Adolescents Living with HIV in Zambia: An Examination of HIV Care and Treatment and Family Planning

STUDY TEAM

FHI 360 conducted this research in collaboration with the following study sites:

- Arthur Davison Children's Hospital
- Ndola Central Hospital
- Kitwe Central Hospital

Objective

To strengthen services for adolescents living with HIV (ALHIV) by better understanding their experiences and concerns with HIV care and treatment, and their sexual and reproductive health.

Background

Little is known about HIV prevention behaviors among adolescents on antiretroviral therapy (ART) in sub-Saharan Africa. Prevention among people living with HIV (PLHIV) includes adhering to ART regimens to suppress virus levels within their bodies and to reduce the transmission efficiency of the virus.[1] Lower viral loads are also important for PLHIV who want to become pregnant while maintaining their health and lowering the risk of mother-to-child transmission. Prevention also includes practicing safe sexual behaviors to reduce the risk of HIV transmission to sex partners and using family planning (FP) to prevent unintended pregnancies.

Studying prevention behaviors among ALHIV is especially important because (1) HIV-infected children and adolescents on ART are living longer and have the opportunity to mature and to become sexually active and (2) they are accessing health care on a regular basis, which provides an opportunity to help them develop the skills they need to adhere to ART and practice safer sex.

FHI 360 conducted a study from 2011 to 2013 in three ART clinics in the Copperbelt Province of Zambia: Arthur Davison Children's Hospital (ADCH), Ndola Central Hospital (NCH), and Kitwe Central Hospital (KCH). The goal of the study was to better understand the experiences and needs of ALHIV related to HIV care and treatment, sex, and contraceptive use, and to inform strategies to meet these needs.

Methods

From December 2011 to February 2012, we conducted in-depth interviews (IDIs) with ALHIV ages 15-18 on ART, their adult family members, and clinic staff at the ART clinics at ADCH and NCH. Each ALHIV completed two interviews. In the first interview, we asked about their experiences with ART and learning about their HIV status. In the second interview, we asked them about their sexual experiences and their use of contraception and HIV prevention strategies. An adult family member was defined as someone age 18 or older who knows that the youth is on ART and who helps the adolescent when she or he is sick or unable to pick up the ARV drugs. Each adult family member and health care provider who participated completed one in-depth interview about their experiences caring for ALHIV. In the second phase, the study team used the findings from the qualitative phase to create a quantitative survey. Trained interviewers used personal digital assistants to administer the survey. In this phase, 311 interviews were conducted between December 2012 to May 2013 with adolescents ages 15-19 attending the ART clinics at ADCH, NCH and KCH. The research team also abstracted information from adolescents' medical and pharmacy charts.

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Results

PARTICIPANT CHARACTERISTICS

Qualitative phase:

Thirty-two ALHIV, 23 adult family members, and 10 clinic staff members completed IDIs. ALHIV included 16 males and 16 females ages 15-18 who were on ART. The most common adult family members interviewed were aunts (7) followed by mothers (4), sisters (3), and grandmothers (3), ranging in age from 23 to 70. ART clinic staff members, six from ADCH and four from NCH, included a clinical officer, nurses (3), adherence counselors (2), a pharmacy technologist, and data entry clerks (3). Most were female (7) and were between 27 and 53 years old.

Quantitative phase:

We interviewed 85% of the estimated 365 ALHIV who were receiving care from the three clinics. The average age of participants was 17 years, and 52% were female. The average age that youth learned they were living with HIV was 12.4 years old and 77% self-reported perinatal HIV acquisition. More than one-third were orphans and almost half of participants did not live with a biological parent. Almost all participants (99%) were single.

