ORIGINAL RESEARCH ARTICLE

Improving Health Services for Adolescents Living with HIV in Sub-Saharan Africa: A Multi-Country Assessment

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Abstract

In sub-Saharan Africa (SSA), the aging of HIV-positive pediatric cohorts and growing numbers of adolescents on treatment, coupled with high HIV incidence in this age group, means the number of adolescents living with HIV (ALHIV) will continue to grow. The clinical, psychological, social, and reproductive health needs of ALHIV remain poorly understood and efforts to mobilize and advocate for their treatment, care, and support have been inadequate. A multi-country assessment of the needs of ALHIV in SSA found that comprehensive, adolescent-friendly services that champion peer support and collaboration between health care organizations can foster successful transitions into adulthood for ALHIV. *(Afr J Reprod Health 2013 (Special Edition); 17[4]: 17-31).*

Keywords: adolescents, HIV/AIDS, reproductive health, youth friendly, peer support, sub-Saharan Africa

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Résumé

En Afrique sub-saharienne (ASS), le vieillissement des cohortes pédiatriques du VIH-positives et le nombre croissant d'adolescents en traitement, y compris une incidence élevée du VIH dans ce groupe d'âge, signifie que le nombre d'adolescents vivant avec le VIH (AVVIH) va continuer à croître. Les besoins cliniques, psychologiques, sociaux et de santé de la reproduction chez des AVVIH restent mal compris et les efforts pour mobiliser et plaidoyer pour leur traitement, leurs soins et leur soutien ont été insuffisants. Une évaluation à travers plusieurs pays des besoins des AVVIH en Afrique subsaharienne a révélé que des services complets et adaptés aux besoins des adolescents qui luttent en faveur du soutien par les pairs ainsi que la collaboration entre les organismes de soins de santé peuvent favoriser la réussite des transitions vers l'âge adulte pour les AVVIH. *Afr J Reprod Health 2013 (Special Edition); 17[4]: 17-31).*

Mots-clés: adolescents, VIH/sida, santé de la reproduction, adapté aux besoins de la jeunesse, soutien par les pairs, Afrique subsaharienne

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Introduction

Adolescents (age 10-19 years) born with HIV in sub-Saharan Africa (SSA) are now surviving into young adulthood for the first time and face a host of treatment, reproductive health and psychosocial challenges that the health sector is unprepared to manage[1-3]. Of the estimated 2.1 million adolescents living with HIV (ALHIV) globally, 85% live in SSA[4,5]. They face a large, unmet need for treatment and support, and many barriers to care[6-8]. Only 360,000 ALHIV globally, and 290,000 in SSA, receive anti-retroviral therapy (ART), representing a fraction of those who currently need it[9]. Even in countries where ALHIV have free universal access to ART, there are hidden costs connected to treatment, including transportation to clinic and lab visits, and fees for certain tests, such as viral load tests[10]. Adolescents who were born with HIV are more likely to be in advanced stages of the illness, with a history of opportunistic infections, viral resistance, and comorbidities with other physical and mental health problems, making their treatment more complex than for those who contracted HIV during adolescence[6,8,11].

In addition to treatment, ALHIV face psychosocial and other challenges that further compound the already significant difficulties that accompany the transition to adulthood[1,12-14]. These challenges impact adherence to medication and engagement in care over time[15]. Like most adolescents, ALHIV engage in high-risk behavior, putting their own and others' lives at risk[16-18].

Keeping ALHIV alive and healthy, coupled with preventing new HIV infections, requires a unique service model and the will of policy makers, health care providers, community members and ALHIV to improve treatment, care and support for this population[19]. To date, pediatric HIV programs have primarily focused on diagnosing and treating illness in infants and young children, excluding adolescents and young people who are often the target for HIV prevention messages only, many of which are designed without a strong understanding of their developmental stage[18-22]. Little guidance has been produced on how to effectively provide services for ALHIV in SSA, and that which does exist lacks the perspectives of ALHIV and those who provide them with health care services. To prepare for the rapidly-increasing population of ALHIV, many of whom are transitioning into adulthood, such voices need to be captured[1,4].

With this in mind, the Africa Bureau of the United States Agency for International Development (USAID), through the Africa's Health in 2010 project, completed key informant interviews with health providers and ALHIV in SSA to better understand the needs of ALHIV so that services for this population might be improved. The methods, findings and recommendations from these key informant interviews are outlined below.

