminate the need for disclosure of HIV status. Healthcare providers reported that such initiatives have been successful in the clinic but require planning.

As far as addressing sexual and partner issues is concerned, the step which we have made so far among these children—for our adolescents here—is that we are able to identify partners who are also positive, and they have been successful in marriage. We have some living examples and they are doing very well. We call that breakthrough and they are giving good testimony. Now, for us as health workers we have to guide them so that they make informed decisions and we see it working. Rather than being hidden and you

don't know your partner's status . . . at least if you are all positive you can know how to handle your issue. You know how you can encourage one another. You know the importance of taking drugs. So there you are all at the same level. This is the breakthrough that is coming out among adolescents [Health provider].

Participants concurred that ALHIV should be provided with comprehensive sex education to ensure that they have the knowledge and skills to prevent the transmission of HIV. Caregivers provided examples of how they have educated their children about sex and prevention of transmission.

For me, I tell him that when you grow up, you can get a good girl who is not HIV positive and you have to go back to your counselors and they counsel you. They tell you that when you get married you have to behave like this and this, so that you can produce children, and keep your marriage [Caregiver].

We have to tell them to counsel them. So when they have reached the age of their adolescence, like engaging in sex before testing, because you may have sex with someone when you don't know their status. You may have another type of virus and they may also have another type of virus. You may find that for him, he has the virus that causes vomiting, and for you, you have the one for wounds. So you may get affected so much. So you have to do what, to abstain, and take your drugs, to see that you sustain your life [Caregiver].

Caregivers and healthcare providers advised that sex education should be started early, to ensure that adolescents have the necessary knowledge and skills to avoid transmission of HIV.

When a boy reaches 18 years, he will have grown. At that age, the boy will have started understanding what sex is. Then, they will know everything and how to go about it . . . let me say like using protection when having sex. He will know that when you want to protect yourself you have to use this and this, and you will be safe [Caregiver].

Adolescent participants also advocated for early sex education, arguing that such discussions would be awkward if conducted at a later age and may not serve the intended purpose of preventing unplanned pregnancies or reinfections if provided after the adolescent has become sexually active.

It will be hard—when I am 25 years old—for you to sit with me and talk with me, because at that time, I may be older than some of the health workers. It would be hard to talk to them about girlfriends and related issues because at that time, they would not be listening or respecting your opinions. But if I am 19, 16, she/he can sit with me and tell me you do like this and this, you tell him/her so that information can help him or her [Adolescent].

The abovementioned quote also alludes to adolescents' concerns about healthcare providers' ability to understand and respond appropriately to their needs and challenges. In our past work, ALHIV has expressed a desire to have providers who are also living with HIV; they perceive that such providers

would be in a better position to relate to their experiences and their needs.

Building Self-Care Partnerships

Caregivers and healthcare providers emphasized the need to strengthen their partnerships with each other in support of ALHIV's self-management. Caregivers reported that lack of communication between the healthcare provider and caregiver diminishes opportunities for the caregiver to support the adolescent.

The health workers spend little time with children. You will find that out of 100% they spend only 2% of the time with the children. It is us parents who spend more time with children. Health workers should talk to us the parents, sometimes we are also new to this information yet children believe in us mostly. So the time the child gets to come to the health facility, talk with them, but it is also important to talk to the parent because it is the parent who talks to the child in most cases. Because for you, you are going to talk to the child today and keep back, but the child will forget what you tell them. So if you teach the parent, they can talk to the child slowly, slowly, one by one [Caregiver].

Healthcare providers noted that the absence of caregivers at clinic visits undermines adolescent HIV care since caregivers are not available to provide healthcare providers with additional information about the adolescents or to support healthcare provider's recommendations when the adolescent is experiencing difficulties.

Without a caregiver, to a child, treatment is hard. That is why we have treatment supporters because for a treatment supporter, even if they switch [drugs] in the presence of caregivers, you ask him/her 'who is giving them medicine now'? . . . Who do we have? Even in the boarding sections you call these people . . . 'who is giving the medicine'? So the caregiver is very important to the treatment and so they are just as important as the person taking medicine actually. So I think they must be empowered with skills and knowledge on how to deal with these children [Healthcare provider].

Caregivers also noted the need to build partnerships with school officials to support adolescents in boarding schools where supervision or support may not be available if the school officials are not aware of the adolescent's HIV status.

You will take the child to the headmaster, as a parent, and you show the headmaster the child, and he also knows the condition of this child. And you will see the wardens, who are in the dormitories at night, and you show them this child and tell them the time the child takes drugs. So children also forget the time for taking drugs but you as a parent, when the time comes at least among those people, you have a friend. You call that person and ask them to tell the child that it is time. Because when the child is at home they will be near you, but when the child is at school, at least you can call the headmaster [Caregiver].