Characteristic	Total (N=311)
Clinic	
ADCH	46%
KCH	37%
NCH	17%
Mean age (years)	17
Currently enrolled in school	78%
Mean age learned HIV status (years)	12.4
Self-reported HIV acquisition	
HIV-positive parents	77%
Don't know	15%
Unprotected sex (consensual or forced)	4%
Other (contaminated blood from medical procedure and shared injection equipment)	4%
Biological parents living	
One living	40%
Neither alive	36%
Both living	24%
Current living situation	
Lives with biological parent	53%
Lives with other family members	43%
Lives at orphanage	4%

Key Findings

ART ADHERENCE AND HIV MANAGEMENT

22% of ALHIV missed two or more days of their ART in the previous three months.

Missing one's drugs for two or more consecutive days increases the risk for a person's viral load to increase and for him or her to become resistant to ARV drugs. One in five ALHIV reported recent gaps in taking their ART for two or more days in a row and another 8% reported missing their ART for a whole day in the past three months. Primary reasons for missing ART doses included:

- ARV drugs made them feel sick/uncomfortable (20%). One female age 17 explained,

  I would be like no today I won't take [my ARV drugs] I have to wake up to study if I don't wake up to study I won't write nicely tomorrow the test, I'll fail. So I used to miss that…because I was feeling like when I drink them [ARV drugs] I used not to feel like waking up for studying, just oversleep.

- They did not want to take ARV drugs around people who did not know their status (16%).

  I sleep over and then I forget to get extra [ART] because I don't want the people that I am staying with to know that I am taking them. — 18-year-old female

- They or the person who stores the drugs were late getting to where the drugs were kept, causing them to miss a dose (18%).

Self-management of HIV care and treatment among ALHIV varies widely, with families and homes playing an important role.

Family members can play a key role in supporting youth with ART adherence and HIV management. The majority of youth surveyed reported that only family members knew their HIV status.

Half of the ALHIV surveyed and almost all of the adult family members who participated in the IDIs reported that family members reminded them to take their ARV drugs. As one female youth age 18 described, "My auntie had to be there…like the time I was taking them, she would follow the time, bring the medicine to me when it's time for me to take them."

ALHIV have varying experiences with self-management of their clinical care. Most adolescents (65%) attended their

past three clinic visits alone. The average age youth started to attend alone was 14.8 years. While the majority of youth reported that they pick up their own medication at the pharmacy and also store their medication at home, about one in five adolescents has a family member who picks up their drugs and about one-third of participants reported that a household member keeps their drugs.

The clinics' ability to engage with families of ALHIV has proved to be challenging because of limited interactions with adult family members. Only one-third of surveyed youth said a clinic staff member had talked to someone they live with about their health or treatment in the past 12 months. Despite these challenges, clinic staff were interested in providing families with more support and information.

Clinic support helps ALHIV adhere to their drugs.

In the IDIs, many ALHIV discussed how the care and encouragement they receive at the clinic helps them adhere to ART and supports them in general. For example, one 17-year-old male said,

> *When I come here at the clinic I feel better because they do take care of us well like that when we come at the end of the month... So it like for me it makes me feel better the way they explaining to us about this, the importance of, aaah, on the illness itself of HIV and AIDS. And how to take the medicine and how to drink it at the right time which we have been given. I do feel better when I come here. It makes me happy.*

SEXUAL AND REPRODUCTIVE HEALTH NEEDS OF ALHIV

One-fifth of ALHIV were sexually active.

About a third of the ALHIV surveyed reported having a boyfriend or girlfriend and 21% reported having had sex. Three females had been pregnant and one male had made a girl pregnant. Two females had one child each. The average age at first sex was 14.9 years. Just over half (54%) of sexually active respondents had sex more than one time and 37% had sex with more than one person.

Many ALHIV had unprotected sex and those who used contraception relied on male condoms only.

Half of sexually active youth reported using contraception at first sex. Among those who had sex more than once, about half reported using contraception at last sex. The most commonly used contraception was male condoms, with only one female using a female condom at first and last sex and one using the pill at first sex. One potential reason more ALHIV are not using a contraceptive method is that they are poorly informed. For example, a quarter of ALHIV surveyed did not know that females on ART could use a method of contraception. Many adult family members interviewed were also misinformed about contraceptive use.