Methods

Two semi-structured interview guides were developed: one for key informants that work with ALHIV as project managers or service providers, and one for older young people (18-25 years old) that are living with HIV and also work/volunteer with ALHIV as peer educators. The project managers'/service providers' and peer educators' interview guides contained 48 and 53 open-ended questions, respectively (the latter had five additional questions on training/certification to be a peer educator). Through a review of the literature, we identified nine key categorical constructs through which to explore the health care needs of ALHIV, and grouped the interview questions accordingly. The key constructs were: drug access and availability, clinical care, nutritional care, sexual and reproductive health, psychological support, social support, transition of care, resources and advocacy. Chain referral (a.k.a. 'snowball') sampling was utilized to identify appropriate key informants. Beginning with the 11-member USAID "Africa's Health in 2010 Adolescent HIV Technical Advisory Group" to seed the sampling process, additional informants were identified through referrals within social and professional networks. Interviews were conducted by three interviewers between February and April 2011. The primary interviewer, a consultant for the Africa's Health in 2010 project, was an American male who had worked with youth and HIV/AIDS programs in multiple countries in sub-Saharan Africa for over 5 years. The second interviewer was an American female who was serving as a volunteer for youth and HIV/AIDS organizations in Uganda and conducted both provider and peer educator interviews in Uganda and the third interviewer was a Canadian female who was working with a pediatric HIV clinic in Botswana and conducted two of the peer educator interviews in Botswana. Interviews were conducted both in person and telephonically. The interviews lasted between one and two hours each and were digitally recorded. Interviewers were carefully oriented to the standard interview guide, which was used in all interviews to ensure consistency. The primary interviewer, also the first author, provided periodic reviews of completed interview questionnaires to ensure quality. Written questionnaires were also accepted when in-person or phone interviews were not possible. Due to the unavailability of a budget to remunerate key informants, participants took part in the study voluntarily and were not compensated.

The interviews were transcribed to allow for thematic content analysis. First, the transcriptions were reviewed for accuracy. Second, the first and second authors coded the transcriptions in close detail (open coding), following a constructivist grounded theory approach[23]. The team held a conference call in order to compare notes and consolidate codes (selective coding) in order to generate key themes, which then informed key recommendations (Sidebar 1). Interview data was analyzed concurrently until thematic saturation of the provider interviews was reached, at which point no new interviews were conducted. Though it would have been preferable to conduct more peer educator interviews, most of the referrals for the peer educators (according to our snowball sample approach) came from providers, and most providers stated that either their organizations did not have peer educators, the peer educators were not over 18 (age required to be eligible for this study), or the peer educators were living in remote areas and did not have access to phones or internet to conduct the interviews.

Participants were assured that their names would not appear anywhere in the data sets, that their identities would be kept confidential, and that published reports may attribute direct quotes to their organizations but not to them individually. Names and other unique identifiers were stricken from the transcription during analysis. According to USAID guidance on human subjects, it was determined that human subjects review was not required to carry out this assessment because key informants were 18 years of age or older and no unique identifiers were used to link the informants with the information provided.

Informant Characteristics

A total of 34 interviews (26 program managers/service providers and 8 peer educators ages 18-25) were conducted with a gender breakdown of 16 females and 18 males representing 29 organizations and facilities. Program manager and service provider informants were from the following countries (with numbers of informants in parentheses): Botswana (2), Uganda (8), Tanzania (1), Mozambique (2), Malawi (1), Zimbabwe (1), Kenya (2), Rwanda (1), South Africa (7), and Swaziland (1). Their highest level of education attained included M.D. or equivalent (12), Ph.D. (1), Master's (8), and Bachelor's (5); and their length of time (in years) working with ALHIV ranged from 1 to 20 (mean = 7.4). Peer educator informants were from Uganda (4) and Botswana (4), ranged in age from 18 to 25 (mean = 21); and their length of time (in years) working as a peer educator ranged from 3 to 6 (mean = 4.1). Twenty-five informants completed the interview in-person or by phone and 9 completed and returned the questionnaire in writing via email. For those informants who had accurate estimates of the ALHIV client population at their organization/facility (n=17), ALHIV enrollments ranged from 50 to 2,000 (mean = 595), 55% of whom were female, and 94% of whom were perinatally infected. Data and salient themes derived from the interviews are summarized below, by categorical construct.

Results

Drug Access and Availability

All of the key informants reported that first and second-line ART is available for ALHIV in their countries, though access remains a challenge. The most common formulations were reported to be twice-daily, though some informants said they provide once-daily regimens or fixed-dosed combinations for pediatric dosing. Third-line is mostly not used, though "salvage therapy"—a drug combination based on the first two lines—is sometimes offered in place of a new third-line regimen. ART is usually provided at no cost to the patient, as it is subsidized by national governments and international donor projects such as the President's Emergency Plan for AIDS Relief (PEPFAR). However, many of the organizations interviewed stated that drug shortages pose a major threat to drug access and availability for ALHIV, particularly in rural areas. One physician explained:

> *"It all boils down to the resources available to procure these drugs at a national level. I think that's the biggest factor. The other one is organizational, just making sure that orders are placed in time, are accurate, and that the supplies reach the health facilities in time." (Pediatrician, HIV/AIDS treatment center, Uganda).*

Those interviewed reported that pediatric dosing for ALHIV complicates treatment protocols. Due to their diminished weight and height, many ALHIV still require pediatric dosing, but health care workers, particularly in rural settings, are often not trained to manage such dosing. Drug access is also constrained by patient-level factors, with many clients lacking the money for transport, visitation fees, or other costs of attending clinic appointments.