Role Modeling

Healthcare providers and caregivers also identified caregivers as important role models for ALHIV, noting that their attitudes and behavior, especially on medication adherence impacted their children's self-management behavior.

When you find a child with poor adherence and you check on the adult- if the mother is up there [in the adult clinic], check their records, you find that this is coming from the adult, and it comes down [Healthcare provider].

Now there are parents who don't take drugs even when they have malaria. The moment you start feeling ok, they say that I am cured so you stop taking the medicine. You are the parent, and you want the child to take ARVs the right way but you the parent you are not acting as an example. I have a challenge at home. When my wife gets ill and feels somehow ok, she stops the drugs and it is the child who has to remind her to take drugs. Now where will the child get the strength to take her drugs every day when you the parent you are not an example? [Caregiver].

Preparation for the Future

Caregivers and healthcare providers noted the need to start preparing ALHIV for the future by providing career guidance and equipping them with job skills.

As a transition, most of them are changing schools, are changing classes, from primary to secondary, and this institution can prepare them—like general counseling, to prepare them for secondary life, to prepare them for boarding life, to prepare them for some of the things they should be doing [Healthcare provider].

They decried the lack of institutional resources to support the education of ALHIV, many of whom were described as orphaned and living with caregivers who did not have the resources to support their education. In addition, healthcare providers noted that stigma and discrimination in the workplace limits the opportunities available for ALHIV to earn gainful employment. Caregivers also discussed the need for more caregiver involvement in order to understand their life goals and aspirations. This would allow them to be better placed in providing the necessary career guidance and skill development.

Even the home, you tell him that, when you grow up, what are you going to do? Are you going to start renting, or you are going to build? He may tell you that before I get enough money, I am going to rent a single room, and I will stay there alone for the time being, but if I get money I will build a house or I will rent a 2 roomed house. You can discuss all that, and you know that this is how my child is going to be. If it comes to the issue of peer groups, you can also talk about it—that do you see these gangs; they arrest them all the time. What do you think about them? And he will say ah, I cannot go to prison, but another one will say I can also fight them, that is where you start to know what your child wants [Caregiver].

Table 1. Summary of Participant Preferences for Self-Management Intervention Approaches.

	Group (Peer Support) Program	eHealth Technology	Individual Counseling	Family- Based Program	Other
Adolescents	17	10	4	3	3
Caregivers	12	6	9	4	3
Health workers	3	6	3	4	0
Total	32	22	16	11	6

Program Approach

One of the goals of this research study was to determine the preferred self-management approach for HIV care. A summary of participant preferences for each intervention is shown above (Table 1). Evidently, the overall order of preference was found to be group (peer support) programs, eHealth technologies, individual counseling, family-based program (joint parent/caregiver and adolescent) and other approaches such as sports/recreation, music, dance and drama, and job skills.

Participants expressed a strong desire for group (peer support) programs arguing that such programs provide a forum for adolescents to share their experiences and challenges in an accepting environment where they can learn from each other. Participants also noted that ALHIV often feel isolated because they perceive themselves as different from their peers and this leads to self-rejection or self-hate. Therefore, gathering in groups provides these adolescents the opportunity to connect with other ALHIV, which can increase their hope, optimism, knowledge, and medication adherence.

Other parents may want their children to know that they are not alone, there are other people who are HIV positive [Adolescent].

For me I think that it's the adolescents coming together because even when they have difficulties and have fear to talk about them but when another person can talk about it, they know how to overcome that problem [Caregiver].

You need to talk to someone, maybe someone who is experienced, and you hear from another adolescent who is talking about it that I was not adhering, but when I started adhering what, what, so you get encouraged, the meetings help them a lot. In my opinion, they share experiences and talk about issues [Healthcare Worker].

The popularity of the eHealth technology was strong among the adolescents and healthcare providers who described this approach as being convenient because it can provide instantaneous answers to their questions and allows for privacy and autonomy in seeking health information. They also described this approach as the most suitable method for introverts who may not feel comfortable asking personal questions in the presence of other people.

I support the computer thing because you may want to go to Internet, so that you know that if I ask this they will answer me this. Because sometimes you may not have time to go the group [Adolescent].

However, the caretakers voiced a concern about misinformation advertised through media, noting a need for more government regulation of these media and parental supervision:

If they have a smartphone, there are even these local phones. The TV they listen to gives them a different education. The Radio they tune into gives them different information. So even if you give them some good advice, we are not there as parents but the radio is there and the TV is there. They have really derailed the children [Caregivers].

While participants perceived many benefits in group and eHealth technology approaches, they also described individual counseling as a suitable platform for adolescents who are not quite ready to embrace their condition in front of large groups of people.