Forced sex is common among ALHIV.

Of the 21% of youth surveyed who reported ever having had sex, 57% had experienced forced sex. Of these, 24% were male and 76% female.

ALHIV want more information and counseling on family planning, and clinic staff want to provide this information.

Most surveyed youth wanted more information about family planning (72%) and about how to avoid infecting a sex partner (92%). The majority of youth (82%) reported feeling comfortable asking clinic staff about pregnancy prevention and most youth (63%) reported that clinic staff talk to them about sex, but not about ways to prevent pregnancy or to prevent HIV transmission to a baby.

More than half of clinic staff members interviewed reported that ALHIV need to learn about and have access to condoms in order to prevent unintended pregnancies and to protect against HIV transmission or re-infection. In addition, more than half of clinic staff members thought it would be effective or beneficial to add family planning counseling and services to the adolescent ART clinics.

Multiple barriers exist to ALHIVs' ability to obtain comprehensive information on family planning.

Adult family members supported teaching abstinence or condom use to ALHIV. For many adult family members, family planning is seen as something for married women only. While supportive, clinic providers reported that they would need to be trained to provide contraception and would need to be authorized to do so.

Very few ALHIV reported accessing family planning services.

Only one participant had been referred to a family planning clinic by clinic staff and three youth (one male and two females) reported ever having been to a family planning clinic.

ALHIV want to have children in the future and want more information about planning for pregnancy.

Nearly all ALHIV reported wanting to have children in the future. Many wanted children after they completed school, were married, or had a job/income. In the IDIs, one 18-year-old female said,

> *I would really like to have children and I really want to do that but...maybe after I graduate yah, I finish my school, and yah I know maybe I will get married in the same situation that I am in. But thank God that they have brought...testing...when you are pregnant and so they can prevent the baby from getting the disease so that's the good thing. Yah it really motivates me, yah, so I would love to have children.*

Ninety-three percent of youth surveyed wanted more information on how to have a healthy baby. While some youth are familiar with various strategies for preventing mother-to-child transmission, participants overwhelmingly wanted more information. One 17-year-old female said,

> *I want to know if it's possible for a positive person to have children that are negative and a positive person when a person is married- is it possible for the other one to be infected even if they are using condoms, coz condoms are not 100%.*

DISCLOSURE AND STIGMA

ALHIV do not disclose their HIV status because of fear of stigma.

Many youth in the survey and IDIs discussed concerns about stigma related to having HIV. Almost 60% of the ALHIV surveyed were worried that their friends would no longer talk to or play with them if they shared their HIV status with them. Half worried that people outside their homes would gossip about them if they knew their HIV status.

> *[I] am afraid because my friends are too talkative and loose with their behavior...I think what if they start discriminating me at school and everyone from everywhere will know. So that is why I wouldn't want to tell them. — 18-year-old female*

About 15% of ALHIV reported having been teased, insulted, excluded, gossiped about, or abused in the past 12 months because of their HIV status.

> *They never knew my status but they used to tease that you are positive. So friends I stopped hanging around with them and they stopped teasing me...I used to feel so bad but I never felt good my friends were teasing me that I was positive. — 16-year-old male*

Among youth who have had sex, the majority reported that their first or last sexual partners did not know their HIV status. One 17-year-old female interviewed discussed reasons for not disclosing to her boyfriend,

> *Ok we've never discussed it about it because I don't really know if whether he's going to be there for me or what I will tell my partner when the right time comes, because sometimes you may tell people you are HIV positive and they go on spreading you know guys, go on spreading rumors about you something that you don't want, so that's how it is.*

Many ALHIV face challenges with guilt and depression.