Clinical Care

Informants reported that ALHIV face a number of challenges in clinical care that threaten their ability to attain optimal health. ALHIV often have complex medical histories and are prone to various acute HIV-associated medical disorders such as tuberculosis, lipodystrophy, nephropathy and certain neuropathies. Informants report that the long-term effects of antiretroviral medication exposure and multi-class drug experience - including implications for metabolism, growth and development - are still poorly understood. In addition, many aspects of the clinical care environment are seen to pose significant barriers to high-quality care for ALHIV, particularly providers with little ALHIV-specific training and services that are not adolescent-friendly.

Per informants, training on ALHIV-specific treatment and care is urgently needed for health care workers, including lay counselors and community health workers (CHWs). Though most lay counselors and CHWs do not prescribe treatment, many are vital in educating their patients on issues such as adherence to medication, mitigation of treatment side effects and disclosure of HIV status. Informants acknowledged the crucial role that these cadres play in an adolescent's support network. Limited training of these personnel can also have a negative impact. One health provider explained how lack of training leads to poor rapport between providers and their adolescent patients:

> *"We have had so many clinicians who don't have the right knowledge, the right skills, or the right techniques to handle adolescents. In most cases, they will just prescribe the drugs and [the patient] leaves. This has been a big challenge because adolescents do not have a good relationship with our clinicians, despite the fact that they are treating them" (Manager, AIDS service organization, Uganda).*

In order to address this gap, some institutions train all of their health care workers, regardless of whether they work in pediatrics or adult care, on how to provide optimal care for adolescents. In addition to the traditional staff of doctors, nurses and counselors, many facilities are also pushing for a greater involvement of ALHIV as expert patients and peer educators. In Botswana, some peer educators are being brought on as staff members:

> *"We have one peer educator, at least here at [our] main center, who is on salary—who is getting paid to provide peer counseling for adolescents. [She] is also one of our adolescents who was perinatally-infected. So we're really hoping that in the years to come, we can train more adolescents with HIV to be peer educators. We [also] have a lot of teen leaders, or adolescent leaders, who [assist] in finding out what adolescents living with HIV need and [serve as] advocates for their peers" (Pediatrician, HIV/AIDS treatment facility, Botswana).*

Some organizations have gone a step further and are building the capacity of their peer educators to serve as advocates and ambassadors to a larger audience:

> *"Out of our peer leaders, we are developing an ambassador program, where children who show remarkable leadership skills are brought into a program where they are taught even more leadership, and are taught to become a voice for the rest of the children—share experiences, but bring to the rest of the country and the world the attention of all these thousands of children who have*

> *overwhelming challenges, just trying to remain healthy and stay alive" (Country Director, AIDS service organization, Uganda).*

One of the peer educators interviewed agreed with this approach:

> *"I think what really works is [fostering] professionalism in the lives of young people living with HIV… like putting them in places of leadership so that they can deliver. Those kids have a lot to offer" (Peer Educator, AIDS service organization, Uganda).*

Alongside ALHIV involvement, informants emphasized that institutions should look toward creating clinical environments that are adolescent-friendly. They explained that many ALHIV no longer feel comfortable in a pediatric clinic, surrounded by children's books and toys, but neither are they comfortable sitting in a waiting room alongside their elders. Many facilities interviewed have specific days for adolescent patients, or have certain areas or hospital wings where adolescents can go to wait for care:

> *"We did a need assessment to inform us about their [ALHIV] needs, being in a clinic where adults are and whether they needed their own clinic. They wanted their own clinic, because there were kids in the clinic with adults. They were blamed—why did they get infected at an early age? Others were sexually harassed by the adults in the clinic, trying to force them into relationships. Then there were the long waiting times. Others felt that they were sharing the same clinic with their uncles and aunties, and it affected their clinical attendance, because they felt uncomfortable coming and meeting their aunties and uncles here. So we set up a Young Adults Clinic on Wednesdays, separate from the Adult Clinic which runs the rest of the week" (Project Coordinator, HIV/AIDS treatment facility, Uganda).*

Some institutions, however, find a family-based approach to be most effective in providing clinical care and support for ALHIV. An informant from Uganda explained how the family model has helped to foster communication and bonding between parents and their adolescent children:

> *"Because it's a family model, we usually encourage the parents to come on the same day. So when I'm targeting this child, I'm also targeting the child with the parents. Originally, we used to provide the adults' or the parents' wing, but now what we basically do is if a service provider or a doctor is seeing one person and has a family, they see them as a whole. So you are basically targeting them as a family, and I think that has worked very, very well" (Head of Field Team, AIDS service organization, Uganda).*

Informants also advocated for the utilization of creative and interactive models of health education that foster participatory learning, rather than the more traditional didactic approaches.