The challenge would be that some of the children here have an element of shyness. For example, like our friend number 6. You cannot say that in a group setting, he can speak up. Now here we are not many but at times, he fears us. So among many people, do you think he can be able to raise his question to the health workers for them to be able to respond to it? But when he is individual, maybe with the counselor, even the counselor he may fear, because what I know, it seems he fears eye contact. But it will be better and to be sure he seems to know about computer [Adolescent].

A few participants—mostly caregivers and healthcare providers—indicated the need for family-based programs that involve joint counseling sessions between a healthcare worker and an adolescent and/or parent. These participants reported that many caregivers are also misinformed or lack information entirely about HIV and antiretroviral therapy, which can lead to self-management challenges such as poor adherence or utilization of alternative health sources such as traditional herbalists and churches in lieu of the health system. Other caregivers and healthcare providers also noted that joint adolescent–parent counseling sessions could provide an opportunity to resolve adolescent–caregiver conflicts that could impact ALHIV’s well-being.

For me, I would prefer a program where the child sits down with the parent because the parent has a lot to tell this adolescent, and the adolescent will learn something. It is better than having the adolescents alone, because I cannot be an adolescent and tell a fellow adolescent my problems, but I can tell them to my parent [Caregiver].

Discussion

The expanded access to anti-retroviral therapy has transformed HIV from a life-threatening illness into a chronic disease.²²

Currently, thousands of children perinatally infected with HIV are now living longer than previously anticipated but adolescence presents a period of heightened vulnerability for ALHIV, with poor HIV care outcomes including increased risk of AIDS mortality.^{6–11} The challenges underlying ALHIV’s heightened vulnerability—poor adherence, psychological distress, HIV stigma and discrimination, and so on—are amenable to psychosocial interventions that impart or strengthen ALHIV’s self-management skills. However, few such interventions have been developed for ALHIV in sub-Saharan Africa.¹³ Developing effective interventions require understanding developmental, cultural, and resource needs and effective strategies for engaging and promoting sustainable gains in their knowledge, cognitive skills, and behavior. This study highlights the perceptions of current gaps and preferences for HIV self-management among ALHIV, caregivers and healthcare workers, as a preliminary step toward developing a self-management program for ALHIV.

Consistent with the complexity of the challenges associated with living with HIV, and variation in ALHIV’s needs and capabilities, participants highlight a multitude of strategies for promoting self-management among ALHIV. Participants express a strong desire for group-based intervention strategies that would provide for social interaction and group learning, and eHealth technologies that allow for convenience, privacy, and autonomy. The strong preference for eHealth interventions among ALHIV reflects the prominence of media and technology in the lives of adolescents and is developmentally appropriate for adolescents. Several innovative eHealth technologies have been developed to support prevention and treatment of HIV.^{23–25} The eHealth interventions are feasible in resource-constrained settings such as Uganda due to expanded access to the Internet and mobile phones across Africa.²⁶ In Uganda, previous studies have documented high levels of access to computers and mobile phones among young people in both urban and rural areas, as well as a willingness to use these devices to access health information.^{27–31} Although there is still a need for more rigorous investigations to provide evidence of the long-term impact on HIV care outcomes,²³ especially among adolescents, these technologies can be harnessed to support the self-management of HIV among ALHIV.

There are several limitations to this study including a study population that may not be representative of the all adolescents living with HIV or their caregivers and healthcare providers in Uganda. However, participants were recruited from one of the largest pediatric HIV clinics in Uganda that provides HIV care to a diverse patient population. Additionally, participation was limited to participants who were aware of their HIV status. This criterion could have introduced some selection bias, as adolescents who were not comfortable with HIV status would have been less likely to participate in the study. As such, our findings (particularly on preference for intervention strategies) may be more representative of the opinions of adolescents who have lesser concerns about stigma and/or privacy.

Despite these limitations, these findings provide valuable insights into current gaps and preferences among key

stakeholder groups in adolescent HIV care and will guide the development of a self-management program for Ugandan ALHIV. More specifically, these findings support the feasibility of using eHealth technologies to promote self-management among ALHIV. Participants' preferences for group and eHealth technology approaches are not mutually exclusive as several existing technology platforms allow for social interactions including peer-to-peer interactions that are typically found in peer support groups. Findings also underscore the need for family-oriented interventions that focus on equipping ALHIV and their caregivers with the HIV self-management knowledge and skills. Finally, these findings highlight the need to equip healthcare workers with resources to support adolescent self-management.

Authors' Note

Adolescent participants were required to provide written informed assent and caregiver consent (if younger than 18 years of age) or written informed consent (if older than 18 years of age). All participants (adolescents, parents/caregivers, and healthcare providers) provided written informed consent prior to enrollment in the study. Adolescents younger than 18 years provided written informed assent and parental consent. Our study was approved by Institutional Review Boards at the University of Michigan (approval no. HUM00105528), Joint Clinical Research Center Kampala, and the Uganda National Council of Science and Technology (approval no. SS4059).


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