More than half feel guilty, worthless, or ashamed because of their HIV status. An 18-year-old female said,

> *At school they didn't know that I was HIV positive, so some used to say that people who are HIV positive some just drop dead from a simple headache. So each time they said this, I used to be affected...I used to feel guilt every time they would talk about that. So most of the time I used to move away.*

Sixteen percent of surveyed youth (13% of males; 19% of females) screened positive for potential depression based on the Hopkins depression scale.[2] A few youth mentioned suicidal thoughts or behaviors in the IDIs and survey, primarily in the context of finding out they had HIV or being abused due to their HIV status.

Support groups help ALHIV feel that they are not alone.

ADCH and NCH have monthly youth groups at the clinics where they discuss HIV care and treatment and other issues and engage in fun activities. In the IDIs, youth spoke enthusiastically about the youth groups, but in the survey, less than half of the youth from ADCH and NCH said they had ever attended a youth group session. Youth from the IDIs enjoyed the youth group because they (1) like and feel comfortable around the clinic staff; (2) enjoy having social interactions with other youth, hearing others' stories, and encouraging one another; (3) appreciate getting information on HIV, adherence, and sex and on how to care for themselves, generally; and (4) like doing activities such as sports and outings. One 16-year-old male described the encouragement he received because of the youth group:

> *The experience is that when am at home may be I feel like am the only person who takes the medicine but when I come here I see a lot of people who take this medicine and who really cares about the same medicine I wanted to stop. One day we went to perform in Chifubu, some they even came with their medicine in plastics those plastics that they have been given it was like 20:00 hrs they went out and they take their medicine. Then I said since it is everybody me also I will go and take my medicine at home.*

In the survey, 93% of youth said they would be interested in attending group sessions with other ALHIV and most (87%) were also interested in having their adult family members attend separate adult group sessions on how to support ALHIV. Most (88%) were also interested in having a mentor, such as a young adult living with HIV, to talk to. When asked if youth would be willing to attend a support group with their adult family members, youth in the IDIs were hesitant to attend groups with them but wanted their adult family members to get more information.

Adult family members were asked if they would be interested in attending meetings with other family members and youth at the clinic. Almost all were enthusiastic about participating in sessions at the clinic. Several said they would like to hear and share experiences from other HIV-affected families and learn how to better support their adolescents. For example, the sister of an 18-year-old male said,

I would be very happy if they introduce such programs so that we could be meeting as parents together with the youths. So that we may be sharing knowledge on how we can be keeping these children. And how we may help them grow up in a better way.

Most youth in the survey and IDIs wanted more information on having a healthy baby, gaining knowledge and skills to get a job, not infecting a sexual partner, adherence to ART, and family planning. In addition, many youth wanted more information on relationships, HIV disclosure, and how to deal with stigma. This information could be given in clinic-run support groups.

Maybe on HIV disclosure you can try to encourage about how I can be drinking, how I can managing to drinking my medication at school, you can try to encourage me on that because there are some of us who are shy, of drinking medicine at school. — 15-year-old male

Conclusion

Our data show that ALHIV are not disclosing their HIV status to friends or sex partners for fear of stigma or rejection, which influences their ART adherence and sexual behaviors. Non-adherence to ART and unprotected sex place ALHIV at risk for drug resistance, HIV transmission, and unintended pregnancy. ALHIV need more information, skills, and support to practice healthy behaviors. Clinic staff and adult family members can and want to support ALHIV by giving them accurate information and encouragement. Our data will inform the development and testing of interventions to strengthen family and clinic support for management of HIV and reproductive health issues among ALHIV.

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ACKNOWLEDGMENTS

We wish to thank the adolescents, adult family members, and clinic staff who participated in this study and the interviewers and clinic staff for helping implement the study.

This work is made possible by the generous support of the American people through the U.S. Agency for International Development (USAID). Financial assistance was provided by USAID to FHI 360 under the terms of the Preventive Technologies Agreement (PTA), GHO A 00 09 00016-00. The contents do not necessarily reflect the views of USAID or the United States Government.

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