All of the informants noted that non-adherence to medication is a key challenge faced by ALHIV who receive ART. They noted that many adolescents keep HIV a secret, making it difficult to find the privacy to take medication on time or when in public places. For those whose HIV status is known, they risk discrimination from peers, teachers and other community members. A number of the peer educators interviewed discussed non-adherence as a direct impact of this type of discrimination. One physician discussed the facility- and provider-level challenges to supporting adolescents with adherence:

> *"Adherence is a huge challenge and overall not addressed in a comprehensive way with counseling or assistance. There is little understanding of the developmental stages of adolescence and that it is common for teens to struggle with adherence. There is not an understanding of the need to help teens to problem solve adherence challenges and for the most part it is often completely ignored as*

> *clinics are very, very busy" (Physician, HIV/AIDS treatment center, Malawi).*

When asked about recommendations for providing adherence support, informants praised programs that provide client-centered, one-to-one counseling within the clinic setting, as well as peer-led support. One informant noted the value of using peers to support adherence:

> *"I would like to suggest the best way to deal with adherence problems is to bring them peer support. First bring them peer support, and let them talk. Let them talk [about] their anger. Let them educate each other. Let them learn from one to the other" (Supervisor, AIDS service organization, Uganda).*

Indeed, both provider and peer educator informants stressed that many ALHIV are more comfortable and open discussing issues of adherence, alongside other sensitive issues, with peers who can draw on their own experiences during counseling. An informant from Zimbabwe described the impact of training community adolescent treatment supporters (CATS) on the provision of counseling and adherence monitoring for ALHIV:

> *"Children and adolescents, supported by adults, take the lead in designing, implementing, monitoring and evaluating all of our programs and activities… [such as our] Community Adolescent Treatment Support (CATS) program…in which ALHIV have been trained as adherence counselors. They work in community clinics providing adherence counseling and also follow-up children and ALHIV at home to monitor pill boxes and adherence. We have found this to be an extremely powerful means of supporting adherence. ALHIV often report challenges more readily to their peers than to adults. The CATS then refer these cases to the outreach team and clinic who follow-up. This has also provided the adolescents with invaluable opportunities for training and work experience and several have now progressed onto nursing training" (Director, AIDS Service Organization, Zimbabwe).*

Health providers also acknowledged that adolescents who have been able to disclose their HIV status to a supportive person in their lives demonstrate an increased likelihood to adhere to their medications than those who have not disclosed. Therefore, they suggest implementing counseling programs that support ALHIV with disclosure to trusted adults and peers.

Nutritional Care

While the nutritional needs of ALHIV are similar to those of other adolescents, health providers noted that ALHIV have an increased caloric requirement due to their chronic illness. Respondents noted that, since many ALHIV are orphaned and/or living in poverty, they are also more prone to malnutrition. With informants report that taking medication on an empty stomach can greatly affect adherence and many ALHIV may stop taking their medications completely when they do not have enough food to eat. One physician in Mozambique highlighted the importance of proper nutrition for ALHIV:

> *"Adolescence is a time [of] higher metabolic needs and increased nutrition. Adding a chronic disease to that stage of life increases the body's nutritional needs even more. Sadly, in most of our settings in Mozambique, poverty is so pervasive that there is rarely enough food to meet these increased needs. Chronic malnutrition is a pervasive problem in Mozambique with 40% of children having short stature" (Pediatrician, HIV/AIDS treatment center, Mozambique).*

Many programs have tried to curb these challenges by providing porridge or full meals during clinic appointments, and maize and soya flour for ALHIV to take home. For qualifying ALHIV who are malnourished, some clinics provide Plumpy Nut (a high-protein, high-energy, peanut-based paste) in the form of Ready to Use Therapeutic Feeding Packets (RUTF). A few organizations are able to provide full meals for very impoverished children, particularly those who head their own households. Given that inadequate resources often limit feeding of all patients, many programs provide complementary services like immunizations against vaccine-preventable diseases, vitamin supplementation, dietician consultation, nutrition education and income generating activities that can help adolescents to access food.

Sexual and Reproductive Health (SRH)

Informants reported that while many of the sexual and reproductive health needs of ALHIV are similar to those of other adolescents, certain areas are of particular concern for this population. These include the added stress and complexity inherent in romantic and sexual relationships with known HIV infection as well as issues surrounding disclosure, including fear of rejection, stigma and blame. One physician broke down the SRH needs of ALHIV as follows:

> *"[ALHIV have] four unique [concerns]: there is the risk of transmitting the disease to their partner; the stigma and trust issues related to disclosing to their partner; the pressures of society for boys to have many girlfriends and for girls to prove their fertility; and most of our patients are physically stunted and enter puberty late. Another [concern] is that many of the ALHIV are orphans and do not have a good family unit to learn about or discuss these issues" (Pediatrician, AIDS service organization, Swaziland).*

Few of our informants, however, were able to identify efforts related to the training of healthcare providers in the areas of sexual and reproductive health counseling. An informant from Uganda described the lack of SRH training throughout many levels of health discipline in the country:

> *"I've gone through a diploma course. I hardly had anything that had to do with sexual and reproductive health. I went through undergraduate. I didn't handle anything like that. Now I'm doing the Master's; still I don't see something like that. So you can imagine I am going to be a psychologist who doesn't have any knowledge about sexual and reproductive health. You can only get this information in [special] courses or go to the Internet and search for information and then prepare yourself. But how many people are able to go to the Internet and search about sexual and reproductive health for adolescents? Very few" (Supervisor, AIDS service organization, Uganda).*

Peer educators commented that health providers often dissociate sex and relationships, concentrating only on whether an adolescent is having sex rather than also providing support with relationships. Peer educators also noted that many health providers do not view ALHIV as sexual beings, incorrectly assuming that ALHIV do not have sex because of their HIV status. One peer educator spoke about the desires of ALHIV to have children:

> *"Kids want to know if it's possible for them to have babies while HIV-positive. And kids want to know if they can have sex without a condom if they are both HIV-positive" (Peer Educator, HIV/AIDS treatment facility, Botswana).*

Informants agreed that major improvements are needed in health care worker training, guidance and policy reform surrounding SRH in order to adequately support ALHIV as they transition to adulthood. This includes the development of health care environments that are non-judgmental and safe for ALHIV to access comprehensive reproductive health education, and free or affordable contraceptive and family planning services. Health care workers need to be specifically trained in sexual health education, and this training needs to be consistent and continuous, rather than offered once, so that health care workers remain up-to-date with promising practices in providing SRH care and services.

Psychological Support

Peer educators noted that ALHIV commonly feel anger, both at themselves and at their parents.

They suffer from self-stigma and self-blame, and perceive that they lack the opportunities available to uninfected peers. Many ALHIV live in denial about their HIV status and the ramifications thereof and this denial can lead to harmful behaviors such as poor medication adherence or unsafe sex. Many ALHIV, say peer educators, live with little or no hope for the future:

> *"I have reached a point in life where I think I understand my needs and [those of] other children who are in my position. I feel that the only challenge I have yet to face is of [what to say] when kids tell me that they feel they don't want to live anymore. They will tell you, "Hey, I don't feel like I should be living anymore, because I already know it (HIV) is going to kill me" (Peer Educator, HIV/AIDS treatment facility, Botswana).*

One health provider spoke in-depth about the effects that HIV stigma and discrimination have on the mental health of ALHIV:

> *"They are mistreated. They are ignored. They are beaten every day, stigmatized by their community. That is how they develop mental illness. Some of them are not really born with such ailments but because of what they go through, they eventually end up developing such problems" (Counselor, AIDS service organization, Uganda).*

Many of the informants' organizations have counselors or social workers on staff, but they range widely in their qualifications and training. Many are not qualified to manage emotional trauma in HIV-positive patients. Others are not trained to deal with issues concerning sex and sexuality. Very few, especially those based in rural settings, are trained to work specifically with adolescents. Clinical psychologists or psychiatrists that can accurately diagnose psychiatric disorders and prescribe medication are almost non-existent. One health care provider in South Africa described the situation as follows:

> *"If you speak to anybody in South Africa, you'll discover that the plans are wonderful but the resources, basically human resources, are very scarce. And people keep hinting that they're going to start training clinical nurses, but it doesn't really materialize. And counseling has been subcontracted to NGOs who allegedly train counselors but in fact only give them about 30 days of training. And they come to us and they really can't cope with the sort of load that you would expect a psychosocial counselor to be able to handle" (Pediatrician, government health agency, South Africa).*

One peer educator mentioned that it is also helpful for ALHIV to be mentored by HIV-positive adults since they can relate to the challenges ALHIV are facing and can serve as role models:

> *"We [sometimes] have an HIV-positive adult come and [talk about] the challenges [we face], because she is older than us. She has been through most of what we are going through right now, and she is helping us—[showing us] how to overcome challenges. I think bringing in people who have been through [similar] experiences or challenges that we are going through does help" (Peer Educator, HIV/AIDS treatment facility, Botswana).*

Our interviews indicated that peer support groups for ALHIV are common though the mission, structure and activities of such groups vary widely. Topics for support group discussions often include adherence to medication, disclosure, sex and sexuality, relationships, managing stigma, and building life-skills. Peer support is viewed as a powerful mechanism and a key component of a holistic package of services for ALHIV. One of the most structured and widespread support groups mentioned by informants is the network of "Teen Clubs" operated through the Baylor International Pediatric AIDS Initiative. With sites in Botswana, Uganda, Malawi, Swaziland, Lesotho and Tanzania, it is described as the largest global network of peer support groups for ALHIV and was cited as a promising practice by multiple informants:

> *"The mission of Teen Club is to empower HIV-positive adolescents to live positively and successfully transition into adulthood. We offer emotional and educational support through structured activities designed to teach life skills, foster relationships, and build confidence. We provide a forum for adolescents to constructively express themselves and discuss issues regarding their condition without the threat of stigma" (Pediatrician, HIV/AIDS treatment center, Swaziland).*

Informants said that ALHIV would potentially benefit from drop-in centers that offer care and support in addition to programs that integrate ALHIV from many different agencies and institutions within a regional setting. This would allow them to share their experiences more broadly and create a wider community of ALHIV for support and guidance. Overall, informants decried a lack of cross-program and cross-country collaboration to improve care and support for ALHIV:

> *"There are a few people doing wonderful things. We don't meet enough so you're left to feel like you're the only ones that are taking [care and support for ALHIV] as a focus and you're constantly hit with resistance around the issue. So more collaboration would be great…. and coming together with best practice models, because many of us have tried and failed at a bunch of things and we keep reinventing the wheel" (Head of Counseling and Prevention, HIV/AIDS treatment facility, South Africa).*

Social Support

According to informants, outside of psychological counseling, most forms of social support are severely limited for ALHIV. This includes basic needs like housing, food, transportation and school fees. One informant described the socio-economic situation of ALHIV in South Africa as follows:

> *"The majority of ALHIV in South Africa come from very poor socio-economic backgrounds. They may have been living with grandparents in rural areas where conditions are very poor. ALHIV in our service are often living in very cramped informal accommodation with very little money or access to food and transport. The death of family members may remove the only income from the home, increasing the financial difficulties" (Principal Medical Officer, government health agency, South Africa).*

Some hospitals and clinics are able to subsidize adolescents' travel to and from services. Those organizations that are able to provide transportation assistance for their patients report substantial improvement in retention in care. Other agencies have programs that support the very needy with school fees, but the majority of ALHIV who are not attending school do not have access to such funds. Some organizations provide vocational training programs in areas such as hairdressing, mechanics and hotel management, as well as some capital so that ALHIV can start small businesses; however, this is rare. Some provide scholastic materials (e.g. books, pens, pencils) and toiletries (e.g. soap, deodorant, sanitary towels) in addition to bedding and mattresses for those ALHIV who are in boarding school and cannot afford them. At times, university fees and equipment for starting a business are available.

In order to provide better social support services for ALHIV, providers suggest holding inter-agency networking meetings within regional settings so that non-governmental organizations and relevant ministries can promote a better understanding of what each is doing and forge stronger referral networks. It is also recommended that agencies place stronger emphasis on economic empowerment through development of livelihood skills and facilitation of income generation activities, so that ALHIV can learn how to support themselves.

Transition of Care

Few organizations have a clear strategy in place to transition their ALHIV from pediatric to adult health care. Agencies vary in terms of when they think ALHIV should transition-anywhere from 18 to 24 years of age-and vary in terms of how much they plan for and support the transition process. One counselor spoke about the difficulty of transitioning young adults who have been coming to the clinic since childhood:

> *"Our oldest pediatric patient is 23. So I don't think we're [transitioning] well, but mainly because the barriers are so great, we end up offering services for way longer than we should be. They've been coming to the clinic for so many years to pick up their ARVs, they don't want to leave. It's a real problem" (Head of Counseling and Prevention, HIV/AIDS treatment center, South Africa).*

Both provider and peer educator informants noted that many ALHIV do not want to transfer to adult clinics, and often when they do transition, they soon self-refer back to pediatric services. One informant warned of the detrimental consequences of transitioning ALHIV without adequate preparation:

> *"This child has a good relationship with this person for the last 10 years or the last 5 years, but now, without any preparation— without any transitional preparation—the child is just shifted, like magic, to the next person. And then, it will take time for that child to build a relationship. It can affect the child's health. It can affect the child's adherence. It can affect a lot of issues to do with the child" (Supervisor, AIDS service organization, Uganda).*

Health care providers also lamented that, during this transitional period, many ALHIV stop engaging in health care altogether. They acknowledged that pediatric providers can be as resistant to transition as the adolescents are; afraid of letting go of patients they have worked with for years. There are also clear external barriers for transitioning adolescents without a source of consistent income or food supply. In many facilities, HIV treatment, counseling and social work services are provided free-of-charge in the pediatric setting, but at a cost in adult settings. In addition, many hospitals that provide food during clinic visits for children do not provide food for adults.

Those informants with transition strategies in place at their facilities advocated for skills-based transition of care, continuity of care, and the promotion of adolescent-friendly services at the adult care level. Such plans call for training to be offered to providers in the adult care environment to understand and manage the specific needs of adolescents. In well-prepared facilities, they noted, ALHIV are included in transition planning, so that they feel empowered and equipped to transition. One informant articulated the importance of including ALHIV in transition planning:

> *"[Adolescents] should design [transition programs], they should get involved, they should own these programs, and they should bring change to themselves if they want" (Supervisor, AIDS service organization, Uganda).*

Overall, informants agreed that the involvement of ALHIV in the design, delivery and evaluation of treatment and support services is a cornerstone of holistic ALHIV care. One ALHIV peer educator articulated:

> *"The successes [of an adolescent-led organization] are that there's passion and ownership of the young people; they are part and parcel of the whole process, and they feel that they cannot do without it. And we also cannot do without them" (Peer Educator, AIDS service organization, Uganda).*

Discussion

Interview findings such as those summarized above capture genuine voices from the adolescent HIV field, telling us the story of a rapidly increasing population of ALHIV who are transitioning into adulthood[4,20]. Key recommendations based on the findings are summarized in Sidebar 1, each emerging from the issues described by key informants, and each building upon themes found elsewhere in the ALHIV literature. It is interesting to note that both health care providers and peer educators tended to agree on the major themes, gaps, and recommendations related to ALHIV service provision, though the peer educators, who are living with HIV and receiving care themselves, tended to place a greater importance on the need for improved psychosocial and reproductive health care. The peer educators interviewed were also more likely to recommend peer-led approaches to care and support, including the training and hiring of peer educators, the expansion of peer support groups, and the creation of opportunities for ALHIV from different organizations and areas to meet together to share ideas and advocate for their evolving needs.

To recap the findings of the key informant interviews, significant barriers exist at the clinical level. Medical challenges for providing care to ALHIV identified by informants include complex clinical histories, disease co-morbidities, viral resistance, and long-term exposure to antiretroviral medications. Training, resources and political will are needed to create systematic change and to build infrastructure that will ensure every ALHIV has access to high quality treatment and care[21]. Equally, assessing and adapting the care environment with an eye for creativity, such as making services more adolescent-friendly, is paramount to improving engagement and retention in care[1,11]. Institutions and policy-makers should look to creating training courses and materials that focus specifically on adolescent development, their unique needs and priorities, and promising practices in providing ALHIV with care and support.

It was clear from the interviews that further efforts must be made in order to provide comprehensive and ongoing training for health care workers in sexual and reproductive health education. Informants agreed that those organizations providing the best SRH services are those that are adolescent-friendly and provide outreach to adolescents and young people within their communities. Providing an open and safe environment for ALHIV to talk about reproductive health will increase their likelihood to disclose pregnancies and access prevention of mother-to-child transmission (PMTCT) services, contraceptive services and family planning[24]. Where possible, this environment could be made separate from the adult care environment so that ALHIV feel comfortable and have ownership of the space[25]. Also, review of informant interviews indicated that condoms should be made accessible but inconspicuous so that ALHIV can retrieve them privately if needed. Further effort should be made to engage ALHIV in dynamic discussions about healthy relationships, as part of SRH services, and overall peer support. As adolescent girls have higher HIV infection rates than boys, girls living with HIV deserve special focus to curb onward transmission of HIV[4]. This includes efforts to prevent sexual transmission to their partners as well as mother-to-child transmission. Efforts should be devoted to educating and empowering adolescent girls with information about prevention, condom negotiation, and delay of sexual debut.

Support for disclosure remains a key component of comprehensive care for ALHIV. This includes support for disclosure of HIV status to ALHIV by providing the caregiver with adequate information and support, as well as support for ALHIV as they prepare to disclose to others[17]. There was consensus among informants that engaging ALHIV and older youth who have had disclosure experiences, both positive and negative, in discussions about disclosure is a promising strategy.

Transition in health care remains a major challenge for health care providers across the world, and requires a joint effort on the part of providers, patients, families and policy makers, in order to be effective[26,27]. While some organizations may have an upper age limit for pediatric patients, there is no perfect age for transition that can be applied universally to all patients. Rather, patients and providers should work together to establish the right time for transition, based on developmental readiness and maturity[28,29]. It is recommended that providers work closely with patients, relevant family members and a multidisciplinary team to develop individualized transition plans and ensure seamless transitions to adult care[21].

While many pediatric providers are hesitant to refer their patients to adult services, it is imperative that they do so, thoughtfully and intentionally, in order to ensure that their patients are retained in high-quality, age-appropriate care[11]. Analysis of informant interviews indicated that few organizations have a clear strategy in place to transition their ALHIV from pediatric to adult care. Policy-makers have a role to play in encouraging the development of clinical guidelines for health care transition at the national and regional levels, but institutions must also work together to adapt and implement guidelines that fit within their organizational structures. This means providing forums for pediatric and adult care providers to come together, alongside ALHIV and their caregivers, in order to develop effective models.

The importance of promoting peer support and of fostering opportunities for the training and capacity building of peer educators and advocates cannot be overemphasized. Both provider and peer educator informants agreed that the meaningful engagement of ALHIV in the design, delivery and evaluation of treatment and support services is a cornerstone of adolescent-friendly service provision. Adolescents' developmental stage of seeking autonomy and control, coupled with their unique expertise in growing up with HIV, makes them ideally placed to inform the development of programs and engage their peers in service delivery.

A recurring theme throughout the interviews was the need to increase collaboration and sharing of best practices among organizations working with ALHIV. Informants called for increased communication, including new platforms to bring ALHIV from different institutions and countries together so that they can share their experiences and work toward creating a unified voice for ALHIV across the world.

Strengths and limitations

One of the strengths of this study was the breadth and depth of the interviews conducted with key informants. The interviews covered a variety of topics pertinent to the care of ALHIV and informants were encouraged to elaborate on any gaps experienced in service provision for ALHIV as well as any promising practices worth sharing. The diversity of the informants in terms of age, gender, background and country of service improves the comprehensiveness of the study findings. The variety of organizations/facilities represented in this study was determined by the Technical Advisory Group to be representative of the major players in the provision of care and support for ALHIV in SSA. For example, one of the organizations represented, the Baylor International Pediatric AIDS Initiative, is the largest medical provider for children and adolescents living with HIV worldwide, treating over 100,000 patients in SSA[30]. Furthermore, the relative consistency of key informant responses in terms of challenges and opportunities surrounding service provision for ALHIV lends credence to the study's key recommendations.

This study also had inherent weaknesses. Since the analysis is based on the perceptions of informants, one must be cautious in extrapolating the subsequent findings and recommendations beyond the organizational settings and geographic locations included. Second, this report provides a snapshot in time of the perceptions and experiences of our key informants – a more longitudinal approach would be needed to assess the impact and efficacy of various interventions and promising practices over time. Third, the key informants for this study were recruited based on the positive recommendations of their peers and therefore may represent best-case scenarios of service provision and organizational support. Similarly, the peer educators interviewed were in many cases those who served in some sort of leadership or peer education capacity and were therefore also likely to have had better treatment experiences and/or exhibited better health behaviors/outcomes than many of their peers. In addition, the lack of compensation for informants could exclude those who were not in a position to participate without additional incentive. Finally, this study did not include any non-peer educator patients or peer educators under the age of 18, due to challenges and limitations in recruitment and consent. There were fewer peer educators interviewed than health care providers, due to reasons cited in the "methods" section. The peer educators we did manage to recruit were from Botswana and Uganda, which seemed to have more advanced pediatric HIV programming, and older perinatally-infected patients, perhaps because they were two of the first African countries to have widespread access to ART and among the first countries with comprehensive pediatric HIV services through public-private partnerships with programs like the Baylor International Pediatric AIDS Initiative. Given that the peer educators were from only two countries, our ability to generally represent patient perspectives was limited. Further complicating the demographic profiling and guidance for this age group is that there are two sub-groups of ALHIV; those who acquire HIV perinatally as addressed in this paper and those who acquire HIV during adolescence i.e. via sexual transmission or injection drug use. This diversity in mode of transmission, in addition to diversity in sexuality, culture, religion, gender and age, is a reminder that ALHIV are a heterogeneous population, and as such require thoughtful, tailored interventions[31].

Conclusion

Efforts to mobilize and advocate for the care, support and treatment of ALHIV in sub-Saharan Africa have not responded to the magnitude of the problem. Innovative strategies and additional resources are needed if health care providers, community-level stakeholders, caregivers, and policy-makers are to respond effectively to the specific needs of ALHIV. As long as ALHIV and their unique clinical, psychological and social needs are overlooked, adolescents will remain one of the most vulnerable populations affected by the HIV pandemic. Our failure to address this vulnerability threatens the lives of these young people and jeopardizes the successes of pediatric HIV treatment efforts to date.

Acknowledgement

The views and opinions expressed in the article are solely those of the authors and do not necessarily reflect those of the US Agency for International Development nor those of the US Government.

Sidebar 1: Key Recommendations for Health Care Providers and Policy Makers

1 **Develop holistic treatment, care and reproductive health services**
    I. Utilize evidence-based strategies
    II. Address the unique needs of ALHIV
    III. Provide support for parents and caregivers
    IV. Champion decentralization of services and community-based approaches when feasible

2 **Provide adolescent-specific training and capacity building**
    I. Address clinical care, psychosocial support, and sexual and reproductive health
    II. Emphasize strategies to improve retention, adherence, and healthy disclosure
    III. Emphasize youth-friendly services
    IV. Include lay counselors and community health workers

3 **Meaningfully involve ALHIV**
    I. Identify, train, and utilize peer educators
    II. Involve ALHIV in design, delivery, and evaluation of programs
    III. Encourage advocacy for and with ALHIV

4 **Improve linkages to care and support**
    I. Offer HIV testing and counseling to all adolescents
    II. Create and monitor appropriate referral pathways
    III. Incorporate sexual and reproductive health services, including PMTCT
    IV. Provide peer support groups and drop-in services, subsidizing transport when possible

5 **Facilitate transition into adult care**
    I. Establish institutional transition policies and protocols
    II. Prepare ALHIV for transition early, utilizing a skills- and knowledge-based approach
    III. Incorporate educational and occupational support services

6 **Improve networking and collaboration**
    I. Share best practices between organizations

II. Hold inter-agency network forums
III. Partner with governmental and non-governmental organizations that provide complementary support services

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